PATIENT PARTICIPATION IN SYMPTOM MANAGEMENT

IN A CHINESE ACUTE SETTING

by

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Submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

Deakin University

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ABSTRACT

Patient participation, as a fundamental component of quality and safety in health care delivery, has a particular salience for cancer symptom management in acute care contexts. The perceptions and enactment of patient participation within Chinese acute cancer care settings however, are poorly understood. Emerging research in western countries indicates discrepancies between patients and clinicians in how patient participation is perceived. A comprehensive understanding of patient participation in symptom management in China requires the exploration of both patients’ and clinicians’ perceptions and enactment of participation in care processes.

This research program explored the synergies between patients’ and clinicians’ perceptions and experience of patient participation in symptom management in a Chinese acute cancer care setting, in order to advance our understanding of the enablers and barriers to patient participation in symptom management. The specific aims were to explore: 1) patients’ and clinicians’ perceptions of patient participation in symptom management; and, 2) patients’ and clinicians’ behaviours during interactions related to symptom management.

The design was a case study (single institution) using mixed-methods and conducted in two medical units in an oncological specialty hospital in Shanghai, China during August 2013 and January 2014. Patients had a cancer diagnosis and had been admitted for at least seven days, and clinicians were doctors and nurses working in the units. Data collection involved survey, individual interviews and naturalistic observation.
Abstract

Perceptions were derived from surveys (patients n=162, doctors n=38, nurses n=34,) and individual interviews (patients n=41, doctors, n=5, nurses n=7). The importance of participatory activities in symptom management was recognized by both patients and clinicians, however participating in decision-making for symptom treatment and care was not perceived to be as important as relaying symptom experience. Differences in perceptions between patients and clinicians were identified. Doctors and nurses were more likely than patients to perceive patient involvement as a hindrance to care delivery because of the time required of clinicians and implications for increased workload (P<0.001). Both doctors and nurses perceived that they provided more symptom information than patients perceived having experienced (Patient-doctor: P=0.016, Patient-nurse: P<0.001) and clinicians perceived they motivated their patients to participate in treatment and care more than patients experienced (P<0.001).

Over 80% of patients in the acute care setting preferred their doctors and nurses to make decisions for them and 64.8% of patients achieved their control preference, with moderate agreement identified (Kw: 0.61, SE: 0.08, 95%CI: 0.45 to 0.77), while 24.5% experienced a more passive role than they preferred. More active preference for participation in decision making was associated with being single (OR: 2.84, 95% CI: 1.00 to 8.12, P=0.051), female (OR:1.88, 95% CI:1.00 to 3.51, P=0.050), employed (OR: 3.64, 95% CI: 1.84 to 7.20, P<0.001), undergoing radiotherapy (OR: 2.38; 95% CI: 1.14 to 4.99, P=0.021) and higher levels of health literacy regarding the ability to appraise information critically (OR: 2.71; 95%CI: 0.88 to 8.31, P=0.081) and to find health information (OR 1.73; 95%CI: 0.96 to 3.12, P=0.069). Patients whose actual experience
of participation agreed with their preference perceived higher quality of care (P=0.007).

There was a shared understanding that patients and clinicians had multiple participatory roles in symptom management. Information exchange was considered key to patient involvement; patients could also be involved in negotiated decision-making and self-management activities such as adjusting psychological status and mood, and controlling their diet or lifestyle. Both clinicians and patients raised concerns about patients’ capacity to make decisions about their care. Patient participatory roles were thought to be influenced by factors related to communication, type of decision, family, peers, and organizational policies. Patients, irrespective of control preference, shared reasons for their preference and these were their role in information exchange, negotiated decision-making and role expectations. The trend in the findings suggested that the more active a role patients preferred, the higher they perceived responsibility for their own health outcomes.

Doctor-patient and nurse-patient interactions during symptom management were captured through naturalistic observation (Doctor-patient n=81, Nurse-patient n=112). These interactions were characterized as low frequency and low duration. Most of the doctors and nurses asked for, or provided information briefly, showing few attempts to engage patients in information exchange. Opportunities were provided by doctors and nurses for patients to express their preferences or opinions and some, but not all patients recognized the opportunity to contribute to decision-making related to symptom management. Nurses involved patients in their self-care through education or encouragement. Communication behaviours of clinicians were observed to facilitate
Abstract

or block patients’ participation in interactions related to symptom management. Family members and other patients were also found to influence patients’ participation.

Post observation surveys indicated patients had a higher preference for participation in nursing activities than in medical treatment (P<0.001) and they achieved this preference (P<0.001). Both doctors and nurses tended to overestimate patients’ participatory preference for, and actual achieved participation in, interactions, displaying poor agreement in patient-doctor dyads (Kw: -0.09, SE: 0.11, 95%CI: -0.30-0.13) and slight agreement in patient-nurse dyads (Kw: 0.12, SE: 1.37, 95%CI: -0.05 to 0.29).

Integration of the data derived from the mixed methods enrich our knowledge of the enablers and barriers to patient participation. Patients’ and clinicians’ recognition of patients’ active roles in symptom management, raising patients’ preference for active participation, and providing patients with opportunities to participate could facilitate patients to participate in symptom management. Barriers to patient participation included patients’ and clinicians’ concerns related to patients’ capacity to participate in decision-making and clinicians’ strategies for involving patients. Patient participation in symptom management in the case study setting was predominately in relation to aspects of exchanging information and self-management of care while patients’ role in negotiated decision-making was limited. Future research is needed that is focused on interventions directed towards patients and clinicians to enhance interactions that facilitate patient participation in their care, and these interventions need to be investigated within the Chinese acute cancer care context.
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Recipient of the ‘School of Nursing and Midwifery Research Scholarship Award (2014)’ which is awarded to a student enrolled in the PhD Doctoral program for outstanding research scholarship.
CHAPTER ONE

The research problem

The notion of patient participation, as a fundamental component of quality and safety in health care, has been growing in momentum internationally since the 1980s (Cahill, 1996, 1998). This momentum has been driven by a recognition that patients and clinicians share power and responsibility in therapeutic relationships (Entwistle, & Watt, 2006; Longtin et al., 2010; Sahlsten et al., 2008), especially in the context of acute care delivery where there has been a shift from the traditional paternalistic model to a more collaborative model of care delivery (Walrath, & Rose, 2008; Weingart et al., 2011). Patient participation has particular salience in the processes of care related to symptom management (Heyn et al., 2013; Lee et al., 2011) because of the subjectivity of the symptom experience. In cancer care settings, effective cancer and/or treatment-related symptom management is a priority (Reilly et al., 2013; Yarbro,Frogge, & Goodman, 2004).

The enactment of patient participation in clinical settings involves complex interactions between patients and clinicians. Moreover, these interactions are influenced by the wider social and cultural environment and/or background of the patient (Miller, 2002; Strohschein et al., 2011). Nations have unique political, economic and cultural conditions that impact on health care infrastructure, systems and processes, and these conditions may influence the extent to which patient participation is enacted in health care.
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It is necessary therefore, to explore patient participation in symptom management within a national context. The focus of the research reported in this thesis is the phenomenon of patient participation in cancer-related and/or treatment-related symptom management within the context of a rapidly evolving health care system in mainland China.

Support for patient participation is based on the belief that patients are important members of the health care team with the right and responsibility to be involved in their health care (Kennedy, 2001; Kizer, 2001; Taylor, & Rutherford, 2010). In acute care settings, patients have frequent interactions with their clinicians, specifically nurses and doctors. These interactions are most commonly controlled by clinicians (Kvangarsnes et al., 2013). Uneven relationships that are often inherent between clinicians and patients are barriers to patient involvement (Kvangarsnes et al., 2013; Schoeb, & Bürge, 2012). Participation does not only depend on patients’ willingness and capacity but also on clinicians providing opportunities for patients to participate in their own care. To date, research into patient participation has focused on either patient or clinician perceptions or actions. Expansion of the investigation of patient participation to include both patients and clinicians, provides a multidimensional view of this complex phenomenon (Salsman et al., 2012; Schoeb, & Bürge, 2012; Storm, & Davidson, 2010). Understanding the synergies between patients’ and clinicians’ perceptions of participation will identify important enablers and barriers to participation that when addressed, will inform safety, quality and patient-perceived

Despite widespread discussion of patient participation in the research literature and health policy documents, there is limited conceptual clarity (Entwistle, & Watt, 2006; Sahlsten et al., 2008) and emerging evidence of a lack of congruence between patients’ and clinicians’ understanding of participation (Eldh, Ekman, & Ehnfors, 2010; Pieterse et al., 2008). Calls for greater patient participation in symptom management are based on the assumption that the subjectivity of symptoms requires patients to participate (Yarbro, Frogge, & Goodman, 2004). In the Chinese acute cancer care setting, there is limited understanding of patients’ preference for, and actual experience of participation in symptom management, or of the congruence between patients’ and clinicians’ perceptions. How patients and clinicians interact and how opportunities for patient participation occur in those interactions are also poorly understood. Factors influencing patient involvement in clinical practice have been reported in the western literature (Cohen, & Botti, 2015; Legare et al., 2008; Sahlsten et al., 2005a) but there has been very little research of the facilitators and barriers to participation within the context of acute care in China.
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1.1 Background and Context

1.1.1 The symptom profile of cancer patients

In 2012, there were 14.1 million new cancer cases and 32.5 million people within five years of diagnosis living with cancer worldwide; with approximately one-fifth of the incidence and prevalence of cancer occurring in China (WHO, 2015a). Patients with cancer experience multiple symptoms that are attributed to both the underlying disease and subsequent treatment (Reilly et al., 2013). According to a recent systematic review of the prevalence of symptoms associated with different cancers (Reilly et al., 2013), fatigue and pain were present in all of the 21 reviewed studies, followed by sleep issues (91%), anorexia and weight loss (91%), gastrointestinal issues such as nausea and vomiting (81%), affect issues such as depression and irritability (76%), and respiratory issues such as cough and dyspnoea (76%). In Esther’s et al. systematic review (Kim et al., 2009b), 22% to 30% of patients reported they experienced more than five symptoms simultaneously, indicating patients rarely present with a single symptom.

Patients’ symptom experience can have significant adverse effects on their functional performance and quality of life (Deimling, Bowman, & Wagner, 2007; Dodd et al., 2010; Dodd, Miaskowski, & Paul, 2001; Oh et al., 2012). Symptom distress, as a dimension of symptom experience, can be burdensome throughout the trajectory of the cancer illness and treatment (Bennion, & Molassiotis, 2013; Zucca et al., 2012). Although a number of
studies have been conducted in outpatient oncology settings (Elizabeth et al., 2002; Skerman, Yates, & Battistutta, 2012; Spichiger et al., 2011a; Yamagishi et al., 2009), there are surprisingly few studies describing symptom distress in inpatient oncology settings, where Clark (2011) found that patients suffered more psychological and physical symptom distress than their outpatient counterparts. Designing processes and delivering effective interventions to reduce the suffering of patients in acute cancer care is fundamental to the delivery of quality care.

1.1.2 Symptom management in cancer care

Helping patients manage cancer symptoms effectively is a significant element of caring for people with cancer (Lee et al., 2011). The aim of symptom management is to prevent or treat the symptoms of disease, treatment side effects, and psychological, social, and spiritual problems that may or may not be related to the disease and/or its treatment (National Cancer Institute, 2012a).

Increasingly, recommendations to guide the effective treatment of cancer and/or treatment related symptoms based on the aggregated findings of empirical studies have become available (Basch et al., 2011; Dy, 2010; Kuchinski, Reading, & Lash, 2009; Lee et al., 2011; Ling, Lui, & So, 2012; Zhang et al., 2012), however patients continue to experience a high number of symptoms suggesting that these guidelines are not always incorporated into practice. For example, in a survey of 1,938 cancer patients from 17 centres in 11 European countries, almost 60% of patients were found to have
received suboptimal treatment of constipation, depression or poor sleep and 45% of patients with nausea were not treated adequately (Laugsand et al., 2011). A seven-year review of a prospective database of 1,038 patients with bone metastases in Canada, revealed that there was no appreciable decline in the proportion of patients who did not receive adequate prescription and/or administration of analgesics i.e. were under-medicated in the period from 1999 to 2006 (Kirou-Mauro et al., 2009).

According to the University of California, San Francisco (UCSF) Symptom Management Conceptual Model, the key dimensions of symptom management theory involve a complex interplay of symptom experience, management strategies, and patient outcomes (Dodd et al., 2001), requiring that clinicians understand patients’ symptom experiences and implement appropriate management strategies. Understanding patients’ symptom experiences through symptom assessment is the first step of symptom management. Although there are various symptom assessment tools available, there is evidence that incomplete assessments continue to be a practice reality (Laugsand et al., 2011; Liu et al., 2012). In clinical settings, symptoms are usually assessed via structured or unstructured questioning during clinician interactions with patients (Jakobsson,Ekman, & Ahlberg, 2008), however patient reports can be affected by factors such as their knowledge and beliefs (Smith et al., 2009; Sun et al., 2007; Tzeng,Chou, & Lin, 2006) as well as their ability to recall their symptom experience. Patients who do not report pain are not always free of pain and an unrecognized symptom
is often an untreated symptom. In addition to the issues related to identifying patient symptoms during an interaction, the reliability of symptom assessment is also influenced by clinicians’ experience and how systematic and thorough assessments are (Jakobsson, Ekman, & Ahlberg, 2008).

When symptom inventories are employed, symptom prevalence and intensity are the most common dimensions measured; frequency and distress measures are often not included (Kirkova et al., 2006; Paice, 2004). In China, screening for psychological symptoms is neither routine nor regular in clinical settings (Sun et al., 2007) but is being integrated into routine care in Western countries. These gaps in symptom assessment can be partially attributed to a lack of standardized and valid instruments and procedures for symptom assessment. Hence, unstructured assessment where questioning is often clinician dependent and therefore variable is regarded as a major barrier to optimal symptom management (Kirkova et al., 2006). The finding that psychological assessments are not common in China may, in part, be due to cultural norms as well as clinician perceptions regarding their role in the management of patients’ psychological issues.

Symptom management strategies are not always optimal in practice. For example, although the three-step analgesic ladder approach for prescribing medications for the management of cancer pain has been promoted by WHO since 1986 (WHO, 1986), it is still not, even when clinically indicated, routinely prescribed and/or administered in practice (Charalambous et al.,
2012; Kirou-Mauro et al., 2009; Shaheen et al., 2010; Sun et al., 2007). In a review of 26 studies evaluating the adequacy of prescriptions using the Pain Management Index, Deandrea (2008) found nearly half of the patients experienced cancer-related pain that was inadequately treated. Often, when there is a prescription of “as needed” or “pro re nata” (PRN) analgesic orders, decisions relating to administering the range of available analgesics are left to individual clinicians. Variability in the way nurses administer analgesics can be influenced by nurses’ interpretation of the intent of an order, insufficient knowledge of analgesic titration or exaggerated concerns about opioid safety (Gordon et al., 2008). Despite availability of the WHO guidelines, the balance between opioid utilisation and control of side effects, such as nausea remains a challenge (Palos, 2008) and may contribute to under treatment of pain.

In addition to these clinician barriers, the literature has also highlighted that patient barriers exist in the form of attitudes to, and knowledge of, symptom management. For example, studies of pain and fatigue report patient fears about: addiction (Akiyama et al., 2012; Naveh et al., 2011; Sun et al., 2012), tolerance of opioid analgesics (Sun et al., 2012), side effects of the use of pain medication including nausea and drowsiness (Chen, Tang, & Chen, 2012; Jacobsen et al., 2010), beliefs that pain and fatigue are inevitable and should be tolerated (Sun et al., 2012), and beliefs that medication should not be used until pain intensity is severe (Naveh et al., 2011). These misconceptions may contribute to patients’ reluctance to report their symptoms to
healthcare providers or accept treatment when it is offered (Royer, Phelan, & Heidrich, 2009; Yeom, & Heidrich, 2009).

Evidence that poor communication between patients and clinicians is a frequent occurrence in clinical settings may contribute to misconceptions about symptom management. For instance, in an investigation about the barriers to management of chemotherapy-induced nausea and vomiting conducted in the USA, patients were more reluctant to use medications to control nausea and vomiting than clinicians. The majority of clinicians suggested cost was one of the barriers to use of medications by patients whereas most patients were concerned about medication side effects and hence tried to limit the number of medications taken (Salsman et al., 2012). The desire to be ‘a good patient’ (i.e. a patient with good compliance and few complaints) may prevent patients from communicating issues with healthcare professionals (Salsman et al., 2012; Tzeng, Chou, & Lin, 2006). Patients undergoing active treatments have been found to be more reluctant to report pain symptoms to their doctors as they believe that complaints regarding pain may distract doctors from treatment of the underlying disease (Sun et al., 2007; Tzeng, Chou, & Lin, 2006).

Patients’ understanding of, and adherence to medication regimes may influence satisfaction with symptom management. Reported rates of adherence vary between studies. In terms of taking the correct dose at the correct time, patients’ adherence to around-the-clock Tramadol was reported at 59% in a Dutch outpatient cancer population (Enting et al., 2007).
In another study conducted in Norway, 46% of patients reported low levels of adherence mostly because they felt better and thus stopped the analgesic medication (Valeberg et al., 2008). Adherence to antiemetic prophylaxis agents among 4,566 patients receiving platinum-based chemotherapy was reported from 60% to 90% according to the Texas Cancer Registry in the USA (Gomez et al., 2013). In regards to managing breakthrough pain, Enting (2007) reported that only 17% of patients took 80% or more of the PRN analgesics prescribed. According to Valeberg (2008) adherence scores are positively associated with pain relief scores. Addressing patients’ understanding of the medications they are prescribed and the impact this has on patient self-administration/management may help to improve the number and severity of symptoms that patients experience.

1.1.3 The role of patients in symptom management

The subjective characteristics of symptoms and multiple barriers (both patient and clinician) to achieving effective symptom control means that symptom management requires collaboration between healthcare professionals and patients. Reducing the barriers associated with optimal symptom management requires more than guidelines, recommendations or staff education. Efforts to advance patients’ knowledge and skills are essential, and patients’ role in contributing to symptom management should be promoted. In Borneman’s quasi-experimental study (2010), a patient education intervention designed to improve patients’ knowledge regarding
pain and fatigue was demonstrated to have significant effects on reducing patient-related barriers to symptom management.

A further example of patient participation can be seen in the outcomes of an individualized intervention designed in three pilot studies (Heidrich et al., 2009), in which older patients with breast cancer decided the symptoms for intervention, set their goals and chose the strategies they would use through discussion with advanced practice nurses. These patients changed their symptom management behaviours more than those in the control group and their symptom distress was significantly lower when compared to the control group. The potential benefits of a collaborative role for patients is further illustrated in the findings relating to women with urinary incontinence where collaboration is the most preferred role in countries such as Austria, Belgium, Denmark, France, Germany, Ireland, Sweden, Switzerland, the Netherlands and the UK (Donnella, Monzb, & Hunskaar, 2007), however this preference might be mediated by patients’ desire to improve their continence and the availability of specialist services for this specific symptom. Despite the significance and, often patients’ preference for a collaborative role in some aspects of symptom management, little is known about how patients with a diagnosis of cancer participate in their symptom management, nor the contribution that doctors and nurses can make to facilitate participation in this context.
1.1.4 Patient participation defined

The term ‘patient’ is defined as “a person who is under medical care or treatment” (Dictionary.com). With the establishment of fee-for-service systems, other related terms, such as client, consumer or service user, have emerged (Cotterell et al., 2011; Sahlsten et al., 2008) but generally, although used interchangeably, the terms refer to health care recipients (Sahlsten et al., 2008; Yu, 2007).

Common synonyms for participation are: involvement, engagement, sharing or cooperation (participation, n.d.). The medical literature refers to participation both in relation to health practice as well as behaviour. For example, the National Cancer Institute (NCI) defines participation as “the act of taking part in an activity” (National Cancer Institute, 2012b), and the International Classification of Functioning, Disability and Health (ICF) defines it as “involvement in a life situation” (WHO, 2001, p. 10). These definitions relate to behaviours that are not well defined. As a subject heading term in the academic databases of empirical literature, the specific activity of decision making is prominent. For example, the definition in Mesh is “Patient involvement in the decision-making process in matters pertaining to health” (CINAHL Headings, 2013; Mesh, 2013).

In academic studies, the definition proposed by Brownlea is the most frequently cited, and it posits four dimensions of participation:

“Participation means getting involved or being allowed to become involved in a decision-making process or the delivery of
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*a service or the evaluation of a service, or even simply to become one of a number of people consulted on an issue or a matter*”(Brownlea, 1987, p. 605).

In this definition, patient participation can be highly variable and is not restricted to decision making. The myriad definitions of patient participation highlight the variety of perspectives and interpretations (Eldh, Ekman, & Ehnfors, 2010; Longtin et al., 2010; Sahlsten et al., 2008) and this is likely to impact on how it is understood and operationalised in healthcare interactions.

1.1.5 Patient participation in health care

The notion of patient participation originated from the campaign “Protecting the Consumer Interest” in the USA in the 1960s, which advocated the consumer’s right to safety, be informed, choose and be heard (Kennedy, 2001). Since then, this concept has been widely accepted in health care as a means of maintaining human dignity, enhancing quality of life and ensuring patient safety (Cahill, 1996). The WHO World Alliance for Patient Safety (2007) has put forward a range of proposals in recent years to enhance the recognition and implementation of patient safety all over the world. Service user involvement is reflected in the health-related regulations and laws of multiple countries, such as Australia (Australian Commission on Safety and Quality in Health care, 2008), UK (Cotterell et al., 2011), USA (Frosch et al., 2012), and Norway (Aasen, Kvangarsnes, & Heggen, 2012). In China, the National Patient Safety Goals also “encourage[s] patients to participate in
medical safety” (Chinese Hospital Association, 2009). Therefore, much attention has been directed towards involving patients in their health care internationally.

The significance of advocating for patient participation in their care in terms of improving safety and patient outcomes is multifactorial. First, involving patients in their care is an ethical imperative. Patients’ right to self-determination is emphasized by humanist principles (Longtin et al., 2010). The autonomy of patients should be respected and it is essential to balance the benefits and risks of treatments from patients’ perspectives (Stiggelbout et al., 2012). Furthermore, patients’ demands for quality services has been supported both in health and other industries since the consumer movement. Both autonomy and consumer demand have contributed to a redefinition of the patient role in health care (Longtin et al., 2010). Second, patient participation is considered one of the most effective ways to maintain patient safety in health care. There is evidence that patients with a high rate of participation experience less adverse events during admission (Weingart et al., 2011). Third, patient participation is vital to enhancing quality of care. Research findings have shown that participation in health consultations enhances patient perceptions of quality of care (Jangland et al., 2012), contributes to patient satisfaction (Gascoigne, & Watson, 2009), improves patient-clinician relationships (Stacey et al., 2011) and reduces decisional regret (Sawka et al., 2012). Finally, patients’ collaboration with health professionals promotes the achievement of positive health outcomes.
Even though the evidence for better health outcomes remains limited and controversial (Stacey et al., 2011; Stiggelbout et al., 2012), there is an increasing body of literature indicating that high levels of participation are associated with more recall of treatment information discussed during interactions with clinicians (Dillon, 2012), better understanding of information provided (Gascoigne, & Watson, 2009; Stacey et al., 2011), and improved adherence to treatment (Arnold, Coran, & Hagen, 2012).

The focus of research into patient participation is currently directed towards the exploration and application of patient participation in all aspects of their care. Patient participation in health care has been more widely incorporated into the management of chronic conditions, especially in terms of self-management (Tol et al., 2012) which entails long-term relationships between patients and health care providers and on-going self-care by patients. Increasingly in chronic illness management, value is placed on patients’ experiences, coping strategies and responsibilities, as well as information obtained and partnerships formed with clinicians (Eldh, Ehnfors, & Ekman, 2006; Haidet, Kroll, & Sharf, 2006). Patients’ roles are prominent and more clearly defined in aspects of self-care or health education in chronic illnesses such as diabetes (Heinrich et al., 2012; Tol et al., 2012) and chronic heart failure (Eldh, Ehnfors, & Ekman, 2006). Less is known however, of the potential role of patients in the acute inpatient setting where care is provided by multiple clinicians and patient interactions tend to be of short duration.
1.1.6 Patient participation in acute care

In contrast to the context of chronic disease management, the role of patients as participants in the acute care setting is an area that has been under researched. Acute care is characterised by the transfer of responsibility for managing 24-hour care from patients to clinicians. Acute care settings are associated with a high intensity of labour (health care professionals), sophistication of technology, and are characterized by transient relationships between clinicians and patients and, generally, in-hospital care delivery (Daniels, Grendell, & Willkins, 2010, p. 446).

There has been a relatively recent shift in models of care in clinical practice away from paternalistic models where professionals play a dominant role towards a shared role between patients and clinicians in achieving health care outcomes through information and knowledge transfer during therapeutic communication (Walrath, & Rose, 2008; Weingart et al., 2011). Furthermore, health professionals are increasingly recognizing the significance of participation and collaboration in relation to patient safety and quality of care (Gascoigne, & Watson, 2009; Jangland et al., 2012; Weingart et al., 2011). With the focus on a philosophy of person-centred care in acute care settings, clinicians are encouraged to individualise their patients’ care and involve patients in their care (Bolster, & Manias, 2010). Involving patients in their care requires both understanding by patients and clinicians of each other’s roles, patient preference for participation and clinician willingness to adapt their care accordingly. The above
characteristics are considered antecedents for patient participation in acute care environments and if present, make it possible for patients to collaborate with their clinicians (Sahlsten et al., 2008).

In acute care settings, there has been much discussion regarding patient participation in decision making specifically related to medical treatment decisions, the hospital where they would like to receive care and end of life decisions (Ernst et al., 2011a; Hamann et al., 2010; Wilkinson et al., 2008). Among the three main models of decision making (paternalistic model, informed or consumer model and shared model), the shared model is currently receiving the most widespread attention internationally as the ‘ideal’ model (Emanuel Ej, 1992). In the shared model, patients are encouraged to ask questions, and make decisions by collaborating with health professionals according to their preferences and values (Hirsch et al., 2012). In nursing the role of patients in care is being re-reviewed in an increasing number of publications (Florin, Ehrenberg, & Ehnfors, 2008; Storm, & Davidson, 2010) and discharge planning (Almborg et al., 2009; Popejoy, 2011), however the role of patient participation in symptom management, an essential aspect of acute care treatment and nursing care, has had less attention.

1.1.7 Patient participation in the Chinese context

Patient participation is a multidimensional concept and its meaning and operationalisation can be influenced by clinical and cultural contexts (Alexander et al., 2012; Frosch et al., 2012; Murray et al., 2009; Schouten et
al., 2007; Young, & Klingle, 1996). Socially sanctioned roles and race or ethnicity are thought to affect patients’ preference for and actual participatory behaviours, however, to date the majority of research has been conducted and published in developed western countries (Alexander et al., 2012; Frosch et al., 2012). Insights into this concept and its integration into models of healthcare, especially in developing countries like China, are limited. The potential to translate research findings of patient participation in cancer care is limited if the context in which it is investigated, and similarities/differences in the context in which it will be applied, are not considered.

China, with a population of 1.39 billion (WHO, 2015b), has experienced a dramatic transition in its economic model that has included extensive alteration of the healthcare system. Current issues of concern in the Chinese health care system focus on the accessibility and affordability of healthcare services and the rights of patients as service users in health care. Given the advocacy for patient participation in western countries, a trend towards improving patients’ involvement in their own health care in China is inevitable. The social and cultural environment is likely to affect Chinese patients’ health seeking behaviours and attitudes towards participating in their care including decision-making during episodes of hospital admission, and may also be evident in the health-related interactions between patients and healthcare professionals in the acute care setting.
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The following overview of the Chinese healthcare system includes a summary of the latest Chinese healthcare reforms; a profile of the healthcare system including health resources and funding model; and, issues remaining despite the efforts to improve the healthcare service. Finally, recognition of patients’ rights and responsibilities are considered.

1.1.7.1 Healthcare reform in China

In 1979, China transformed from a “planned economy” model to a “market economy” model. Since then, healthcare coverage in China has experienced a transition from a government-subsidized welfare system to a consumer-paid, fee-for-service system (Hui, 2010). The Chinese government delegated its power to the local authorities of different provinces and reduced healthcare expenditure by approximately 5% of the gross domestic product (GDP), lower than the average percentage (8.5%) of the GDP in developed countries. Approximately 40% of the overall healthcare expenditure is provided by government while average expenditure worldwide is over 60% (Zhang, 2009). The shift of the healthcare system from a state-run to a market-led system was to cope with financial problems and meet the increasing needs of the population, however despite the adjustments it does not yet meet all the needs of the general population.

The latest plans for healthcare reform were released in April 2009 (Sinclair, 2009). This new reform was designed to ensure everyone had access to a basic healthcare. It is a long-term policy and aims to be achieved over 10 years. There are five major programs: 1) Medical security: to expand the
coverage of health insurance to both urban and rural residents; 2) Pharmaceutical supply system reform: to establish an essential drug supply system by setting a drug list based on government reference prices; 3) Primary healthcare: to improve primary care infrastructure by establishing a comprehensive network to maximise coverage throughout China; 4) Public health services: to promote equitable access to public health services by full government funding for a minimum package of the essential services; and 5) Pilot hospital reforms: to strengthen the regulation of public hospitals and reform their revenue structure. The reforms have government taking back part of the ownership and governance of public hospitals, taking action to slash the surcharges on drugs, replace government subsidies and fees-per-service (Li, 2011; Lin, 2012; Sinclair, 2009). In May 2015, the Guiding Opinions of the Urban Public Hospital Comprehensive Reform Pilot was released and emphasised the fundamental role of public hospitals in aspects of public welfare in the Chinese healthcare system (General Office of the State Council, 2015).

1.1.7.2 Chinese healthcare system profile

*Health resources*

The healthcare system in China, headed by the Ministry of Public Health (MOH), is a multi-tiered structure. In May 2015, there were 987,000 healthcare institutions, of which the number of hospital and grass-roots health care institutions was 26,000 and 922,000, respectively. In China’s hospital system, public hospitals make up 51.3% of the total number of
hospitals (Ministry of Health, 2015). In the public system there are three main hospital tiers: third-level (>500 beds), second-level (100-500 beds) and first-level (<100 beds) accounting for 7%, 27.9% and 25.6% of the distribution of hospitals respectively (Ministry of Health, 2014c). In 2005-2012, the number of hospital beds per 10,000 population was 39 beds, the same as Australia (39 beds) and slightly higher than the USA (30 beds). The number of healthcare staff per capita is very limited in China. The number of doctors per 10,000 population is 14.6 and the number of nurses and midwives is 15.1, while in Australia the number of doctors per 10,000 population is 38.5 and the number of nurses and midwives is 95.9; in the USA, the ratio of doctors is 24.2 and nurses and midwives, 98.2 per 10,000 population (Ministry of Health, 2014c).

Funding model

The national healthcare funding system in China is through social medical insurance involving three key types: 1) Urban Employees Basic Medical Insurance (UEBMI), employer-based to cover urban workers and is funded by payroll taxes paid by both employers and employees; 2) Urban Residents Basic Medical Insurance (URBMI), financed by voluntary contributions and various government bodies, covers the urban population at a household level not covered by UEBMI; and 3) New Rural Cooperative Medical System (NRCMS) for rural residents and financed similar to the URBMI.

In 2008, the rate of coverage of social medical insurance (including health insurance schemes not mentioned above) was 87%, which, following the
new healthcare reform, increased to 95% in 2011 (Ministry of Health, 2014b, p. 73). In addition, private health insurance, a supplement to social medical insurance, is encouraged by the government as another option to cater for the needs of various populations (Sinclair, 2009). Since 2000, private health insurance has experienced a rapid expansion and was reported to cover 7% of the population by 2010 (Growth Analysis, 2013). In 2012, private health accounted for 44.1% of the total health expenditure in China. In contrast 31.5% of the population have private health insurance in Australia and 20.0% in Japan (Ministry of Health, 2014c). The demand for private health insurance is increasing especially in developed cities like Beijing, Guangdong and Shanghai, and has become one of the most popular personal insurance products in recent years (Dahlberg, 2007).

1.1.7.3 Current issues in Chinese healthcare

There has been an increasing focus on hospitals and healthcare in Chinese society since the reform of the system. The issue of healthcare reform, which is named “Yi Gai” in Chinese, is frequently reported and discussed in news reports. The grass-roots medical and health care infrastructure has also made progress, increasing by approximately 4,000 institutions including Community Health Centres, Outpatient Departments, Clinics, etc., from 2009 to 2015 (Ministry of Health, 2014c, 2015). There has also been much work on an open and transparent purchasing system for essential drugs (Mccann Healthcare Worldwide, 2012), particularly in urban public hospitals (General Office of the State Council, 2015). However, despite the increase in insurance
coverage and medication access systems some experts suggest that the problems of “poor access and high costs”, have not been relieved through healthcare reforms since 2009 (Bai, & Cao, 2014).

**Insufficient and unevenly distributed medical resources**

The disparity between medical care demands and resources has been debated over the years. With an ageing population, increasing living standards and education, the demand for medical care has increased dramatically in the past decade (Lin, & Ai, 2008). The Ministry of Health reported that the number of visits in health institutions increased from 40.97 (per 100 million) to 68.88 (per 100 million), and the number of inpatients increased from 7,184 (per 10 thousand) to 17,812 (per 10 thousand) during the period from 2005 to 2012 (Ministry of Health, 2014b). This increase may also be linked to the increased number of hospitals and clinics that have made medical care more accessible.

On the other hand, insufficient medical resources, particularly the limited number of healthcare staff per capita has long been regarded as a significant problem in China. The number of nurses per 10,000 population is approximately one-sixth of that in developed countries, such as Australia, and the USA (Ministry of Health, 2014c). Another significant figure contributing to the crisis is the ratio of nurses to doctors in China which is 1.03, while the ratio in Australia is 2.49 and in the USA is 4.05 during the period from 2005 to 2012 (Ministry of Health, 2014c). In the Chinese clinical setting, the limited number of nurses per patient means that nurses have
more patients under their care reducing the amount of time that they can spend with each patient (Wong, 2010).

With establishment of the market economy model, the gap in medical resource distribution has widened. First, regional disparities in medical resources are particularly large between rural and urban areas. The population in rural areas accounts for over 70% of the total population in China, while only receiving 24% of the total health expenditure (Ministry of Health, 2014c). High-quality medical resources are mostly located in urban areas. For example, in terms of the number of beds in hospitals per 1000 population, the three highest concentrated areas are Shanghai (7.01), Beijing (6.99) and Tianjin (4.72), while the three lowest concentrated areas are Guizhou (2.05), Jiangxi (2.08) and Guangxi (2.08) (An, 2011). Consequently, many people travel to cities such as Shanghai and Beijing in order to access high quality and technology-based health services, placing an enormous burden on health services in metropolitan areas. In addition, because of the underdevelopment of referral pathways and poor understanding of the three tiered system by both patients and healthcare professionals, patients tend to go to third-level (>500 bed) hospitals for their primary care needs. This has resulted in the third tier hospitals being overburdened with issues that would be better managed in other healthcare settings. The Ministry of Health reported that the number of outpatients in the third-level hospitals is six times that in the first-level hospitals (<100 beds), and utilization rate in
the third-level hospitals is 104.5%, compared with first-level hospitals where utilisation was only 60.4% (Ministry of Health, 2014c).

**High cost of care**

Healthcare affordability is another significant issue for the general population in China. The most critical factor is government administration and regulation of the price of healthcare services and medicines. Total health expenditure accounted for 5.51% of the GDP in 2011 commensurate with the 5% recommended by the WHO (Ministry of Health, 2014b). Healthcare costs accounted for 7.2% of the national per capita spending in 2014 according to the latest national statistical data (National Bureau of Statistics of China, 2014). Despite comprehensive coverage offered by the three basic medical insurance types, the proportion of reimbursements is insufficient and varies between each type of health insurance. Basic medical insurance only covers part of basic medicine, examination, therapy and services while other costs, especially for new or imported medicines that are usually expensive and have to be paid out of pocket. Reimbursement from insurance for inpatient costs was only 47% in 2011. Even though the percentage had increased significantly from around 15% in 2003 it still leaves patients with considerable out of pocket expenses (Meng et al., 2012).

The market-run funding in China means that the survival of hospitals depends on profit earnings through pricing and marketing mechanisms (Hui, 2010). Where medical services in hospitals are driven by profit there is the risk of over-provision of medical procedures and over-prescription of
medication, which can lead to soaring medical expenses for patients (Boynton, Ma, & Schmalzbach, 2012). Complaints about high medical costs are frequently reported in the domestic media, and in one of the provinces in China, more than 10,000 doctors were sanctioned for over-prescription of medications in 2014 (Zhang, 2015).

Evidence suggests that high cost for medical care is associated with patients’ participatory preference, with higher payments linked to more active participation (Li, 2009). It is therefore important that the economic context of health care is taken into account when investigating patients’ decision making behaviours and participation.

*Relationships between patients and health professionals*

In ancient China, under the influence of Confucianism which regarded benevolence and care as its core values, doctors, who behaved with high moral principles, were owed a fiduciary trust (Hou, & Xiao, 2012). Doctors were on friendly terms with their patients and provided holistic care (mind, body and spirit). However, in modern society, along with social, medical and technological developments together with the drive for specialization, doctors have gradually changed their focus to illness instead of patients as individuals. According to Hou (2012), some argue that efficiency, profit-maximization and rationality might be the pursuit of some health professionals, particularly after the initial Chinese economic and healthcare system reforms. At the same time, however, patients have become more aware as consumers, expecting higher quality in regards to their experience
and outcomes of care. Poor access and high fees in contemporary healthcare have widened the gap between patients’ expectations and their actual experience (21 Century, 2012; Hou, & Xiao, 2012). When patients’ demands are not met, patients’ trust in doctors is reduced and healthcare staff working in clinical settings often become the target of frustration from patients (Hou, & Xiao, 2012; Wang, 2010). These factors can impact on relationships between patients and healthcare professionals (He, Zhang, & Lan, 2011) which can also impact patients preference for, and ability to participate in healthcare interactions.

The Chinese Hospital Association conducted an investigation on hospital violence from 2008 to 2012, involving 316 hospitals, 8,388 healthcare providers and 8,204 patients nationwide and found that the incidence of hospital violence had increased. The proportion of healthcare providers who reported being abused or threatened increased from 90% to 96% and the proportion of healthcare providers attacked and harmed rose from 47.7% to 63.7%. The investigation showed there were three main incentives for behaviours of concern: the large gap between treatment outcomes and patients’ expectations, poor communication between clinicians and patients; and treatment expense beyond patients’ affordability (Jia et al., 2014).

Effective communication is an important element in clinician–patient relationships. Patient participation has been found in western countries to improve patients’ perception of quality of care (Jangland et al., 2012), contribute to patient satisfaction (Gascoigne, & Watson, 2009) and improve
patient-clinician relationships (Stacey et al., 2011). It is not unreasonable to suggest that if patients are provided with increased opportunities to participate in their care including but not limited to providing informed consent in treatment decisions, their perception and experience of communication with clinicians may improve (He, Zhang, & Lan, 2011; Wu, 2010).

1.1.7.4 Recognition of patients’ rights and responsibilities in China

In some developed countries, such as the USA, Finland, Holland and Japan, patients’ rights are protected by law (Yu, 2007). In China, there is currently no legislation on the rights of patients; however, there is reference in laws and documents, including Practicing Physicians Law and The Regulation on the Handling of Medical Accidents, where patients’ rights to equal access to health care services, decision-making, information, informed consent, respect for his/her intimacy and dignity, and access medical record documentation is recommended albeit not yet sanctioned through Federal legislation (Yu, 2007). These recommendations are a good step towards enhancing patients’ awareness of their rights and facilitating clinicians to recognise and respect patients’ rights in China.

Apart from their role as consumers, patients are increasingly being recognised as having a responsibility as co-producers in health interactions and contributors to their own care (Buetow, 1998). In China, despite patients’ rights and responsibilities not being regulated in laws, patients are encouraged to be involved in their care, especially in terms of patient safety.
Encouraging patients to participate in medical safety is one of the targets of the National Patient Safety Goals. Patients are, for example, invited to confirm the location of surgery and to check the medicines they take. Patients are also advised to report their medical history and condition accurately and take a role in their care (Chinese Hospital Association, 2009). Despite the lack of legally defined patients’ rights and responsibilities, existing documents in China acknowledge the necessity and demand for patients to be involved in health care activities. The notion of patient participation is expanding as is the research into this concept (Li, 2009; Ma, & He, 2005).

In summary, the healthcare system in China has experienced significant change. The Chinese government has endeavoured to improve the healthcare delivery system in China. There is, however, an obvious disparity in medical care demands and medical resources between urban and rural areas and between medical costs and patients’ affordability impacting health seeking behaviours. Context-related factors such as population density, time during medical consultations and clinician availability during an inpatient admission, may impact on patients’ ability to participate (Alexander et al., 2012; Höglund et al., 2010). Tensions between patients and health professionals are sometimes unavoidable but the study of patient participation has a unique significance in China, particularly as the relationship between patients and healthcare professionals has undergone multiple changes from the core values of benevolence and care influenced
by Confucianism to a more paternalistic model, then back to patient-centred care. Given the multiple factors that influence the values and behaviours of patients and health professionals during clinical interactions it is critical that any investigation into patient participation is explained in terms of the current Chinese context.

1.2 Purpose statement and research program

The purpose of this study was to advance understanding of the enablers and barriers to patient participation in symptom management in acute cancer care environments. This study focused on exploring the synergies between patients’ and clinicians’ perceptions of patient participation in a Chinese acute cancer care setting. A mixed methods, single case study (one institution) design was used. Data were collected from both patients and clinicians in a level three (>500 beds) Chinese health care setting. Specific aims were identified to achieve this overall purpose as follows:

Aim 1: To explore patients’ and clinicians’ perceptions of patient participation in symptom management.

Aim 2: To explore patients’ and clinicians’ behaviours during interactions related to symptom management.

1.3 Thesis structure

This research program exploring patient participation in symptom management in a Chinese acute care setting is presented in eight chapters. In this first chapter, the background of the problem in respect to the
potential for suboptimal symptom management in cancer care and patients’ collaborative roles in health care was presented in order to highlight the need for and importance of exploring patient participation in symptom management. The Chinese healthcare system was introduced with a discussion of recent reforms and current issues in Chinese healthcare settings to provide an overview of the social and cultural environment for patient participation in practice.

The focus of Chapter 2 is a review of the literature relating to patient participation from a worldwide perspective. The definition of patient participation and the related understandings in acute care settings are discussed to explore some of the implications of differing definitions for implementation. Patients’ roles in participation and factors associated with preferred and actual roles are reviewed to identify gaps in current understandings of patient participation within acute care settings. The research associated with patient participation in the Chinese context is reviewed to identify issues and deficiencies in current Chinese studies involving this topic.

In Chapter 3, the methodological approach and specific methods employed are described. The research program comprises a one-institution case study employing a mixed methods design. The methods used for data collection included naturalistic observation, individual interviews and surveys. Rigor and bias control during data collection and ethical considerations throughout the program are explained in this chapter.
The findings and related discussion are presented in the following four chapters (Chapters 4 to 7 inclusive). The case study attributes in terms of participants’ characteristics, patients’ symptom profiles and the distribution of patients’ participatory roles are described in Chapter 4. In Chapters 5 and 6, perceptions of patient participation in symptom management of both patients and clinicians are described. Behaviours of patients and clinicians during interactions related to symptom management are analysed in Chapter 7.

In the final chapter of this thesis, integration of the findings, implications for practice and future research agenda are discussed.
CHAPTER TWO

Perceptions and practices associated with patient participation in acute care settings

Interest in patient participation in acute care contexts in Western society, particularly in the past decade, has generated a substantial body of research whereas relatively few studies have been conducted in mainland China. Systematic narrative reviews of Western and Chinese literature were used to identify existing knowledge about patient and clinician perspectives and preferences, enablers and barriers, and the questions and methods directing research into patient participation.

This chapter is comprised of three sections. The strategies used to search international and Chinese databases to identify publications for a systematic narrative review of patient participation in acute care environments worldwide and in China, are detailed in Section 2.1. The substantive literature review in Section 2.2 includes a discussion of perceptions of patient participation in acute care settings, patients’ preferred and actual participatory roles, and clinicians’ perceptions of patients’ roles. The range of factors known to affect patients’ preference for participation and actual achievement of participation are then summarized. In Section 2.3, research questions and methods used in studies of patient participation in Chinese
Chapter 2 Perceptions and practices associated with patient participation in acute care settings

contexts are discussed with an emphasis on a critique of the status of contemporary research in China.

2.1 Literature search strategies

The literature review was conducted using both international and Chinese databases. Because of the limited studies on patient participation in the context of symptom management in cancer care, the search was expanded to participation in acute care settings in general.

2.1.1 Literature search in international databases

In order to provide an overview of the worldwide literature on the topic of patient participation in treatment and care in acute care settings, subject-related databases were searched through EBSCOhost, such as CINAHL, MEDLINE, PsycINFO, Psychology and Behavioral Sciences Collection and Health Source: Nursing/Academic Edition and through PubMed using the following search strategy:

("patient participation") OR ("consumer participation") OR ("client participation") OR ("patient involvement") OR ("patient engagement") OR ("patient empowerment") and (("inpatient"") OR ("hospitaliz"") OR ("acute care") OR ("nursing care")) NOT (infant or child or adolescent).
Chapter 2 Perceptions and practices associated with patient participation in acute care settings

The date of publication was limited from Jan 2005 to July 2015 to reflect the literature in the past decade commensurate with the patient participation movement, and the manuscripts in English or Chinese were reviewed.

The literature search procedures and results are presented in Figure 2.1. During manual searching of titles and abstracts, articles were excluded if they were study protocols, not original studies, not focusing on acute care, about patient participation in transition, discharge planning, rehabilitation, end of life decision-making, psychiatric care, clinical trials or teaching, the development of instruments, or focusing on patients under 18 years of age. At total of 155 articles related to the topic of patient participation in acute care settings were identified.

Twenty studies (13%) that were designed to examine the effect of an intervention related to patient participation were identified. The remaining studies (n=135, 87%), used methods of survey, interview or observation and aimed to explore patients’ and/or clinicians’ perceptions of patient participation, patients’ preference for and/or actual experience of participation; factors associated with patients’ degree of participation; or associated effects of patient participation. Of the 155 articles identified, the context in which patient participation was studied included participation in treatment or care (n=87), decision making (n=30), general activities (n=25), or patient safety (n=13). There were 12 (7.7%) articles focusing specifically on symptom management or symptom-related care such as pain.
management (Latimer, Chaboyer, & Gillespie, 2014; Manias, & Williams, 2008; McTier, Botti, & Duke, 2014; Zoëga et al., 2015), reporting acute deteriorating conditions or care (Kocks et al., 2013; See et al., 2014), pressure injury prevention (Chaboyer, & Gillespie, 2014; Gillespie et al., 2014; Latimer, Chaboyer, & Gillespie, 2014; McInnes et al., 2014), continence management (Engkasan, Ng, & Low, 2014), and general cancer symptom management (Cohen, 2012). Among the 155 articles, only one study
investigated patients’ level of participation in treatment decision making in Mainland China (Zhang et al., 2011).

2.1.2 Literature search in Chinese databases

A comprehensive review of Chinese literature was conducted in order to gain insight into the status of patient participation research in Chinese acute care settings. Both academic journal articles and dissertations were searched separately across three databases: China Knowledge Resource Integrated Database, Wan Fang Database and China Biomedicine Database. The publication dates ranged from 2005 to 2015. The search strategy used (患者参与 or 病人参与) or (患者授权 or 病人授权) as keywords meaning ‘patient participation’ or ‘patient empowerment’. The search results and screening procedures are presented in Figure 2.2. A total of 220 articles were retrieved after replicated articles were deleted. During the manual screen, articles not involving patients in acute care settings or not reporting on original studies
Chapter 2 Perceptions and practices associated with patient participation in acute care settings were excluded. After reviewing the titles and abstracts individually, 47 articles were included.

![Flowchart](image)

Figure 2.2 Flowchart of the search strategy of Chinese literature to identify patient participation in Chinese acute settings

Of the 47 Chinese articles, 26 (55.3%) articles reported cross-sectional studies: 19 surveys, three semi-structured interviews and four mixed method designs. There were 16 (34%) studies with an interventional design and six (12.8%) studies that aimed to develop tools related to patient participation (one study was a cross-sectional study in which a tool was also developed).

Seven (14.9%) of the studies addressed patient participation in general; approximately half (n=26, 55.3%) focused on patient participation in patient safety: 17 general safety, four medication safety and five clinical errors; eight
studies (17.0%) focused on patient participation in medical and/or nursing decision making and six (12.8%) focused on participation in nursing care. No study specific to symptom management was identified.

2.2 Patient participation in acute care

This section, has as its focus, an analysis of the state of knowledge of patient participation in acute care. The literature is presented according to four key topics: perceptions of patient participation, patient roles in acute care, predictors of patients’ preference for participation, and barriers to patient participation in acute care.

2.2.1 Perceptions of patient participation in acute care

Sahlsten et al. (2008) conducted a concept analysis of patient participation which involved a review of articles about patient participation published between 1996 and 2005. The authors concluded that there were four attributes of patient participation within the context of nursing practice: 1) An established relationship between nurse and patient; 2) A surrendering of some power or control by the nurse; 3) Shared information and knowledge; and 4) Active engagement in intellectual and/or physical activities. These attributes provided a useful framework for analysing the findings of studies identified for review.
Twenty-four studies identified in western databases and four studies in Chinese databases exploring the perception of the meaning of patient participation were grouped and summarized depending on the study participants in Appendices 1-3: Appendix 1 summarises studies of patients’ perceptions (14 articles); Appendix 2 summarises studies of clinicians’ perceptions (7 articles); and Appendix 3 summarises studies of that explored both patients’ and clinicians’ perceptions (7 articles).

2.2.1.1. Establishing relationships

Opportunity for patients to participate often occurs during interactions between clinicians and patients; thus their relationship is both an essential attribute and prerequisite to patient participation (Sahlsten et al., 2008). Seventeen of the 24 studies investigating non-Chinese populations and three of the four studies of Chinese populations explored the relationship between patients and clinicians.

Patient-clinician relationships are based on mutual respect. In the paternalistic model of care, clinicians expect respect and trust from patients, while in the collaborative care model, the expectation is of mutual respect. For example, Eldh (2010) interviewed 362 Swedish inpatients and outpatients and found patients want to be respected and regarded as individuals whose preference should be taken into account. The perceived requirements of being acknowledged, being treated courteously within an
atmosphere of equality has been found in other studies where patients were interviewed (Frank, Asp, & Dahlberg, 2009b; Larsson et al., 2007) (Wåhlin, Ek, & Idvall, 2006). In one Swedish study, nurses described showing respect by supporting patients to present their opinions and experience (Sahlsten et al., 2009).

The nature of interactions has been identified as fundamental to the process of patient participation. Tutton et al (2005), who explored the meaning of participation for older inpatients and their nurses in the UK, highlighted the dynamic nature of the concept of patient participation in a hospital setting, and noted that partnership between patients and clinicians that were based on negotiation, respect and trust was an essential part of the process. In an Australian study of 10 patients’ perceptions of participating in the handover process, patients spoke about interactions with nurses in handover as an inclusive approach and were grateful to be recognized as partners in their care (McMurray et al., 2011). “Working together” appeared to be a common expression used by patients when they were asked about their understanding of patient participation in studies conducted in Australia (McInnes et al., 2014) and Iran (Soleimani, Rafii, & Seyedfatemi, 2010). Clinicians’ perception that patients need to be viewed as co-workers or partners where they strive to achieve common goals and positive results through mutuality and intimacy were found in both Swedish (Sahlsten et al., 2009) and Australian (Tobiano et al., 2015a) studies.
Chapter 2 Perceptions and practices associated with patient participation in acute care settings

Chinese patients also identified the importance of patient-clinician relationships in facilitating patients’ communication and decision-making (Li, Zhang, & Yang, 2014) and the salience of mutual respect or trust (Liu, 2012; Zeng, & Yan, 2014). Emotional reciprocity was identified as one of the significant elements in patients’ response to a patient participation competence survey (Liu, 2012). Encouragement to participate was a clear concept in the opinions of 17 experts who were involved in the process of developing a module for patient participation in intravenous chemotherapy safety (Zeng, & Yan, 2014).

2.2.1.2 Surrendering power

Patients’ increased involvement in health care has altered the power relationships between clinicians and patients. Soleimani (2010) reported that expressing views and making decisions was at the highest level of participation and named this as “true participation” (Soleimani, Rafii, & Seyedfatemi, 2010). Clinicians surrendering power, as a significant element in facilitating patient participation, was featured in the description of patient participation in 17 of the 24 studies of non-Chinese populations and all four of the studies investigating the perceptions of patients and clinicians in China.

Larsson (2007) analysed the perceptions of 26 Swedish patients, using a grounded theory approach, and concluded that there is a joint responsibility between patients and nurses where patients are provided with information
and have rights to choose and make decisions in their nursing care. Patients in Eldh’s et al study described patient participation as patients having control over healthcare contact and their own disease and being included in planning their care (Eldh, Ekman, & Ehnfors, 2010). Surrendering of “clinician power” in healthcare was achieved using varying approaches, such as encouraging patients to express opinions (Frank, Asp, & Dahlberg, 2009a), communicating agreement or rejection of a treatment plan (Frank, Asp, & Dahlberg, 2009a), and making decisions (Bolster, & Manias, 2010; Heggland, & Hausken, 2013; Löfman, Håggman-Laitila, & Pietilä, 2008; Sahlsten et al., 2005b; Tobiano et al., 2015a). These factors were repeatedly identified by both patients and clinicians in the international studies, however there was divergence in opinions about control and power reported in some of the studies that compared patients’ and clinicians’ perceptions of participation regarding the role of the patient. Clinicians highlighted concerns with patients’ capability to participate (Macdonald et al., 2014) and reported difficulty with empowering or supporting patients’ participation (Heggland, & Hausken, 2013). Höglund’s (2010) study found that active involvement in medical decision-making was emphasised less by patients than clinicians which suggests that clinicians’ and patients’ perceptions of the patient role and what it means to participate may differ.

The concept of patient participation in decision making was prominent in the Chinese literature. Liu (2012) constructed four elements of patients’
Chapter 2 Perceptions and practices associated with patient participation in acute care settings

participation competence comprising: autonomous decision-making, information seeking, communication and emotion management. Other Chinese studies emphasised the collaborative role of patients in decision making. For example, Ye (2011), using grounded theory research, explored the concepts, content and strategies of patient participation in patient safety to develop a three-step patient safety framework: condition/illness acknowledgement, doctor/hospital seeking decisions and diagnosis/treatment involvement, in which patients’ actual participation was defined as completely dominant, completely compliant or interactive. Decision involvement was identified as one of the key strategies of interactive participation. Zeng (Zeng, & Yan, 2014) developed a patient participation in intravenous chemotherapy safety model based on Ye’s theory and other related literature. This model explained decisive involvement as involving indicators such as: reporting current or previous side effects, knowing options and collaborating in decision making. In Li’s (2014) findings based on a factor analysis of the data from a self-developed patients’ participation behaviours questionnaire, interactive communication was one of the identified factors. One measurement indicator within this factor was that patients were keen to propose opinions and suggestions, however this indicator had the lowest factor loading compared with other indicators. This would suggest that patients’ involvement in decision making was perceived as one part of a range of participatory activities.
2.2.1.3 Information and knowledge sharing

Flow of information from health professionals to patients has been suggested to be fundamental for participation. Soleimani described patients’ information-seeking behaviours as “involving” and patients’ or clinicians’ contributing their knowledge or experience as “sharing” (Soleimani, Rafii, & Seyedfatemi, 2010). Consistent in the findings of all of the research studies included in the review is the notion of information sharing.

The perception of patients accessing and seeking information was a finding in both patients’ and clinicians’ interviews (Bolster, & Manias, 2010; Frank, Asp, & Dahlberg, 2009b; Frank, 2009; Heggland, & Hausken, 2013; Kolovos et al., 2014b; Larsson et al., 2007; Thyssen, & Beck, 2014; Tobiano et al., 2015b). Furthermore, some patients and health professionals viewed obtaining information as the primary or even exclusive way patients can participate in care (Ekdahl, Andersson, & Friedrichsen, 2010; Höglund et al., 2010).

Some patients, however, reported dissatisfaction with simply being informed. Eldh et al (2010) reported from their survey that around 80% of patients asked for explanations about their symptoms or problems and wanted to understand procedures or what had been planned for them. Analysis of responses to open–ended questions identified that participation, from the patients’ perspectives, referred to having knowledge and understanding of
their care and treatment rather than just being informed. This view of participation needs to be explored further among clinicians to determine whether it is also recognised or shared by health care providers.

In addition to information being delivered from the clinician to patient, the patient’s role in exchanging information about themselves to clinicians has also been reported as a method of patient participation. Most patients talked about their desire to have more contact or dialogue with clinicians during interactions (Frank, Asp, & Dahlberg, 2009b; Larsson et al., 2007). Tobiano et al (2015b) reported that in addition to seeking understanding about their care, sharing their experiences with nurses was a way for patients to participate in nursing care. From the perspective of clinicians, obtaining information from patients was perceived to be a form of patient participation. For example, registered nurses in Sahlsten’s study (2009) became acquainted with patients by focusing on listening. Perceptions of patient participation during a hospital admission was described by nursing staff in Greece (Kolovos et al., 2014b) and Sweden (Sahlsten et al., 2005b) as a process of information exchange between patients and clinicians, including patients’ symptom reporting. This bi-directional communication i.e. from clinician to patient and patient to clinician was perceived as promoting shared understanding while also recognising the value of patients’ self-knowledge in coordinating their care (Eldh, Ekman, & Ehnfors, 2010; Löfman, Häggman-Laitila, & Pietilä, 2008).
Similar to the International literature, Chinese patients also reported collecting or seeking information as patient participation (Li, Zhang, & Yang, 2014; Liu, 2012; Ye, 2011). There was agreement with this concept of information seeking by patients as a form of participation by healthcare experts in a Delphi investigation (Zeng, & Yan, 2014). There was less evidence about the notion of patients providing information about their conditions and responses as a form of participation, however, two Chinese studies did find that participation can be described by patients as an information resource, reporting their own situations to clinicians (Li, Zhang, & Yang, 2014; Zeng, & Yan, 2014).

### 2.2.1.4 Patient engagement in care

According to the definition of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) and other researchers (Eldh, Ekman, & Ehnfors, 2010; Longtin et al., 2010), decision making is not the only activity requiring patients to participate. Patients have described participation as interacting with health professions rather than merely partaking in decision making (Eldh, Ekman, & Ehnfors, 2010). Specific participatory activities were presented in 15 studies, four of which (26.7%) were undertaken in China.

From patient and nurse perspectives, patients can participate in self-care or daily activities, including administration of medication, moving or repositioning, eating and drinking, and personal hygiene (Kvangarsnes et al.,...
Chapter 2 Perceptions and practices associated with patient participation in acute care settings

2013; Löfman, Häggman-Laitila, & Pietilä, 2008; Latimer, Chaboyer, & Gillespie, 2014; McInnes et al., 2014; Sahlsten et al., 2009; Thyssen, & Beck, 2014; Tobiano et al., 2015a). These activities suggest that participation involves general engagement between patients and clinicians in the everyday aspects of care. The notion of compliance with clinician instructions was described as a patient role by Iranian patients (Soleimani, Rafii, & Seyedfatemi, 2010), Swedish clinicians (Frank, Asp, & Dahlberg, 2009a), and Greek nurses (Kolovos et al., 2014b).

Participation in nursing care was also investigated in research conducted in China (Ye, 2011; Zeng, & Yan, 2014). Following doctors’ advice, (Li, Zhang, & Yang, 2014; Ye, 2011; Zeng, & Yan, 2014) and managing personal distress (Liu, 2012) were perceived by Chinese patients as participation. There has also been increasing interest from Chinese researchers into examining participatory behaviours associated with patient safety; for example, the need for patients to report any perceived errors or omissions during their treatment and nursing care (Ye, 2011).

2.2.1.5 Summary

The concept of patient participation in acute care settings has been explored in international research. Patient participation has most commonly been described in terms of a relationship that is established between patients and clinicians based on mutual respect and partnership; power is surrendered by
clinicians while patients’ involvement in decision making may be partial or complete; patients obtain information, receive information or contribute their self-knowledge; and can be involved in various healthcare activities. Although the evidence is limited, both agreement and disagreement between patients’ and clinicians’ perceptions of what participation encompasses were identified in the literature reviewed. The biggest area of discordance was in regard to decision-making. More specifically, patients did not appear to consider making the decisions as highly as being provided with and understanding information. Clinicians on the other hand were more likely to discuss the role of the patient in making decisions, however, they also raised concerns about patients’ capacity to undertake this role.

From a Chinese perspective, the meaning of patient participation in acute care settings has been explored in very few studies and this research has been in the context of either patient safety or general participation rather than symptom management or nursing care. Further, research in China has been focused on participation in decision making, obtaining information. There appears to be substantial commonality in the findings of these few studies with those in the western literature however Chinese patients identified the importance of emotional exchange in addition to being respected. It is of significant interest to note that Chinese patients saw compliance with clinician determined treatment plans as a means of participation whereas this view of participation although found, was not as
common in western studies. The available research in China has not explored clinicians’ perspectives in any depth, nor compared perceptions between patients and clinicians.

2.2.2. Patient roles in acute care

In this section, patient roles are discussed in terms of patient preference for the degree to which they would like to participate, patients’ actual experience of participation and clinicians’ perception of patients’ roles.

A number of different tools have been used to examine patients’ preference for participation in particular roles however, the most widely used has been the Control Preference Scale (CPS) (Degner, Sloan, & Venkatesh, 1997), which categorized five roles according to level of control in decision-making: active role, active-shared, collaborative, passive-shared, and passive. When reporting results the majority of authors who have used the CPS have followed the original developers of the tool by combining the active and active-shared role as active preference and combined passive-shared role and passive role as passive preference. The CPS was used in 13 studies, two of which investigated Chinese populations while others were conducted in Sweden, Australia, UK, Germany and Ireland. Patients’ participatory role in acute care settings has been investigated with the CPS in various decision-making contexts such as treatment management, medication management,
Chapter 2 Perceptions and practices associated with patient participation in acute care settings

nursing care and symptom management. A summary of patients’ role distribution in studies using the CPS tool is presented in Table 2.1.

2.2.2.1 Patients’ preference for participation

The importance of understanding preference for participation is apparent in decisional situations of high uncertainty in which the pros and cons of different options needed to be weighed and the preferred option chosen. It is also significant in situations of low uncertainty where there were strong recommendations for treatment yet treatment outcomes are reliant on patient willingness and compliance (Weijden et al., 2012). Even though participation in health care is widely advocated, not all patients want to be involved when they interact with clinicians (Thompson, 2007). Forcing patients to participate when they do not want to, would be inappropriate, even harmful or distressing (Stiggelbout et al., 2012). There was agreement in the literature that promotion of participation should align with patients’ preferences (Collins et al., 2007; Kiesler, & Auerbach, 2006; Sahlsten et al., 2008). Therefore it is essential for clinicians to understand patients’ desire to participate within specific contexts while simultaneously ensuring that patients consent to their treatment.

Patient preferences for participation was explored in 24 studies published in English. Of the 47 Chinese studies, six studies reported patients’ preference. With the exception of seven studies exploring patients’ preferences using
Chapter 2 Perceptions and practices associated with patient participation in acute care settings

qualitative interviews, most of the studies published in English and all of the studies in Chinese assessed patient preference in a quantitative way, 11 studies in English and two in Chinese used the CPS.
Table 2.1 Summary of studies on the distribution of patients’ preferred participatory roles using the Control Preference Scale

<table>
<thead>
<tr>
<th>Author Date</th>
<th>Journal</th>
<th>Country</th>
<th>Participants</th>
<th>Criteria</th>
<th>Patients’ preference (%)</th>
<th>Patients’ actual participation (%)</th>
<th>Percentage of match (%)</th>
<th>Patients’ preference vs actual participation</th>
<th>Clinicians’ perception vs patients’ preference</th>
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<tr>
<td>(McTier, 2012; McTier, Botti, &amp; Duke, 2015; McTier, Botti, &amp; Duke, 2014)</td>
<td>Clinical Journal of Pain</td>
<td>Australia</td>
<td>Patients with cardiovascular disease (130 reported preferred role and 98 of them reported actual experienced role)</td>
<td>Pain management</td>
<td>Active: 6, Active-shared: 64</td>
<td>Active: 64</td>
<td>64</td>
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<tr>
<td></td>
<td>PhD thesis</td>
<td></td>
<td></td>
<td>Medication management</td>
<td>Active: 21, Passive: 75</td>
<td>100</td>
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<td></td>
<td>Australian Critical Care</td>
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<td></td>
<td>Pulmonary management</td>
<td>Active: 23, Passive: 22, Collaborative: 73</td>
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<td></td>
<td></td>
<td></td>
<td>Changing the dose</td>
<td>Active: 2, Active-shared: 11, Passive: 45, Collaborative: 26</td>
<td>Collaborative: 16</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Stopping a medicine</td>
<td>Active: 2, Active-shared: 10, Passive: 46, Collaborative: 30</td>
<td>Collaborative: 12</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>(Vestala, &amp; Frisman, 2013)</td>
<td>The Open Nursing Journal</td>
<td>Sweden</td>
<td>39 patients in medical wards (control group 21)</td>
<td>Care decision-making</td>
<td>24</td>
<td>43</td>
<td>33</td>
<td>14</td>
<td>33</td>
</tr>
<tr>
<td>Author Date</td>
<td>Journal</td>
<td>Country</td>
<td>Participants</td>
<td>Criteria</td>
<td>Patients' preference (%)</td>
<td>Patients' actual participation (%)</td>
<td>Percentage of match (%)</td>
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<tr>
<td>(Ernst et al., 2011b)</td>
<td>European Journal Of Cancer Care</td>
<td>German</td>
<td>117 haematology patients</td>
<td>Active</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Ernst et al., 2011a)</td>
<td>Psycho-Oncology</td>
<td>German</td>
<td>533 inpatients with solid cancer</td>
<td>Active</td>
<td>0.6</td>
<td>17</td>
<td>53</td>
<td>26</td>
<td>4</td>
</tr>
<tr>
<td>(Ekahel et al., 2011)</td>
<td>BMC Geriatrics</td>
<td>Sweden</td>
<td>153 elderly patients 83.1 years, male 46.5%,</td>
<td>Medical decision making</td>
<td>5</td>
<td>20</td>
<td>28</td>
<td>33</td>
<td>16</td>
</tr>
<tr>
<td>(Wilkinson et al., 2008)</td>
<td>Quality &amp; Safety in Health Care</td>
<td>Ireland</td>
<td>152 acute medical inpatients, 74 years (20-96ys), male 50%</td>
<td>Medical decision making</td>
<td>9</td>
<td>7</td>
<td>23</td>
<td>24</td>
<td>37</td>
</tr>
</tbody>
</table>

Patients' preference vs actual participation

Clinicians' perception vs patients' preference

Moderate agreement (k=0.57), 44% totally match, 33% achieving a more passive role, 21% achieved more active role

No agreement between patients' preferences and their doctors' predictions of those preferences. Agreement in 34 pairs, overestimation in 74 pairs, underestimation in 44 pairs.
<table>
<thead>
<tr>
<th>Author Date</th>
<th>Journal</th>
<th>Country</th>
<th>Participants</th>
<th>Criteria</th>
<th>Patients’ preference (%)</th>
<th>Patients’ actual participation (%)</th>
<th>Percentage of match (%)</th>
<th>Patients’ preference vs actual participation</th>
<th>Clinicians’ perception vs patients’ preference</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Florin, Ehrenberg, &amp; Ehnfors, 2008)</td>
<td><em>Journal of Clinical Nursing</em></td>
<td>Sweden</td>
<td>428 persons, newly discharged from inpatient care, male 60%</td>
<td>Nursing care</td>
<td>5</td>
<td>17</td>
<td>27</td>
<td>29</td>
<td>22</td>
</tr>
<tr>
<td>(Florin et al., 2006)</td>
<td><em>Journal of Clinical Nursing</em></td>
<td>Sweden</td>
<td>76 patient-nurse dyads</td>
<td>Nursing needs</td>
<td>9</td>
<td>30</td>
<td>61</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Physical needs</td>
<td>34</td>
<td>24</td>
<td>41</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Psychosocial needs</td>
<td>25</td>
<td>37</td>
<td>37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Ramfelt, Lützen, &amp; Nordström, 2005)</td>
<td><em>European Journal of Cancer Care</em></td>
<td>Sweden</td>
<td>55 patients with colorectal cancer before surgery</td>
<td>Treatment decision-making</td>
<td>0</td>
<td>71</td>
<td>24</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese population</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>(Zhang et al., 2011)</td>
<td><em>Medical Decision Making</em></td>
<td>China</td>
<td>178 Chinese patients with chronic hepatitis</td>
<td>Treatment decision making</td>
<td>11</td>
<td>45</td>
<td>44</td>
<td>5</td>
<td>30</td>
</tr>
<tr>
<td>(Hou et al., 2014)</td>
<td><em>Chinese Journal of Nursing</em></td>
<td>China</td>
<td>113 colorectal cancer patients in general surgery departments</td>
<td>Treatment decision making</td>
<td>7</td>
<td>25</td>
<td>42</td>
<td>16</td>
<td>12</td>
</tr>
</tbody>
</table>
Patients’ preference for participation was highly variable across studies. In terms of medical or treatment decision making, patient preference for an active role (including the roles of Active and Active-shared) ranged from 0% to 24%, for collaborative role from 21% to 71%, and for the passive role (including the roles of Passive-shared and Passive) from 24% to 75% (Ekdahl et al., 2011; Ernst et al., 2011a; Hou et al., 2014; McTier, Botti, & Duke, 2014; Mohsin-Shaikh, Garfield, & Franklin, 2014; Ramfelt, Lützen, & Nordström, 2005; Wilkinson et al., 2008; Zhang et al., 2011). In terms of nursing care and symptom management, patients’ preference for active role ranged from 9% to 34%, for collaborative role from 24% to 64%, and for passive role from 33% to 61% (Cohen, 2012; Florin, Ehrenberg, & Ehnfors, 2006a; Florin, Ehrenberg, & Ehnfors, 2008; McTier, 2012; Vestala, & Frisman, 2013). Despite the variability in patient preference for participation and the wide range of patients selecting each role preference, active role preference consistently represents the smallest proportion of patients.

Seven studies explored Chinese patient preferences specifically. Five of these studies assessed preference using questionnaires designed specifically for the study, finding that patients had a ‘strong desire’ to participate in activities such as patient safety (Li et al., 2012b; Yu, 2014; Yue, 2014), treatment decisions (Zhang et al., 2010), or nursing care (Zhao, Chui, & Fei, 2007).
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However, it is unclear what is meant by ‘strong desire’ because a clear definition was not provided.

Only two studies focusing on Chinese patients used the CPS to explore preferences. Zhang et al (2011) investigated 178 hospitalised Chinese patients with chronic hepatitis in two provinces of China. The researchers reported that 45% and 44% of patients preferred a collaborative or passive role, respectively, for treatment decision-making; while only 11% of patients preferred an active role. In the other study, 113 Chinese patients with colorectal cancer in general surgery departments were asked about their preference for treatment decision-making (Hou et al., 2014). 42% preferred doctors to make the final decisions. The role of the family in healthcare and more specifically in decision-making, sometimes to the exclusion of the patient, is a cultural norm in China (Li et al., 2014a). In order to capture this, Hou et al (2014) modified the CPS by adding one participatory role statement that specifically asked about preference for family members making decisions and found 27% preferred their family members to make decisions for them. The distribution of Chinese patients’ preferences for participation in treatment decisions were comparable to the findings reported in the International literature, however, given the limited number of studies conducted in China more research is required.
2.2.2.2 Achievement of patients’ preferred participation

Patients’ actual experience of participation in health care and the synergy between patients’ preference and actual experience has been identified as an indicator of patient satisfaction and the quality of care delivered (Brown et al., 2012; Jangland et al., 2012; Pipe et al., 2005; Weingart et al., 2011). Investigation of patients’ achievement of their preferred level of participation has been limited. One study of actual participation was conducted in Germany (Ernst et al., 2011a) and five studies focusing on Australian (McTier, 2012), Swedish (Ekdahl et al., 2011; Vestala, & Frisman, 2013) and Chinese patients (Hou et al., 2014; Zhang et al., 2011) compared patients’ actual achieved participation with their preference.

Congruent with the variability in patients’ preferences for participation reported in the literature, the proportion of patients whose experience matched their preferred level of participation ranged from 20% to 69%. Patients who achieved a more passive role than what they preferred ranged from 28% to 54% or a more active role, ranged from 3% to 39% (Ekdahl et al., 2011; Florin, Ehrenberg, & Ehnfors, 2006a; Ramfelt, Lützen, & Nordström, 2005; Zhang et al., 2011). The large reported ranges and the few studies available make it difficult to assess what factors might have impacted on the enactment of participation at a patients’ preferred level in practice.
Different statistical methods were used to compare preferences to actual experience in these studies. McTier (2012), used a descriptive analysis, and reported a difference between preference and actual experience in decisions regarding pain, medication and pulmonary management. Mohsin-Shaikh (2014) using Wilcoxon tests found patients desired more involvement than they actually experienced about medication-related decision-making among a sample of 100 UK patients. Vestala (2013) found a significant correlation in medical wards using the Spearman rank correlation test and Ekdahl (2011) using Kappa analysis reported a moderate agreement between patients’ preference and achievement. Zhang et al (2011) reported 69% agreement but still concluded based on the results of Bowker’s test of symmetry that there was a significant discrepancy between preferred role in participating and actual role achieved. Despite the different analyses used, all authors concluded that there was a mismatch between patient’s preference for participation and actual experience of participation.

In addition to Zhang’s study that surveyed Chinese patients with chronic hepatitis, Hou (2014), using the CPS, found 63% of patients with colorectal cancer achieved an actual level of participation in treatment decision-making that matched their preferred level and the Kappa value was 0.476, indicating moderate agreement. Hou’s finding about agreement was similar to that of Zhang’s.
Other Chinese studies (n=5) that investigated patients’ actual participation, mostly with study specific-designed questionnaires rather than the CPS, found patients’ behaviour scores were lower than their knowledge and attitudes scores, which indicated that while patients were accepting and supportive of the notion participation, they did not display behaviours required for them to participate (Luo, Wang, & Liang, 2015; Ma, & He, 2005; Ming et al., 2010; Yu, 2014; Yue, 2014). More specifically, despite supporting the notion of patient participation these patients did not want to participate. Whether or not patients’ attitudes (support of the notion of participation) and preferences (desire to participate and display of behaviours characteristic of participation) are consistent is not yet clear, so comparisons between attitudes and behaviour and preference and actual participation should be interpreted with caution. The difference between attitudes and preference needs to be clarified and further comparison between preferred level and actual achieved level of participation in different clinical contexts in China is necessary.

2.2.2.3 Clinicians’ perceptions of patients’ level of participation

The significance of understanding clinicians’ perceptions of patient participation has been gaining momentum. Clinicians’ perceptions of patients’ preference may influence how they interact with patients, present treatment choices and involve patients in decision making. Inaccurate
perceptions of patients’ preference for participating held by clinicians may contribute to the lack of congruence between patients’ preferred and actual participation reported in numerous studies (Elkin et al., 2007; Pieterse et al., 2008).

Three studies reported both patients’ and clinicians’ responses using the CPS and all found low agreement. For example, in Ireland, Wilkinson et al (2008) used the kappa statistic to compare acute medical inpatients’ preferences and their doctors’ prediction of patient preferences. The findings revealed low agreement with 34 pairs (22.4%) in agreement, 74 pairs (48.7%) where doctors overestimated and 44 pairs (28.9%) where doctors underestimated preference. Florin investigated 76 patient-nurse dyads in Sweden and found, using the Sign test to determine if there were differences between the pairs of observations, that patients preferred a more passive role than nurses perceived in decision making about nursing needs, physical needs and psychosocial needs (Florin, Ehrenberg, & Ehnfors, 2006a). Mohsin-Shaikh using Wilcoxon tests also found an overestimation of patients’ preference by 104 clinicians in the UK (doctors, pharmacists and nurses) and 100 patients (Mohsin-Shaikh, Garfield, & Franklin, 2014). These findings suggest that healthcare professionals expected that patients preferred a more active role than patients did. No studies were found that compared clinician perceptions with patients’ reported preferred level of participation in China.
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2.2.2.4 Summary

Studies that have investigated patients’ preference for participation have consistently reported high variability in the extent to which patients want to participate in their care decisions. Further, the majority of patients did not achieve their preferred participation. Less research has explored the accuracy of clinicians’ perceptions of patients’ preferred level of involvement, however, what is known suggests that clinicians overestimate patients’ preferences for active participation. Even less is currently known about Chinese patients’ preferred and actual level of participation and the little research that has been done has focused on treatment decision making. Clinicians’ perceptions of patients’ preference have not yet been investigated in China. A further limitation of the research to date, is the variability in assessment tools used making comparisons across studies difficult.

2.2.3 Predictors of patients’ preference for participation

As reported above, patients vary in their preference for participation in health care decision-making and clinician accuracy in predicting patient preferences is poor. Research into patient participation has also explored patient characteristics associated with an active or passive preference in order to inform judgements about patients’ preferred participation. Forty-four studies reported in the international literature and four studies in China have explored predictors of participation preference. The findings are
discussed in the sections to follow in terms of patients’ demographic characteristics and illness-related factors.

2.2.3.1 Demographic predictors

Age is a commonly explored predictor of participation. Willingness to participate in health care appears to be associated with younger age (Chung et al., 2012; Florin, Ehrenberg, & Ehnfors, 2006a; Frank et al., 2011; Hansson, Fridlund, & Hallström, 2006; Uldry et al., 2013). Two Chinese studies reported that patients aged 20-59 years had the strongest desire to be involved in managing care associated with enhancing patient safety (Li et al., 2012b) and hospital care (Zhao, Chui, & Fei, 2007). Zhang (2011) also reported more active preferences of younger Chinese patients. A study of 35 patients recruited from medical and surgical areas of a large tertiary hospital in Hong Kong that tested patients’ desire for participation in surgical decision making, found the effect of younger age was only significant for male patients (Henderson, Shum, & Chien, 2006) suggesting that gender may be an interacting factor. No correlation between age and preferred role of participation was found in Ekdahl’s (2011) and Wilkinson’s study (2008) studies exploring medical decision making preferences. Ekdahl’s study, however, only focused on elderly patients with an average age of 83 (min-max: 76-98) years, and Wilkinson’s study was interested in acutely ill patients. Both studies reported a relatively high proportion of patients preferring a
passive role. It is possible, that the limited age range in Ekdahl’s study and the impact of illness severity might have confounded the effect of age.

In terms of the impact of gender on patient participatory preferences, females have consistently been reported to be more likely to adopt an active role (Arnetz, & Arnetz, 2009; Chung et al., 2012; Davis, Koutantji, & Vincent, 2008; Florin, Ehrenberg, & Ehnfors, 2008; Mohsin-Shaikh, Garfield, & Franklin, 2014). Two Chinese studies also found more active preferences for participation amongst females participants (Hou et al., 2014; Li et al., 2012b). The effect of gender was found to be age specific in Arnetz’s study (Arnetz, & Arnetz, 2009) in which female patients younger than 70 years of age were more likely to prefer more active roles in their care post myocardial infarction than male patients in the same age range. There are however studies that have failed to confirm gender as a factor predicting preference for participation (Alexander et al., 2012; Ekdahl et al., 2011; Florin, Ehrenberg, & Ehnfors, 2006a; Wilkinson et al., 2008). The inconsistency in reported findings require further studies to explore the effect of gender on patient preferences and determine the real-world utility of predicting patient preference.

Level of education has long been considered to have an impact on patients’ preferences for participation. Patients with higher levels of education have been found to be more willing to participate in their care (Chung et al., 2012;
Davis, Koutantji, & Vincent, 2008; Florin, Ehrenberg, & Ehnfors, 2008; Frank et al., 2011; Hamann et al., 2011; Hansson, Fridlund, & Hallström, 2006; Henderson, Shum, & Chien, 2006; Loeffert et al., 2010; Tak, Ruhnke, & Meltzer, 2013; Uldry et al., 2013). For example, compared with patients with no high school diploma, those with a university or postgraduate degree were reported to be less likely to leave their decisions to clinicians in a USA study (Chung et al., 2012), which was consistent with the findings from a Chinese study (Li et al., 2012b; Zhang et al., 2011). Again however, the effect of education was not a consistent finding. Similar to the findings related to age and sex, Ekdahl failed to find a significant effect of education level on patient preference for participation (Ekdahl et al., 2011). Kolovos (2014a) found through inferential comparative analyses that patients with a higher level of education only reported greater participation in daily activities while those with lower levels of education reported greater participation in decisions related to treatments and schedules, which is in contrast to other studies reported in the literature. By exploring two distinct participatory activities, Kolovos was able to show that specific activities in health care may influence patients’ preference for participation further highlighting the complexity of the operationalisation of patient participation in acute care.

Others factors included in prediction modelling such as marital status, employment status and religion have all been found to have varying success in predicting participation. Living alone may be a factor in patients’
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preference for an active role in clinical decision making (Florin, Ehrenberg, & Ehnfors, 2008) as is patients’ employment status, with patients who are employed more likely to want to participate (Davis, Koutantji, & Vincent, 2008). However, one Chinese study found patients with higher economic or social burden reported a desire to participate more actively (Zhao, Chui, & Fei, 2007). Patients who were religious, especially those who frequently attended religious services, reported wanting their doctors to make decisions for them (Chung et al., 2012).

2.2.3.2. Illness-related predictors

A large number of illness-related factors have been investigated to determine their impact on patient behaviours and preferences for participation in care. Physical performance status has been explored as a factor that may affect patients’ preference for participating in interactions with clinicians; however there is little consensus on its effect. Findings from some studies suggest that patients may want to participate more when they have better physical strength, and being overwhelmed by illness may reduce patients’ desire to participate in acute care (Chung et al., 2012; Cohen, & Botti, 2015; Kvangarsnes et al., 2013; Löfman, Häggman-Laitila, & Pietilä, 2008; Latimer, Chaboyer, & Gillespie, 2014; Lever, O’Reilly, & Pryor, 2008; Malmgren, To¨rnvall, & Jansson, 2014; Mclnnnes et al., 2014; Silva et al., 2012). Chung et al (2012), in their study using multiple regression found a positive
association between patients’ physical performance status and preference for participation. The authors explained that acute or life-threatening illness may promote patient participation in decision making. The finding by Chung is, however in contrast to a large number of study findings that have reported acutely ill patients with poorer health were more likely to prefer to leave decisions to their doctors. Other studies did not find severity of illness or type of surgery as being associated with patients’ desire for participation (Henderson, Shum, & Chien, 2006; Uldry et al., 2013; Wilkinson et al., 2008). It is likely that other subtle factors may play a role in patients’ preference for participation. For example, a Chinese study found that among patients with colorectal cancer, those with a colostomy were more likely to have a passive preference than those without. The possible explanation for this finding provided by the author was that there may have been fewer surgical options available to these patients due to the extent/location of their disease and this may have impacted on the number of treatment options and thus their preference for participation (Hou et al., 2014).

The impact of psychological status has been investigated by exploring the effect of anxiety and depression on participation. Anxiety level was perceived by doctors to be a key barrier to involving patients in decisions because anxiety could prevent logical thought, recall, ability to prioritise and objectivity (Shepherd, Butow, & Tattersall, 2011). This finding does not, however, consider patients’ preference for participation. Preference for
more active participation was found to be negatively associated with scores of depression and anxiety (Schneider et al., 2006). The effect of psychological status on patient preference for or predictors of participation has not been investigated in the Chinese population.

Length of time since diagnosis and disease progression may impact on patients’ preference for participation. Cohen (2012) assessed cancer patients’ Control Preference over a period of five days during a hospital admission and found patients’ preference was relatively stable. This finding suggests that patients might not change their preferred roles within a short period, particularly if their illness/symptoms are stable during the same period. There is, however, evidence that the longer patients have an illness or the greater exposure they have with health care may influence their preference for a more active role. Vestala reported that patients were more likely to participate in nursing documentation if they had been diagnosed for more than five years (Vestala, & Frisman, 2013). Similarly, Li (2012b) found Chinese patients who had been hospitalized three times or more preferred more active participation in safety management than patients during their first admission.

2.2.3.3 Summary

The trend in international research findings is that patients who are younger, female, and with higher levels of education tend to prefer a more active
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Participatory role in various healthcare activities, although these findings are not consistent. Patients with poor physical status, or with anxiety and depression are more likely to prefer more passive participation roles. The stability of patient preference during the trajectory of an illness and short term hospitalisation has also been investigated. Studies of Chinese patient preferences are very limited.

2.2.4 Barriers to patient participation in acute care settings

Comparisons between patients’ preferences for, and actual participation in their care, indicate that patients are not always able to participate in their care as much as they would prefer. This implies that there are barriers to more active preferences for participation in acute care that need to be better understood if patient enactment of participation at their preferred level is to become a reality. Factors that facilitate or block patient participation were investigated in 35 studies conducted in western countries and eight in China. The factors investigated are discussed according to whether they are related to patient, clinician, or context (type of participation or clinical setting) factors.
2.2.4.1 Patient-related barriers

In interviews or surveys of patients’ perceived barriers to participation, patients often attributed their preference for a passive role or poor achievement of participation to lack of knowledge (Eldh, Ekman, & Ehnfors, 2008; Höglund et al., 2010; Löfman, Häggman-Laitila, & Pietilä, 2008; Larsson et al., 2011a; Rainey et al., 2013; Vestala, & Frisman, 2013) or difficulty in understanding information (Malmgren, Törnvall, & Jansson, 2014)(Ekdahl et al. 2011)(Cohen, & Botti, 2015). Patients’ ability to communicate with clinicians has also been reported as an important factor associated with patients’ involvement in care (Löfman, Häggman-Laitila, & Pietilä, 2008; Penney, & Wellard, 2007; Swenne, & Skytt, 2014). In the eight Chinese studies, one (Li, Li, & Yang, 2015) identified through interviews with eight cardiac surgical patients that they lacked knowledge of their role in patient safety management; three studies reported this same barrier but from clinicians’ perspective (Li, Ye, & Jiang, 2012; Yue, 2014; Zhang et al., 2006).

Patients’ beliefs of their role in their treatment or care also influence their behaviours when they interact with clinicians. Some patients did not feel ready to participate (Lever, O’Reilly, & Pryor, 2008) or perceived a power imbalance between them and clinicians (Tobiano et al., 2015b). Patients also reported trust in their healthcare staff and felt they should follow expert advice (Cohen, & Botti, 2015) or allow staff to perform any investigations
needed (Malmgren, To¨rnvall, & Jansson, 2014). Patients who hesitated to ask questions or make requests of clinicians indicated they did not want to trouble the staff (Malmgren, To¨rnvall, & Jansson, 2014; Seale et al., 2015). Other patients also reported choosing not to collaborate with clinicians because they held their own views and participated in care in their own way (Lever, O’Reilly, & Pryor, 2008). Chinese patients, similar to findings in the international research into patient safety have been found to lack of confidence and have concerns about troubling doctors or nurses (Li, Li, & Yang, 2015; Yue, 2014).

2.2.4.2 Clinician-related barriers

The perceived quality of the relationship between patients and clinicians is a widely considered precondition for patient participation, therefore any relationship that lacks encouragement, respect, trust, openness and empathy, has been reported by patients as a barrier to being involved (Eldh, Ekman, & Ehnfors, 2006, 2008; Larsson et al., 2011a, 2011b). This conclusion is also supported by two Chinese studies that explored the perceptions of patients (Ye, 2011) and clinicians (Zhang et al., 2008).

How effectively clinicians involve patients in decision making or nursing care depends on their own perceptions of the role of the patient and how they value patient participation. Poor understanding of patients’ roles from both
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the patient and clinician perspective limits patient involvement because healthcare staff, who are often accustomed to a paternalistic model of care, fail to consult patients thereby preventing them from being involved in their own care other than expecting them to be compliant (Löfman, Häggman-Laitila, & Pietilä, 2008; Larsson et al., 2011a; Lever, O’Reilly, & Pryor, 2008; Li, Ye, & Jiang, 2012; Sahlsten et al., 2005a). The positive effects of clinicians’ acknowledging patients’ rights and initiating interactions with patients have been reported in several studies (Larsson et al., 2011b; Latimer, Chaboyer, & Gillespie, 2014; Malmgren, Törnvall, & Jansson, 2014; Sahlsten et al., 2005a) while insufficient or poor communication by clinicians has been shown to impair patients’ ability to be involved in their own care (McTier, Botti, & Duke, 2015; Ommen et al., 2011). A Chinese study found that some patients perceived clinicians’ dominance as blocking them from making decisions when they attempted to participate in intravenous infusion safety (Yue, 2014). Although decision assistance from doctors and caring assistance from nurses were reported in Zeng’s study of patient participation in intravenous chemotherapy safety (Zeng, & Yan, 2014), detailed description from first-hand data is still limited in China, however, it is likely that many of the barriers reported in the western literature are similar.
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2.2.4.3 Context-related barriers

Constraints related to the context in which care was delivered appeared to influence patient participation. Time constraints have been identified by both patients and clinicians as barriers to patient involvement (Bolster, & Manias, 2010; Cohen, & Botti, 2015; Doherty, & Doherty, 2005; Drach-Zahavy, & Shilman, 2015; Lever, O'Reilly, & Pryor, 2008; Rainey et al., 2013; Sahlsten et al., 2005a). Time pressure not only led to brief interactions with clinicians but also resulted in limited time for patients to digest information before they were required to make decisions (Cohen, & Botti, 2015). Limited time to communicate with doctors was identified by both patients (Zhang et al., 2010) and clinicians in China (Li, Ye, & Jiang, 2012; Zhang et al., 2006; Zhang et al., 2008).

In acute care settings, clinicians usually perform treatment and care based on ward routine and some patients who preferred to be more involved in decisions, especially about their daily activities, such as when they shower or sit out of bed, reported being constrained by routine practice (Malmgren, To¨rnvall, & Jansson, 2014; Sahlsten et al., 2005a; Willard, & Luker, 2006).

Other potential context-related factors relate to the processes of care and opportunities for privacy. Poor continuity of care, common in acute
environments where patients have multiple nurses in a 24 hour period and often multiple doctors involved in their care throughout their admission, means that patients interact with many clinicians reducing their ability to establish rapport and opportunities for involvement (Bolster, & Manias, 2010; Cohen, & Botti, 2015; Doherty, & Doherty, 2005; Ekdahl, Andersson, & Friedrichsen, 2010; Larsson et al., 2011a; Sahlsten et al., 2005a). Sharing rooms with other patients can have both positive and negative consequences on patient participation. On one hand, it limits patients’ opportunity to have a private conversation with clinicians so they may withhold important information, particularly if it is considered intimate or embarrassing. On the other hand, sharing rooms offers the opportunity for patients to exchange information and gain support from peers (Larsen, Larsen, & Birkelund, 2014).

In China, family members are usually key care givers during patients’ hospitalisation. In the study by Yue, the influence or involvement of family members was regarded by patients as a factor blocking patient participation (Yue, 2014) because clinicians consulted with the family to provide diagnosis information and to establish treatment plans rather than the patient.

**2.2.4.4 Summary**

Patients’ opportunities to participate in acute health care settings are influenced by patient, clinician and context related factors. Research has
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provided some insights into the barriers to patient participation and some of these barriers have also been shown in the Chinese context. The influence of clinicians’ behaviours and the unique context of care including hospital routines and ward environments have not yet been investigated in China.

2.3 Evaluation of patient participation research in China

The 47 research papers identified that have reported on aspects of patient participation in Chinese acute care settings reflects the evolving recognition of this aspect of health care in mainland China. There are, however, significant limitations to our understanding of patient participation, strategies for improving participation and application of assessment tools.

2.3.1 Knowledge of patients’ and clinicians’ understanding and experience

Although 47 Chinese studies reported different aspects of patient participation, knowledge of perceptions of, preferences for and experience of participation of patients and clinicians in China is limited. Only three qualitative studies have explored patients’ (Ye, Liu, & Liu, 2013) and clinicians’ (Li, Ye, & Jiang, 2012) perceptions of patient participation in patient safety and patients’ experience and needs in regards to informed consent for surgery (Yu, 2014). The complexity of the concept of patient participation requires a comprehensive exploration. Qualitative studies that allow for a
more in depth exploration of patients’ and clinicians’ understanding of and experiences of patient participation in care are needed in order to plan effective interventions.

2.3.2 Limited strategies for promotion of patient participation

The outcomes of interventions designed to improve patient participation were reported in 16 studies. These studies aimed to increase patient participation in nursing care. Patients in the intervention group were provided with additional care information, encouraged to perform self-care and followed up more frequently when they were discharged, compared with control groups (Guo, 2013; Jiang, Liu, & Wang, 2007; Li et al., 2014b). In interventions for patient participation in safety management, patients were mostly encouraged to contribute to identity checking and monitoring as well as obtaining safety information (Guan, Lin, & Long, 2014; Li, 2014; Wan, & Wan, 2013; Zhou, Huang, & Zhang, 2012). To date initiatives to increase patient participation are limited and tend to focus on one aspect of care.

In some studies, patients were involved in the development of nursing-care plans and actual nursing care (Jiang, Liu, & Wang, 2007; Liu, Chan, & Chan, 2005) or rehabilitation plan discussion (Tan, & Yang, 2009). Although these strategies were found to be effective, the authors did not provide detailed explanation of how nurses incorporated patients’ opinions when preparing nursing-care plans, what the specific processes and strategies of
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Communication between clinicians and patients were, and how patients were involved when nursing care was provided to them. Without illustration of the processes for including patients these interventions cannot be replicated nor findings generalized.

Additionally, in studies examining the effects of these interventions on patients’ actual participation, the level of perceived participation was seldom measured as the dependent variable (Guo, 2013; Jiang, Liu, & Wang, 2007; Li et al., 2014b; Mei, 2013; Tan, & Yang, 2009). The lack of evaluation of the effects of an intervention on actual participation weakens these studies.

### 2.3.3 Inconsistency in use of assessment tools

Five papers reported the development of assessment tools related to patient participation. Four of the tools were designed by the authors: the *Patient Satisfaction with Participation in Medical Decision-making Scale* (Xu, 2010), the *Patients’ Expectation of Participation in Medical Decision Making Scale* (Xu et al., 2012), the *Patients to Participate in Hand Hygiene Promotion in Medical Institutions* (Zhang et al., 2015) and the *Patient Participation in Patient Safety Willingness and Behaviour Scale* (Li et al., 2015) The questionnaire: *Patients’ Involvement and Patients’ Attitude on Safety* was modified from an existing Chinese tool (Yang et al., 2013).
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In addition to these tools, that were developed or modified in the Chinese context, there were other tools that measured patient participation that have been shown to have good validity and reliability in Chinese populations (Ding, 2011; Henderson, Shum, & Chien, 2006; Ma, 2004; Shen, 2010); however, these tools have not been used widely in the Chinese studies that fit the inclusion criteria for this review. The ability to compare Chinese patients’ preferred and actual level of participation in specific treatment and nursing activities with those of international studies is limited because of the tendency for authors to use their own purposefully-designed tools rather than validated tools.

2.4 Conclusions

Studies conducted outside of China, predominately in western countries, through qualitative methods, have explored the concept of patient participation from patients’ and clinicians’ perspectives. Patients’ preference for participation has most often been investigated quantitatively using the Control Preference Scale. This research has expanded our understanding of patients’ experience of participation and factors that either facilitate or block patients’ ability to participate at their desired level.

In the past decade, 47 papers have been published on the topic of patient participation in acute care settings in China. One-third of these studies aimed
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to improve patient participation with targeted interventions. Areas that have received little research focus include the perceptions of patient participation from both patients’ and clinicians’ perspectives. More widely used, validated measurement tools need to be applied to Chinese populations to enable comparisons both within China and internationally.

The clinical context of patient participation in treatment or care and decision-making has been explored in western countries, however studies in oncological symptom management are very limited worldwide and non-existent in China. Chinese patients appear to share understandings with western populations related to their participation in decision-making and information sharing, and some of the demographic predictors and patient-related barriers, however these potential similarities are based on limited research in China. It is not clear how perceptions and participatory experiences of patients and clinicians in Chinese clinical settings may vary. Questions that need to be addressed include for example: how do patients and clinicians interact in clinical settings? What are patients’ and clinicians’ perceptions of patient participation in hospital care, especially in cancer symptom management? How much do patients prefer to be involved and how much are they actually involved during cancer symptom management? Why do patients prefer certain participatory roles and what factors facilitate or block achievement of these preferences?
Interactions between clinicians and patients, considered fundamental to patients’ ability to participate, are likely to be dependent on shared perceptions of the notion of participation between patients and clinicians. Few studies worldwide have explored discrepancies between clinicians’ and patients’ understanding of the concept of patient participation highlighting that clinicians were poor at predicting patient preference for participation. This has not been studied in China nor in the context of cancer symptom management worldwide.

In summary, Mainland China is a country currently facing extensive change within its healthcare system. The significance of patients participating in their own health care has been recognised but acknowledgement of this concept and the enactment of patient participation at their desired level are not the same. What is needed is a better understanding of patients’ perceptions of participation, the distribution of patients’ control preferences within acute care settings and in the specific context of symptom management, as well as barriers and enablers to participation. This knowledge is necessary to inform evidence-based, context valid interventions to promote patients’ ability to participate in their care in China and improve health care delivery in terms of patient safety and care quality.
CHAPTER THREE

The research program and methods

Patient participation is a multifaceted and complex phenomenon, dependent on interactions between patients and clinicians as well as the clinical and cultural context. This research program has as its focus, patients’ and clinicians’ perceptions of patient participation, the synergies in perceptions, and how patient participation is enacted in an acute cancer care setting in Shanghai, China, to enhance understanding of the facilitators and barriers to promoting optimal involvement of cancer patients in their treatment and nursing care.

In this chapter, the research program and methodological approaches used are described. The chapter is divided into three sections. In the first section, the research program, conceptual framework and research design are outlined, followed by a detailed description of the research setting and participants and a discussion of the issues of external validity. The methodological approaches used together with the description of the procedures and analyses are also presented. The ethical considerations related to the research are reported in the final section of this chapter.
3.1 The research program

The purpose of this concurrent, mixed methods research was to advance our understanding of the enablers and barriers to patient participation in symptom management in acute cancer care environments. The focus of this research was on exploring the synergies between patients’ and clinicians’ perceptions of patient participation within a Chinese acute cancer care setting. The research was conducted as a single institutional case study. Mixed methods included survey, semi-structured interviews and naturalistic observations to address the following research questions:

1. How do patients and clinicians perceive and experience patient participation within the context of symptom management?

2. What are the synergies between patients’ and clinicians’ perceptions and experience of patient participation?

3.1.1 Aims and objectives

Aim 1: To explore patients’ and clinicians’ perceptions of patient participation in symptom management.

Using survey methods, the specific objectives were to:

1. Describe and compare how patients, doctors and nurses rate the importance of participatory activities in symptom management;

2. Describe and compare how patients, doctors and nurses rate patients’ actual participation in symptom management;
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3. Describe patients’ control preference in relation to participation in symptom-related decision-making;

4. Calculate the congruence between patients’ preferred and actual participation in symptom management;

5. Analyse patient-related factors that are associated with patients’ preference for participation in symptom-related decision-making;

6. Analyse associations between preference and experience of participation in decision-making, and patients’ perceptions of care quality and satisfaction with symptom management.

In a subset of the surveyed patients, doctors and nurses, semi-structured interviews were conducted to:

7. Probe patients’, doctors’ and nurses’ understanding of participation and patient roles in symptom management;

8. Probe patients’, doctors’ and nurses’ experience of facilitators and barriers to participation in symptom management;

9. Identify the factors patients consider when describing their particular control preference for participation in symptom-related decision-making;

10. Compare and contrast quantitative and qualitative data to identify any similarities or differences between patients’ and clinicians’ understanding and perceptions of patient participation.
Aim 2: To explore patients’ and clinicians’ behaviours during interactions related to symptom management.

Using naturalistic observation and survey methods, the specific objectives were to:

1. Describe how and under what circumstances patients communicate with clinicians during interactions related to symptom management;
2. Identify clinicians’ communication behaviours that facilitate or impede patient participation during interactions related to symptom management;
3. Analyse the congruence between clinicians’ and patients’ perceptions of preferred and actual participation in symptom-management related decision-making.

3.1.2 Conceptual framework

The conceptual framework for this research program was derived from Entwistle and Watt’s framework (Entwistle, & Watt, 2006), *Patient involvement in treatment decision making*, which was developed from a conceptual review of the literature. In Entwistle and Watt’s framework, both clinician and patient perspectives were incorporated into seven domains: patients’ efforts and contributions relating to decision making; patients’ views and feelings about their role; efforts and contributions in relation to decision-making; clinician-patient communication relating to decision-
making; patients’ views and feelings about their relationship with their clinician(s); clinicians’ efforts and contributions relating to decision-making; clinicians’ views and feelings about their role, efforts and contributions relating to decision-making, and, clinicians’ views and feelings about their relationship with the patient. This broad conceptual framework reflects the multidimensionality and complexity of the concept of patient involvement in their care. Importantly this framework acknowledges the contribution from both patients and clinicians.

The adapted conceptual framework for this research, “Patient participation in acute oncological symptom management” (see Figure 3.1), focuses on the interactions and synergies between patients and clinicians. Four key concepts make up the inner circle of the framework. Two of these relate to patients’ and clinicians’ understanding of, and attitudes towards, patient participation in symptom management in acute care settings and were explored and compared in this study using survey and interviews. The other two concepts in the inner circle were patients’ and clinicians’ behaviours during symptom management. These behaviours were investigated using survey and non-participant observation during patient and clinician interactions.

The outer circle displays another four concepts: patients’ preference for participation in decision-making, clinicians’ perceptions of patients’ preference for decision-making, patients’ actual experience of participation
in decision making and clinicians’ perception of patients’ actual participation in decision-making. Patients’ preference and actual experience were assessed through survey and compared to identify whether patients were able to achieve their desired level of participation. Clinicians’ and patients’ perceptions of the degree to which patients participated during a patient-clinician interaction were also compared to examine the extent to which clinicians were able to assess patients’ preferred and actual level of participation.

Central to the conceptual framework are patients’ demographic characteristics, diagnoses and treatments, symptom profiles and health literacy as well as doctors’ and nurses’ demographic characteristics and work experience. These factors were indicated in the literature as important variables to measure when exploring patient participation (Legare et al., 2011; Mathews, Secrest, & Muirhead, 2008; Pierce, & Hicks, 2001; Strauss, & Thomas, 2012).
Chapter 3 The research program and methods

3.1.3 Research design

The notion of patient participation in symptom management in acute care settings is complex and requires an exploration from various perspectives and dimensions. The research program reported in this thesis employed a concurrent, mixed methods design with both qualitative and quantitative data collection methods (survey, semi-structured interview and naturalistic observation).
The choice of methodology was justified by the complexity of the concept of participation that demanded the use of a multifaceted approach to advance understanding and insights (Andrew, & Halcomb, 2006; Halcomb, & Andrew, 2009). Mixed methods design provides the methodological strengths of both quantitative and qualitative research with the advantage of the complementarity of both approaches and enhancement of the validity of the findings (Polit, & Beck, 2012). This design was chosen for the purpose of comparing the quantitative results with qualitative data in order to achieve corroborated and valid findings. The design also enabled the synthesis of complementary data for a comprehensive understanding of the issue of interest (Creswell, & Clark, 2011).

The research was conducted in one hospital using a single case study framework. The case study approach is considered appropriate to answering questions such as “how” or “why” and allows real-life phenomena to be investigated *in situ* (Yin, 2009). A case study allows for analyses to be multi-perspective, and in this research this involved investigation of both the voice of participants (patients and clinicians) as well as the interactions between them (Tellis, 1997). Although the case study in this research (one hospital) was not randomly selected, data generated from an individual case is most often in-depth and can resonate with readers as they reflect on their own experiences, a process known as "naturalistic" generalization (Stake, 1995).
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The enactment of patient participation in everyday interactions between patients and clinicians in acute cancer care is complex. The case study approach provided an opportunity to derive insights into the complex activities associated with incorporating patients as participants in symptom management during a hospital admission. As this study was a primary exploration of the phenomenon of patient participation in the Chinese acute cancer care setting, selecting the case was critical to maximizing the knowledge obtained during the time available for the study.

The study was conducted in two phases: 1) patient and clinician interactions related to symptom management and 2) exploration of patients’ and clinicians’ (doctors and nurses) perceptions of patient participation. The research design and procedures for the two phases are summarised in Figure 3.2 and Figure 3.3.

Phase 1 involved naturalistic observation of doctor-patient and nurse-patient interactions, with a specific focusing on examining discussions related to symptom management. The naturalistic observation was conducted first (Phase 1) because there was a concern that clinicians may change their behaviours if they had the opportunity to explore the notion of participation through interviews and surveys (i.e. the potential for Hawthorn effect). The limitation of conducting the observations in Phase 1 meant that data derived from the other methods (survey and interview) could not inform the observations. Full analysis of the observed interactions occurred after the
analysis of clinician and patient perceptions of the meaning of participation. Consequently, the findings from the observations were not used to inform the questions in the survey or interview components of this research program. This decision was in part due to the time constraints during the data collection period. Data from all methods were triangulated to add depth to the analysis and reduce the limitations associated with the sequential collection of data in this research program. The numbering of the phases was required only to differentiate the order in which data were collected.
Phase 1 Exploration of Clinician-Patient Interactions

Exclusion
- Non-registered staff (e.g., interns, nursing students, and patient care assistants)

Eligibility

Inclusion
- Registered doctors or nurses working in one of the units

Clinician recruitment
- Participant Information and Consent Form provided to clinicians at the Ward Information Session

Patients could be re-approached later during the data collection period

Written consent

Verbal consent

Exclusion
- Cognitive impairment
- Too unwell

Inclusion
- 18 years or older
- Cancer diagnosis and undergoing treatment
- Length of stay in hospital ≥ 7 days

Patient recruitment
- Primary nurses discussed the study with eligible patients’ and disclosed names of interested patients to the researcher
- Patients had the details of the project explained by the researcher

Naturalistic observation
- Doctor-patient interactions during morning medical ward rounds
- Nurse-patient interactions during morning nursing ward rounds and intensive (high frequency patient contact) working hours

Control Preference Scale
- Brief survey with the Control Preference Scale in doctor-patient dyads and nurse-patient dyads

Figure 3.2 Research design and procedure (Phase 1 exploring interactions)
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**Phase 2 Exploration of perceptions of patient participation**

**Doctor/Nurse questionnaire including:**
- Demographic and work experience information
- Clinicians’ Views and Behaviours about Patient Involvement in care (modified)-Doctor/Nurse Version

**Doctor/nurse subgroup interview**
Doctors and nurses were purposefully selected to ensure a range of experience.
- Understandings of, and attitudes towards, patient participation in symptom management
- Facilitators and barriers to involving patients in symptom management

**Consecutive patients admitted to the one of two hospital wards between 11 Nov 2013 to 25 Jan 2014**

**Exclusion**
- Cognitive impairment
- Too unwell
- Participation in study during a previous admission

**Inclusion**
- 18 years or older
- Cancer diagnosis and undergoing treatment
- Length of stay in hospital ≥ 7 days

**Patient recruitment**
- Primary nurses discussed the study with eligible patients and disclosed names of interested patients to the researcher.
- Participant Information and Consent Form provided to patients

**Written consent**
- No
- Excluded
- Yes

**Patient subgroup interview**
Patients were selected for interview according to their Control Preference
- Reasons for their preferred control roles
- Understandings of and attitudes towards patient participation in symptom management
- Facilitators and barriers to being involved in symptom management

**Figure 3.3 Research design and procedure (Phase 2 exploring perceptions)**
3.1.4 Research setting

This study was conducted in the Fudan University Shanghai Cancer Centre. This Cancer Centre has been designated as Grade A tertiary level, indicative of the highest level hospitals by the Chinese Ministry of Health. The setting for the case study was two medical oncology units in the Cancer Centre. All patients admitted to these two units receive radiotherapy and/or chemotherapy for their cancer.

The Fudan University Shanghai Cancer Centre was chosen because it is a well-known oncological specialty hospital in China. In 2009 it had 1,100 beds with an annual out-patient visit load of 592,441 and annual in-patient admissions of 22,515 (FUSCC, 2009). Patients were recruited from the medical oncology units because treatments with radiotherapy and/or chemotherapy are associated with numerous side effects (Ciura et al., 2011; Clark et al., 2011; Li et al., 2012a). Effective symptom management is one of the critical goals of these units. The average length of stay in the units at the time of data collection was 30 days (i.e. for the duration of radiotherapy treatment). During their admission, patients had the opportunity to become accustomed to the hospital system and ward and the model of Attending in Charge\(^1\) and Primary Nursing that promotes the building of relationships and

\(^1\) Attending in Charge: It is a type of medical model. There are 3-4 medical groups in a unit. Each medical group consists of one Attending Physician, 1-2 Fellow(s) and several Resident Medical Officers (RMO). The medical group, led by the Attending Physician, is responsible for the diagnosis and treatment processes including clinical consultations, admission, operations, consultation arrangements and follow up visits.
rapport between patients and clinicians during medical treatment and nursing care activities. In summary, these units were chosen because of the model of nursing and medical care, the long length of patient stay and the complexity of care. These factors were considered ideal for gaining insights into the processes of patient participation in symptom management.

### 3.1.5 Research participants

This project involved two groups of participants: patients and clinicians (doctors and nurses).

#### 3.1.5.1 Patients

Patients were eligible if they were over 18 years of age and admitted with a cancer diagnosis to one of the two medical oncology units. Patients were recruited into the study if they had been in hospital for seven days or longer. One of the reasons for recruiting patients at this time point was to ensure that patients had sufficient time to become familiar with the hospital processes such as routines of care, and to the ward environment in general. Another reason was that this time period provided an opportunity for patients and clinicians to establish a therapeutic relationship. Patients were not included if they had a cognitive disorder such that they could not communicate with the research staff. Those who had participated in this study during a previous admission were not eligible to participate during subsequent admissions.

Primary Nurses were all provided information about the study. Each day the
primary nurses reviewed the eligibility of the patients for whom they were providing care and asked patients who met the inclusion criteria for their permission to be approached by the researcher. The primary nurses provided the final list of eligible patients to the researcher.

At the first meeting with eligible patients, the researcher introduced herself and explained the study. Verbal consent was obtained for patients recruited into Phase 1: *exploring patient and clinician interactions*. For patients recruited into Phase 2, *exploring patients’ and clinicians’ perceptions*, they were given a copy of the Participant Information and Consent Form and asked to provide written consent. Patients consenting to Phase 2 were informed that participation involved taking part in a survey and, depending on eligibility they might also be invited to participate in a semi-structured interview. All patients who consented were recorded in the research ledger in terms of their name and time/date of consent. Every patient was assigned an ID number that was also recorded in the research ledger. If patients did not want to participate, they were asked to provide a brief reason.

### 3.1.5.2 Clinicians

The term ‘clinician’ in this study refers to both doctors and nurses. All the doctors and nurses who formed the major workforce on the nominated units were eligible and invited to participate in the study. Non-Registered staff, that is, nursing students and patient care assistants were excluded.
An invitation letter was sent to the doctors and nurses via email, informing them of the study and the time and location of the information sessions. Two separate information sessions were held in each of the two units, during which the researcher introduced herself, the research team, the purpose of the study and the requirements of participation. A copy of the Plain Language Statement and Consent Form was provided to clinicians who indicated interest in participating. The head nurse on each ward approached doctors and nurses who could not attend the Information Sessions or who were new to the unit, to ask permission for the researcher to approach them, explain the study and seek consent.

3.1.6 External validity

The case study design requires consideration of potential factors that might influence the generalizability of the findings to other comparable acute oncology settings (Yin, 2009, p. 43).

In the two medical oncology units chosen, the diagnoses of patients were mostly head and neck, rectal or breast cancer. The limited case-mix on the ward meant that there were specific symptom profiles with particular management protocols that staff were familiar with and this could influence patients’ and clinicians’ perceptions of patient participation in symptom management practices. The data however, were collected in real-world settings from patients at different times in their illness and treatment stage. For example, according to the treatment protocol for head and neck cancer,
such as nasopharyngeal cancer, radiotherapy is the main and preferred treatment method for both early and advanced stages. Further, for most patients diagnosed with rectal or breast cancer, radiotherapy usually followed surgery and chemotherapy.

Nursing shortages during the data collection period meant that nurses in their first two years of practice were assigned as primary nurses. Normally several years of experience is required before a nurse is eligible to become a primary nurse. This meant that less experienced primary nurses were managing patient symptoms. In addition, senior primary nurses usually had teaching tasks in addition to primary nursing. Therefore, when providing patient care, there were often several nursing students or new employees present and the senior nurses had to provide opportunities for these learners to practice. These factors may have affected patients’ perceptions of the patient-nurse relationship and development of rapport.

The majority of the Resident Medical Officers (RMOs) were trainee doctors from various hospitals nationwide (i.e. they were doctors undergoing specialty training in oncology) and interns in their first or second year of training who rotate onto different units every two or three months. The medical staff turnover meant residents were relative novices and this might have influenced their decisions relating to symptom management. Although all the Consultants and Chief were permanent staff, they were involved in outpatient consultation in addition to their inpatient load so had limited time
to spend on the wards.

The reputation and specialist nature of Fudan Cancer Centre means that patients receiving treatment can be from any province in China. Consequently, the diversity of patients in terms of their socio-economic status, education level and number of local dialects spoken is likely to be higher when compared to other acute care inpatient wards. It is normal in acute care settings to provide care to a wide range patients from different backgrounds therefore while the amount/type of diversity may be different it is likely that other units would have comparable issues.

These ward and clinician characteristics influence the quality of interactions between patients and clinicians during the management of cancer-related or treatment-related symptoms and may have implications for the external generalizability of the findings.

3.2 Methods

The methodological approaches used in the two phases of the research program are described in detail below.

3.2.1 Phase 2 exploring perceptions of patients and clinicians

In the phase exploring perceptions of patient participation in symptom management, a survey and semi-structured interviews were conducted.
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3.2.1.1 Survey

Both patients and clinicians (doctors and nurses) were invited to complete a purposefully designed questionnaire to gain data about their preferences and views about patient participation in symptom management.

3.2.1.1.1 Patient Survey

3.2.1.1.1.1 Design: patient survey

Patients’ preference for and actual perception of participation in symptom management was assessed using the Control Preference Scale (CPS) (Degner, Sloan, & Venkatesh, 1997; Zhang et al., 2011). The CPS was modified for this study so that each role statement asked patients about their preference for participation in “symptom management” with “doctors and nurses”.

In addition to the CPS, The Patient Participation in Symptom Management-Patient Questionnaire (PPSMPQ) is a compilation of a number of existing and purposefully designed tools for this research program. It consisted of six sections: demographic and cancer information, symptom burden, participation, understanding health, satisfaction with symptom management, and quality of care. The specific tools used in each sections are outlined in detail in section 3.2.1.1.3 and displayed in Appendix 4.

3.2.1.1.2 Sampling: Patient survey

Consecutive sampling was used to recruit patients during the data collection period from November 2013 to January 2014. Consecutive sampling is
regarded as the best option of all non-probability techniques because all accessible subjects who meet the inclusion criteria over a specified period are included. This method is more likely to derive a sample that is representative of the target population and reduces the risk of selection bias (Polit, & Beck, 2012).

Of primary interest was patient preference for, and perception of actual participation in symptom management which was assessed using the modified CPS. The sample size was chosen to allow a reasonably accurate estimate of the proportion of patients whose actual participation would coincide with their preference. Using the data from Cohen’s (2012) study into patient participation in symptom management it was estimated that the proportion of patients with concordance between their preference and actual experience of participation would be approximately 40%. Following the approach of Krishnamoorthy and Peng (2007), to calculate a 95% confidence interval for the proportion with a half-width of 8%, the required number of patients was 142. This figure was rounded to 150 to allow the identification of a proportion between 32% and 48%.

3.2.1.1.3 Data collection procedures: Patient survey

Once patients had provided written consent, the CPS was administered in person by the researcher. Patients’ responses were recorded in the CPS survey table alongside participant ID, survey date and time.
On completion of the CPS, patients were provided with a hard copy of the PPSMPQ, had the instructions read to them by the researcher and were then asked to self-administer the questionnaire. The questionnaires took patients approximately 30 minutes to complete. Patients had the option to complete the questionnaire over several periods if they felt too tired to finish it at one time. The researcher was available if patients had questions or did not understand the instructions. Some patients, due to low literacy or sight problems, required assistance to complete the questionnaire. Questionnaires were reviewed for completeness on collection to minimise missing data.

3.2.1.1.2 Clinician survey

3.2.1.1.2.1 Design: Clinician survey

Clinicians’ perceptions about patient participation and their behaviours during symptom management were also explored using survey methods. The questionnaire for clinicians had two versions: The Patient Participation in Symptom Management-Doctor Questionnaire (PPSMDQ) (Appendix 5) and The Patient Participation in Symptom Management-Nurse Questionnaire (PPSMNQ). Both versions consisted of two sections. Section 1 included questions to elicit demographic and work experience information, such as age, sex, medical education, oncology training experience, job title, role on ward, length of employment in the radiotherapy unit and length of experience working in oncology. To facilitate higher levels of accuracy and
completion the nurse and doctor versions were customised to their possible professional roles and training. Section 2 was designed to investigate clinicians’ views and behaviours relating to patient participation. One of the tools used in the patient questionnaire (Views and Behaviours about Patient Involvement in care (modified) – see section 3.2.1.1.3.7) was adapted to capture doctors’ and nurses’ perspectives as well as allow comparisons between patients and clinicians.

3.2.1.1.2.2 Sampling: Clinician survey

As with the patient survey, clinicians were recruited via consecutive sampling. All doctors and nurses who worked on one of the two wards during the data collection period from September 2013 to January 2014 were invited to participate.

3.2.1.1.2.3 Data collection procedures: Clinician survey

The clinician survey period commenced immediately after the naturalistic observations to avoid missing clinicians who rotated out of the unit.

Clinicians were given a hard copy of the questionnaire. The questionnaires were identifiable by clinicians’ ID number so that clinicians could be followed up if they did not return a completed questionnaire. The questionnaire took approximately five minutes to complete which resulted in a number of clinicians completing them immediately after receiving it. Clinicians who could not fill it in immediately were reminded to return the completed questionnaire to the researcher in the following few days.
3.2.1.1.3 Survey measurement tools

The measurement tools used in the PPSMPQ and clinician survey are explained in detail in this section.

3.2.1.3.1 Control Preference Scale (CPS) (modified)

The CPS is used to elicit patients’ preference for their level of participation in healthcare decisions. It originated from a grounded theory study that developed the control preference construct. The definition of control preference is “the degree of control an individual wants to assume when decisions are being made about medical treatment” (Degner, Sloan, & Venkatesh, 1997). The CPS comprises five cards. Each card has a separate statement that portrays a role that patients could have in treatment decision-making, ranging from the patient making the decision alone (Active), patient making his/her own decision after considering doctors’ opinion (Active-shared), patient sharing the responsibility with doctors (Collaborative), doctors making the decision after considering a patient’s opinion (Passive-shared) and doctors making the decision alone (Passive). Despite the original card design, the CPS has also been validated as a paper and pencil tool (Ford, Schofield, & Hope, 2003). Patients are asked to rank the five statements in order of role preference.

The CPS has reported reliability in cancer populations (Brown et al., 2012; Degner, & Sloan, 1992). It has been shown to be easily understood by patients and has been translated into different languages, including Chinese.
The CPS has been mostly used in studies concerning medical treatment decision-making (Gong et al., 2011; Singh et al., 2010), but has also been used in varied health-related contexts, such as cancer care (Florin, Ehrenberg, & Ehnfors, 2006a), and hospital discharge destination decisions (Popejoy, 2011).

In this research, the CPS was modified to investigate decision-making in symptom management. During Phase 1, Patients and clinicians were asked to select both patients’ preferred and achieved Control Preference roles. During Phase 2 where patients’ and clinicians’ perceptions of participation were explored, patients were given role statement cards. Patients used the CPS: 1) To rank the roles according to their preference from most preferred to least preferred role, and 2) To select the card that best reflected their actual participation. Copies of the CPS used in Phase 1 and 2 are presented in Appendix 6.

3.2.1.3.2 Memorial Symptom Assessment Scale (MSAS) (modified)

The MSAS is a multi-dimensional instrument used to assess 32 common cancer-related symptoms. Symptoms are rated in terms of presence, frequency, severity and distress experienced during the past week. Frequency is scored using a Likert scale from 1 to 4: ‘rarely’, ‘occasionally’, ‘frequently’ and ‘almost constantly’. Severity is rated on a four-point Likert scale (1-4): slight; moderate; severe and very severe. Distress is measured on a five-point Likert scale (0.8 – 4) (not at all; a little bit; somewhat, quite a bit
and very much) (Portenoy et al., 1994a).

For the purpose of this study, the MSAS was modified in the following ways. First, in Part 1, for all symptoms, patients were asked whether they had experienced the symptom during the past 24 hours rather than the past week in order to capture patients’ current symptom burden. The change in timeframe was to enable more in-depth exploration in relation to patients’ preference for participation in symptom management. Symptoms in Part 2 of the MSAS, including hair loss and changes in the way food tastes, are not transient so the original timeframe ‘during the past week’ was unchanged. Two of the symptoms in this section however, mouth sores and/or constipation, were modified to ask whether the symptom was present in the past 24 hours. The timeframe for assessment for these two symptoms was changed because they are both amendable to pharmacological treatment. Second, one of the symptoms in the original list of 32 ‘lack of sexual desire or interest’ was removed because patients were recruited during an episode of hospitalisation. Third, fatigue, reflux and fever were added to the list of symptoms. In the original tool, lack of energy is assessed in clinical practice. Lack of energy and fatigue are two terms used interchangeably by both health professionals and patients (Chang et al., 2000a; Cohen, 2012). Thus fatigue was added to identity whether patients in this study interpret these two terms differently. Finally, in addition to asking patients about the frequency, severity and distress of all symptoms that they experienced,
patients were asked if their doctors or nurses were aware of that symptom.

There are four subscales in the MSAS: 1) the Global Distress Index (MSAS-GDI), an indicator of overall symptom distress. This index is the average of the frequency of four prevalent psychological symptoms (feeling sad, worrying, feeling irritable, and feeling nervous) and the distress of six prevalent physical symptoms (lack of energy, pain, lack of appetite, feeling drowsy, constipation, dry mouth); 2) the Physical Symptom subscale (MSAS-PHYS), the average of the frequency, severity and distress associated with 12 prevalent physical symptoms (lack of energy, pain, lack of appetite, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness); 3) the Psychological Symptom subscale (MSAS-PSYCH), the average of the frequency, severity and distress of six prevalent psychological symptoms (worrying, feeling sad, feeling nervous, difficulty sleeping, feeling irritable, and difficulty concentrating), and 4) the Total Symptom Score (TMSAS), the average score of all the symptoms in the MSAS (Chang et al., 2004).

The MSAS has been shown to have good validity in various cancer populations, for example American (Chang et al., 1998) and Turkish (Yildirim et al., 2011). It has also been translated into Chinese and its validity has been tested with Hong Kong cancer patients by Cheng et al (2009). The reported content validity (CVI) and semantic equivalence CVI were both 0.94 in the Chinese version of the MSAS (MSAS-Ch). Construct validity was confirmed
with a good fit (goodness-of-fit indices all above 0.95). The MSAS also displayed a moderately high internal consistency for the reliability of subscales and total scale with Cronbach’s alpha coefficients ranging from 0.79 to 0.87. The MSAS-Ch has been used to assess symptoms during cancer therapy and has proved to have satisfactory validity and reliability in Chinese-speaking patients in the early post-treatment stage. In the current program, the MSAS-Ch was modified slightly to be presented in simplified Chinese to enable it to be more easily understood by patients in Mainland China.

3.2.1.3.3 Hospital Anxiety and Depression Scale (HADS)

The HADS is designed to measure depression and anxiety (Zigmond, & Snaith, 1983). There are 14 items in the scale, with two seven-item subscales. Each item is measured using a 0-3 point scale, ranging from not being present to extreme presence. Total scores in each subscale range from 0 to 21 indicating the severity of depression and anxiety. A wide range of cut-off values have been proposed in the literature using various populations. Looking specifically at the thresholds suggested for cancer patients, anxiety varied from 7 to 10 and for depression from 5 to 10 (Bjelland et al., 2002; Zhang, 2012 #1987; Singer et al., 2009). The most frequent cut-off scores for both the anxiety and depression subscales were ≥ 8 (Bjelland et al., 2002) and this was the cutoff used in this study.

The HADS has high sensitivity (80%) and specificity (88%) (Wu, & Kelley,
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2007). The HADS is available in several languages and has been translated to Chinese and tested on older adults in Hong Kong (Tang et al., 2004); chronic obstructive pulmonary disease patients in Hong Kong and coronary heart disease patients in Xian (Wang et al., 2009). Wang et al., (2009) reported the Chinese version of HADS (HADS-Ch) had high internal consistency with a Cronbach’s alpha of 0.85 and satisfied the intra-class correlation coefficient of 0.90.

3.2.1.3.4 Eastern Co-operative Oncology Group Performance Status (ECOG-PS)

The ECOG-PS was developed to assess subjective patient responses to treatment and is used widely among oncology populations (Conill, Verger, & Salamero, 1990; Oken et al., 1982; Sørensen et al., 1993). “Performance status is an assessment of patients' actual level of function and capability for self-care.” (Sørensen et al., 1993, p. 773) It is a significant indicator of progression and quality of life in cancer treatment (Oken et al., 1982).

The ECOG scale has six values ranging from 0 to 5 where 0 is described as “Fully active and able to carry on all pre-disease performance without restriction”, 4 refers to “Completely disabled and cannot carry on any self-care” and 5 represents death (Oken et al., 1982, p. 654). Previous research has shown that the scale’s validity and reliability varies according to whether the tool is completed by doctors or by patients (Conill, Verger, & Salamero, 1990; Sørensen et al., 1993). Self-report from patients is considered the gold
standard (Conill, Verger, & Salamero, 1990). In this study, patients identified their performance status. The option of “dead” was removed from the tool, therefore in this study, performance status was measured on a scale from 0-4.

3.2.1.3.5 Symptom information and communication behaviours

Symptom information and patient communication behaviours and the role of support persons were explored using 10 questions from Cohen’s research (2012) into patient participation in symptom management to investigate patients’ experience during symptom management in the past 24 hours. Questions were related to information provision from clinicians to patients (3 questions): language used by doctors and nurses (e.g. laymen’s terms), symptom treatment options provided to patients, and the value of this information. Patients’ normal process for reporting symptoms (3 questions): importance of symptom identification, communication of symptoms, specifically the acceptability and frequency of using the call bell to report symptoms. Patients were also asked if they had withheld any information about their symptoms in the previous 24 hours and if yes, they were asked to provide further information about their rationale.

The role of support persons in decision-making was explored through three questions to identify who the patient’s “support person” was and factors related to their opportunity to involve their “support person” in decisions about symptom treatment.
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3.2.1.3.6 The perceived importance of participatory activities (modified)

This tool was developed from Eldh’s et al. questionnaire (2010) designed to elicit patients’ perceptions of patient participation. The 11 items contained in the questionnaire represent different aspects of care. Patients were instructed to identify which items corresponded to their perception of patient participation. The items were generated from previously published findings in the literature (Ehrenberg, Ehnfors, & Thorell-Ekstrand, 1996) as well as earlier studies conducted by the authors (Eldh, Ehnfors, & Ekman, 2004). The questions are categorized into the themes of being confident, comprehending, seeking and maintaining a sense of control and performing self-care. Questions in the tool were asked in the yes/no response format and this tool also contained open-ended questions to elicit additional perspectives about patient participation. This tool had been used among both inpatients and outpatients in Sweden and suggested satisfactory validity (Eldh, Ekman, & Ehnfors, 2010).

The original tool was modified by Cohen (2012) to facilitate the evaluation of the value of patient participation in the acute care setting. The original yes/no response format was replaced by a five-point Likert scale with ratings from no importance (1) to of the highest importance (5). This study followed Cohen’s version but did not include open-ended questions.
3.2.1.3.7 Views and Behaviours about Patient Involvement in Care (VBPIC) (modified): Patient/clinician version

Arnetz et al. (2008b) developed the Staff Views and Behaviours regarding Patient Involvement in Care (VBPIC) questionnaire using focus groups with cardiology staff (nurses and doctors) to evaluate their perceptions and behaviours regarding patient involvement in care post myocardial infarction. This tool with 30 items in total is comprised of two dimensions. One dimension reflects staff views in two scales: Patient involvement (6 items) and Hindrance (3 items), each measured by a four-point Likert scale, ranging from agree completely (4), agree somewhat (3), don’t agree very much (2) to don’t agree at all (1). The other dimension describes behaviours about patient involvement in four scales: Information (5 items), Patient needs (4 items), Activity and Motivation (9 items) measured by four alternative responses to each item: to a very great degree (4), to a fairly great degree (3), to a certain degree (2) and not at all (1). For all scales except the Hindrance scale, higher scores illustrate ratings that are more positive. Cronbach’s alphas for each of the scales were over 0.74, indicating good internal homogeneity (Arnetz et al., 2008b).

In addition to the questionnaire for staff, Arnetz et al. (2008a) developed another version of the VBPIC to measure patients’ views and behaviours regarding patient involvement in acute care after myocardial infarction. The patient version of the questionnaire has 32 items in six scales: Patient involvement, Illness experience, Information, Patient Needs, Activity and
Treatment planning. The response alternatives for the Patient Involvement scale are the same as those in the staff version, although response option are modified slightly to reflect the way the items are stated, for example, in the Information subscale, response options are: to a great degree, somewhat, not especially and not at all. The questionnaire indicated satisfactory internal homogeneity, with Cronbach’s alphas for each scale of 0.75 or higher (Arnetz et al., 2008a).

Both the staff and patient version of the VBPIc were translated into Chinese by Shen (Shen, 2010) who conducted a pilot study with a large sample to explore the potential factors affecting patient involvement in managing doctor-patient relationship. In the pilot study, the VBPIc was found to be reliable in Chinese patient and medical staff populations (Shen, 2010).

The original tools were modified slightly and named as: Patients’ views and behaviours about patient involvement in care (VBPIc-Patient) and Clinicians’ views and behaviours about patient involvement in care (VBPIc-Clinician) in the current study to enable the research questions designed to investigate symptom management in acute care to be answered. Some items in the original questionnaires were modified by making symptom management activities more explicit in the questions. For example, the original item: Ask questions was modified to Ask questions about his/her symptoms. In the original scale, Activity measures the degree to which patients discuss with staff various activities they can perform after their discharge. These are
physical activity (for example heavy lifting); driving; sexual activity; housework; gardening; and return work. Because this study focused on cancer patients’ involvement in symptom treatment and nursing care during their hospitalization rather than activities after discharge, the scale of Activity was deleted completely in both the clinician and patient versions. Another two items about discharge in the Motivation scale of the staff version were also deleted. These were: Inform the patient about whom he/she can contact with questions after being discharged from the hospital and Discuss lifestyle changes with the patient (for example, smoking cessation, exercise and diet). Instead, an item Provide the patient with the opportunity to ask questions before they are discharged was added.

Although Arnetz et al. designed the questionnaire with two versions to explore the same phenomenon from the perspectives of patients and staff, the scales and items in these two versions are not exactly the same. In order to facilitate better comparison between patients’ and clinicians’ perceptions and behaviours in this study, items were added to the questionnaires so that there were 27 items in both of the patient and clinician versions with the same content for each item asked either from patients’ or clinicians’ perspectives. For example, the item Were you treated with respect was present in the original patient version rather than the staff version, so the question of Treat the patient with respect was added in the staff version. The
whole scale of Hindrance in the staff version was also added to the patient version.

In this study, scale values in the VBPI were calculated for each case by totalling the scores on the component scale items and converting that sum to a percentage of the maximum possible score (100%). Scores for all subscales are reported as median percentage scores (Arnetz et al., 2010). Higher scores in all scales except the Hindrance scale are indicative of more positive perceptions of patient participation. Higher scores in the Hindrance scale reflect more negative perceptions towards patient involvement.

3.2.1.3.8 Satisfaction with participation in symptom management

Satisfaction with participation was derived from specific questions in the American Pain Society Patient Outcomes Questionnaire and additional questions used by Cohen who conducted a study focusing on Australian cancer patients’ participation in symptom management (Cohen, 2012). Five closed-ended questions were used to assess patients’ satisfaction with symptom management received in the 24 hours prior to the survey. Questions were asked in terms of the outcomes of symptom treatment overall, the way nurses and doctors responded to patients’ report of symptoms and the information provided in relation to symptoms and treatment. Patients rated their level of satisfaction along a 6-point Likert scale ranging from 1 (very dissatisfied) to 6 (very satisfied). An open-ended question at the end this series of questions asked patients to state the
reasons for satisfaction/dissatisfaction with symptom treatment.

3.2.1.3.9 Health Literacy Questionnaire (HLQ)

Health literacy is defined by the WHO as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (Nutbeam, 1998). Health literacy is considered a significant determinant of whether patients can take responsibility for their own healthcare (Jordan, Buchbinder, & Osborne, 2010). The Health Literacy Questionnaire (HLQ) is based on the health literacy conceptual framework developed from patients’ perspectives (Osborne et al., 2013).

The 44-item HLQ consists of two sections, with nine scales covering the main conceptual areas of health literacy: 1) Feeling understood and supported by healthcare providers; 2) Having sufficient information to manage my health; 3) Actively managing my health; 4) Social support for health; 5) Appraisal of health information; 6) Ability to actively engage with healthcare providers; 7) Navigating the healthcare system; 8) Ability to find good health information; and 9) Understanding health information well enough to know what to do.

The first section including scales 1-5, asks “How strongly you disagree or agree with the following statements”, with response options on a four-point Likert scale ranging from 1-**strongly disagree** to 4-**strongly agree** for 23 items.

The second section, scales 6-9, asks “How easy or difficult the following tasks are for you to do now”, with response options on a five-point scale ranging
from 1-\textit{cannot do} to 5-\textit{very easy} for 21 items. The average scores of each scale were calculated. The higher the score on a scale, the higher the health literacy of the patient in that particular aspect.

The HLQ is targeted to various demographic groups within health promotion, public health, clinical intervention and population health surveys. In order to be applied in a wider range of population and cultural settings, the translation of the HLQ to various languages has been conducted by the HLQ research team. The Chinese version (Mandarin Chinese) was completed by the HLQ research team prior to commencement of data collection for this study.

\textit{3.2.1.3.10 Quality from the Patient’s Perspective (QPP) – short form (modified)}

The QPP questionnaire was developed from grounded theory, based on the theoretical model of quality of care from a patient perspective. According to the theory, quality of care contains two aspects: the resource structure of the care organisation and patients’ preferences (Wilde et al., 1993). The QPP questionnaire measures these two aspects across four dimensions: medical–technical competence of the caregivers, physical–technical conditions of the care organization, degree of identity-orientation in the attitudes and actions of the caregivers, and socio-cultural atmosphere of the care organisation. The evaluation of each dimension includes two steps: one is to assess what has been experienced in terms of quality of care using a four-point Likert
scale ranging from 1 (Do not agree at all) to 4 (Completely agree); the other step is to examine the subjective importance of various aspects of care on a four-point Likert scale from 1 (of little or no importance) to 4 (of the very highest importance).

The original QPP is measured by 68 items with 22 subordinate factors. A short form of the QPP consisting of 24 items has also been developed (Larsson, & Larsson, 2002). The Cronbach’s alpha coefficients for the short form on the dimension of the perceived reality scale and the subjective importance scale range from 0.67-0.97 and 0.65 to 0.89, respectively (Larsson, & Larsson, 2002). The short version was used in this study.

To answer the research questions of this study, the QPP was further modified in the following ways. The scale of Physical–technical conditions of the care organisation was deleted because it was irrelevant to the research questions. Some items in the original tool were modified by highlighting symptom management activities. For instance, the item “I received useful information on how examinations and treatments would take place,” was changed to, “I received useful information on how symptom assessments and treatments would take place”. Similar changes were made to another four items in the tool.

The QPP questionnaire is used mostly in Sweden (Fröjd et al., 2011; Wilde et al., 1995). Consequently, there was no Chinese version available; therefore, two native Chinese speakers translated this tool into Chinese for the purpose
of this study. Both the translators had nursing education and research 
backgrounds. Following the forward translation, a bilingual professional who 
was an expert in nursing research and familiar with the topic of patient 
participation compared the English and Chinese versions and made 
suggestions for revision of the translated version. The revised Chinese 
version was then translated back into English by a Chinese speaker who was 
blind to the original English version. Three supervisors in the research team 
compared the original and back-translated English versions, identified any 
discrepancies and the Chinese version was modified to produce a final 
questionnaire.

In order to derive a score representing the overall perception of quality of 
care, the score of Personal Quality of care Index (PQI) was calculated. PQI is 
an important index that reflects the quality of care perceived by participants. 
It is calculated based on the rank order of the difference between subjective 
importance and perceived reality. The calculation formula is:

\[ \text{PQI} = \text{Subjective Importance Score} \times (2 \times \text{Perceived Reality Score} - \text{Subjective Importance Score}) \]

This formula is based on the principle: Highest personal quality of care score 
should be obtained if a person gives the highest rating (that is, 4) on both 
perceived reality and subjective importance; lowest personal quality of care 
score is obtained if a person gives the lowest rating (1) on perceived reality, 
and the highest rating (4) on subjective importance. The range of the PQI on
a given item is from 8 (lowest quality) to 16 (highest quality) (Wilde et al., 1994).

3.2.1.1.4 Data analysis - survey

The completed questionnaires were coded and entered into SPSS version 21®. Frequencies and descriptive statistics were used to summarise the demographic characteristics and symptom profile of participants.

Congruence between patients’ preferred and actual participation in decision-making was identified through weighted kappa statistics. Given the ordinal responses in the preference and actual participation variables, a weighted Cohen’s Kappa (Kw) statistic was used to quantify the level of agreement between each patient’s preferred roles and actual participatory roles. Weighted Kappa “provides for the incorporation of ratio-scaled degrees of disagreement (or agreement) to each of the cells of the K×K table such that disagreements of varying gravity (or agreements of varying degree) are weighted accordingly” (Cohen, 1968, p. 213). For instance, disagreement between preferred passive role and actual collaborative role is regarded as stronger than between preferred passive role and actual passive-shared role while in a normal Kappa all disagreement cells are treated equally. Quadratic weighting is used to calculate the coefficient of weighted Kappa with STATA version 12. The standards for strength of agreement for the Kappa coefficient are displayed in Table 3.1.
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Table 3.1 The standards for strength of agreement for the Kappa coefficient*

<table>
<thead>
<tr>
<th>Kappa coefficient</th>
<th>Strength of agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤0</td>
<td>Poor agreement</td>
</tr>
<tr>
<td>0.01-0.20</td>
<td>Slight agreement</td>
</tr>
<tr>
<td>0.21-0.40</td>
<td>Fair agreement</td>
</tr>
<tr>
<td>0.41-0.60</td>
<td>Moderate agreement</td>
</tr>
<tr>
<td>0.61-0.80</td>
<td>Substantial agreement</td>
</tr>
<tr>
<td>0.81-1</td>
<td>Almost perfect agreement</td>
</tr>
</tbody>
</table>

*Extracted form (Sim, & Wright, 2005)

The associated factors that may influence/predict patients’ preference for participation were analysed with ordinal logistic regression by the Link function of Logit in SPSS Version 21. Univariate analyses were performed first to identify any potential factors. During multivariate analyses, a two-step model selection strategy was performed with \( P_{\text{enter}}=0.1 \), \( P_{\text{delete}}=0.05 \) in step one and \( P_{\text{delete}}=0.1 \) in step two.

The patients’, doctors’ and nurses’ responses to the survey regarding the attitudes towards, or experience of, patient participation were compared using the Kruskal-Wallis test with an accepted significance level of 0.05. If the responses were found to be different between the three cohorts, further pairwise comparisons were performed with the nominal significance level of 0.017. One-way ANOVA was used to examine the correlation between the participation level and outcome variables assessed. The level of significance was set at 0.05.
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3.2.1.2 Semi-structured interview

3.2.1.2.1 Design: Interview

Individual interviews are considered a useful research method for accessing individuals’ motives and opinions and exploring their experiences (Silverman, 2006). From a pragmatic perspective, a research interview is an interaction between participant and researcher. Unlike the data from naturalistic observation, an interview can explore participants’ interpretations and understanding of events (Ritchie et al., 2013).

Following participation in the survey component, a subgroup of patients, doctors and nurses were invited to participate in a semi-structured individual interview to explore their perceptions of patient participation in acute care environments, especially during the process of symptom management. Patients were specifically asked their reasons for selecting their Control Preference role. The preferred control roles and the perceived facilitators and barriers for the achievement of patients’ preferred level of participation were identified by exploring clinicians’ and patients’ clinical experience. Focusing on the data related to participation, comparisons were made between doctors, nurses and patients in order to explore commonalities or disparities in how patient participation was understood and enacted in acute care.
3.2.1.2.2 Sampling: semi-structured interview

Clinicians were selected via purposive sampling to enhance the richness of information (Polit, & Beck, 2012). Clinicians with various roles in the working environment, for example, doctors with different levels of experience, such as consultant physician, attending physician and RMO and both the head nurse and primary nurses, were invited to participate in a semi-structured interview.

Stratified purposive sampling was used to select patients for the semi-structured interview. This type of sampling provides a good way to guarantee appropriate representation of different population segments (Polit, & Beck, 2012, p. 281). Patients were stratified according to their most preferred CPS role (active, active-shared, collaborative, passive-shared or passive) to provide heterogeneity in terms of control preference. In each control preference group, those who were physically capable and consented to be interviewed, were recruited.

3.2.1.2.3 Data collection procedure: Interview

A suitable time was negotiated with the interviewees after they completed the survey in order not to interrupt the regular operation of the ward. The interviews were conducted in an interviewee-preferred location, such as a consultant’s office, demonstration room, nurse’s station or patient’s room. Interviews with clinicians lasted approximately 60 minutes and the interviews with patients lasted about 30 minutes. Some of the participants
completed the interview over two sessions because the first interviews were suspended, because either nurses did not have enough time or the patients were too tired to go on with the interview. All the participants except one consented to be audio-recorded during the interviews. The researcher took handwritten notes for the one who refused to be audio-recorded. All the interviewees’ expressions, behaviours and the interview surroundings were recorded in field notes by the researcher.

Two versions of the semi-structured interview guide were used appropriate for clinician and patient interviews. Flexibility was valued and allowed for impromptu questions that were responsive to the participants’ answers. Interviewees were respected and encouraged to express their opinions. Similar questions were posed to both patients and clinicians in order to capture shared or different opinions. The interview guides are in Appendix 7.

3.2.1.2.4 Data analysis:-Interview

The audio recordings of the interviews were transcribed verbatim and imported into NVivo version 10. The demographic information of the participants and the control preference roles of patients were also imported into NVivo as node classifications. The transcripts were analysed based on framework analysis. The framework analysis involved five processes (Ritchie, & Spencer, 2002): 1) Familiarisation: an overview of the transcripts was gained by listening to the recordings, reading transcripts and reviewing observation notes. During the process of familiarisation, key ideas and
recurrant themes were listed. 2) Identifying a thematic framework: a thematic framework was identified from the topic guide of this study initially and modified with the emergent issues raised by participants and identified in the familiarisation stage. 3) Indexing: the thematic framework was applied to the transcriptions through annotating the key reference in the transcripts line by line according to the framework. 4) Charting: a thematic approach was adopted for the analysis, and three major topic charts were constructed, including: perceptions of patient participation in symptom management, reasons for control preference and factors influencing actual participation. In each chart, the subheadings of the columns were the themes and subthemes under the corresponding topic and the rows listed the cases of the participants or the case groups based on patients’ control preference. 5) Mapping and interpretation. Based on the charts formulated, the data were interpreted by defining the concepts of patient participation in symptom management, creating typologies of reasons perceived for the control preference and providing explanations for the facilitators and barriers of participation in actual practice.

For the purpose of analysis triangulation, peer debriefing occurred with supervisors throughout all stages of data analysis; 22 of the total 41 interview transcripts (53.7%) were translated from Chinese to English. Two transcripts from the doctor interviews (n=5) and two from the nurse interviews (n=7), were purposefully selected for translation. Given the small
number of clinician interviews, it was considered important to choose those with the richest information. The decision regarding which patient interviews to transcribe was determined by the number of patients in each Control Preference group. The majority of patients interviewed had a passive or passive-shared preference. Five transcripts were randomly selected for translation from both passive and passive-shared control preference groups. All transcriptions from patients reporting a collaborative (n=20), active-shared (n=5) or active (n=1) control preference were translated. Three supervisors in the research team read the translated transcripts and examined the node book and thematic framework developed by the student researcher. Members of the team shared their understandings and discussed the initial results. Areas of disagreement required re-examination of the original data and further discussion until agreement was reached.

3.2.2 Phase 1: exploring clinician-patient interactions

In the phase exploring patient and clinician interactions during symptom management, naturalistic observations were conducted together with administration of the CPS to establish patients’ preference for and perception of actual participation during the period under observation, and clinicians’ estimation of patient preference and actual participation.

3.2.2.1 Naturalistic observation

Observation in qualitative research is designed to gain a detailed understanding of the behaviours and experience of people as they actually
occur in real-life settings (Polit, & Beck, 2012). This method is used widely in the study of care delivery to uncover everyday behaviours in healthcare settings, decreasing the potential bias that may be present in interview accounts (Pope, van Royen, & Baker, 2002).

3.2.2.1.1 Design: Observation

Naturalistic observations provided rich data about communication between patients and clinicians during their daily interactions. These data were integral to understanding the context of patient-doctor and patient-nurse interactions, the way that symptoms were assessed and managed, and facilitating or blocking behaviours that may influence patient participation. The context of care and patient-clinician interactive behaviours observed were compared to participants’ self-reported data, enabling a more comprehensive insight into the nature of patient participation in symptom management.

In this study, naturalistic observations were conducted as a reactive observation where participants are informed that they are being observed for the purposes of research but the observer does not interact with the participants (Angrosino, 2007). The observer was the PhD student researcher who was neither a staff member or cancer patient. The observer then, was an outsider without a relationship with the participants. Participants were aware of the observer but the observer did not attempt to change participants’ behaviour. This approach decreased the risk of researcher bias
and also reduced the possible coercion of potential participants (Yin, 2009, p. 113).

Patients’ and doctors’ interactions related to symptom management were observed during the morning medical ward rounds. The decision to observe the medical ward round was because it was one fixed occasion that patients had the opportunity to communicate with their doctors during their admission. The interactions between nurses and patients occurred frequently not only during nursing ward rounds but throughout the day. Therefore, the medical and nursing ward rounds and the intensive nursing working hours, characterised by high frequency nurse-patient interactions, were chosen as the observation points in this study to gain insights into patient participation in symptom management.

3.2.2.1.2 Sampling: Observation

The naturalistic observations were conducted in August and September, 2013. One day prior to a doctor team or primary nurse observation, the researcher approached all the eligible patients that were to be cared for by the doctor team or primary nurse for the purpose of explaining the study and gaining verbal consent. If a patient refused to be observed, any activities relating to that patient were not recorded. Patients who were observed during the medical ward rounds were also eligible to participate in the observation of patient-nurse interactions.

All (100%) of the eligible doctors consented to participate. Each doctor team
was observed on at least one day during their morning ward round. Prior to commencing the observation, the researcher rechecked the consent of relevant doctors (the chief or consultant who led the ward round and the resident medical officers (RMOs) whose patients had agreed to participate) and advised them that the observation was planned for the next morning. The RMOs involved were also reminded that they would be asked two simple questions about patient participation after the observed ward round.

The observation of doctors’ ward round was completed prior to the commencement of nurse-patient observations. Primary nurses’ ward rounds and high intensity nursing working hours from 8:30am to 10:30am and 1:30pm to 3:30pm were chosen as the observation periods. The rationale for selecting primary nurses was that they were responsible for the care of 10-12 patients and in line with the Primary Nursing model, had the opportunity to build rapport with their patients during the inpatient period, an important precondition for facilitation of patient participation (Sahlsten et al., 2008). Data were collected from patients who met the eligibility criteria (admitted for ≥ 7 days) and where the primary nurse had nursed a patient for at least three shifts. Primary nurses were only observed more than once when they were providing care for different patients. Patients who had previously been observed in relation to nurse-patient interactions were not observed again.
3.2.2.1.3 Data collection procedure: Observation

On the day of observation, the researcher arrived on the ward prior to the ward round. The timing of the ward round was not fixed but commenced after the morning staff meeting ended. When the doctor team/primary nurse to be observed on that day began their ward round, the researcher followed the team/primary nurse as an observer.

During the observation of medical ward rounds, a research assistant worked as a time keeper to help the researcher record the duration of each interaction between patients and the medical team using an electronic stopwatch. The principles for time keeping are presented in Table 3.2. During the nurse-patient observations, the student researcher recorded the time.

<table>
<thead>
<tr>
<th>Timing</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timing started when any of the following activities commenced:</td>
<td>The observed patient’s chart was opened by the leader of the team</td>
</tr>
<tr>
<td></td>
<td>The senior doctor began to listen to the RMO’s report of the patient’s disease history or current situation</td>
</tr>
<tr>
<td></td>
<td>The senior doctor began to talk with the patient</td>
</tr>
<tr>
<td>Timing stopped when the following activities ended:</td>
<td>The conversation between the patient and any of the doctors in the team was over and any discussion among the doctors about the patient’s situation or treatment was over</td>
</tr>
<tr>
<td>Timing suspended when:</td>
<td>The senior doctor dealt with other things that had nothing to do with the observed patient, i.e. answered the phone</td>
</tr>
<tr>
<td></td>
<td>The senior doctor left the ward room and the ward round was suspended</td>
</tr>
</tbody>
</table>
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The researcher took real-time field notes recording all conversations and behaviours of doctors/primary nurses and patients during the observation period. A digital Dictaphone was not used as planned because most of the doctors and nurses did not agree to digital recording of their conversations.

A framework for the naturalistic observations was developed according to the research objectives and literature review (Cohen, 2012) (see Table 3.3).

This framework was used as a guide for systematically recording and

<table>
<thead>
<tr>
<th>Context</th>
<th>Question</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interaction context</td>
<td>What are the characteristics of the interaction?</td>
<td>Participants involved: patient, doctor, nurse</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Frequency: overall/per patient</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Purpose: Task related (conduct vital sign assessment, deliver medication, hygiene)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Response to patient buzzer</td>
</tr>
<tr>
<td>Symptom-specific context</td>
<td>How are symptoms assessed?</td>
<td>Person who initiates the symptom interaction: patient/family or clinician</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Methods of assessment: questions/instrument tools</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Presence of symptoms identified</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other information obtained from assessment: frequency/distress/...</td>
</tr>
<tr>
<td></td>
<td>How are the symptoms</td>
<td>Person who provides/suggests the</td>
</tr>
</tbody>
</table>
analysing the data. During each observation, a checklist based on the framework was used (Appendix 8). The key content of the conversation as it occurred during the observation period was recorded in writing alongside the checklist.

3.2.2.1.4 Data analysis—observation

The observation field notes recorded during the naturalistic observations were imported into NVivo 10. The notes were analysed using framework analysis as described in Section 3.2.1.2.4.

To ensure rigour, 10% of the observation transcripts were translated from Chinese to English for analysis triangulation by the research team (including the candidate and her three supervisors). Analysis triangulation was performed by the research team in the same way as the analysis of the interview data (see Section 3.2.1.2.4).
3.2.2.2 Clinician-patient CPS

A brief survey of control preference was conducted following the completion of each medical ward round and primary nurse observation period. The CPS was administered to patients, nurses and resident doctors after each observation period (e.g. medical ward round and primary nurse interactions). The purpose of administering the CPS to both clinicians and patients after the observation was to assess the synergies related to patient preference and actual participation within patient-doctor dyads and within patient-nurse dyads that were specific to the interactions observed. In other words, administration of the CPS was to explore patients’ preference for participation in relation to the person or persons they had interacted with (i.e. doctors or nurses) as distinct from its use in Phase 2, where they were asked their preference with clinicians overall. Patients were asked to select their most preferred role from the five CPS statements as well as the CPS statement that best reflected the degree to which they were able to participate during the interaction that was observed. Nurses and doctors were also asked to review the five CPS roles and provide their estimation of patients’ preference for participation and the statement which best reflected patients’ actual participation during the observed interaction (Degner, Sloan, & Venkatesh, 1997; Zhang et al., 2011) (Appendix 6). Data on patients’ age, gender and province were also collected. Information in the checklist and responses in the CPS tool were coded and entered into SPSS version 21. The data were analysed using frequency and descriptive statistics. Congruence
between patients’ and clinicians’ perceptions of patients’ preferred and actual participation in decision-making was compared through weighted kappa statistics.

### 3.2.3 Rigor and bias control during data collection

Principles of no harm and confidentiality were explained fully to potential participants during recruitment. All participants were reassured that any data collected would not negatively impact their care and/or treatment or their relationship with the hospital or employers, in order to reduce concerns about providing responses that they thought might not be consistent with mainstream views.

The researcher spent one month on the ward prior to data collection to establish familiarity with clinicians in an attempt to minimise the potential for Hawthorne effects (Sims & Wright, 2000) and enhance the validity of the findings.

The naturalistic observations were conducted using a non-participant approach. The researcher had minimal contact with participants and did not disturb care activities or interactions. The observation times were selected to capture the highest number of doctor team and primary nurse interactions with patients. The observations covered almost all patients admitted to one of the two participating oncology units during the observation period. All conversations that occurred during the observation period were recorded verbatim if possible. Every attempt was made to
reduce personal bias by rapid recording of all interactions as they were observed without subjective comment. In addition to the freestyle notes, the predesigned checklist (see Table 3.3) enabled the researcher to tick the appropriate boxes quickly and conveniently to maximise the reliability of the information recorded.

The patient and clinician questionnaires were given to each participant by the researcher who provided instructions and clarified any queries participants might have had about the questions. Instructions and explanations were consistent because there was only one data collector.

In the topic guide for the semi-structured interviews, most of the questions were open-ended; for example, what do you think about patients being involved in the management of their symptoms while they are in hospital? The questions were asked in as neutral a way as possible to decrease the potential for participants to provide socially desirable responses (Zohrabi, 2013). The interviewer was nonjudgmental and neutral to all responses from participants no matter if they had positive or negative attitudes towards patient participation. The researcher treated every participant with respect and encouraged responses during the interview in order to establish rapport and elicit more in-depth answers.

Careful consideration was given to the order in which the phases of research were conducted in order to reduce the potential for participation in one phase to influence participants in the subsequent phase.
Chapter 3 The research program and methods

As noted earlier, the PhD student researcher did not have previous or professional relationships with clinicians or patients. She is a registered nurse and educator in the university attached to the cancer centre in which data were collected. Peer discussions with supervisors were continuous throughout the analysis process in particular because some data were derived from non-translated transcripts, to ensure that interpretations occurred within the context in which they were obtained.

An audit trail of the analytical process is possible through the following documents: interview transcripts; field notes, reflections and notes of supervision meetings; and analytical frameworks for each theme including coding definitions and associated raw data.

### 3.3 Ethical considerations

Approval for the research program was obtained from the Human Research Ethics Committee (HREC) of Deakin University, and the Clinical Pharmacology Base and Clinical Research Ethics Committee (CREC) of Fudan University Shanghai Cancer Centre (Appendix 9). The progress of the research was reported annually to the HREC and CREC as required. The main ethical issues raised by the research are presented in this section, including patient safety and burden, informed consent, anonymity, confidentiality and data storage and disposal.
3.3.1 Participant safety and burden

The priorities of patient safety and reducing patient burden were key considerations throughout the period of data collection. During naturalistic observations, there was the potential to observe unsafe clinical practices. If an unsafe practice was witnessed, the observer was responsible for reporting this to reduce or prevent risk. This situation did not occur during the data collection period. During the survey or interviews, when a patient reported any symptoms or problems that were moderate or severe in intensity or distressing, the patient was encouraged to disclose their symptoms or problems to nurses responsible for their care.

To minimize the burden of participation in this research program, the survey and interview time and location were negotiated with participants to reduce any interruption to staff’s work or patients’ care activities. Participants were also able to complete the questionnaires at a time convenient to them. If patients felt tired or the clinical staff had to deal with other issues during the interview, the interview was paused and another time was negotiated.

3.3.2 Informed consent

In Phase 1, exploring patient-clinician interactions, verbal consent was obtained from eligible patients after they were informed of the purpose and requirements of participation. In Phase 2, exploring patients’ and clinicians’ perspectives of participation, all eligible patients were provided with a Plain Language Statement and Consent Form and asked to provide written consent.
All eligible clinicians were provided with a copy of the Plain Language Statement and Consent Form and asked to provide written consent for participation in both Phase 1 and Phase 2. Prospective participants were assured that their participation was voluntary and withdrawal from the study would have no effect on their care and treatment or work relationships. The consent form was signed and dated by both the participant and the researcher.

### 3.3.3 Anonymity

To ensure anonymity of the research participants, identifying information including name, address and Email address were not recorded on data collection sheets. All participants were allocated a unique identification number, which was used on all data collection documents. The researcher kept a separate document that linked the participant ID number to participants’ identifying information. Only the researcher had access to this document.

Total anonymity of participants was not possible because the data were collected on the ward and participants would have been known to each other.

### 3.3.4 Confidentiality and data storage

Confidentiality of participant data was maintained throughout the research. All responses on the questionnaires were recorded by paper and pencil. The data in the questionnaires were entered into the statistics software. The Dictaphone recordings of the individual interviews were transcribed in full.
Chapter 3 The research program and methods

These digital data documents including the questionnaires and transcriptions were kept on a password-protected computer. The student and the supervisors were the only people with access to these records. Others involved in the transcribing and translating process were required to sign a Confidentiality Agreement before they were given access to the raw data. The original questionnaires and Dictaphone recordings were retained as permanent records of the study and will be stored in the designated location of Deakin University for a minimum of five years from the date of publication.

3.3.5 Disposal of data

After the allotted time, information collected in digital form will be deleted as per university policy. This includes digital audiotapes, transcripts, SPSS spread sheets, and descriptive data. Information in hard copy will be shredded using a secure disposal service.

3.4 Summary

The research program was designed to explore patient participation in symptom management from a multidimensional perspective. The design of the research was mixed methods. Data were collected using survey, semi-structured interviews and naturalistic observation and involved both patients and clinicians (doctors and nurses) within two medical oncology units in a grade A tertiary hospital in China. The research findings are presented and discussed in the following four chapters (Chapter 4 to Chapter 7 inclusive). The integrated findings and discussion of the clinical and research implications of the findings are presented in Chapter 8.

Table 3.4 below provides an overview of the specific analyses presented in each chapter.
Table 3.4 Overview of the presentation of findings in this thesis

<table>
<thead>
<tr>
<th>Chapter 4</th>
<th>Chapter 5</th>
<th>Chapter 6</th>
<th>Chapter 7</th>
<th>Chapter 8</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Title</strong></td>
<td>Describing the case study: case setting and characteristics of participants</td>
<td>Perceptions of patient participation in symptom management (Part I)</td>
<td>Perceptions of patient participation in symptom management (Part II)</td>
<td>Interactions between clinicians and patients in symptom management</td>
</tr>
<tr>
<td><strong>Aims</strong></td>
<td>To provide an overview of the case setting.</td>
<td>To explore patients’ and clinicians’ perceptions of patient participation in symptom management</td>
<td></td>
<td>To explore patients’ and clinicians’ behaviours during interactions related to symptom management</td>
</tr>
<tr>
<td><strong>Objectives</strong></td>
<td>1. Introduce the case setting; 2. Describe demographic characteristics of patient and clinician participants, patients’ symptom profiles and other data collected.</td>
<td>1. Describe and compare how patients, doctors and nurses rate the importance of participatory activities in symptom management; 2. Describe and compare how patients, doctors and nurses rate patients’ actual participation in symptom management; 3. Describe patients’ control preference for participation in symptom management-related decision making; 4. Calculate the congruence between patients’ preferred and actual participation in symptom management;</td>
<td>1. Explore patients’, doctors’ and nurses’ understanding of participation and patient roles in symptom management; 2. Explore patients’, doctors’ and nurses’ experience of facilitators and barriers to participation in symptom management; 3. Explore patients’ reasons for selecting a particular control preference for participation in symptom management-related decision making; 4. Compare and contrast quantitative and qualitative findings to identify any</td>
<td>1. Describe how and under what circumstances patients communicate with clinicians during interactions related to symptom management. 2. Identify clinicians’ communication behaviours that facilitate or impede patient participation during interactions related to symptom management. 3. Analyse the congruence between clinicians’ and patients’ perceptions of preferred and actual participation in symptom-management related decision-making.</td>
</tr>
<tr>
<td>Sample</td>
<td>162 consecutive cancer inpatients, 38 doctors and 34 nurses working in the oncology medical units</td>
<td>A subsample of 41 patients, 5 doctors and 7 nurses</td>
<td>81 doctor-patient dyads 112 nurse-patient dyads</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Data collection methods</td>
<td>Survey</td>
<td>Survey</td>
<td>Semi-structured interview</td>
<td>Naturalistic observation Survey</td>
</tr>
<tr>
<td>Analysis methods</td>
<td>Quantitative data: descriptive exploratory</td>
<td>Quantitative data: descriptive exploratory</td>
<td>Qualitative data: framework content analysis</td>
<td>Quantitative data: descriptive exploratory Qualitative data: content analysis</td>
</tr>
<tr>
<td></td>
<td>Chapter 4</td>
<td>Chapter 5</td>
<td>Chapter 6</td>
<td>Chapter 7</td>
</tr>
</tbody>
</table>
CHAPTER FOUR

Describing the case study: Case setting and characteristics of participants

Contextual factors play an important role in the interactions between patients and clinicians in clinical settings. Patients’ demographic and illness related characteristics have been reported to be associated with patients’ preference for participation in care activities (Chung et al., 2012; Cohen, & Botti, 2015; Florin, Ehrenberg, & Ehnfors, 2008). Further, patients’ and clinicians’ perceptions of patient participation and the facilitating/blocking behaviours observed during interactions may be influenced by patient-clinician rapport and clinical setting (Larsson et al., 2011a; Sahlsten et al., 2005a). Given the multidimensional factors associated with patients’ ability to participate in their care it is important to understand the context of care in the case study hospital where this research was undertaken. While the specific intent of a case study is not to generalize findings to a larger population, examining the context allows for the assessment of generalizability beyond the current case.

The aim of this chapter is to provide an overview of the case study. The data presented in this chapter were obtained via clinician and patient surveys in Phase 2 of the research program. The findings are presented in four sections and discussed in the fifth section. In the first section of the chapter, the case
setting is introduced, followed by a description of clinicians’ demographic and work related characteristics. Patient participants are described in terms of demographic and illness-related characteristics and physical and psychological profiles.

4.1 The case setting

This study was conducted in two medical oncology units (referred to as wards A and B) in a Grade A, tertiary hospital in China. The team of clinicians working in each unit comprised doctors and nurses with varying levels of experience. A Chief Doctor was in charge of medical matters and nursing services for the ward. There were two teams of doctors on Ward A and three on Ward B. The medical model of ‘Attending in Charge’ was used in these two units whereby every medical team consisted of Consultant Physician(s) (n=1-2), Attending Physician(s) (n=1-2) and Resident Medical Officers (RMOs) (n=4-6). Each RMO was in charge of the care of 4 to 6 patients. Within the doctor group, the Chief, Consultant and Attending Physicians were permanent staff of the ward, while most of the RMOs were trainee doctors from various hospitals nationwide and interns in their first one or two years of practice. Both the trainee doctors and interns had a ward rotation every two or three months. This doctor training model attributed to the high resident-physician turnover in the ward.

The nursing staff consisted of one Head Nurse and approximately 11 nurses in each unit. The majority were Registered Nurses who had worked for more
than one year on the ward, three were in their first year on the ward. A Primary Nursing care delivery system formed the model of care in the two case study units. This model supports the notion of patient-centred care (Jewell, 1994). Every primary nurse was responsible for approximately 12 to 16 patients (three or four patient rooms) when they worked on day shifts. Four of the primary nurses only worked day shifts on weekdays. Most of the other nurses rotated onto night shift every four or five days but worked as primary nurses when they worked day shifts.

Unique to the case study hospital was the organisational policy that all oral and externally applied medications were, once prescribed by the medical team, dispensed directly to the patient who was then responsible for self-administration. Personal communication between the student researcher, the Nursing Director and other managers revealed that this process was in place for two reasons: 1) to reduce nurses’ workload, and 2) because of the requirement for patients to pay upfront for their medication. This policy allowed specific and expensive medications, such as Capecitabine (an oral chemotherapy), to be dispensed directly to the patients in their original packing. The latter reassured patients that they received the medication that they had agreed to pay for. Once the doctor had prescribed an oral or topical medication, often after consultation with the patient, the medications were dispensed to the patient. Instructions (both written and verbal) were then provided by the nurse to the patient and/or their family and the onus for administration was on the patient. To ensure, however, that high risk
medications such as antineoplastic medicines, adjuvants to antineoplastic medicines, narcotic analgesics or antiarrhythmic oral medications, the nurses had administration checklists which provided them with an overview of their patients’ current medications and order details (e.g. frequency and dose). While administration of these medications still rested with the patient and/or their family, the nurses were required to remind patients to take their medications and ask their patients, once per day, whether they were taking their medications as prescribed and to assess the efficacy of certain medications, for example analgesics, by asking patients about their pain three times per day. The policy at Fudan that gives ‘patients the responsibility for administering all oral and topical medications is unique in China. The variability in medication administration practices between Fudan and other acute care settings may have an impact on the symptom outcomes of patients as well as their perceptions of participation.

4.2 Characteristics of the clinician sample

4.2.1 Clinician recruitment and participation

Both doctors and nurses working in the units between 19 Aug, 2013 to 24 Jan, 2014 were recruited for Phase 2: Patient Participation in Symptom Management (PPSM)-clinician survey and individual interview. The numbers of eligible and recruited clinicians are presented in Figure 4.1. A total of 90
clinicians (56 doctors and 34 nurses) met the eligibility criteria. Of the 56 doctors, 18 doctors did not participate. In all but one instance this was because the mobile nature of doctors’ work meant that the researcher was not able to find an appropriate time to discuss the project with them. All eligible nurses consented to participate. The response rate was 67.9% for doctors and 100% for nurses. Among the recruited participants, five doctors and seven nurses were purposively selected for individual interviews.

### 4.2.2 Demographic characteristics and work experience of the clinician sample

Data on age, sex and highest level of education completed were collected from the clinicians. The demographic characteristics of both doctors and nurses are presented in Table 4.1. Almost two-thirds, 65.8% (n=25) of doctors
were aged less than 34 years with an average age of 33.24 (SD=5.04) years and ranged between 26 and 51 years. Thirty nurses (88.3%) in the sample were aged less than 34 years with an average age of 28.21 (SD=5.96) years and ranged between 22 and 50 years. Two-thirds (65.8%) of doctors and all nurses (100%) were female. Half of the doctors in the sample had a Master degree and for approximately half of the nurses, an Associate Diploma was the highest level of education; 41.2% of the nursing staff had a bachelor degree.

Table 4.1 Demographic characteristics of the clinician participants: n (%)  

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Doctors (n=38)</th>
<th>Nurses (n=34)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td>Mean(SD)</td>
<td>Mean(SD)</td>
</tr>
<tr>
<td>Less than 25</td>
<td>0</td>
<td>11 (32.4)</td>
</tr>
<tr>
<td>25-34</td>
<td>25 (65.8)</td>
<td>19 (55.9)</td>
</tr>
<tr>
<td>35-44</td>
<td>11 (28.9)</td>
<td>3 (8.8)</td>
</tr>
<tr>
<td>45-54</td>
<td>2 (5.3)</td>
<td>1 (2.9)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td>n(%)</td>
<td>n(%)</td>
</tr>
<tr>
<td>Male</td>
<td>13 (34.2)</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>25 (65.8)</td>
<td>34 (100)</td>
</tr>
<tr>
<td><strong>Highest level of education completed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary school</td>
<td>0</td>
<td>2 (5.9)</td>
</tr>
<tr>
<td>Associate Diploma</td>
<td>0</td>
<td>18 (52.9)</td>
</tr>
<tr>
<td>Bachelor Degree</td>
<td>7 (18.4)</td>
<td>14 (41.2)</td>
</tr>
<tr>
<td>Master Degree</td>
<td>19 (50.0)</td>
<td>0</td>
</tr>
<tr>
<td>PhD</td>
<td>12 (31.6)</td>
<td>0</td>
</tr>
</tbody>
</table>
Clinicians’ work experience characteristics are presented in Table 4.2. The majority of the doctor group comprised of RMOs (44.7%) and Attending Doctors (47.4%). The doctors had worked in the radiotherapy unit for a median duration of one year and the median length of overall oncological experience was five years. Nurses working as Primary Nurses accounted for 67.6% of the nurse sample. The nurses had been employed in the one of the two wards for a median of two years and had a median duration of oncological experience close to four years. 73.7% of doctors were trainee doctors or doctors in their first year after graduation.

Table 4.2 Work characteristics of the clinician sample: n (%)  

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Doctors (n=38)</th>
<th>Nurses (n=34)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Resident 17 (44.7)</td>
<td>Assistant Nurse 6 (17.6)</td>
</tr>
<tr>
<td></td>
<td>Attending 18 (47.4)</td>
<td>Primary Nurse 23 (67.6)</td>
</tr>
<tr>
<td></td>
<td>Consultant 2 (5.3)</td>
<td>In-charge Nurse 2 (5.9)</td>
</tr>
<tr>
<td></td>
<td>Chief 1 (2.6)</td>
<td>Head Nurse 2 (5.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Research assistant* 1 (2.9)</td>
</tr>
<tr>
<td>Time in unit (year)</td>
<td>Median 1.00 (0.17,6.00)</td>
<td>Median 2.00 (0.33,6.13)</td>
</tr>
<tr>
<td></td>
<td>(P_{25}, P_{75}) 0.08-29</td>
<td>Min-Max 0.08-15</td>
</tr>
<tr>
<td>Time in oncology (year)</td>
<td>Median 5.00 (2.00,10.00)</td>
<td>Median 3.75 (1.00,9.75)</td>
</tr>
<tr>
<td></td>
<td>(P_{25}, P_{75}) 0.08-29</td>
<td>Min-Max 0.25-29</td>
</tr>
</tbody>
</table>

*The research assistant working on the ward was a Registered Nurse. Her role, however, was to support the research conducted by the medical teams.
4.2.3 Summary

The final clinician sample comprised 67.9% of doctors and 100% of nurses who worked in the units during the data collection period. The average age of the doctors and nurses was 33.2 (SD=5.0) years and 28.2 (SD=6.0) years, respectively. There were 44.7% of doctors who were RMOs and 67.6% of nurses who were Primary Nurses. Approximately half of the doctors had worked in the unit for one year and half of the nurses for two years.

4.3 Characteristics of the patient sample

4.3.1 Patient recruitment and participation

Patients were recruited for Phase 2, the patient survey and individual interviews, between 11 November, 2013 and 25 January, 2014. During this period, 403 patients were admitted in one of the two designated units. Of these, 300 patients (87.5%) met the eligibility criteria. Given the case study design it is important to capture all patients that were admitted to the ward during the data collection period. The specific reasons why patients were not eligible to participate or excluded from the study are detailed Table 4.3.

<table>
<thead>
<tr>
<th>Criteria</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not meet the inclusion criteria</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admitted &lt;7 days</td>
<td>24</td>
<td>23.3</td>
</tr>
<tr>
<td>No confirmed diagnosis of cancer</td>
<td>1</td>
<td>.01</td>
</tr>
<tr>
<td>Readmitted (previously participated)</td>
<td>62</td>
<td>60.2</td>
</tr>
<tr>
<td>Met the exclusion criteria</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>11</td>
<td>10.7</td>
</tr>
</tbody>
</table>
Of the 300 eligible patients, 138 (46%) were not recruited. The detailed reasons for eligible patients’ refusal were recorded and are listed in Table 4.4. Illiteracy was not one of the exclusion criteria in this study. If a patient identified themselves as being illiterate, the researcher offered to complete the survey through interview, however, some patients still refused to participate based on literacy skills. A total of 162 patients (54%) participated in the study. Figure 4.2 shows the final patient recruitment and patient participants in each stage.

Table 4.4 Reasons for patient non-recruitment (n=138)

<table>
<thead>
<tr>
<th>Reasons</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharged before approached</td>
<td>56 (40.5)</td>
</tr>
<tr>
<td>Refusal reasons</td>
<td></td>
</tr>
<tr>
<td>Feeling sick</td>
<td>42 (30.5)</td>
</tr>
<tr>
<td>Did not want to</td>
<td>31 (22.4)</td>
</tr>
<tr>
<td>Illiteracy</td>
<td>9 (6.5)</td>
</tr>
</tbody>
</table>
Data regarding non-participants’ sex, age and type of cancer were compared with the characteristics of the participants and significant differences in the characteristics between these two groups were identified. The mean age of non-participants was 54.0 years, significantly older compared to participants, who were approximately 6 years younger (t=4.64, P<0.001). Approximately two-thirds of patients who refused to participate were male (χ²=11.26,
P=0.01). The distribution of patients’ cancer diagnoses was also different between these two groups ($X^2=16.24$, $P=0.013$). A detailed comparison of the two groups is presented in Table 4.5.

Table 4.5 Comparison of the characteristics of patient participants and non-participants

<table>
<thead>
<tr>
<th></th>
<th>Participant (n=162)</th>
<th>Non-participant (n=138)</th>
<th>$t/X^2$</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age: year, mean (SD)</strong></td>
<td>47.5 (12.2)</td>
<td>53.99 (12.0)</td>
<td>4.64 (t)</td>
<td>0.000*</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>78 (48.1)</td>
<td>93 (67.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>84 (51.9)</td>
<td>45 (32.6)</td>
<td>11.26 ($X^2$)</td>
<td>0.01^</td>
</tr>
<tr>
<td><strong>Type of cancer</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>5 (3.1)</td>
<td>9 (6.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel</td>
<td>27 (16.7)</td>
<td>28 (20.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>39 (24.1)</td>
<td>18 (13.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oesophageal</td>
<td>2 (1.2)</td>
<td>7 (5.1)</td>
<td>16.24 ($X^2$)</td>
<td>0.013^</td>
</tr>
<tr>
<td>Head and neck</td>
<td>60 (37.0)</td>
<td>57 (41.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lymphoma</td>
<td>21 (13.0)</td>
<td>8 (5.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others~</td>
<td>8 (4.9)</td>
<td>11 (8.0)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*P<0.001  
^P<0.05  
~“others” included: 5T soft tissue sarcoma, pelvic cavity cancer, urinary tract tumour, gastric cancer.

4.3.2 Demographic characteristics

Demographic characteristics of the patient sample are presented in Table 4.6.

A total of 162 patients participated in the PPSM-patient survey. There were 10 patients who withdrew after the CPS survey. Data related to their
demographic and disease/treatment characteristics were limited to age, sex and diagnosis. The remaining 152 participants also had information related to their marital status, education, income, insurance and work status collected. The mean age of the 162 patients was 47.49 (SD=12.19) years, with the youngest patient aged 21 years and oldest, 75 years. There were slightly more females (51.9%) than males (48.1%). Men were four years older on average than women and an independent-samples T-test shows there is a significant difference in age between them (t=2.37, P=0.019)(see Table 4.7).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years) (n=162*)</td>
<td>47.49</td>
<td>12.19</td>
</tr>
<tr>
<td>Sex (n=162)*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>78</td>
<td>48.1</td>
</tr>
<tr>
<td>Female</td>
<td>84</td>
<td>51.9</td>
</tr>
<tr>
<td>Highest level of education obtained</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary level or less</td>
<td>26</td>
<td>17.1</td>
</tr>
<tr>
<td>Secondary level</td>
<td>77</td>
<td>50.7</td>
</tr>
<tr>
<td>Tertiary level</td>
<td>49</td>
<td>32.2</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>8</td>
<td>5.3</td>
</tr>
<tr>
<td>Married</td>
<td>137</td>
<td>90.1</td>
</tr>
<tr>
<td>Divorced/Widowed</td>
<td>7</td>
<td>4.6</td>
</tr>
<tr>
<td>Work status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed (still working)</td>
<td>11</td>
<td>7.2</td>
</tr>
<tr>
<td>Employed (on leave)</td>
<td>59</td>
<td>38.8</td>
</tr>
</tbody>
</table>
Chapter 4 Describing the case study

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-employed</td>
<td>37</td>
<td>24.3%</td>
</tr>
<tr>
<td>Retired</td>
<td>30</td>
<td>19.7%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>15</td>
<td>9.9%</td>
</tr>
</tbody>
</table>

**Income level per month (RMB)**

<table>
<thead>
<tr>
<th>Income Level</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;=1000</td>
<td>34</td>
<td>22.4%</td>
</tr>
<tr>
<td>1001-3000</td>
<td>58</td>
<td>38.2%</td>
</tr>
<tr>
<td>3001-6000</td>
<td>41</td>
<td>27.0%</td>
</tr>
<tr>
<td>6001-10000</td>
<td>13</td>
<td>8.6%</td>
</tr>
<tr>
<td>&gt;10000</td>
<td>6</td>
<td>3.9%</td>
</tr>
</tbody>
</table>

**Medical insurance**

<table>
<thead>
<tr>
<th>Insurance Status</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>4</td>
<td>2.6%</td>
</tr>
<tr>
<td>Yes</td>
<td>148</td>
<td>97.4%</td>
</tr>
</tbody>
</table>

*The age and sex of participants includes the 10 who withdrew after completing the CPS

### Table 4.7 Patients’ age according to sex (n=162)

<table>
<thead>
<tr>
<th>Sex</th>
<th>Mean (SD)</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>49.81 (12.03)</td>
<td>2.37</td>
<td>0.019*</td>
</tr>
<tr>
<td>Female</td>
<td>45.33 (12.02)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p<0.05

Approximately one-third (32.2%) of patients had completed at least an undergraduate education. The majority of patients were married (90.1%). Almost half (46%) of the patients were still employed, 7.2% were still working during their hospitalization while the remainder were on sick leave. Those still working were for example, white collar workers who were able to work remotely. The largest proportion of patients (38.2%) reported their income level per month to be between RMB 1,000 and 3,000. The average monthly
income in China is RMB 1525 (The national bureau of statistics of the People’s Republic of China, 2014). The majority of patients had medical insurance (97.4%).

All patients were of Chinese nationality and were from 14 provinces or municipalities of China. The number of patients from each province or municipality are presented in Table 4.8 and Figure 4.3. Due to the hospital’s location in Shanghai, a Southeast city of China, the majority of patients were from the southeast of China (Jiangsu, Zhejiang, Shanghai, Anhui, Jiangxi, Fujian and Shandong). The proportion of patients from Jiangsu and Zhejiang, the two provinces closest to Shanghai comprised nearly half of the number of the total study sample. Residents of Shanghai most commonly received their radiotherapy/chemotherapy in the outpatient setting which explains why they do not comprise the largest group.

<table>
<thead>
<tr>
<th>Province or municipality</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jiangsu</td>
<td>38</td>
<td>25.0</td>
</tr>
<tr>
<td>Zhejiang</td>
<td>36</td>
<td>23.7</td>
</tr>
<tr>
<td>Shanghai</td>
<td>24</td>
<td>15.8</td>
</tr>
<tr>
<td>Anhui</td>
<td>23</td>
<td>15.1</td>
</tr>
<tr>
<td>Jiangxi</td>
<td>14</td>
<td>9.2</td>
</tr>
<tr>
<td>Fujian</td>
<td>6</td>
<td>3.9</td>
</tr>
<tr>
<td>Shandong</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td>Others*</td>
<td>9</td>
<td>6.1</td>
</tr>
</tbody>
</table>

*Other provinces include Hunan, Xinjiang, Beijing, Guangxi, Heibei, Heinan and Neimenggu.
4.3.3 Illness and treatment related characteristics

As shown in Table 4.9, the most common types of cancer were head and neck cancer (37.0%), breast cancer (24.1%), bowel cancer (16.7%) and lymphoma (13.0%). Prior to their current admission, approximately one third of patients had received chemotherapy (34.4%) and/or radiotherapy (30.9%) and one quarter (25.3%) had undergone surgery for their cancer. The majority of patients were admitted to the ward for radiotherapy alone (59.2%) or in combination with chemotherapy (32.2%). The majority of patients receiving treatment for their cancer had been diagnosed for less than one year. The median time since diagnosis was 0.32 years ($P_{25}=0.19$, $P_{75}=0.67$). Minimum time was less than one month and maximum was 11.59 years.
### Table 4.9 Illness and treatment related characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cancer type</strong> (n=162)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel</td>
<td>27</td>
<td>16.7</td>
</tr>
<tr>
<td>Breast</td>
<td>39</td>
<td>24.1</td>
</tr>
<tr>
<td>Head and neck</td>
<td>60</td>
<td>37.0</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>21</td>
<td>13.0</td>
</tr>
<tr>
<td>Others</td>
<td>15</td>
<td>9.3</td>
</tr>
<tr>
<td><strong>Past treatment type</strong> (multiple choices) (n=152)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>72</td>
<td>25.3</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>98</td>
<td>34.4</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>88</td>
<td>30.9</td>
</tr>
<tr>
<td>Endocrine therapy</td>
<td>9</td>
<td>3.2</td>
</tr>
<tr>
<td>Traditional Chinese medicine</td>
<td>14</td>
<td>4.9</td>
</tr>
<tr>
<td>Others^</td>
<td>4</td>
<td>1.4</td>
</tr>
<tr>
<td><strong>Treatment type during this admission (n=152)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy alone</td>
<td>13</td>
<td>8.6</td>
</tr>
<tr>
<td>Radiotherapy alone</td>
<td>90</td>
<td>59.2</td>
</tr>
<tr>
<td>Chemo-radiotherapy</td>
<td>49</td>
<td>32.2</td>
</tr>
<tr>
<td><strong>Median (P_{25}, P_{75}) Min-max</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of time since diagnosis (year) (n=146)(^\sim)</td>
<td>0.32(0.19, 0.67)</td>
<td>0.04-11.59</td>
</tr>
</tbody>
</table>

* Bowel cancers include: rectal cancer, carcinoma of sigmoid and anal cancer.

Head and neck cancers include: nasopharynx cancer, gum cancer, tonsil cancer, nasal malignant melanoma, and paranasal sinus cancer.

Lymphoma include: CNS lymphoma, Diffuse Large B Cell Lymphoma, and nasal lymphoma patients.

Other cancer types include soft tissue sarcoma, pelvic cavity cancer, urinary tract tumour, lung cancer, gastric cancer, oesophageal cancer.

^Other treatment types include target therapy and immunotherapy.

\(^\sim\) In addition to the 10 patients who withdrew after CPS survey, six patients were unable to remember the exact time of diagnosis.
4.3.4 Family caregivers’ participation

In China, patients are usually accompanied by family members during their admission. The proportion of patients who had this support was collected to explore the impact of family presence on patient participation. Figure 4.4 shows the number and percent of patients who had family caregivers present to provide care to them on the ward and the average length of time these family caregivers spent during each 24-hour period of admission (as reported by patients). There were 126 (73.7%) patients who had family or friends to provide care for them while they were in hospital and 41.4% had family members or friends present on the ward for more than 12 hours in a 24-hour period.

![Figure 4.4](image)

Figure 4.4 Length of time spent with patients by family caregivers in a 24-hour period
4.3.5 Health literacy

The Health Literacy Questionnaire (HLQ) consists of 9 scales. Cronbach’s alpha coefficients for the scales are displayed in Table 4.10. In this study, six scales had coefficients above 0.7.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare provider support</td>
<td>0.73</td>
</tr>
<tr>
<td>Having sufficient information</td>
<td>0.70</td>
</tr>
<tr>
<td>Actively managing health</td>
<td>0.76</td>
</tr>
<tr>
<td>Social support</td>
<td>0.67</td>
</tr>
<tr>
<td>Critical appraisal</td>
<td>0.65</td>
</tr>
<tr>
<td>Active engagement with healthcare providers</td>
<td>0.82</td>
</tr>
<tr>
<td>Navigating the healthcare system</td>
<td>0.80</td>
</tr>
<tr>
<td>Ability to find good health information</td>
<td>0.83</td>
</tr>
<tr>
<td>Reading and understanding health information</td>
<td>0.69</td>
</tr>
</tbody>
</table>

In total, 139 patients (91.4%) completed the health literacy questionnaire in the PPSM. In Table 4.11 the mean scores of each scale according to the health literacy component it informs is presented. The higher the score on each scale, the higher the health literacy of the patient. In terms of the scales relating to attributes, resources or approaches to health literacy, mean scores for each scale were above 2.80 and the highest response was for social
support (Mean=3.00, SD=0.32). High scores were also found on the scales relating to patient competence which ranged from 3.42 to 3.86.

Table 4.11 Mean (SD) score for each scale in the HLQ (n=139)

<table>
<thead>
<tr>
<th>Part A: attributes, resources or approaches (1-strongly disagree to 4-strongly agree)</th>
<th>Mean (SD)</th>
<th>Min-max</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Healthcare provider support</td>
<td>2.83 (0.35)</td>
<td>1.75-3.75</td>
</tr>
<tr>
<td>2. Having sufficient information</td>
<td>2.83 (0.34)</td>
<td>2.00-4.00</td>
</tr>
<tr>
<td>3. Actively managing health</td>
<td>2.89 (0.31)</td>
<td>2.00-4.00</td>
</tr>
<tr>
<td>4. Social support</td>
<td>3.00 (0.32)</td>
<td>2.00-4.00</td>
</tr>
<tr>
<td>5. Critical appraisal</td>
<td>2.87 (0.30)</td>
<td>2.00-4.00</td>
</tr>
</tbody>
</table>

Part B: Competence (1-cannot do to 5-very easy)

| 6. Active engagement with healthcare providers | 3.43 (0.61) | 1.60-5.00 |
| 7. Navigating the healthcare system | 3.42 (0.44) | 2.17-4.50 |
| 8. Ability to find good health information | 3.63 (0.58) | 1.20-5.00 |
| 9. Reading and understanding health information | 3.86 (0.46) | 2.20-4.80 |

Cluster analysis was used to group the participants (hierarchical approach using Ward’s method for linkage), based on the mean scores of the nine scales of the HLQ. As there was no information available on the appropriate number of clusters in the data set, several cluster analysis runs were conducted with a range of cluster solutions from 3 to 18 identified in order to select a suitable number. The principle behind identifying the number of clusters was to minimise the remaining variance in each scale within each cluster (the standard deviations are suggested to be below 0.6) and to ensure
that clusters were representative of a different patterns of needs and strengths across the nine scales of the HLQ (Batterham et al., 2014).

Using the analysis process outlined above, nine patient clusters were identified. The number of patients together with the mean score of each scale split by the cluster solution are shown in Table 4.12. These nine clusters were grouped into three major categories. Clusters 6, 8 and 1 suggested the patients had an overall high health literacy (n=49, 35.2%) with the overall mean scores ranging from 3.89 to 3.46. Clusters 7, 5, 3 and 2 were four clusters that indicated patients had moderate health literacy (n=70, 50.4%) with the overall mean scores from 3.30 to 3.07. The last two clusters, 4 and 9, represented patients with low health literacy (n=20, 14.4%) with the overall mean scores from 2.85 to 2.52.

Table 4.12 Mean score for each cluster

<table>
<thead>
<tr>
<th>Health literacy group</th>
<th>Cluster number</th>
<th>Number of people</th>
<th>Part A Needs</th>
<th>Part B Competence</th>
<th>Mean for all scales</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cluster number</td>
<td>Number of people</td>
<td>Healthcare</td>
<td>Health</td>
<td>Social support</td>
</tr>
<tr>
<td>High</td>
<td>6</td>
<td>3</td>
<td>3.00</td>
<td>3.00</td>
<td>3.00</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>4</td>
<td>3.50</td>
<td>3.44</td>
<td>3.45</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>42</td>
<td>2.98</td>
<td>2.98</td>
<td>2.96</td>
</tr>
<tr>
<td>Moderate</td>
<td>7</td>
<td>15</td>
<td>2.92</td>
<td>2.95</td>
<td>3.03</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>19</td>
<td>2.99</td>
<td>2.67</td>
<td>2.85</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>27</td>
<td>2.86</td>
<td>2.94</td>
<td>3.01</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>9</td>
<td>2.36</td>
<td>2.58</td>
<td>2.64</td>
</tr>
<tr>
<td>Low</td>
<td>4</td>
<td>13</td>
<td>2.40</td>
<td>2.31</td>
<td>2.58</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>7</td>
<td>2.21</td>
<td>2.54</td>
<td>2.37</td>
</tr>
</tbody>
</table>
4.3.6 Summary

Patients who were older and male were more likely to refuse to participate in the survey component of this study. In total, 162 patients were recruited in the survey representing a participation rate of 54%, however, 10 of these patients only completed the CPS. The mean age of patient participants was 47.5 years and 51.9% were female. Patients were diagnosed with a range of cancers and 50% had been diagnosed for a median of four months prior to the survey. All patients were admitted for radiotherapy and/or chemotherapy. Approximately three-quarters of patients had family or friends supporting and providing care to them during their hospital admission. More than 80% of patients were found to have a moderate or high level of health literacy.

4.4 Symptom profile of the patient sample

4.4.1 Physical performance

Patients' level of function and capability for self-care was assessed using the Eastern Co-operative Oncology Group Performance Status (ECOG-PS). As shown in Figure 4.5, almost half (44.6%) of the sample reported “Restriction in physically strenuous activity but able to carry out work of a light or sedentary nature” and only 8.1% reported being “capable of only limited self-care”.
4.4.2 Anxiety and Depression

Patients’ anxiety, depression and emotional distress were assessed using the Hospital Anxiety and Depression Scale (HADS), comprising two subscales (anxiety and depression) with a total score of 21 for each. The Cronbach’s alpha coefficients in the current study sample were 0.80 for the depression subscale and 0.87 for the anxiety subscale.

A total of 145 patients, 89.5% of all patients who participated in the PPSM survey, completed the HADS. For the anxiety scale, the average score was 5.47 (SD=4.03), with the minimum score of 0 and maximum of 18. For the subscale of depression, the average score was 4.87 (SD=3.86), with the range from 0 to 16.
Patients with a score of eight or more in each of the subscales were, in the current study, indicative that they were experiencing symptoms of anxiety and/or depression. This cut-off score was based on the most frequent cut-off score reported in the literature (Bjelland et al., 2002). Table 4.13 shows there were 38 (26.2%) and 31 (21.4%) patients who had scores that were suggestive of anxiety or depression, respectively.

Table 4.13 Anxiety and depression of the patient sample assessed by HADS (n=145)

<table>
<thead>
<tr>
<th></th>
<th>Anxiety</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Abnormal (≥8)</td>
<td>38 (26.2)</td>
<td>31 (21.4)</td>
</tr>
<tr>
<td>Normal (&lt;8)</td>
<td>107 (73.8)</td>
<td>114 (78.6)</td>
</tr>
</tbody>
</table>

4.4.3 Symptom experience

Patients in this study all had a diagnosis of cancer and were receiving at least one cancer treatment (radiotherapy and/or chemotherapy). Consequently, symptom experience was considered a vital characteristic of the patient sample. In order to assess their symptom profiles comprehensively, the Memorial Symptoms Assessment Scale (MSAS) (modified) was used. The MSAS enabled the capture of the multidimensional symptom experience of 26 symptoms during the past 24 hours and 8 symptoms in the past week. The MSAS was modified for this study to explore, from a patient perspective, their perception of clinicians’ knowledge of the presence of each symptom
they reported. This modified MSAS had satisfactory reliability in the current study population, with Cronbach’s alpha coefficients of all the subscales above 0.8; the Physical Symptom Distress Score (PHYS): 0.94, the Psychological Symptom Distress Score (PSYCH): 0.95, the Global Distress Index (GDI): 0.82, and the Total Symptom Score (TMSAS): 0.96. A total of 150 patients, 92.6% of all patients who commenced the PPSM answered the MSAS.

4.4.3.1 Multiple symptom presentation

The majority of patients reported that they had experienced at least one symptom during the period investigated (either previous 24 hours or one week). Figure 4.6 displays the distribution of the number of symptoms experienced simultaneously by patients. Two patients reported no symptoms and two patients reported 27 concurrent symptoms which was the maximum number possible. On average, patients experienced 10.71 (SD=6.72) symptoms simultaneously.
4.4.3.2 Symptom prevalence and individual symptom scores

The prevalence of each symptom is displayed in Table 4.14. The five most prevalent symptoms experienced by patients were: dry mouth (68.0%), pain (58.7%), fatigue (52.0%), difficulty sleeping (50.7%), and lack of energy (50.0%). Fatigue was added to the MSAS tool in this study for the purpose of examining whether patients understood the terms of fatigue and lack of energy in the same way. The results indicated that patients had similar interpretation of these two terms.

Individual symptom scores (ISC) were calculated, by averaging the frequency, severity and distress for each symptom (Chang et al., 2004). The detailed values for each symptom are presented in Table 4.14. The top five symptoms in terms of the mean score for ISC were difficulty swallowing (2.52), mouth
sores (2.50), change in food tastes (2.44), lack of appetite (2.42) and dry mouth (2.39).

Table 4.14 Symptom prevalence and individual symptom score (ISC) for patients who reported experiencing the symptom from most prevalent to least prevalent (n=150*)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Prevalence</th>
<th>Individual symptom score*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Dry Mouth</td>
<td>102</td>
<td>68.0</td>
</tr>
<tr>
<td>Pain</td>
<td>88</td>
<td>58.7</td>
</tr>
<tr>
<td>Fatigue</td>
<td>78</td>
<td>52.0</td>
</tr>
<tr>
<td>Difficulty Sleeping</td>
<td>76</td>
<td>50.7</td>
</tr>
<tr>
<td>Lack of Energy</td>
<td>75</td>
<td>50.0</td>
</tr>
<tr>
<td>Change in Food Tastes</td>
<td>73</td>
<td>48.7</td>
</tr>
<tr>
<td>Lack of Appetite</td>
<td>70</td>
<td>46.7</td>
</tr>
<tr>
<td>Changes in Skin</td>
<td>63</td>
<td>42.0</td>
</tr>
<tr>
<td>Weight Loss</td>
<td>61</td>
<td>40.7</td>
</tr>
<tr>
<td>Cough</td>
<td>60</td>
<td>40.0</td>
</tr>
<tr>
<td>Sweats</td>
<td>60</td>
<td>40.0</td>
</tr>
<tr>
<td>Feeling Drowsy</td>
<td>53</td>
<td>35.3</td>
</tr>
<tr>
<td>Difficulty Swallowing</td>
<td>53</td>
<td>35.3</td>
</tr>
<tr>
<td>Itching</td>
<td>50</td>
<td>33.3</td>
</tr>
<tr>
<td>Feeling Nervous</td>
<td>48</td>
<td>32.0</td>
</tr>
<tr>
<td>Worrying</td>
<td>45</td>
<td>30.0</td>
</tr>
<tr>
<td>Feeling Irritable</td>
<td>44</td>
<td>29.3</td>
</tr>
<tr>
<td>Nausea</td>
<td>43</td>
<td>28.7</td>
</tr>
<tr>
<td>Feeling Sad</td>
<td>42</td>
<td>28.0</td>
</tr>
<tr>
<td>Mouth Sores</td>
<td>41</td>
<td>27.3</td>
</tr>
<tr>
<td>Numbness Tingling</td>
<td>40</td>
<td>26.7</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th></th>
<th>Prevalence</th>
<th>Individual symptom score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Reflux</td>
<td>39</td>
<td>26.0</td>
</tr>
<tr>
<td>Constipation</td>
<td>39</td>
<td>26.0</td>
</tr>
<tr>
<td>Difficulty</td>
<td>38</td>
<td>25.3</td>
</tr>
<tr>
<td>Concentrating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling Bloated</td>
<td>36</td>
<td>24.0</td>
</tr>
<tr>
<td>Vomiting</td>
<td>31</td>
<td>20.7</td>
</tr>
<tr>
<td>Hair Loss</td>
<td>31</td>
<td>20.7</td>
</tr>
<tr>
<td>Dizziness</td>
<td>26</td>
<td>17.3</td>
</tr>
<tr>
<td>Don’t Look Like</td>
<td>22</td>
<td>14.7</td>
</tr>
<tr>
<td>Myself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>20</td>
<td>13.3</td>
</tr>
<tr>
<td>Shortness of</td>
<td>18</td>
<td>12.0</td>
</tr>
<tr>
<td>Breath</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fever</td>
<td>16</td>
<td>10.7</td>
</tr>
<tr>
<td>Swelling</td>
<td>13</td>
<td>8.7</td>
</tr>
<tr>
<td>Problems with</td>
<td>12</td>
<td>8.0</td>
</tr>
<tr>
<td>Urination</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* The individual symptom score was only calculated for patients who reported they had symptom(s) during the period investigated.

### 4.4.3.3 Symptom characteristics in frequency, severity, distress and known by clinicians

Using the MSAS, when a symptom is present, it is rated by patients in relation to frequency, severity and distress. Frequency is scored from 1 to 4 ranging from ‘rarely’ to ‘almost constantly’. Severity is rated on a four-point Likert scale: slight; moderate; severe and very severe. Distress is measured on a five-point Likert scale although the score is still out of 4 (not at all=0.8; a little
bit=1.6; somewhat=2.4, quite a bit=3.2 and very much=4) (Portenoy et al., 1994a). Table 4.15 reveals the percentage of patients reporting high level in frequency, severity and distress dimensions as a result of the particular symptom and the percentage of patients having the symptom known by clinicians. High level of frequency in the current study was defined by patient descriptions of symptoms occurring as either ‘frequent’ or ‘almost constantly’; high level of severity was defined as ‘severe’ or ‘very severe’ and; high level of distress was defined as ‘quite a bit’ or ‘very much’ (Portenoy et al., 1994b). Mean scores of frequency, severity and distress for each symptom are also presented.

Dry mouth was the most common symptom experienced by patients. It was also the symptom that when present was reported by (66.7%) patients as being present either ‘frequently’ or ‘almost constantly’ in the 24 hours prior to the survey with a mean frequency score of 2.83 (SD=0.91). Lack of appetite and difficulty swallowing were also symptoms that were reported by patients (62.4% and 60.9% respectively) as being present either frequently or constantly in the 24 hour prior to the survey. Constipation was reported by 39 patients (26%), however 36 of these patients (92.3%) reported it as severe or very severe, mean severity score 2.28. In terms of the distress caused by symptoms, the symptom that when present caused the distress was mouth sores with 51.2% reporting ‘quite a bit’ or ‘very much’ distress.
It also can be seen in Table 4.15 that fever was a symptom always known by clinicians (100%), followed by weight loss (95.1%), pain (93.2%) and mouth sores (92.7%). With the exception of pain, these symptoms are not reliant on self-report to determine their presence.

There were seven symptoms not listed in the MSAS, but reported by patients in the ‘other’ section. These symptoms were nasal discomfort (including “sniffle” i.e. runny nose, dry nose and epistaxis) (n=7), blurred vision (n=2), toothache (n=2), hearing loss (n=1), hiccoughs (n=1), cold limbs (n=1), and excessive oral mucus (n=1). Except for toothache, which was perceived by one patient as ‘somewhat distressing’, all the symptoms reported in the ‘other’ section ranged in distress from ‘quite a bit’ to ‘very much’. These symptoms were all known by clinicians except for blurred vision.

The mean scores for frequency, severity and distress for each symptom are displayed in Figure 4.7, ordered from highest to lowest mean frequency. As the mean scores of frequency, severity and distress were not normally distributed, Spearman’s correlation test was used to explore the relationship between symptom frequency, severity, distress and whether patients reported that symptom presence was known by clinicians. This analysis revealed a strong correlation between the average scores of frequency, severity, and distress. Symptoms with high frequency scores tended to be more severe (r=0.78, P<0.001) and cause more distress (r=0.66, P<0.001). Symptoms which were more severe caused more distress (r=0.51, P=0.002). The symptoms that were more likely to be known by clinicians were those
that were more frequent in the 24-hour period ($r=0.76$, $P<0.001$) prior to survey or were more severe ($r=0.78$, $P<0.001$). The correlation between the distress score and whether patients perceived the symptom to be known by clinicians was not significant ($r=0.24$, $P=0.177$).

![Figure 4.7 Mean frequency, severity and distress score for each symptom order from highest to lowest mean frequency](image-url)
Table 4.15 Symptom prevalence, frequency, severity and distress characteristics (n=150)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Prevalence</th>
<th>Frequency</th>
<th>Mean frequency score</th>
<th>Severity</th>
<th>Mean severity score</th>
<th>Distress</th>
<th>Mean distress score</th>
<th>Known by clinicians</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>N</td>
<td>%</td>
<td>Mean</td>
<td>SD</td>
<td>N</td>
<td>%</td>
<td>Mean</td>
</tr>
<tr>
<td>Dry Mouth</td>
<td>102</td>
<td>68</td>
<td>66.7</td>
<td>2.83</td>
<td>0.91</td>
<td>84</td>
<td>82.4</td>
<td>2.21</td>
</tr>
<tr>
<td>Pain</td>
<td>88</td>
<td>39</td>
<td>44.3</td>
<td>2.48</td>
<td>0.98</td>
<td>57</td>
<td>64.8</td>
<td>1.86</td>
</tr>
<tr>
<td>Fatigue</td>
<td>78</td>
<td>30</td>
<td>38.5</td>
<td>2.21</td>
<td>0.92</td>
<td>56</td>
<td>71.8</td>
<td>1.94</td>
</tr>
<tr>
<td>Difficulty Sleeping</td>
<td>76</td>
<td>35</td>
<td>46.1</td>
<td>2.28</td>
<td>0.89</td>
<td>50</td>
<td>65.8</td>
<td>1.93</td>
</tr>
<tr>
<td>Lack of energy</td>
<td>75</td>
<td>38</td>
<td>50.7</td>
<td>2.45</td>
<td>0.89</td>
<td>54</td>
<td>72</td>
<td>1.89</td>
</tr>
<tr>
<td>Change in Food Tastes</td>
<td>73</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>59</td>
<td>80.8</td>
</tr>
<tr>
<td>Lack of Appetite</td>
<td>70</td>
<td>44</td>
<td>62.9</td>
<td>2.67</td>
<td>0.78</td>
<td>60</td>
<td>85.7</td>
<td>2.29</td>
</tr>
<tr>
<td>Chang in Skin</td>
<td>63</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>38</td>
<td>60.3</td>
</tr>
<tr>
<td>Weight Loss</td>
<td>61</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>40</td>
<td>65.6</td>
</tr>
<tr>
<td>Cough</td>
<td>60</td>
<td>13</td>
<td>21.7</td>
<td>1.98</td>
<td>0.77</td>
<td>25</td>
<td>41.7</td>
<td>1.58</td>
</tr>
<tr>
<td>Sweats</td>
<td>60</td>
<td>20</td>
<td>33.3</td>
<td>2.1</td>
<td>0.8</td>
<td>35</td>
<td>58.3</td>
<td>1.72</td>
</tr>
<tr>
<td>Feeling Drowsy</td>
<td>53</td>
<td>18</td>
<td>34</td>
<td>2.02</td>
<td>0.91</td>
<td>28</td>
<td>52.8</td>
<td>1.72</td>
</tr>
<tr>
<td>Difficulty Swallowing</td>
<td>53</td>
<td>32</td>
<td>60.4</td>
<td>2.75</td>
<td>1.09</td>
<td>44</td>
<td>83</td>
<td>2.36</td>
</tr>
<tr>
<td>Itching</td>
<td>50</td>
<td>12</td>
<td>24</td>
<td>1.88</td>
<td>0.82</td>
<td>26</td>
<td>52</td>
<td>1.62</td>
</tr>
<tr>
<td>Feeling Nervous</td>
<td>48</td>
<td>11</td>
<td>22.9</td>
<td>1.92</td>
<td>0.9</td>
<td>28</td>
<td>58.3</td>
<td>1.69</td>
</tr>
<tr>
<td>Worrying</td>
<td>45</td>
<td>11</td>
<td>24.4</td>
<td>1.96</td>
<td>0.8</td>
<td>31</td>
<td>68.9</td>
<td>1.82</td>
</tr>
<tr>
<td>Feeling Irritable</td>
<td>44</td>
<td>10</td>
<td>22.7</td>
<td>1.91</td>
<td>0.8</td>
<td>28</td>
<td>63.6</td>
<td>1.8</td>
</tr>
<tr>
<td>Nausea</td>
<td>43</td>
<td>14</td>
<td>32.6</td>
<td>2.19</td>
<td>0.85</td>
<td>27</td>
<td>62.8</td>
<td>1.81</td>
</tr>
<tr>
<td>Feeling Sad</td>
<td>42</td>
<td>11</td>
<td>26.2</td>
<td>1.98</td>
<td>0.87</td>
<td>29</td>
<td>69</td>
<td>1.81</td>
</tr>
<tr>
<td>Mouth Sores</td>
<td>41</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>32</td>
<td>78</td>
</tr>
<tr>
<td>Numbness Tingling</td>
<td>40</td>
<td>16</td>
<td>40</td>
<td>2.33</td>
<td>0.94</td>
<td>21</td>
<td>52.5</td>
<td>1.78</td>
</tr>
<tr>
<td>Reflux</td>
<td>39</td>
<td>17</td>
<td>43.6</td>
<td>2.23</td>
<td>0.84</td>
<td>27</td>
<td>69.2</td>
<td>2.05</td>
</tr>
<tr>
<td>Constipation</td>
<td>39</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>36</td>
<td>92.3</td>
<td>2.28</td>
</tr>
<tr>
<td>Difficulty Concentrating</td>
<td>38</td>
<td>8</td>
<td>21.1</td>
<td>1.92</td>
<td>0.78</td>
<td>24</td>
<td>63.2</td>
<td>1.74</td>
</tr>
<tr>
<td>Feeling Bloating</td>
<td>36</td>
<td>8</td>
<td>22.2</td>
<td>2</td>
<td>0.83</td>
<td>16</td>
<td>44.4</td>
<td>1.53</td>
</tr>
<tr>
<td>Vomiting</td>
<td>31</td>
<td>11</td>
<td>35.5</td>
<td>2.1</td>
<td>0.94</td>
<td>22</td>
<td>71</td>
<td>2.06</td>
</tr>
<tr>
<td>Hair Loss</td>
<td>31</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>23</td>
<td>74.2</td>
<td>2.39</td>
</tr>
<tr>
<td>Dizziness</td>
<td>26</td>
<td>6</td>
<td>23.1</td>
<td>1.88</td>
<td>0.95</td>
<td>14</td>
<td>53.8</td>
<td>1.69</td>
</tr>
<tr>
<td>Do not look like myself</td>
<td>22</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>14</td>
<td>63.6</td>
<td>2.14</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>20</td>
<td>10</td>
<td>50</td>
<td>2.3</td>
<td>1.13</td>
<td>14</td>
<td>70</td>
<td>2.1</td>
</tr>
<tr>
<td>Shortness of Breath</td>
<td>18</td>
<td>4</td>
<td>22.2</td>
<td>1.83</td>
<td>0.92</td>
<td>9</td>
<td>50</td>
<td>1.72</td>
</tr>
<tr>
<td>Fever</td>
<td>16</td>
<td>5</td>
<td>31.3</td>
<td>2.19</td>
<td>0.98</td>
<td>9</td>
<td>56.3</td>
<td>1.81</td>
</tr>
<tr>
<td>Swelling</td>
<td>13</td>
<td>NE</td>
<td>NE</td>
<td>NE</td>
<td>5</td>
<td>38.5</td>
<td>1.62</td>
<td>0.87</td>
</tr>
<tr>
<td>Problems with Urination</td>
<td>12</td>
<td>1</td>
<td>8.3</td>
<td>1.5</td>
<td>0.91</td>
<td>7</td>
<td>58.3</td>
<td>1.75</td>
</tr>
</tbody>
</table>

* percentage frequently to constantly;  † Percentage severe to very severe;  ‡ percentage quite a bit to very much;  NE, not evaluated in the MSAS tool;
4.4.3.4 Mean scores for each MSAS subscale

The scores for GDI, PHYS, PSYCH, and Total MSAS reflect patients’ overall symptom experience. The calculation methods for these scores were presented in detail in Chapter 3 Section 3.2.2.3. The mean scores for each subscale are presented in Table 4.16, higher scores for the subscales indicated that the symptoms were more likely to have an impact on patients.

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Mean (SD)</th>
<th>Min-max</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHYS</td>
<td>0.83 (0.67)</td>
<td>0.00-2.92</td>
</tr>
<tr>
<td>PSYCH</td>
<td>0.64 (0.68)</td>
<td>0.00-2.79</td>
</tr>
<tr>
<td>GDI</td>
<td>0.83 (0.71)</td>
<td>0.00-3.20</td>
</tr>
<tr>
<td>Total MSAS</td>
<td>0.65 (0.49)</td>
<td>0.00-2.49</td>
</tr>
</tbody>
</table>

*The calculation of subscale scores includes patients who did not have the symptom.

The correlation between the MSAS subscale scores and patients’ demographic and illness-related characteristics are displayed in Table 4.17. Patients’ age and sex was found not to be significantly correlated with the four MSAS scores. Type of cancer and current treatment were significantly correlated with the scores of GDI, PHYS, Total MSAS but not with the score for PSYCH. Further analysis of cancer types found patients with head and neck cancer reported significantly higher GDI, PHYS and Total MSAS scores than patients with breast (P<0.001), bowel (P=0.002), and other types of cancer (P=0.002). The Bonferroni correction was used to allow for multiple
corrections thus all effects were assessed using the revised alpha level of 0.01. In terms of current treatments, further pairwise comparisons identified a significant difference between patients that were having radiotherapy and chemotherapy in terms of the scores of the GDI (P=0.015), PHYS (P=0.001) and TMSAS (P=0.029) subscales, and patients receiving radiotherapy alone versus patients receiving both chemotherapy and radiotherapy in terms of PHYS (P=0.003) and TMSAS (P=0.040). The Bonferroni correction was used for these analyses so all effects were assessed using the revised alpha level of 0.017.

Table 4.17 Correlations between MSAS subscale scores with patients’ demographic and illness-related information

<table>
<thead>
<tr>
<th></th>
<th>GDI</th>
<th>PHYS</th>
<th>PSYCH</th>
<th>TMSAS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r/U/H^</td>
<td>P</td>
<td>r/U/H</td>
<td>P</td>
</tr>
<tr>
<td>Age</td>
<td>0.06(r)</td>
<td>0.453</td>
<td>-0.09</td>
<td>0.276</td>
</tr>
<tr>
<td>Sex</td>
<td>0.20(U)</td>
<td>0.844</td>
<td>-1.45</td>
<td>0.149</td>
</tr>
<tr>
<td>Type of cancer</td>
<td>26.14(H)</td>
<td>0.000*</td>
<td>50.21</td>
<td>0.000*</td>
</tr>
<tr>
<td>Current treatment</td>
<td>7.35(H)</td>
<td>0.025~</td>
<td>16.79</td>
<td>0.000*</td>
</tr>
</tbody>
</table>

*P<0.001
~P<0.05
^r: Spearman rank correlation; U: Mann-Whitney U test; H: Kruskal Wallis H test

4.4.4 Summary

In terms of self-reported physical performance status, 62.8% of patients reported they could carry out activities without any restriction or with some physical restriction; 26.2% and 21.4% of patients had scores indicative of
Chapter 4 Describing the case study

anxiety and depression, respectively. Cancer patients during radiotherapy and/or chemotherapy usually experienced multiple symptoms concurrently with an average number of 10 symptoms during the period investigated. Dry mouth was the most common and frequent symptom patients experienced. Constipation was reported as the most severe, mouth sores was the most distressful for patients and fever, weight loss, pain and mouth sores were the symptoms patients perceived most frequently as being recognised by clinicians. Symptoms with higher frequency scores tended to be more severe and cause more distress. The mean scores of the MSAS subscales (PHYS, PSYCH, GDI and TMSAS) ranged from 0.64 to 0.83. Patients with head and neck cancer had significantly higher levels of symptoms (prevalence, frequency, severity and distress) than patients with other cancer types and those undergoing chemotherapy reported higher scores on the GDI, PHYS and TMSAS subscales than those undergoing radiotherapy.

4.5 Discussion

The purpose of the analyses presented in this chapter was to describe the case study in terms of the setting where the data were collected and the characteristics of patients, nurses and doctors who participated in this study. These findings provide an important contextual basis for the analysis of the concept of patient participation in terms of patients’ and clinicians’ perceptions and experiences that are presented in subsequent chapters. In addition, the characteristics of clinicians and patients in the case study have
implications for the external generalisability of the findings. The analyses are discussed in terms of clinician characteristics, patient characteristics and patient symptom profiles.

4.5.1 Clinician characteristics

In this study, clinicians (doctors and nurses) who worked on one of the two data collection wards and interacted therapeutically with patients during the data collection period were recruited. Clinicians’ demographic characteristics such as age, education level and years of experience and workplace culture, model of care and systems and processes are factors that may have impacted on clinicians’ attitudes towards, and understandings of, patient participation. These factors, while only having been explored in a few studies, have been shown to influence behaviours that facilitate or limit patient involvement in their care (Daneman, Macaluso, & Guzzetta, 2003; Hamann et al., 2010).

Clinician participants were recruited from a tertiary hospital in Shanghai, China; 65.8% of doctors and 88.3% of nurses were aged less than 34 years. According to the Ministry of Health report, 27.5% of doctors and 57.2% of nurses in China were aged less than 34 years in 2012 (Ministry of Health, 2014a). The present sample was younger than the national data. The high proportion of trainee doctors in this study contributed to the increased percentage of younger doctors in this study. Approximately 74% of RMOs in
the doctor sample were doctors-in-training or doctors one year after graduation who were mostly aged between 25-34 years.

Half of the doctors in the current study had obtained a Master level degree and 31.6% had a PhD. More than 50% of nurses had Associate Diplomas and those who had a bachelor degree accounted for 41.2% of the sample. The percentage of doctors with postgraduate degrees and nurses with diploma or above education were significantly higher than the national data in which doctors with postgraduate degrees and nurses with diploma or above qualifications accounted for 9.9% and 56.0% of clinicians respectively (Ministry of Health, 2014a). This large difference can be explained by the regional discrepancy of human resources for health in China, which is also the case in tertiary hospitals such as Guangzhou, in which 52.7% of doctors held Master degrees or above and 59.5% of nurses had associate diplomas or above (Dai, 2008).

Despite the higher educational preparation of clinicians working in the case study hospital, many clinicians were at the beginning of their clinical careers. This is consistent with the young age of the clinician samples. Years of oncological experience of doctors in the case study was much less than the national average for doctors working in clinical practice. There were 25% of doctors working in the oncological setting for two years or less which is considerably less than the National statistics of 25% with nine years or less work experience (Ministry of Health, 2014a). Half of the nurses in the case study had worked in the units less than two years (median=2) and their
experience working in oncology was less than 4 years (median=3.75); whereas the national data suggested that 50% of nurses had 9 years or less work experience (Ministry of Health, 2014a).

The clinician participants in this case study therefore were younger, had attained a higher education level and a relatively shorter oncological clinical experience than the national average. According to the limited available literature (Daneman, Macaluso, & Guzzetta, 2003) health professionals with higher education levels and professional experience may be more likely to hold positive attitudes towards patient participation. However, Hamann et al (Hamann et al., 2010) did not find significant associations between clinicians’ age, sex and professional experience and their ability to predict their patients’ participation preference; however, this study did not look at clinicians’ attitudes towards participation overall. Clinicians’ characteristics may need to be taken into account when their responses to and behaviours towards patient participation are interpreted in this case study.

4.5.2 Patient characteristics

Patients in this case study had a fairly heterogeneous cancer profile. Variation in cancer types of patients admitted to an inpatient unit is a clinical reality, and is a consequence of using case study methodology where a real-life phenomenon is investigated in situ (Yin, 2009). Most of the patient participants were admitted for radiotherapy and/or chemotherapy in their first year after diagnosis.
Comparisons of age, sex and type of cancer between participants and non-participants revealed that patients who were older and male were more likely to decline to participate in the survey and a different distribution of cancer diagnosis was identified between these two groups. That older cancer patients are more reluctant to participate in research is not unique to this study. Similar phenomena has been found in previous studies (Cohen, 2012; Murthy, Krumholz, & Gross, 2004). ‘Feeling too sick’ was one of the common reasons given by non-participants (n=42, 30.5%) for declining to participate. Patients’ symptom profile therefore might have been an important factor determining participation. Evidence was found in this study that patients with different cancer types had significantly different symptom profiles based on the GDI, PHYS and TMSAS scores in the MSAS. High participation rates of female patients with breast cancer may have been related to their relatively lower reports of symptom distress, whereas patients with head and neck cancer who had a lower participation rate, reported significantly higher levels of symptom distress than patients with other cancer types. Age and sex have been found to be predictors of patients’ preference for participation in previous studies (Arnetz, & Arnetz, 2009; Chung et al., 2012; Florin, Ehrenberg, & Ehnfors, 2008), therefore these factors need to be further examined in this case study.

Education level and income status, are indicators of a person’s socio-economic status and provide insight into patients’ knowledge and ability to deal with health related decision-making and interaction with health
professionals (Eldh, Ekman, & Ehnfors, 2010; Hamann et al., 2011; Tak, Ruhnke, & Meltzer, 2013; Uldry et al., 2013; Willems et al., 2005). In the present sample, patients with at least an undergraduate degree accounted for 32.2% of the patient sample, a rate much higher than the national average of 7% of residents with education levels of university diploma or above (Institute of Social Science Survey of Peking University, 2013). Nearly 40% of patient participants had a monthly income of more than RMB 3000 while the per capita monthly disposable income of China in 2013 was RMB 1525 (The national bureau of statistics of the People’s Republic of China, 2014). As the case study was conducted in a leading hospital in Shanghai, it is possible that patients admitted to this hospital have a higher socio-economic status than patients hospitalized in regional or rural areas. This assumption is supported by data from a study focusing on cancer patients’ compliance with Peripherally Inserted Central Catheters in a tertiary hospital of Shanghai which reported 65% of patients had at least high school education (Xu et al., 2011), similar to the percentage in this study (57.9%). Whether patients with higher socio-economic status had more knowledge or ability to communicate and discuss their symptoms with health professionals and whether this status had implications for their desire to be involved in their own treatment and care is an important consideration highlighting the need for further exploration.

Patients’ ability to take responsibility for their own healthcare can be influenced by their health literacy and was considered a potentially
important predictor for preference and actual participation during their admission. Health literacy has been identified as a potential predictor of patients’ preference for participation in previous studies (Ekdahl et al., 2011; Höglund et al., 2010; Larsson et al., 2011a; Naik et al., 2011). In the current study, cluster analysis of mean scores derived from the nine scales of the Health Literacy tool found 35.2% of patients were grouped in three high health literacy clusters; 50.4% in four moderate health literacy clusters and 14.4% into two low health literacy clusters.

As the Health Literacy Questionnaire HLQ (Osborne et al., 2013) is a newly developed tool there were no published findings of this tool where comparisons could be made. However in previous studies, patients’ health literacy has been investigated using different tools. Koay et al (Koay et al., 2013) assessed the health literacy level of 93 patients with lung cancer or head and neck cancer with the Shortened Test of Functional Health Literacy in Adults (S-TOFHLA) and Health Literacy Management Scale (HeLMS). The results from the S-TOFHLA was that patients with inadequate and marginal health literacy accounted for 5.4% and 6.5 %, respectively while the HeLMS revealed that 17% of patients had health literacy difficulties. An investigation conducted in 32 areas of China with an investigator-developed questionnaire found that residents who had adequate health literacy made up 6.48% in total, with 9.94% in urban and 3.43% in rural areas (Yan et al., 2012). Another Chinese study Chinese citizens’ Health Literacy Questionnaire (2009) reported that cancer patients had higher levels of health literacy than
healthy residents on two aspects: basic knowledge and concept of health, health life style and behaviours, with values being 71.68% and 59.92% in cancer patients and 45.59% and 36.37% in healthy residents (Zhang et al., 2013).

Comparing health literacy levels between studies using different measures is problematic because health literacy is understood from different perspectives. It can be seen as a stable individual capacity, a dynamic individual state during a health care encounter or an achieved level of health knowledge. This lack of shared meaning has had consequences for its measurement with various tools that have not focussed on the same domains of health literacy (Baker, 2006). In the Chinese population, self-developed tools from national health literacy documents have been used to measure the general population’s or patients’ health literacy level, compare urban or rural residents (Yan et al., 2012), or to analyse factors predicting health outcomes (Morris et al., 2013). The health literacy measure used in this case study revealed that the majority of patients had a moderate or high level of health literacy. Whether this is representative of the population of patients with cancer in China is not known and therefore needs to be accounted for in analyses and interpretations.

4.5.3 Patient symptom profiles

In this cohort, more than 60% of patients reported relatively good physical performance (ECOG-0 fully active =18.2%, ECOG-1 restriction in physically
strenuous activity but ambulatory =44.6%) during their admission for radiotherapy and/or chemotherapy. Varying results of ECOG-PS for patients undergoing radio/chemotherapy have been reported in past studies. One study assessed physical performance of 109 consecutive patients diagnosed with Stage III or IV non-small cell lung cancer who received initial treatment of chemotherapy or palliative radiotherapy. It reported 55% of patients presented with ECOG PS ≤1 (Dajczman et al., 2008). Patients in that study had worse physical status than those in current study, however their advanced diagnosis and older age (half of the patient sample was over 65 years) may have explained the difference. A Chinese study focused on a patient cohort undergoing radiotherapy with or without concurrent use of chemotherapy with similar cancer types as reported in the current study (Cacicedo et al., 2014), found that 92.2% of patients reported ECOG-PS levels of 0 or 1, indicating a better performance status than that reported in the present study, even though patients in that study were older (median age =60 years) than those in current study (median age =47 years).

The findings that 26.2% of patient participants had scores commensurate with anxiety and 21.4% with depression based on the HADS are largely consistent with previous studies conducted in patients with varying cancer diagnoses in acute care settings (Annunziata, Muzzatti, & Bidoli, 2010; Lampic et al., 1996; Singer et al., 2009).

The symptom burden of the patient participants was high with a reported average of 10.7 symptoms experienced simultaneously. Again this finding is
commensurate with those of previous studies where the range of simultaneous symptom reported was 6.5 to 14 (Chang et al., 2000a; Cheng et al., 2009; Cohen, 2012; Deshields et al., 2014; Kim et al., 2009a; Spichiger et al., 2011a, 2011b; Tranmer et al., 2003). The broad range reflects patients with varied cancer types (Deshields et al., 2014), different extent of disease progression (Chang et al., 2000a), and whether they were inpatient or outpatient cohorts (Chang et al., 2000b; Spichiger et al., 2011a, 2011b).

The most prevalent symptoms experienced by more than 50% of patients were dry mouth, pain, fatigue, difficulty sleeping, and lack of energy. Of interest is the finding that symptom severity is not necessarily associated with symptom distress. Dry mouth was the most frequent symptom, constipation was perceived as the most severe symptom, and mouth sores distressed patients most. Chang et al (Chang et al., 2000a) also found inconsistencies in associations between symptom severity and symptom distress. However, overall there were significant positive correlations for most symptoms between the frequency, severity and distress dimensions identified, which is congruent with the results by Cohen (Cohen, 2012) who surveyed the symptom experience of 171 Australia cancer patients.

As would be expected, patients with different cancer types reported different symptom profiles. For example, Kim et al (Kim et al., 2009a) investigated 160 patients with breast or prostate cancer undergoing radiation treatment and found feeling drowsy and excessive sweating as highly prevalent as in the findings of Hofsø’s et al study (Hofsø et al., 2013).
Patients with head and neck cancer during radiotherapy are more likely to experience dry mouth and difficulty swallowing (Cheng et al., 2009). Regardless of the types of cancer, pain, lack of energy and difficulty in sleeping remain the most prevalent reported symptoms for patients undergoing radiotherapy and/or chemotherapy (Chang et al., 2000a; Cohen, 2012; Deshields et al., 2014; Spichiger et al., 2011a).

The question of whether patients perceived that clinicians were aware of their symptoms was included in the MSAS tool in this study. The symptoms where patients perceived clinicians were most aware were fever and weight loss, pain and mouth sores. These symptoms are reflective of patient assessment processes in the units in that temperature and pain assessment occur at least once a day and patients are routinely weighed once a week. Patients’ perceived that that clinicians were more likely to know about symptoms that were frequent or severe, but were less likely to know about distressing symptoms. Given that these data were derived from patients’ perceptions rather than by directly asking clinicians we cannot determine whether clinicians in fact knew about the variety of symptoms experienced by patients but the findings do suggest that patients may not have been asked about other symptoms or had not communicated all their symptoms and therefore did not think that their clinicians were aware of them. It is also possible that patients may not perceive that clinicians can do anything about distress which is directly related to patients’ experience of their symptoms.
thus clinicians focusing on treating the frequency and severity of symptoms might have a synergistic effect on distress.

Patients in this research study had mean scores of the PHYS, PSYCH, GDI and TMSAS in the MSAS ranging from 0.64 to 0.83. As there are no cut-off scores of symptom levels indicated by the MSAS, the values of each subscale can be compared with results from other studies. The results in this study are congruent with Chang’s report (Chang et al., 2000a) of 240 medical cancer patients in which the mean scores of these subscales were between 0.62 and 0.94. However, another study, investigating patients with solid tumours during chemotherapy or radiotherapy in the hospital setting, reported scores of greater than 2 in all the subscales (Cheng, 2009 #152. These data indicate that while patients in the current study were experiencing a high number of symptoms their overall experience of was not as intense as that reported in other studies. It should be noted that in Cheng’s study the major treatment was chemotherapy and patients who received radiotherapy alone accounted for 21.1% of the sample while in the present study radiotherapy was the main treatment and patients receiving chemotherapy alone represented 8.6% of the sample. In the study reported here, patients undergoing chemotherapy had higher scores in the MSAS subscales than those undergoing radiotherapy. This could partly explain why Cheng’s results exceeded the values in the current study.
4.6 Conclusions

Data presented in this chapter have provided an overall description of the participants in the case study. Of the eligible participants during the data collection period, 67.9% of the doctors, 100% of the nurses and 54% of the patients were recruited into the study. The clinician participants were younger, had attained a higher education level and a relatively shorter oncological clinical experience than the national average in China. Patients had a higher socio-economic status than patients hospitalized in regional or rural areas and most displayed a moderate or above level of health literacy. Patient participants, admitted for radiotherapy and/or chemotherapy, mostly had relatively good physical and psychological performance. Patients experienced multiple symptoms associated with their cancer and/or treatments simultaneously. These data may reflect the contextual characteristics of hospitals in metropolitan areas in China, especially in hospitals affiliated to a university and therefore raises questions about the transferability of the findings to health care in remote and rural areas in China.

Demographic characteristics, such as high levels of education, moderate to high levels of health literacy and good physical performance, have been found in previous research to be associated with positive attitudes towards patient participation by clinicians and active preference for participation by patients. However, much of this research has been conducted in western countries. Whether clinicians and patients in the case setting in China have similar attitudes, perceptions and preferences and is not known and will be explored in the analyses reported in the chapters to follow.
CHAPTER FIVE

Perceptions of patient participation in symptom management (Part I)

In the context of acute care delivery, patient participation has a particular salience in the processes of care related to symptom management (Heyn et al., 2013; Lee et al., 2011) because of the subjectivity of symptom experiences. In developed countries like the United States (Frosch et al., 2012), Australia (Australian Commission on Safety and Quality in Health care, 2008), and the UK ( Cotterell et al., 2011) there is growing recognition of the need to incorporate patients as participants in acute care and this is reflected in the volume of research and healthcare policy in the area (Cohen, 2012; Prey et al., 2014). In China, although patients’ rights and responsibilities in care are recognized (Chinese Hospital Association, 2009; Yu, 2007), the enactment of patient participation in clinical treatment and care has not been investigated or evaluated. A clearer understanding of Chinese clinician and patient perceptions is necessary in order to understand how the learnings derived from western research may inform patient participation in China. It is necessary therefore, to clarify how patients and clinicians perceive patient participation in symptom management in terms of its meaning and experience in Chinese acute care settings and the synergies between patients’ and clinicians’ perceptions and experience of patient participation.
In this and the chapter to follow, the findings relating to the first aim of this research, the exploration of patients’ and clinicians’ perceptions of patient participation in symptom management, are presented. The outcomes of the analyses of the survey data are reported in this chapter and address the specific objectives as follows:

1. Describe and compare how patients, doctors and nurses rate the importance of participatory activities in symptom management
2. Describe and compare how patients, doctors and nurses rate patients’ actual participation in symptom management
3. Describe patients’ control preference for participation in symptom management-related decision making
4. Calculate the congruence between patients’ preferred and actual participation in symptom management
5. Analyse patient-related factors that are associated with patients’ preference for participation in symptom management-related decision making
6. Analyse associations between preference and experience of participation in decision-making, and patients’ perceptions of care quality and satisfaction with symptom management.

5.1 Methods

The detailed description of the data collection and analysis processes are presented in Chapter 3. Survey data were collected from patients (n=162), doctors (n=34) and nurses (n=38) by means of a self-report survey using the
Patient Participation in Symptom Management Questionnaire (PPSMQ)-Patient/Doctor/Nurse Versions.

The survey findings reported in this chapter include responses to items in the: 1) Perceived importance of participatory activities (modified) (Eldh, Ekman, & Ehnfors, 2010) (11 items); 2) Patients’ and Clinicians’ Views and Behaviours about Patient Involvement in Care (VBPIC) (modified) (Arnetz, Höglund et al. 2008a, Arnetz, Höglund et al. 2008b); 3) Symptom information and patient communication behaviours (Cohen, 2012) (10 questions); 4) Control Preference Scale (CPS) (modified) (Degner, Sloan, & Venkatesh, 1997); 5) Patients’ characteristics including demographic, illness and treatment-related information; the Memorial Symptom Assessment Scale (MSAS) (Portenoy et al., 1994a) (32 symptoms), the Hospital Anxiety and Depression Scale (HADS) (Zigmond, & Snaith, 1983) (14 items), the Eastern Co-operative Oncology Group Performance Status (ECOG) (Oken et al., 1982) (5 levels), the Health Literacy Questionnaire (HLQ) (Osborne et al., 2013) (44 items); 6) Patients’ satisfaction with symptom management (Cohen, 2012) (5 questions) and the Quality of Care from Patient’s Perspective (QPP)- short form (modified) (Larsson, & Larsson, 2002) (24 items).

Survey data were analysed using descriptive statistics. Scale values in the VBIC were calculated for each case by totalling the scores for each scale item and converting that sum to a percentage of the maximum possible score (100%). Scores for all subscales are reported as median percentage scores. Higher scores indicate more positive perceptions except for the hindrance
subscales. Non-parametric, inferential statistics with a significance level of 0.05 were used to compare patients, doctors and nurses subscale scores. If the responses were found to be significantly different between the three cohorts, pairwise comparisons were performed and the P value was adjusted using the Bonferroni method.

Based on patients’ rated preference for participation, comparisons between their preferred and actual participation were assessed using weighted kappa statistics. Predictors of patients’ control preference were identified through ordinal logistic regression. Patients’ perception of quality of care and satisfaction with symptom treatment and care were compared across patients’ preference achievement groups (less than preferred, preferred and exceeded preferred groups) through One-way ANOVA (α =0.05). When significant differences were identified across the groups, Bonferroni pairwise comparisons were conducted with an adjusted significance level (α =0.017).

5.2 Findings

Findings of the quantitative analyses reported in this chapter are presented in five sections. Subjective importance of patient participation and actual participation ratings are described in the first two sections. Patients’ experience of participation in terms of preferred and achieved roles of participation in symptom management-related decision making are reported in the third section, followed by the analyses of the predictors of patients’ preference for decision making. In the final section associations between preference and experience of participation in decision-making, and patients’
perceptions of care quality and satisfaction with symptom management are examined.

5.2.1 Subjective importance of patient participation

5.2.1.1 The perceived importance of participatory activities – Patient perceptions

The distribution of responses to each of the 11 statements in the perceived importance of participatory activities (Defining Participation-modified) section of the PPSMQ is presented in Table 5.1, according to perceived importance of the items nominated by patients. A total of 146 (90.1%) patients who commenced the PPMSQ completed these questions. Each participatory activity was rated as important or very important by at least 60% of patients. The statement “to tell about your symptoms/problems” was perceived as important or very important by 91.1% of patients, placing it highest in order of importance. Whereas “to take part in planning of care and/or treatment” and “to perform care yourself” were rated as important or higher by a lower proportion of patients; 69.9% (n=102) and 65.1% (n=95) of patients, respectively.
Table 5.1 Patients’ responses to 11 statements ‘Defining Participation’ (n=146)

<table>
<thead>
<tr>
<th>Items</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>To tell about your symptoms/problems</td>
<td>133</td>
<td>91.1</td>
</tr>
<tr>
<td>To get explanations about your symptoms/problems</td>
<td>132</td>
<td>90.4</td>
</tr>
<tr>
<td>That the staff explain procedures</td>
<td>125</td>
<td>85.6</td>
</tr>
<tr>
<td>To know whom you can or should contact</td>
<td>124</td>
<td>85.0</td>
</tr>
<tr>
<td>To know what to do in order to feel well</td>
<td>121</td>
<td>82.8</td>
</tr>
<tr>
<td>To know what has been planned</td>
<td>115</td>
<td>78.8</td>
</tr>
<tr>
<td>That the staff listen to you</td>
<td>115</td>
<td>78.7</td>
</tr>
<tr>
<td>To perform self-care (e.g. adjust diet)</td>
<td>110</td>
<td>75.3</td>
</tr>
<tr>
<td>To set your own goals</td>
<td>103</td>
<td>70.5</td>
</tr>
<tr>
<td>To take part in planning of care and/or treatment</td>
<td>102</td>
<td>69.9</td>
</tr>
<tr>
<td>To perform care yourself (e.g. take medication/change clothes)</td>
<td>95</td>
<td>65.1</td>
</tr>
</tbody>
</table>

5.2.1.2 Perceived importance of patient involvement in care – Patient and clinician perceptions

Table 5.2 displays the level of agreement of patients, doctors and nurses to the ‘involvement in care’ subscale items in the VBPIC. All doctors (100%) and all nurses (100%) and almost all patients agreed on the importance of care related to “getting clear information” (n=140, 99.3%) and “asking questions about symptoms” (n=138, 97.8%). When compared with information exchange, fewer patients (albeit still the majority) agreed with the importance of exchanging opinions about care, with 91.5% (n=129) agreement with “express patients’ views” and 84.4% (n=119) agreement
with being “involved in discussions about symptom treatment and care”.

There were similarities between the doctors’ and nurses’ rating on the importance of each item. Differences were noted between patients’ and the doctors’ and nurses’ ratings, particularly in the items that required higher patient participation and the consequences of it, for example: “involved in making decisions” and “bears responsibility for future health” (Kruskal-Wallis test of significance, X²=8.2, P<0.05). Pairwise comparisons were used to identify differences between patients’ and doctors’ and patients’ and nurses’

### Table 5.2 Patient and clinician agreement with patient involvement in care (VBPIC)

<table>
<thead>
<tr>
<th>Dimension and items</th>
<th>Patients (n=141)</th>
<th>Doctors (n=38)</th>
<th>Nurses (n=34)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gets clear information</td>
<td>140 (99.3)</td>
<td>38 (100)</td>
<td>34 (100)</td>
</tr>
<tr>
<td>Asks questions about their symptoms</td>
<td>138 (97.8)</td>
<td>37 (97.3)</td>
<td>34 (100)</td>
</tr>
<tr>
<td>Expresses his/her views</td>
<td>129 (91.5)</td>
<td>36 (94.7)</td>
<td>34 (100)</td>
</tr>
<tr>
<td>Is involved in discussions about their symptoms and care</td>
<td>119 (84.4)</td>
<td>35 (92.1)</td>
<td>32 (94.1)</td>
</tr>
<tr>
<td>Bears the responsibility for his/her future health</td>
<td>114 (80.9)</td>
<td>37 (97.4)</td>
<td>34 (100)</td>
</tr>
<tr>
<td>Is involved in making decisions about his/her treatment and care</td>
<td>105 (74.5)</td>
<td>32 (84.2)</td>
<td>28 (82.3)</td>
</tr>
<tr>
<td>Median % agreement (Q₁, Q₃)</td>
<td>87.5 (79.2,95.8)</td>
<td>87.5 (78.1,96.9)</td>
<td>91.7 (87.5,100)</td>
</tr>
</tbody>
</table>

*Kruskal-Wallis test (α=0.05): H(3)=8.2 P=0.017  
Pairwise comparisons (α=0.017): Patient-doctor: P=0.525, Patient-nurse: P=0.004, Doctor-nurse: P=0.069
responses. Differences in responses were only significant between responses from patients and nurses (P<0.017), indicating nurses rated the importance of these patient participatory activities higher than patients.

The ‘hindrance’ subscale of the VBPIC consisted of three items exploring to what extent patient involvement is perceived to hinder clinicians’ work. The findings clearly showed a difference between patients’ and clinicians’ perceptions (see Table 5.3). Specifically, less than one-third of patients agreed with the notion that their involvement would increase clinicians’ workload (n=43, 30.5%), create problems for clinicians (n=34, 24.1%), or take clinicians’ time away from other patients (n=31, 22.0%). In contrast, the proportion of clinicians who perceived that patient involvement would hinder their ability to work ranged from 42% to 62%. A significant difference was found between the ratings of patients, doctors and nurses overall ($X^2=26.9$, p <0.001). Pairwise comparisons identified these differences were significant for both patient-doctor and patient-nurse comparisons (P<0.001).

These findings indicate that doctors and nurses were more likely than patients to perceive patient involvement as a hindrance to their work.
Table 5.3 Patient and clinician perceptions on the impact of patient involvement in hindering work (VBPIC)

<table>
<thead>
<tr>
<th>Dimension and Items</th>
<th>Patients (n=141)</th>
<th>Doctors (n=38)</th>
<th>Nurses (n=34)</th>
</tr>
</thead>
<tbody>
<tr>
<td>To what degree do you agree with the following:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients who are involved in their care increase clinicians’ workload</td>
<td>43(30.5)</td>
<td>23(60.5)</td>
<td>21(61.8)</td>
</tr>
<tr>
<td>Patients who are involved in their care create problems for clinicians in their work</td>
<td>34(24.1)</td>
<td>16(42.1)</td>
<td>20(58.8)</td>
</tr>
<tr>
<td>Patients who are involved in their care take clinicians’ time away from other patients</td>
<td>31(22.0)</td>
<td>21(55.2)</td>
<td>16(47.0)</td>
</tr>
<tr>
<td>Median % agreement (Q₁, Q₃)*</td>
<td>50</td>
<td>66.7</td>
<td>66.7</td>
</tr>
<tr>
<td></td>
<td>(41.7,58.3)</td>
<td>(50,75)</td>
<td>(56.3,75)</td>
</tr>
</tbody>
</table>

*Kruskal-Wallis test (α=0.05): H(3)=26.9, P<0.001
Pairwise comparisons (α=0.017): Patient-doctor: P<0.001, Patient-nurse: P<0.001, Doctor-nurse: P=0.90

5.2.1.3 Summary

The findings from responses to these two questionnaires identified a shared perception by patients, doctors and nurses that receiving or providing information about symptom experience as the most important aspect of patient involvement in symptom management. Although rated highly, patients participating in decision-making for symptom treatment and care was the least important. Nurses were more likely to rate the importance of patient involvement higher than patients, however nurses as well as doctors were more likely than patients to consider patient involvement a hindrance to their work.
5.2.2 Experience of participation

5.2.2.1 Information and communication related to symptom management: Patient perceptions

Responses by patients to the seven questions about their recent experience of symptom information and communication with clinicians are presented in Table 5.4. A total of 146 patients (90.4%) completed these questions in the PPSMQ.

The majority of patients, in the previous 24 hours, had been told the importance of symptom treatment and been encouraged to report any symptoms they experienced (87.1%, n=128). Patients reported that they understood the language clinicians used when providing symptom information (93.2%, n=137). However, less patients had received information about treatment options (59.9%, n=88) and of those who had, there was a wide variation in their perceptions of how helpful that information was with responses ranging from 0 (Not at all helpful) to 10 (extremely helpful) on the 11-point scale (mean 6.88, SD 2.46).

The majority of patients had accepted symptom management treatment in the past 24 hours; nine patients (6.1%) indicated that they had refused prescribed treatment offered by clinicians.
Table 5.4 Patients’ experience of information and communication related to symptom management (n=146)

<table>
<thead>
<tr>
<th>Dimensions and items</th>
<th>Response option</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past 24 hours, did a doctor or nurse make it clear to you that they consider treatment of symptoms very important and that you should tell them when you are experiencing a symptom?</td>
<td>Yes</td>
<td>128</td>
<td>87.1</td>
</tr>
<tr>
<td>Has the information provided about symptoms been presented to you using language/terms that you understand?</td>
<td>Yes</td>
<td>137</td>
<td>93.2</td>
</tr>
<tr>
<td>Do you usually report your symptoms to the doctors and nurses or wait until you are asked?</td>
<td>Report</td>
<td>100</td>
<td>68.0</td>
</tr>
<tr>
<td>Using the following scale please indicate whether you would press your patient call bell to report a symptom?</td>
<td>Never</td>
<td>73</td>
<td>68.0</td>
</tr>
<tr>
<td></td>
<td>Rarely (&lt;10% of time)</td>
<td>22</td>
<td>15.0</td>
</tr>
<tr>
<td></td>
<td>Sometimes (50% of time)</td>
<td>33</td>
<td>22.4</td>
</tr>
<tr>
<td></td>
<td>Usually (75% of time)</td>
<td>11</td>
<td>7.5</td>
</tr>
<tr>
<td></td>
<td>Always (100% of time)</td>
<td>8</td>
<td>5.4</td>
</tr>
<tr>
<td>Have you received any information about your symptom treatment options?</td>
<td>Yes</td>
<td>88</td>
<td>59.9</td>
</tr>
<tr>
<td>How helpful was this information on a scale of 0 (not at all helpful) to 10 (extremely helpful)</td>
<td>Mean</td>
<td>6.88</td>
<td></td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>2.46</td>
<td></td>
</tr>
<tr>
<td>Have you refused symptom management medication that is prescribed on a regular basis in the past 24 hours?</td>
<td>Yes</td>
<td>9</td>
<td>6.1</td>
</tr>
</tbody>
</table>

5.2.2.2 Behaviours related to patient involvement in care: Patient and clinician perceptions

In the VBPIC, three subscales measured patients’ perceptions of the degree to which they received information, had their needs met, and were
motivated and provided with opportunities to participate. 87% of patients answered the VBPIC. The questions were modified to enable clinicians to report the degree to which they believed they had exhibited the behaviours described. Participant responses to five questions about the information they received (patients) or provided (clinicians) were on a four-point Likert scale: to a very great degree (4), to a fairly great degree (3), to a certain degree (2) and not at all (1). Results of the information subscale are presented in Table 5.5 and are reported as the number of respondents who indicated level 3 or 4 agreement on the Likert scale. Approximately 60% of patients reported that they were, to a great degree, informed about the five types of information related to symptom management explored in the subscale.

There were differences in the perceptions of patients, doctors and nurses about the amount of information received or provided ($H=17.7$, $P<0.001$). Further pairwise comparisons identified a significant difference between patients and doctors ($P<0.017$) and between patients and nurses ($P<0.017$), whereby both doctors and nurses perceived that they provided more symptom information than patients perceived that they had received.
Table 5.5 Patient and clinician agreement with information received or provided (VBPIC)

<table>
<thead>
<tr>
<th>Dimension and Items</th>
<th>Patients (n=141)</th>
<th>Doctors (n=38)</th>
<th>Nurses (n=34)</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td>During this admission, did you receive/provide information about:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Why specific examinations or treatments are done?</td>
<td>93(66.4)</td>
<td>33(86.8)</td>
<td>32(94.1)</td>
</tr>
<tr>
<td>Possible pain/discomfort that can develop in conjunction with examinations/treatments?</td>
<td>90(64.3)</td>
<td>31(81.6)</td>
<td>31(91.1)</td>
</tr>
<tr>
<td>How specific examinations or treatments are done?</td>
<td>89(63.6)</td>
<td>23(60.5)</td>
<td>28(82.4)</td>
</tr>
<tr>
<td>What will occur during the acute phase?</td>
<td>83(59.3)</td>
<td>33(86.8)</td>
<td>29(85.3)</td>
</tr>
<tr>
<td>Your symptoms and their course?</td>
<td>80(56.7)</td>
<td>30(78.9)</td>
<td>29(85.3)</td>
</tr>
<tr>
<td>Median % agreement (Q₁, Q₃)*</td>
<td>70 (55, 85)</td>
<td>85 (65, 91.3)</td>
<td>85 (80, 96.3)</td>
</tr>
</tbody>
</table>

*Kruskal-Wallis test (α=0.05): H(3)=17.7, P<0.001
Pairwise comparisons (α=0.017): Patient-doctor: P=0.016, Patient-nurse: P<0.001, Doctor-nurse: P=0.103

In terms of behaviours related to meeting patients’ needs (Table 5.6), approximately 60% of patients reported they understood the information received, had opportunities to ask questions about symptoms, that clinicians were sensitive to their needs and were asked whether they were worried about their symptoms. The responses of patients, doctors and nurses were compared and a significant difference was found between the proportion of patients and nurses (P<0.017) who agreed with these statements, but not...
Chapter 5 Perceptions of patient participation in symptom management (Part I)

between patients and doctors (P>0.017). Nurses perceived that they met their patients’ needs to a greater degree than patients had experienced.

Table 5.6 Patient and clinician agreement with behaviours related to meeting patients’ needs (VBPI)

<table>
<thead>
<tr>
<th>Dimension and Items</th>
<th>Patients (n=141)</th>
<th>Doctors (n=38)</th>
<th>Nurses (n=34)</th>
</tr>
</thead>
<tbody>
<tr>
<td>During this admission:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you understand the information you received?</td>
<td>91(64.5)</td>
<td>30(79.0)</td>
<td>29(85.3)</td>
</tr>
<tr>
<td>Did you have the opportunity to ask questions about your symptoms?</td>
<td>88(62.4)</td>
<td>18(47.3)</td>
<td>25(73.5)</td>
</tr>
<tr>
<td>Were the doctors and nurses sensitive to your needs and requests?</td>
<td>80(56.7)</td>
<td>19(50.0)</td>
<td>23(67.7)</td>
</tr>
<tr>
<td>Were you worried about your symptoms?</td>
<td>79(56.0)</td>
<td>18(47.4)</td>
<td>29(85.3)</td>
</tr>
<tr>
<td>Median % agreement (Q1, Q3)*</td>
<td>68.8</td>
<td>65.6</td>
<td>78.1</td>
</tr>
<tr>
<td></td>
<td>(56.3, 81.3)</td>
<td>(56.3, 75)</td>
<td>(68.8, 89.1)</td>
</tr>
</tbody>
</table>

*Kruskal-Wallis test (α=0.05): H(3)=11.3, P=0.004

Pairwise comparisons: Patient-doctor (α=0.017): P=0.180, Patient-nurse: P=0.008, Doctor-nurse: P<0.001

Patient and clinicians’ perceptions of behaviours promoting activities and motivation for patient involvement are presented in Table 5.7. Over 60% of patients reported that they were treated with respect, motivated to take responsibility for their own health, or received information about their examination/treatment results or information about medications. However, only approximately 20% of patients reported they were involved in
Table 5.7 Patient and clinician agreement with motivational behaviours promoting patient involvement

<table>
<thead>
<tr>
<th>Dimension and Items</th>
<th>Patients (n=141)</th>
<th>Doctors (n=38)</th>
<th>Nurses (n=34)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>During this admission:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you want the opportunity to ask questions before you are discharged?</td>
<td>111(79.3)</td>
<td>35(92.1)</td>
<td>29(85.3)</td>
</tr>
<tr>
<td>Were you treated with respect?</td>
<td>110(78.0)</td>
<td>37(97.4)</td>
<td>33(97.1)</td>
</tr>
<tr>
<td>Did you want to take part in planning follow-up care i.e. what would happen after you are discharged from hospital?</td>
<td>108(77.7)</td>
<td>32(84.2)</td>
<td>30(88.3)</td>
</tr>
<tr>
<td>Did you receive information you wanted about the results of exams/treatments?</td>
<td>102(72.4)</td>
<td>34(89.5)</td>
<td>28(82.4)</td>
</tr>
<tr>
<td>Did you receive information you wanted about your medications?</td>
<td>101(72.2)</td>
<td>34(89.5)</td>
<td>32(94.1)</td>
</tr>
<tr>
<td>Have doctors/nurses motivated you to take responsibility for your future health?</td>
<td>88(62.9)</td>
<td>29(76.3)</td>
<td>31(91.2)</td>
</tr>
<tr>
<td>Have you been involved in making decisions about symptom care and treatment with the doctors and nurses?</td>
<td>33(23.4)</td>
<td>28(73.7)</td>
<td>26(76.5)</td>
</tr>
<tr>
<td>Did you take part in discussions about examinations or treatment with your doctors and nurses?</td>
<td>30(21.3)</td>
<td>26(68.4)</td>
<td>24(70.6)</td>
</tr>
<tr>
<td>Did you discuss the goals of your symptom care and treatment with your doctors and nurses?</td>
<td>29(20.6)</td>
<td>27(71.0)</td>
<td>25(73.5)</td>
</tr>
<tr>
<td><strong>Median % agreement (Q₁, Q₃)</strong>*</td>
<td>66.7 (55.6, 77.8)</td>
<td>81.9 (71.5, 91.7)</td>
<td>86.1 (77.8, 94.4)</td>
</tr>
</tbody>
</table>

Kruskal-Wallis test (α=0.05): H(3)=42.8, P<0.001
Pairwise comparisons (α=0.017): Patient-doctor: P<0.001, Patient-nurse: P<0.001, Doctor-nurse: P=0.110

discussing examinations/treatments (n=30, 21.3%), goal setting (29, n=20.6) and decision-making (n=33, 23.4%) related to symptom management. In contrast, the proportion of doctors and nurses who reported that they
exhibited behaviours related to these three negotiated decision-making activities was around 70%. Significant differences were identified between patients’ and doctors’ (P<0.017) and between patients’ and nurses’ (P<0.017) ratings for the activities and motivation subscale, indicating that both doctors and nurses thought that they engaged in behaviours to motivate their patients to participate in treatment and care more than was perceived by patients.

**5.2.2.3 Summary**

The findings from the VBPIC-patient and VBPIC-clinician questionnaires reflected that the majority of patients had received information on symptom treatment or care but less patients would initiate reporting symptoms to their clinicians. A minority of patients reported that they were involved in symptom-management related discussion or decision making. Comparisons between patients’ and clinicians’ responses revealed that both doctors and nurses thought they provided more symptom information than patients perceived they had received. Nurses reported they met their patients’ needs to a greater degree than perceived by patients. Doctors and nurses thought they motivated their patients to participate in treatment and care more than patients had experienced.
5.2.3 Patients’ preference for participation and perceptions of actual role in symptom management-related decision-making

The distribution of patients’ preference for participation in symptom management as measured by the Control Preference Scale and their perceptions of the role they were able to achieve when interacting with doctors and nurses is presented in Figure 5.1. Of the 162 patients surveyed, 64 (39.5%) patients preferred to leave all decisions to clinicians (Passive role) and 72 (44.4%) patients preferred their clinicians to make final decisions but to have their own opinions considered (Passive-shared role) before decisions were made. Only one (0.6%) patient preferred to make decisions without clinicians’ involvement (Active role). The remaining 15.5% of patients preferred a collaborative or active shared role.

After selecting their preferred role, patients were asked to select which role statement best described their actual experience in symptom management-related decision-making. The responses are also displayed in Table 5.8. Three
of the 162 patients did not report their achieved roles because they felt that there had not been any occasion that had required decision-making during their admission. Nearly half of the patients (n=77, 48.4%) reported that decisions about their symptom management were made solely by clinicians, followed by 68 patients (42.8%) who believed that their own opinions were considered when their doctors and nurses made decisions.

The extent to which patients’ preference for participation was congruent with their actual experience during interactions with doctors and nurses were examined and are presented in Table 5.8. An agreement with moderate strength was found between patients’ preferred roles and actual roles in decision-making (Kw: 0.61, SE: 0.08, 95%CI: 0.45 to 0.77). There were 64.8% (n=103) of patients who reported their actual experience of participation was consistent with their preference whereas 24.5% (n=39) of patients experienced a more passive role than they preferred and 10.7% (n=17) experienced a more active role than they preferred.

In summary, more than 80% of patients preferred to leave all decisions to their clinicians or have clinicians make final decisions once their opinions had been heard, and 64.8% of patients achieved their control preference, indicating moderate agreement between preferred and actual participation in the patient sample. Of the remaining patients, 24.5% experienced a more passive role than their preference and 11% had a more active role than they preferred.
Table 5.8 Relationships between patients’ preferred and actual level of participation during clinician interactions

<table>
<thead>
<tr>
<th>Preferred Participation</th>
<th>Actual participation</th>
<th>Passive</th>
<th>Passive shared</th>
<th>Collaborative</th>
<th>Active shared</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive</td>
<td>51</td>
<td>12</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>63</td>
</tr>
<tr>
<td>Passive-shared</td>
<td>22</td>
<td>45</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>72</td>
</tr>
<tr>
<td>Collaborative</td>
<td>4</td>
<td>10</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>18</td>
</tr>
<tr>
<td>Active-shared</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Active</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>77</td>
<td>68</td>
<td>8</td>
<td>8</td>
<td>8</td>
<td>159*</td>
</tr>
</tbody>
</table>

*Three patients did not report their actual level of participation

5.2.4 Predictors of patients’ preference for participation in symptom management-related decision-making

To explore factors associated with patients’ preference for participation in symptom-related decision-making, patients’ demographic characteristics, illness-related characteristics, symptom profile indicators and health literacy were analysed as independent variables. Since only one patient preferred an active control role in symptom management decision-making, the active category was removed. The remaining four roles (passive, passive-shared, collaborative and active-shared) were analysed in the ordinal logistic regression.
5.2.4.1 Demographic characteristics

Independent demographic variables were tested for their association with patients’ preference for participation in decision-making in symptom management. These variables were: age, sex, level of education, marital status, work status, income level and availability of caregivers during their admission. Table 5.9 shows the distribution of these demographic characteristics across the four preference categories and the results of the univariate analyses. The findings indicate that age (P=0.045), sex (P=0.008), marital status (p=0.033), and work status (P<0.001) were significant factors in determining patients’ preference for participation.

Table 5.9 The relationship between patient demographic characteristics and control preference

<table>
<thead>
<tr>
<th>Control preference</th>
<th>Passive shared (n=58)</th>
<th>Passive shared (n=68)</th>
<th>Collaborative shared (n=20)</th>
<th>Active shared (n=5)</th>
<th>OR (95%CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>Mean 50.52</td>
<td>44.64</td>
<td>48.95</td>
<td>43.80</td>
<td>0.98</td>
<td>0.045*</td>
</tr>
<tr>
<td></td>
<td>SD 10.61</td>
<td>11.90</td>
<td>15.18</td>
<td>16.86</td>
<td>(0.95, 1.00)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>Female 24 (37.5)†</td>
<td>44 (61.1)§</td>
<td>11 (55.0)</td>
<td>4 (80.0)</td>
<td>2.26 (1.24, 4.10)</td>
<td>0.008*</td>
</tr>
<tr>
<td></td>
<td>Male 40 (62.5)‡</td>
<td>28 (38.9)</td>
<td>9 (45.0)</td>
<td>1 (20.0)</td>
<td>1 (ref)</td>
<td></td>
</tr>
</tbody>
</table>
### Chapter 5 Perceptions of patient participation in symptom management (Part I)

#### 5.2.4.2 Illness-related characteristics

Illness-related factors that were analysed as independent variables for control preference were: length of time since diagnosis, type of cancer, and current type of treatment (see Table 5.10). The results indicated that current treatment \((p=0.029)\) was a significant factor influencing patients’ preference for participation in symptom management decision making.

#### Level of education achieved

<table>
<thead>
<tr>
<th></th>
<th>Achieved</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>University degree</td>
<td>13 (22.4)</td>
<td>25 (36.8)</td>
<td>7 (35.0)</td>
<td>3 (60.0)</td>
<td>1.90 (0.99, 3.64)</td>
<td><strong>0.052</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary school or below</td>
<td>45 (77.6)</td>
<td>43 (63.2)</td>
<td>13 (65.0)</td>
<td>2 (40.0)</td>
<td>1(ref)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Marital status

<p>| | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Single/divorced/widowed</td>
<td>2 (3.5)</td>
<td>8 (11.7)</td>
<td>2 (10.0)</td>
<td>2 (40.0)</td>
<td>3.09 (1.09, 8.74)</td>
<td><strong>0.033</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>56 (96.5)</td>
<td>60 (88.3)</td>
<td>18 (90.0)</td>
<td>3 (60.0)</td>
<td>1 (ref)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Work status

<p>| | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed/retired</td>
<td>29 (50.0)</td>
<td>46 (67.6)</td>
<td>19 (95.0)</td>
<td>5 (100)</td>
<td>3.72 (1.89, 7.31)</td>
<td><strong>0.000</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>29 (50.0)</td>
<td>22 (32.4)</td>
<td>1 (5.0)</td>
<td>0</td>
<td>1 (ref)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Level of income (Yuan)

<p>| | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 3000/yr</td>
<td>40 (69.0)</td>
<td>38 (55.9)</td>
<td>12 (60.0)</td>
<td>1 (20.0)</td>
<td>0.82 (0.32, 2.09)</td>
<td>0.125</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3000-6000/yr</td>
<td>12 (20.7)</td>
<td>17 (25.0)</td>
<td>8 (40.0)</td>
<td>3 (60.0)</td>
<td>1.72 (0.62, 4.84)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6000-10000/yr</td>
<td>6 (10.3)</td>
<td>12 (17.6)</td>
<td>0</td>
<td>1 (20.0)</td>
<td>1(ref)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers available</td>
<td>40(69.0)</td>
<td>53(77.9)</td>
<td>16(80.0)</td>
<td>3(60.0)</td>
<td>1.40(0.70,2.79)</td>
<td>0.340</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*P<0.1

~Demographic information for 10 patients was missing because they withdrew after the CPS survey. Only age and sex were recorded.

#n=64, ^n=72
Table 5.10 The relationship between patients’ illness-related characteristics and control preference

<table>
<thead>
<tr>
<th>Illness-related characteristics</th>
<th>Control preference</th>
<th>OR (95%CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Passive shared (n=54)</td>
<td>Passive shared (n=67)</td>
<td>Collaborative shared (n=19)</td>
</tr>
<tr>
<td>Time since diagnosis (year)</td>
<td>.34 (.17,.68)</td>
<td>.30 (.20,.68)</td>
<td>.28 (.17,.64)</td>
</tr>
<tr>
<td>Median (Q₁, Q₃)</td>
<td>0.89(0.72,1.12)</td>
<td>0.323</td>
<td></td>
</tr>
<tr>
<td>Type of cancer</td>
<td>1.12 (.47, 2.65)</td>
<td>0.190</td>
<td></td>
</tr>
<tr>
<td>Bowel</td>
<td>11 (20.3)</td>
<td>17 (24.6)</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td>Breast</td>
<td>10 (18.5)</td>
<td>15 (21.7)</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>7 (13.0)</td>
<td>10 (14.5)</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>Head and neck</td>
<td>26 (48.2)</td>
<td>27 (39.2)</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td>Current treatment</td>
<td>1.68(0.66,4.33)</td>
<td>1(ref)</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>5 (8.6)</td>
<td>7 (10.3)</td>
<td>1 (5.0)</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>27 (46.6)</td>
<td>44 (64.7)</td>
<td>13 (65.0)</td>
</tr>
<tr>
<td>Combined</td>
<td>26 (44.8)</td>
<td>17 (25.0)</td>
<td>6 (30.0)</td>
</tr>
</tbody>
</table>

*P<0.1
~Six patients did not record the time since their cancer diagnosis. Fifteen other cancer types not included in the table. ^ n=69, #n=58, \#n=68, †n=20

5.2.4.3 Symptom profile, psychological and physical performance characteristics

Patients’ symptom profile, and psychological and physical performance characteristics included in the analyses were: the number of symptoms, Global Distress Index (GDI), Physical Symptom Distress Score (PHYS), Psychological Symptom Distress Score (MSAS-PSYCH), Total Symptom Score (TMSAS), anxiety, depression and ECOG. Table 5.11 displays the frequencies
of these indicators across the four control preference groups. There were no significant differences in symptom profile between patients with different control preferences.

Table 5.11 The relationship between patients’ symptom profile and control preference

<table>
<thead>
<tr>
<th>Symptom-related characteristics</th>
<th>Control preference</th>
<th>OR (95%CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Passive (n=57)</td>
<td>Passive shared (n=68)</td>
<td>Collaborative (n=19)</td>
</tr>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td>MSAS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of symptoms</td>
<td>11.2(6.81)</td>
<td>10.6(6.55)</td>
<td>9.9(7.14)</td>
</tr>
<tr>
<td>GDI</td>
<td>.90(.74)</td>
<td>.79(.69)</td>
<td>.72(.61)</td>
</tr>
<tr>
<td>PHYS</td>
<td>.88(.69)</td>
<td>.83(.67)</td>
<td>.72(.68)</td>
</tr>
<tr>
<td>PSYCH</td>
<td>.62(.69)</td>
<td>.67(.70)</td>
<td>.53(.58)</td>
</tr>
<tr>
<td>Total MSAS</td>
<td>.68(.48)</td>
<td>.66(.50)</td>
<td>.58(.49)</td>
</tr>
<tr>
<td>HADS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>4.6(3.9)</td>
<td>5.3(4.1)</td>
<td>4.6(2.9)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5.1(3.9)</td>
<td>5.8(4.2)</td>
<td>5.3(3.4)</td>
</tr>
<tr>
<td>ECOG*</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>ECOG-0</td>
<td>11(19.6)</td>
<td>7(10.4)</td>
<td>7(36.8)</td>
</tr>
<tr>
<td>ECOG-1</td>
<td>25(44.6)</td>
<td>33(49.3)</td>
<td>5(26.3)</td>
</tr>
<tr>
<td>ECOG-2</td>
<td>13(23.2)</td>
<td>24(35.8)</td>
<td>5(26.3)</td>
</tr>
<tr>
<td>ECOG-3</td>
<td>7(12.5)</td>
<td>3(44.8)</td>
<td>2(10.5)</td>
</tr>
</tbody>
</table>

*ECOG-0: Fully active, able to carry on all pre-disease performance without restriction
ECOG-1: Restriction in physically strenuous activity but ambulatory and able to carry out light or sedentary work
ECOG-2: Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about 50% of waking hours.
ECOG-3: Capable of only limited self-care, confined to bed or chair more than 50% of waking hours

5.2.4.4 Health literacy

The mean scores of the nine subscales of the Health Literacy Questionnaire (HLQ) and health literacy cluster groups compared across the four categories of the CPS are shown in Table 5.12. The subscale scores of Critical Appraisal
(P=0.040) and Ability to find good health information (P=0.016) were found to have significant impact on patients’ control preference. The higher the patients’ ability to read and understand health information, the more active their preference for participation, this trend, however was not statistically significant (P=0.076).

<table>
<thead>
<tr>
<th>HLQ subscale</th>
<th>Preference Mean (SD)</th>
<th>OR (95%CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Passive</td>
<td>Passive-</td>
<td>Collaborative</td>
</tr>
<tr>
<td></td>
<td>(n=52)</td>
<td>shared (n=62)</td>
<td>(n=19)</td>
</tr>
<tr>
<td>Healthcare provider support</td>
<td>2.84 (0.28)</td>
<td>2.83 (0.39)</td>
<td>2.76 (0.40)</td>
</tr>
<tr>
<td>Having sufficient information</td>
<td>2.80 (0.35)</td>
<td>2.81 (0.36)</td>
<td>2.91 (0.25)</td>
</tr>
<tr>
<td>Actively managing health</td>
<td>2.91 (0.32)</td>
<td>2.86 (0.34)</td>
<td>2.93 (0.18)</td>
</tr>
<tr>
<td>Social support</td>
<td>3.00 (0.31)</td>
<td>3.00 (0.29)</td>
<td>3.02 (0.32)</td>
</tr>
<tr>
<td>Critical appraisal</td>
<td>2.82 (0.30)</td>
<td>2.86 (0.27)</td>
<td>2.99 (0.32)</td>
</tr>
<tr>
<td>Active engagement with healthcare providers</td>
<td>3.32 (0.56)</td>
<td>3.49 (0.56)</td>
<td>3.34 (0.78)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HLQ subscale</th>
<th>Preference Mean (SD)</th>
<th>OR (95%CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Passive</td>
<td>Passive-</td>
<td>Collaborative</td>
</tr>
<tr>
<td></td>
<td>(n=52)</td>
<td>shared (n=62)</td>
<td>(n=19)</td>
</tr>
<tr>
<td>Navigating the healthcare system</td>
<td>3.36 (0.38)</td>
<td>3.45 (0.42)</td>
<td>3.33 (0.54)</td>
</tr>
</tbody>
</table>
Chapter 5 Perceptions of patient participation in symptom management (Part I)

| Ability to find good health information | 3.47 (0.59) | 3.71 (0.50) | 3.59 (0.62) | 4.16 (0.68) | 2.04 (1.14, 3.64) | 0.016* |
| Reading and understanding health information | 3.77 (0.45) | 3.90 (0.44) | 3.80 (0.45) | 4.36 (0.33) | 1.90 (0.93, 3.88) | 0.076* |

Health literacy (HL) cluster groups: n (%)

| High HL (Cluster 6, 8, 1) | 14 (26.9) | 23 (37.1) | 7 (36.8) | 4 (80.0) | 2.34 (0.86, 6.33) | 0.163 |
| Moderate HL (Cluster 7, 5, 3, 2) | 28 (53.8) | 32 (51.6) | 9 (47.4) | 1 (20.0) | 1.36 (0.53, 3.50) |
| Low HL (Cluster 4, 9) | 10 (19.3) | 7 (11.3) | 3 (15.8) | 0 (ref) |

*P<0.1

5.2.4.5 Multivariate analysis of demographic and illness factors associated with control preference

A two-step model selection strategy was performed. In step one, all demographic factors found to be significant in univariate analyses (age, sex, level of education, marital status, and work status) were analysed using a backward elimination variable selection strategy with P_{enter}=0.1 and P_{delete}=0.05. As shown in Table 5.13, patients who were female, single (including divorced and widowed), and employed or having been employed (retired) had more active preference for participation in symptom related decision making than those who were male (OR: 1.88, 95% CI: 1.00 to 3.51, p=0.050), married (OR: 2.84, 95% CI: 1.00 to 8.12, p=0.051) or not/never employed (OR: 3.64, 95% CI: 1.84 to 7.20, p<0.001).
Table 5.13 Outcomes of multivariate ordinal logistic regression of demographic characteristics associated with control preference.

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>OR (95%CI)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.99(0.96,1.02)</td>
<td>0.399</td>
</tr>
<tr>
<td>Sex</td>
<td>1.88(1.00,3.51)</td>
<td>0.050*</td>
</tr>
<tr>
<td>Level of education</td>
<td>0.96(0.46,2.00)</td>
<td>0.903</td>
</tr>
<tr>
<td>Marital status</td>
<td>2.84(1.00,8.12)</td>
<td>0.050*</td>
</tr>
<tr>
<td>Work status</td>
<td>3.64(1.84,7.20)</td>
<td>0.000*</td>
</tr>
</tbody>
</table>

*P≤0.05

In the second step (see Table 5.14), independent factors associated with control preference (current treatment, three subscales of health literacy: Critical appraisal, Ability to find good health information and Reading and understanding health information) were evaluated one at a time while adjusting for the significant demographic factors identified in Step one. The variable selection method was backward elimination with $P_{\text{enter}}$ and $P_{\text{delete}}$ as 0.1 for both. After adjusting for significant demographic covariates (sex, marital status and work status), it uncovered that the OR of patients’ selection of a particular control preference were over two times higher (OR: 2.38; 95% CI: 1.14 to 4.99, P=0.021) in patients undergoing radiotherapy compared with those undergoing concurrent chemo-radiotherapy treatment. For every one unit increase in the mean scores of critical appraisal, patients were nearly three times (OR: 2.71; 95%CI: 0.88 to 8.31, P=0.081) more likely to prefer more a more active participatory role. Further, for every one unit increase in mean scores of ability to find good health information, patients
were almost two times more likely to choose a more active control preference role (OR 1.73; 95%CI: 0.96 to 3.12, P=0.069).

Table 5.14 Outcomes of multivariate ordinal logistic regression of treatment and health literacy factors associated with patients’ control preference

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>OR (95%CI)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>1.34(0.40,4.51)</td>
<td>0.000*</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>2.38(1.14,4.99)</td>
<td>0.635</td>
</tr>
<tr>
<td>Combined radio-chemotherapy</td>
<td>1(ref)</td>
<td></td>
</tr>
<tr>
<td>Critical Appraisal</td>
<td>2.71(0.88,8.31)</td>
<td>0.081*</td>
</tr>
<tr>
<td>Ability to find good health information</td>
<td>1.73(0.96,3.12)</td>
<td>0.069*</td>
</tr>
<tr>
<td>Reading and understanding health information</td>
<td>1.65(0.80,3.42)</td>
<td>0.174</td>
</tr>
</tbody>
</table>

*P<0.1
Note: Adjusted covariate variables were sex, marital status and work status.

5.2.4.6 Summary

Findings from the ordinal logistic regression analysis indicated that patients who were single, female, employed, undergoing radiotherapy or had higher levels of health literacy regarding the ability to critically appraise information and to find health information, tended to prefer a more active participatory role in their symptom management.

5.2.5 Outcomes associated with preference for, and actual experience of participation

5.2.5.1 Patients’ perception of quality of care

Perception of quality of care index (PQI) was calculated based on the rank order of the difference between subjective importance and perceived reality for questions related to quality of care received. The PQI score indicates the
quality of care perceived by participants. The detailed calculation formula is presented in Chapter 3 Section 3.2.1.3.10.

The PQI mean scores were compared within four categories of control preference (passive – active shared) for participation through one-way ANOVA. The results in Table 5.15 show that there were no differences in the mean scores of PQI between control preference categories (P=0.722). Similarly, no significant differences were found when comparing mean PQI scores within categories of actual participation achieved (P=0.519).

Table 5.16 shows the PQI mean scores for patients grouped according to their participation outcomes, specifically whether patients were able to achieve their preference for participation or their experience of participating was either less active or more active than their preference. The scores were compared using one-way ANOVA. The PQI mean scores were not similar across the three groups (F=4.54, P=0.012). Further Bonferroni pairwise comparisons were conducted revealing that the mean PQI scores were significantly higher for patients whose actual participation was commensurate with their preferred role when compared to patients whose participatory role was less active than their preference (P=0.007).
Table 5.15 Comparison of PQI mean score within preference for and actual participation groups

<table>
<thead>
<tr>
<th>Preference for participation (n=138)</th>
<th>Passive (n=52)</th>
<th>Passive-shared (n=62)</th>
<th>Collaborative (n=19)</th>
<th>Active-shared (n=5)</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>PQI mean (SD)</td>
<td>10.97 (2.87)</td>
<td>10.60 (3.36)</td>
<td>9.40 (2.57)</td>
<td>10.02 (2.79)</td>
<td>0.35</td>
<td>0.722</td>
</tr>
<tr>
<td>Actual participation (n=136)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PQI mean (SD)</td>
<td>10.32 (3.28)</td>
<td>10.72 (2.88)</td>
<td>10.09 (3.73)</td>
<td>12.18 (3.09)</td>
<td>0.76</td>
<td>0.519</td>
</tr>
</tbody>
</table>

Table 5.16 Comparison of PQI mean scores between patients who did not achieve their preferred level of participation and patients whose preference was commensurate with their experience (n=139)

<table>
<thead>
<tr>
<th>Level of participation achieved</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less active than preferred</td>
<td>36</td>
<td>9.34</td>
<td>3.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commensurate with preference</td>
<td>89</td>
<td>10.97</td>
<td>2.93</td>
<td>4.16</td>
<td>0.018*</td>
</tr>
<tr>
<td>More active than preferred</td>
<td>14</td>
<td>11.25</td>
<td>3.28</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*P<0.05 ; Bonferroni pairwise comparisons (α =0.017): Less active than preferred vs. commensurate with preference P=0.007; less active than preferred vs. more active than preferred P=0.045; commensurate with preference vs. more active than preferred P=0.744

5.2.5.2 Satisfaction with symptom management

As shown in Table 5.17, the majority of patients reported they were satisfied with symptom treatment in the acute care setting. Nearly 90% of patients reported they were satisfied or very satisfied with symptom treatment
overall and the way their doctors and nurses responded to their reports of symptoms. The percentage of very satisfied or satisfied with symptom or symptom treatment information provided was slightly lower than the previous three items, but still accounted for more than 75% of patients.

Table 5.17 Patients’ satisfaction with symptom management

<table>
<thead>
<tr>
<th>Item</th>
<th>Very dissatisfied or dissatisfied n(%)</th>
<th>Slightly dissatisfied n(%)</th>
<th>Slightly satisfied n(%)</th>
<th>Very satisfied or satisfied n(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How satisfied or dissatisfied are you with:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. The results of your symptom treatment overall in the past 24 hours (n=139)</td>
<td>3 (2.2)</td>
<td>3 (2.2)</td>
<td>10 (7.2)</td>
<td>123 (88.5)</td>
</tr>
<tr>
<td>2. The way your doctors responded to your reports of symptoms in the past 24 hours (n=139)</td>
<td>0</td>
<td>3 (2.2)</td>
<td>13 (9.4)</td>
<td>123 (88.5)</td>
</tr>
<tr>
<td>3. The way your nurses responded to your reports of symptoms in the past 24 hours (n=138)</td>
<td>1 (0.7)</td>
<td>2 (1.4)</td>
<td>12 (8.7)</td>
<td>123 (89.1)</td>
</tr>
<tr>
<td>4. The information that you have been provided with relating to your symptoms (n=138)</td>
<td>3 (2.2)</td>
<td>4 (2.9)</td>
<td>26 (18.8)</td>
<td>105 (76.1)</td>
</tr>
<tr>
<td>5. The information that you have been provided with relating to the treatment of your symptoms (n=138)</td>
<td>3 (2.2)</td>
<td>3 (2.2)</td>
<td>26 (18.8)</td>
<td>106 (76.8)</td>
</tr>
</tbody>
</table>

Responses to five questions relating to satisfaction with symptom management were correlated with patients’ preference for participation, actual experience of participation and whether patients’ preference was achieved. The Kendall’s tau-c correlation analysis did not find any association
except for a weak positive association between satisfaction with nurses’ response to patients’ symptom reports and patients’ actual experience of participation ($r=0.09$, $P=0.012$), as displayed in Table 5.18.

Table 5.18 Correlations between patient satisfaction and preference for participation, actual participation and whether preferred level was achieved.

<table>
<thead>
<tr>
<th>Item</th>
<th>Preference for participation</th>
<th>Actual participation</th>
<th>Preference achievement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$r$</td>
<td>$P$</td>
<td>$r$</td>
</tr>
<tr>
<td>How satisfied or dissatisfied are you with:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. The results of your symptom treatment overall in the past 24 hours</td>
<td>-0.03</td>
<td>0.475</td>
<td>0.03</td>
</tr>
<tr>
<td>2. The way your doctors responded to your reports of symptoms in the past 24 hours</td>
<td>0.01</td>
<td>0.827</td>
<td>0.04</td>
</tr>
<tr>
<td>3. The way your nurses responded to your reports of symptoms in the past 24 hours</td>
<td>0.03</td>
<td>0.413</td>
<td>0.09</td>
</tr>
<tr>
<td>4. The information that you have been provided with relating to your symptoms</td>
<td>-0.01</td>
<td>0.831</td>
<td>-0.01</td>
</tr>
<tr>
<td>5. The information that you have been provided with relating to the treatment of your symptoms</td>
<td>-0.02</td>
<td>0.734</td>
<td>0.02</td>
</tr>
</tbody>
</table>

*P<0.05

5.2.5.3 Summary

Exploration of the associations between outcomes and patients’ preference for and actual experience of participation indicated that patients’ perception of quality of care was related to patients’ preferred level and actual experience of participation. When patients’ actual experience was
commensurate with their preference, patients were more likely to perceive that they had received higher quality of care than those who had not achieved their preference for participation. Patients’ preference for participation and their actual experience of participation in symptom management was not found to be correlated with patients’ satisfaction with care delivery during symptom management.

5.3 Discussion

The analyses of the survey data in this chapter aimed to explore patients’ and clinicians’ perceptions of patient participation in symptom management in terms of subjective importance ratings for participatory activities; actual participation; patients’ preferred and actual participatory roles experienced in symptom management-related decision making; predictors of patients’ preference for participation; and outcomes associated with preferred and actual experience of participation. The findings provide important understandings of patients’ as well as clinicians’ perceptions of patient participation in symptom management and the relationships between preference and patient characteristics.

5.3.1 Attitudes towards patient participation in symptom management

Participatory activities related to symptom management were perceived as important by the majority of patients, doctors and nurses. Further, activities related to information exchange were rated higher in importance than activities related to decision-making. The importance of patient participation
has been universally accepted in the literature (Davis et al., 2012). Evidence of the high importance ratings indicate that participants in the case study acknowledged the notion of patient involvement in their treatment and care, which is a precondition for any participation promoting interventions. Few studies have investigated attitudes towards different participatory activities (Ding, 2011), however, the greater importance placed on information-related activities in symptom management compared to decision-making activities suggests that patients and clinicians in this case study expect a lower level of patient participation according to Soleimani’s conceptual analysis of patient participation (Soleimani, Rafii, & Seyedfatemi, 2010). Essentially this model suggests that if participation in decision-related activities is perceived as less important, patients are less likely to participate in those types of activities and clinicians provide less opportunities for patients to participate.

Despite the high importance ratings clinicians placed on participatory activities, both doctors and nurses were more likely than patients to perceive patient participation as a hindrance to their ability to carry out their work; the median percentage of clinicians who agreed that patient participation would increase workload, create problems or take clinicians’ time was 67%. The tool used in the survey was originally developed by Arnetz et al (2008b) who investigated views about patient involvement in their care of 53 doctors, 132 licensed practical nurses and 303 registered nurses in the cardiology departments of 12 Swedish hospitals. The findings of that study were similar
in that approximately 60% of clinician respondents perceived that patient involvement would hinder their work. In the Swedish study, patients’ perceptions were not explored so it is not known whether patients shared the perception of their involvement hindering clinicians’ work. Previous qualitative research has found that patients are concerned with troubling clinicians and increasing clinicians’ workload (Malmgren, To¯rnvall, & Jansson, 2014)(Seale, 2015 #2184) but these concerns have not been compared with those of their clinicians.

5.3.2 Experience of symptom management

The findings related to patients’ and clinicians’ experiences of receiving or providing opportunities to participate revealed interesting differences in perceptions between patients and clinicians. Although over 90% of patients reported that receiving information about symptom treatment or care was important, approximately 60% agreed that they had received this information during their admission. These findings indicate a significant gap between what patients perceive as important and their experience. Having adequate information is a prerequisite for patient participation in their treatment and care (Eldh, Ekman, & Ehnfors, 2006). Lack of information is the most commonly identified barrier to participation in healthcare activities (Eldh, Ekman, & Ehnfors, 2008; Höglund et al., 2010; Löfman, Häggman-Laitila, & Pietilä, 2008; Larsson et al., 2011a; Rainey et al., 2013; Vestala, & Frisman, 2013).
In addition to information flow from clinicians to patients, information exchange requires that patients contribute their information or knowledge to clinicians (Kolovos et al., 2014b; Sahlsten et al., 2005b; Sahlsten et al., 2009). In this case study, approximately two-thirds of patients stated that they would report their symptoms, however half the patients would not press a call bell to report a symptom, which suggests that patients prefer other opportunities to report their symptoms. In an Australian study, Cohen et al found that although 61.1% of patients would initiate a report of their symptoms approximately 10% would not use a call bell to do this (Cohen, 2012). Therefore although the Australian and Chinese cohorts may be similar in terms of their willingness to report symptoms, Chinese patients may be more reluctant to use more active forms of alerting clinicians. However, an important contextual difference in care in the case study hospital is the expectation that patient manage their own medications. It may be that patients have less need to alert clinicians of the need for symptom management if they have the medications available to them.

Participating in decision-making was reported by patients in the VBPIC as one of their least frequent experiences as less than one-fourth of patients were involved in discussing examinations or treatments, goal setting and decision making. This finding is not unique. Limited opportunities for patients to participate in decision making related to treatment and care have been reported in previous investigations, which were in the context of pain management in Australia (McTier, Botti, & Duke, 2014) and in USA (Isaacs et
al., 2013), medical decision-making in Lithuania (Brogiene, & Gurevicius, 2009) and decisions about treatment and care in Hong Kong (Wong et al., 2012). These findings indicate that, in many clinical settings, paternalistic models of care still dominate patient-clinician interactions, especially when treatment or care decisions are discussed and made.

Significant differences were identified between patients’ and clinicians’ perceptions of their behaviours in terms of information provision, meeting patient needs and patient motivation. Similar results of different perceptions of patient experience were reported by Timonen (2000) who compared nurses’ and patients’ responses to patients’ experience of participation in bedside handover. The researchers found 79% of nurses reported patients were ‘always’ or ‘often’ involved in the bedside handover while only 57% of patients reported that frequency of participation. Over 90% of nurses compared to less than 50% of patients agreed that patients were encouraged to participate. Timonen concluded that the nurses perceived communication to be more interactive than the patients, which is consistent with the findings reported in this chapter. Papastavrou et al (2015) revealed similar disparities between patients’ and nurses’ perceptions of information provision and patients’ actual involvement in decision making.

Reasons for the lack of congruity between patients’ and clinicians’ experience perceptions need to be explored further. A possible explanation may be that patients and clinicians have different expectations of clinical interactions. Some patients prefer to have knowledge and understanding
rather than just being informed (Eldh, Ekman, & Ehnfors, 2010), however, clinicians are often more concerned with providing essential information rather than determining whether patients have difficulty in understanding the information provided. In a study examining General Practitioners’ (GP) assessments of their patients’ health literacy, it was found that GPs overestimated the literacy of their patients (Rogers, Wallace, & Weiss, 2006). Information provided by clinicians might not be fully understood by patients and this can explain discrepancies in perceptions of information provision between patients and clinicians and more attention should be given to the quality of medical information delivery from clinicians to patients.

5.3.3 Patients’ preference for participation in making decisions related to symptom management

This study identified that over 80% of patients preferred their doctors and nurses to make decisions about symptom management, while only 3.7% of patients preferred to make decisions themselves considering clinicians’ opinions or independently. Another Chinese study investigated preference in treatment decision making of patients with colorectal cancer and found 68.5% of patients preferred to leave decisions to their doctors or family members (Hou et al., 2014). Cancer patients’ preferences for participation in symptom management was investigated by Cohen et al, in Australia. Close to 60% of patients preferred passive or passively shared control roles and 7.6% of patients desired an active role, suggesting that patients in the Chinese case study may prefer a more passive role in decision making.
A possible explanation for this is that patient participants in this study were drawn from a Chinese acute care setting. The cultural context, which is different to the Australian context, might have impacted on patients’ preferences. A paternalistic style in interactions between patients and clinicians continues to have dominance in Chinese healthcare delivery in which doctors are considered authoritative and dominant in medical processes while patients are in a more subordinate position (Zhang et al., 2011). Despite the increasing recognition of patients’ rights in China, concepts like patient participation or patient empowerment, are still relatively novel to both health professionals and patients. These concepts were explored further in the qualitative interviews. Participation in decision making is likely to be influenced by patients’ perceptions of their understanding of medical treatment and care and their roles and responsibilities in decision making, particularly within the acute care context.

In this study, certain patient demographic characteristics, treatment type and abilities related to health literacy were found to be significant factors influencing patients’ preference for participation in decision-making during symptom management. Identification of these factors could provide evidence to predict or explain patients’ preferred roles of participation in the context of symptom management.

Patients who were female, single, and employed tended to prefer more active participatory roles in their care. The influence of gender has been confirmed in previous studies where females desired a more active role than
roles (Arnetz, & Arnetz, 2009; Chung et al., 2012; Davis, Koutantji, & Vincent, 2008; Florin, Ehrenberg, & Ehnfors, 2008; Mohsin-Shaikh, Garfield, & Franklin, 2014). In previous research, living alone has been found to be a factor predicting patients’ preference for a more active role (Florin, Ehrenberg, & Ehnfors, 2008) and patients who were employed were more willing to ask clinicians questions about their treatment (Davis, Koutantji, & Vincent, 2008). Gender, marriage status and employment are all associated with notions of personal responsibility. For example, women in China are usually expected to take responsibility for family care. Those who are single and do not have a partner may be more likely to rely on their own judgement. Similarly, when people are working and have a regular income, they tend to be more independent not only in economic terms but also in regards to their family status. Similar interpretations were found in the discussion by Florin who indicated that taking responsibility for care is more intertwined in the female social role than in the male role (Florin, Ehrenberg, & Ehnfors, 2008). Therefore, the characteristics related to independent responsibility might account for more active preference for participation in health care.

Performance status has been found to be associated with patient preferences in some studies (Chung et al., 2012; Cohen, & Botti, 2015; Kvargarusness et al., 2013; Lofman, Haggman-Laitila, & Pietilä, 2008; Latimer, Chaboyer, & Gillespie, 2014; Lever, O’Reilly, & Pryor, 2008; Malmgren, To¨rnvall, & Jansson, 2014; Marc et al., 2013; McInnes et al., 2014). Although symptom profiles, psychological and physical status were not found
to be significantly associated with patients’ preference for participation in this study, patients undergoing radiotherapy preferred to adopt a more active role in decision-making than those who were undergoing concurrent chemo-radiotherapy. As demonstrated in the symptom investigation in Chapter 4, patients undergoing chemotherapy had greater symptom severity, with higher scores in the GDI and PHYS of the MSAS when compared with those who were having radiotherapy. Hence, treatment type could indirectly affect the relationship between illness status and participatory preference.

Health literacy was identified as an important predictor in this study, specifically, related to patients’ ability to appraise information critically or to find health information. Patients who rated highly on these abilities may have less difficulty accessing and understanding information related to treatment options. It is reasonable to expect that these patients will have a stronger desire to participate in the process of decision making in contrast with patients who have lower levels of health literacy. The positive association between health literacy and participatory preference identified in this study is in accordance with the findings in Naik’s et al. study which demonstrated that patients with inadequate functional health literacy preferred more passive decision making styles. In addition, 40% of patients preferring passive styles had adequate functional health literacy, and these patients were found to be more likely to change their preference to more active styles if they perceived support or encouragement from their doctors (Naik et al., 2011).
Other characteristics such as age, level of education and income level, were not significantly associated with control preference in this study, although they have been found to be significant factors in some previous studies (Chung et al., 2012; Florin, Ehrenberg, & Ehnfors, 2006b; Frank et al., 2011; Hansson, Fridlund, & Hallström, 2006; Uldry et al., 2013; Zhang et al., 2011). Length of time since diagnosis and number of past treatments were also not found to be correlated with patients’ preference. This finding may be explained by the fact that the present patient participants were recruited during their cancer treatment for non-hospice purposes, therefore most of them were in their first year after diagnosis and had experienced similar treatments.

Clarification of patients’ characteristics could be beneficial to our understanding of patients’ participation preferences and may provide evidence for health professionals to predict patients’ preference for decision-making in the process of symptom management. However, these results were obtained from the analyses of preferences from a group of patients. It is likely that preference for participation is an individual characteristic that may not be static over time and will have multi-factorial influences and should therefore be assessed on an individual basis.

5.3.4 Patients’ actual participation in decision making

The findings of this survey identified a moderate agreement between patients’ preferred roles and actual participatory roles, with nearly two-thirds of patients achieving their preference for participation in symptom
management. This result is consistent with previous studies in which patients’ participatory roles were assessed using the CPS tool in acute care settings. Zhang et al (2011) investigated 178 Chinese patients with chronic hepatitis and found 69% of patients’ actual experience of participation matched their preference. Moderate agreement was also indicated in a study of 153 elderly inpatients in Sweden with 44% total agreement between preference and actual participation related to medical decision-making (Ekdahl et al., 2011). Another Swedish study found a similar relationship among 39 medical patients in decisions related to patient care (Vestala, & Frisman, 2013). Studies reporting less congruency between preferred and actual roles have also been reported. For example, Florin reported a congruency of 29% in patient interactions with nurses (Florin, Ehrenberg, & Ehnfors, 2006a) and Ramfelt reported 30% congruency in preferred and actual treatment decision-making among patients with colorectal cancer (Ramfelt, Lützen, & Nordström, 2005).

Given the high percentage of reported passive roles both in patients’ preferred and actual experience, the moderate agreement might not mean that patients collaborated well with clinicians. The moderate congruency may in fact reflect that the majority of patients in this study had a more passive preference for participation. Patients with preference for passive participation may be easier for clinicians to interact with than patients who want a more active role, particularly when models of care and interactions are based on a paternalistic framework. Supporting evidence can be found
in Pardon’s findings that high levels of congruency between preferred and actual participation were only found in patients who preferred an absolute passive or absolute active role while those who preferred more collaborative or shared decision-making roles with their clinicians often reported lower achievement of their preference. The authors concluded that the latter patients were more critical and achievement of preferences were more open to nuances (Pardon et al., 2011).

Among patients who did not report congruency between preferred and actual experience of participation, 24.5% of patients experienced a more passive role than their expectation, which was higher than the proportion of patients whose actual participation exceeded their preference. Many previous studies also found that patients wanted more participation in decision-making than they actually achieved (Ekdahl et al., 2011; Florin, Ehrenberg, & Ehnfors, 2006a; Mohsin-Shaikh, Garfield, & Franklin, 2014; Ramfelt, Lützen, & Nordström, 2005; Tariman et al., 2010; Zhang et al., 2011). This gap between preferred and actual participation reveals a significant issue in patients’ experience of care in acute care environments.

The significance of this gap in preferred and actual roles in decision-making is illustrated by the finding that patients perceived they had received higher quality of care when their actual participation roles agree with their preferred participation roles. There are few studies that have investigated the impact of achieving participation preferences on the perception of quality of care, as most of the studies have explored differences between
level of actual participation and quality of care (Jangland et al., 2012; Weingart et al., 2011) which, in this Chinese study was found to not be significantly correlated. The findings therefore, indicate that supporting patients to achieve their preferred level of participation may be more important in achieving good care quality than focusing activities on encouraging patients to adopt a more active preference or actual experience of participation. This finding needs to be confirmed in future studies.

Previous research findings have suggested that patients’ satisfaction with hospital-based care is associated with the degree of patient engagement (Gascoigne, & Watson, 2009; Vaughn, 2014; Wong, Peterson, & Black, 2011). However, in the study reported here, satisfaction with symptom management was not found to be significantly different among patients with various participatory preferences or different levels of actual participation. The majority of patients were satisfied with the overall symptom treatment they received and the information or responses provided by doctors and nurses regardless of their level of participation. Henderson also reported similar results in that the patients in his study felt satisfied with the decision-making processes no matter whether they had a more or less active preference for participation (Henderson, & Chien, 2007). This phenomenon was also shown by Lam et al. who investigated 154 Chinese women undergoing breast cancer surgery in a Hong Kong hospital and found that all the women in the sample were satisfied with their medical consultation no matter whether or not their preferred and actual participation in treatment
decision making were congruent (Lam et al., 2003). The impact of a positive response bias in studies where patients evaluate medical staff is very strong (Fung et al., 2001; Lam et al., 2003) and needs to be considered when evaluating patient satisfaction studies.

5.4 Conclusions

The perceived importance of patient participation was shared by patients and clinicians, although participating specifically in decision-making relating to symptom treatment and care was not perceived to be as important as relaying symptom experience. Patients’ perceptions of clinicians’ information provision were not optimal and there were few opportunities for patients to be involved in decision making. Significant differences were identified between patients’ and clinicians’ perceptions in terms of how participation may hinder care processes, the amount and type of information related to symptom treatment and care clinicians provided, whether patients’ needs of asking questions and being answered were met and whether clinicians motivated patients to participate in their own treatment and care.

The majority of patients preferred to leave decisions to clinicians. Moderate agreement was identified between patients’ preferred and actual participation and those who did not achieve their preferred level of participation were more likely to have experienced a more passive role than they preferred. More active preference for participation in decision making was associated with being single, female, employed, undergoing
radiotherapy and higher levels of health literacy regarding the ability to appraise information critically and to find health information. Patients whose actual experience of participation agreed with their preference perceived they had received higher quality of care.

In Chapter 6, patients’ and clinicians’ perceptions of patient participation are explored further through qualitative analyses of semi-structured interviews conducted to probe understandings of patient participation in symptom management, facilitators and barriers to participation and patients’ perceived reasons for their preferred roles.
CHAPTER SIX

Perceptions of patient participation in symptom management (Part II)

The analyses presented in this chapter continue to explore patients’ and clinicians’ perceptions of patient participation in symptom management. In this chapter, findings from semi-structured interviews with patients and clinicians are presented to achieve the following objectives:

1. Explore patients’, doctors’ and nurses’ understanding of participation and patient roles in symptom management;

2. Explore patients’, doctors’ and nurses’ experience of facilitators and barriers to participation in symptom management;

3. Explore patients’ reasons for selecting a particular control preference for participation in symptom management-related decision making;

4. Compare and contrast quantitative and qualitative findings to identify any similarities or differences between patients’ and clinicians’ perceptions of patient participation.

6.1 Method

The full description of the methods used are reported in Chapter 3, section3.2.1.2. A subset of patients (n=41) who participated in the survey component of this research program were invited to participate in a semi-
structured interview. Stratified purposive sampling was used to recruit patients according to their most preferred control preference role reported in the survey. Previous research has shown that patient preference for participation is variable (Cohen, 2012; Zhang et al., 2011) thus this method of sampling ensured that there was representation by patients with varying Control Preferences in the semi-structured interviews.

Doctors (n=5) and nurses (n=7) also participated in semi-structured interviews. Purposive sampling was used to recruit doctors and nurses. The method of sampling enabled clinicians with various roles in the inpatient unit to be interviewed so that responses were provided by clinicians with varying roles and experience.

Semi-structured interviews were guided by broad topics and open-ended questions (Appendix 7).

In patient interviews, three main topics were explored:

1. When patients select a Control Preference what does it mean to them?

Patients were asked to provide their rationale for their most preferred role and describe the types of care activities related to their symptoms they could participate in.

2. What types of care activities related to symptoms have patients participated in during their current admission?
Patients were questioned about their understandings of patient participation in symptom management, symptom communication and experience in participating in symptom treatment and care.

3. What do patients perceive are the factors influencing their participation in the acute care setting?

Patients were asked to describe any barriers and/or facilitators to participating in symptom management.

Two topics guided Clinician (doctor and nurse) semi-structured interviews:

1. How do clinicians perceive patient participation in symptom management?

Doctors and nurses were asked about their attitudes and perceptions of patients participating in their symptom management; their perceptions of patients’ preference for participating in their symptom management; and experience of family members’ participation.

2. What are the barriers and facilitators of patient participation in symptom management on the ward?

Doctors and nurses were asked how the structures and processes on the ward made it either easier or more difficult for patients to participate in their symptom management including hospital or ward policies they were aware of regarding patient participation.

Framework analysis was used to analyse the data related to interviewees’ understanding of patient participation in symptom management and
experience including factors influencing patient participation and reasons why patients may or may not participate or comply with treatment goals. The analyses of factors influencing patients’ perceptions of symptom management included responses from specific closed-ended survey questions and open-ended survey questions in addition to the in-depth responses from the semi-structured interviews. These data were analysed in a descriptive and comparative way to explore patients’ and clinicians’ perceptions of patient participation in symptom management and probe similarities in their perceptions.

6.2 Characteristics of patients, nurses and doctors who participated in the semi-structured interviews

A total of 162 patients participated in the survey component of this research program, 41 were recruited (25.3%) into the semi-structured interview. Patient demographic and illness-related characteristics are presented in Table 6.1. The average age of these 41 patients was 45.4 years (SD=10.5), 51.2% (n=21) were males. Over 90% of patients had completed a secondary education level or above. All of these characteristics were not significantly different when compared with those of patients in the overall survey sample, except for education level ($X^2=0.34$, $P=0.024$). Less patients with only primary level education were interviewed.

The differences in the distribution of patients’ control preferences between the patients who participated in the semi-structured interview and the patients who participated in the survey are presented in Table 6.2. There was
no significant difference in the percentage of control preference roles between patients in the overall survey sample and those in the interview sample.

Table 6.1 Demographic and illness-related characteristics of the semi-structured interview patients compared to the survey patients overall

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Survey (n=162)</th>
<th>Semi-structured interview (n=41)</th>
<th>T(χ²)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Age (in years)</td>
<td>47.5</td>
<td>12.2</td>
<td>45.4</td>
<td>10.5</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Male</td>
<td>78</td>
<td>48.1</td>
<td>21</td>
<td>51.2</td>
</tr>
<tr>
<td>Female</td>
<td>84</td>
<td>51.9</td>
<td>20</td>
<td>48.8</td>
</tr>
<tr>
<td>Education (n=152)</td>
<td></td>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Primary</td>
<td>26</td>
<td>17.1</td>
<td>3</td>
<td>7.3</td>
</tr>
<tr>
<td>Secondary</td>
<td>77</td>
<td>50.7</td>
<td>18</td>
<td>43.9</td>
</tr>
<tr>
<td>Tertiary</td>
<td>49</td>
<td>32.2</td>
<td>20</td>
<td>48.8</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Bowel</td>
<td>27</td>
<td>16.7</td>
<td>9</td>
<td>22.0</td>
</tr>
<tr>
<td>Breast</td>
<td>39</td>
<td>24.1</td>
<td>12</td>
<td>29.3</td>
</tr>
<tr>
<td>Head and neck</td>
<td>60</td>
<td>37.0</td>
<td>12</td>
<td>29.3</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>21</td>
<td>13.0</td>
<td>4</td>
<td>9.8</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
<td>9.3</td>
<td>4</td>
<td>9.8</td>
</tr>
</tbody>
</table>

*P<0.05
The purpose of the stratified sampling technique was to ensure that patients with all five control preferences were represented in the semi-structured interviews. All patients with active-shared or active control preferences were selected to participate as patients with these preferences only accounted for 3.7% of the survey sample thus it was important that their perspectives were captured.

The work and experience level of clinicians (nurses and doctors) who participated in the semi-structured interview are presented in Table 6.3. The five doctors interviewed represented 13.1% of those surveyed and included representation from the key levels of experience of those working on the ward. The seven nurses interviewed represented 20.6% of those surveyed and also included representation from the key levels of experience on the ward. This distribution of experience was considered important because it allowed for different perspectives according to role and experience to be captured.

Table 6.2 Control Preference of patients in the semi-structured interview sample and the overall survey sample

<table>
<thead>
<tr>
<th>Control Preference</th>
<th>Survey (N=162)</th>
<th>Semi-structured interview (n=41)</th>
<th>Spearman $\chi^2$</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>64</td>
<td>11</td>
<td>0.10</td>
<td>0.156</td>
</tr>
<tr>
<td>%</td>
<td>39.5</td>
<td>26.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Passive-shared</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>72</td>
<td>22</td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>44.4</td>
<td>53.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collaborative</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>20</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>12.3</td>
<td>12.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active-shared</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>5</td>
<td>2</td>
<td>0.10</td>
<td>0.156</td>
</tr>
<tr>
<td>%</td>
<td>3.1</td>
<td>4.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>0.6</td>
<td>2.4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 6.3 Characteristics of the clinicians in the semi-structured interview sample compared to the survey sample overall

<table>
<thead>
<tr>
<th>Work characteristics</th>
<th>Survey (n=72)</th>
<th>Semi-structured interview (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Doctor (n=38)</td>
<td>Nurse (n=34)</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Doctors’ roles on the ward</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resident</td>
<td>17</td>
<td>44.7</td>
</tr>
<tr>
<td>Attending</td>
<td>18</td>
<td>47.4</td>
</tr>
<tr>
<td>Consultant</td>
<td>2</td>
<td>5.3</td>
</tr>
<tr>
<td>Chief</td>
<td>1</td>
<td>2.6</td>
</tr>
<tr>
<td>Nurses’ roles on the ward</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistant Nurse</td>
<td>6</td>
<td>17.6</td>
</tr>
<tr>
<td>Primary Nurse</td>
<td>23</td>
<td>67.6</td>
</tr>
<tr>
<td>In-charge Nurse</td>
<td>2</td>
<td>5.9</td>
</tr>
<tr>
<td>Head Nurse</td>
<td>2</td>
<td>5.9</td>
</tr>
<tr>
<td>Research assistant</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td></td>
<td>Median</td>
<td>P_{25}</td>
</tr>
<tr>
<td>Time in ward (year)</td>
<td>1</td>
<td>0.17-</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>6.13</td>
</tr>
<tr>
<td>Time in oncology (year)</td>
<td>5</td>
<td>2-10</td>
</tr>
<tr>
<td></td>
<td>9.75</td>
<td>17.5</td>
</tr>
</tbody>
</table>

6.3 Findings

Findings in this chapter are presented in three sections. In the first section, findings related to understandings of and attitudes towards patient participation in symptom management from both patient and clinician
interviews are presented. The analysis of the reasons patients gave for their preferred roles in order to explore further patients’ perceptions of participation is presented in the second section. The analysis of data from patients’ open-ended responses in the survey and semi-structured interviews to describe factors influencing patients’ participation in symptom management are presented in the final section in this chapter.

6.3.1 Understandings of and attitudes towards patient participation in symptom management

To further our understanding of the underlying meanings of patient participation in symptom management, patient and clinician perceptions were explored through in depth, semi-structured interviews for the purpose of confirming, elaborating and complementing the findings from the surveys. Themes related to understandings of and attitudes towards patient participation were extracted from doctors’, nurses’ and patients’ responses to questions about the meaning of patient participation and activities patients could be involved in to manage symptoms. Analyses of the data revealed three themes of patient participation in symptom management: information exchange, negotiated decision-making and patient self-management. The themes, and underlying categories are presented in Table 6.4. The findings are presented in this chapter according to each theme and category.

Inherent in the three themes is the notion of patient participation as a mutual interaction requiring actions and behaviours from both patients and health professionals. Doctors and nurses emphasised that clinicians were not the only persons who provided information and made decisions, but that
patients should contribute information and participate in decision-making processes. Patients were expected to collaborate with doctors and nurses during interactions. The phrases of “work together” and “a team” were common in doctors’ and nurses’ responses. From the perspectives of patients, clinicians were expected to communicate their knowledge, competence and commitment while patients should express their problems, feelings and preferences. Terms like “cooperation” and “interaction” were common in patients’ responses.
Table 6.4 Themes, subthemes and categories regarding patients’ and clinicians’ perceptions of patient participation in symptom management

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub Themes</th>
<th>Categories</th>
</tr>
</thead>
</table>
| Information exchange is key to patient involvement | Professional knowledge transmitted from clinicians to patients | i) Explaining illness and symptoms to minimise distress  
ii) Providing information about treatment to facilitate understanding  
iii) Providing information about treatment to aid decision making  
iv) Providing information about treatment or care to elicit cooperation and positive compliance  
v) Providing information about treatment or care to facilitate self-care  |
| Self-knowledge transmitted from patients to clinicians | | i) Reporting symptoms in order to obtain treatment  
ii) Patients providing information as a reminder or feedback  
iii) Patients are the best source of knowledge for subjective experience  |
| Information sought by patients from sources other than clinicians | | i) Patients access multiple sources of information  
ii) Problems related to the use of other sources relate to the quality of available information  |
| Negotiated decision-making can be achieved in various ways | Knowing options to make informed decisions | |
|                                              | Knowing professional opinions | |
|                                              | Knowing patients’ preferences | i) Patients’ preferences are important  
ii) Patients do not have the requisite knowledge to have a preference  
iii) Clinicians’ concerns with the consequences of patient participation  |
|                                              | Making decisions | i) Patients are responsible for making their own decisions  
ii) Who is eligible to make the final decision?  |
| Patients’ self-management as a form of patient involvement | Patients responsible for psychological status | |
|                                              | Patients control own diet or life style | |
6.3.1.1 Information exchange is key to patient involvement

Information exchange refers to the different types of information transmitted between clinicians and patients. It was one of the key elements described by patients and clinicians when they explained their understanding of patient participation. The interviewees agreed that doctors and nurses could provide professional knowledge to patients, and that patients were an essential source of information, specifically their self-knowledge about symptoms and experience. In addition, there was acceptance that patients seek information from other sources. Hence, different information is exchanged through ‘mutual interaction’.

6.3.1.1.1 Professional knowledge transmitted from clinicians to patients

Professional knowledge delivered from clinicians to patients included explaining the illness or associated symptoms and providing information about treatment or care in order to minimise distress, facilitate patients’ understanding overall, aid decision making, elicit cooperation and compliance, and facilitate self-care. This transmission of information was considered a key role of healthcare professionals by doctors, nurses and patients.

i) Explaining illness and symptoms to minimise distress

Explaining the underlying causes of illness and symptoms to patients was seen as a way to reduce patients’ distress. This understanding was shared between both clinicians and patients.
In terms of symptom management ...... we mostly explain [the symptoms] to them. Or some symptoms when they are aggravated [due to the treatments] we usually give the patient some explanations...... Because patients usually have some psychological burdens, they will feel......when their symptoms change slightly......they will feel very nervous [due to their interpretation of the symptom], as these kinds of cancer patients do. (Doctor_1.2)

Of course we hope the information we give them is delivered in a comforting way because we can foresee what will happen to them and how severe it will be (Nurse_2.10)

My understanding is to report to the doctors when I have any symptoms. And I also hope he will inform me of the side effects or the potential complications before the treatment starts otherwise I’ll panic. As a person, after all, everyone has fears because of a lack of understanding of the situation (Patient_5.92)

*ii) Providing information about treatment to facilitate understanding*

Doctors and nurses indicated that they needed to explain or instruct patients about treatments or investigations for the purpose of facilitating patients’ understanding overall. Doctors believed they should tell patients why they perform particular treatments and what the expected outcomes of the treatments are. Nurses talked more about instructing patients how to self-administer prescribed medications.

_About patient participation, I think, first of all, patients have the right to be informed. We’d like to let patients know the benefits_
of the treatment and side effects as well. Both aspects, patients should know thoroughly (Doctor_1.34)

We try our best to advise them [patients], like what kind of adjuvant therapy is necessary to deal with the problems [symptoms] that happen to them. Most of the patients accept our advice (Nurse_2.10).

Similar to clinicians’ understanding, many of the patients reported that participation was about getting to know the treatment plan and instructions about medication administration from clinicians.

Patient: Participation means, in a perfect way, after a plan is made ..., there should be... a general communication, not a very complicated one because we can’t understand doctors’ professional language. It just lets us get to know it a little bit. There is no other way for us [to be involved] after all. ......

Interviewer: Is there anything else about your understanding?

Patient: Others... if there is a medicine treatment, it would be better to get some instructions from the doctors.

Interviewer: How to administer the medicine?

Patient: Yes. (Patient_5.119)

Because...it’s impossible for patients to know nothing at all. ......

We should be informed, that is to say, patients should get to know some of their own treatment methods from the doctors, consultants or nurses. If the patient knows something about the treatment, he could follow the plan. If he knows nothing, it would be very troublesome. (Patient_5.153)
Patients recognised the importance of being informed so that they could recognise signs and symptoms that may indicate progression or problems, and so that they could manage their symptoms appropriately.

_Patients should get information about what kind of reactions might emerge, how severe the symptoms might be. That is to say, this information should be known, otherwise patients themselves will not pay attention to them._ (Patient_5.153)

### iii) Providing information about treatment to aid decision making

The belief that treatment information could aid patients’ decision making was shared by both clinicians and patients.

_We should inform patients of their situations, and then discuss with them about some of the treatment options because sometimes there are several treatment options available._ (Doctor_1.2)

__Some treatments are conservative, while some are risky. I should be informed of all. Then the doctors and I can consider both opinions and have a discussion together. If we [patients] know nothing, we have to only depend on the doctors’ opinion and we have no ability to make the decision. We have no idea of the treatment specific to our situation, and that’s why we should ask the doctors._ (Patient_5.145)

### iv) Providing information about treatment or care to elicit cooperation and positive compliance

It was evident that provision of professional knowledge from clinicians to patients was perceived as a relatively one-way exchange by both clinicians...
and patients. Although it was seen as a means of eliciting understanding of the treatment plan, a key function of information exchange appeared to be to promote positive compliance and self-management by patients.

The notion of positive compliance, i.e. adherence to treatments, means a patient follows clinicians’ treatment prescriptions or nursing instructions. This perception was shared by most of the nurses and patients but was almost absent in the responses of doctors who mostly assumed that patients would comply with their treatment plans.

*It is mostly doctors who make the decision because many patients follow......After all, the doctors are professionals, but we will inform the patients, like this... patients usually follow doctors’ orders. (Doctor 1.2).*

From the nurses’ perspective, positive compliance appeared to be a core element of patient participation because they were working towards a mutually desired goal. They expected their patients to not only agree with prescribed treatments, but to do so having received information and having understood the significance of this information. One nurse explained patient participation in the following way:

*What’s more, patients are expected to collaborate with us actively in order to improve the treatment of their disease. We tell patients about the importance and significance of the things we are going to do to make them cooperate with us, in order to achieve a win-win goal for both of us. (Nurse_2.10)*

In the majority of patients’ responses, they emphasized the notion of participation as cooperating with clinicians to achieve their goals, by following clinicians’ advice, taking prescribed medicines or doing what they
were instructed to do. Many patients emphasized ‘cooperation’ only, while some pointed out it should be on the basis of sufficient knowledge and understanding.

*Interview:* What does patient participation mean and what’s your understanding?

*Patient:* I should comply with the treatment.

*Interviewer:* What types of activities do you participate in?

*Patient:* I do what he tells me... For example, they gave me advice about my diet and some notes, like not to touch cold water, then I cooperate with him through following the advice. He asked me to have some investigations and I did. (Patient_5.84)

I would listen to the doctors (follow doctors’ advice). If I must do it, I hope to have a deep understanding....... I will follow the doctor’s advice. (Patient_5.92)

*Patients should be informed of the current situation, the possible prognoses and ways to cooperate with the doctors.* (Patient_5.70)

v) Providing information about treatment or care to facilitate self-care

As well as medication management and nursing care, the necessity to provide patients with information of what to do to feel well was identified by doctors and nurses because they believed that patients could be involved in their own care when equipped with this knowledge. Nurses perceived information provision as a way of facilitating patients to care for themselves.

*We must encourage patients...we, especially nurses, must pay attention to patients, providing them with health education in a*
certain way to help patients be better involved in their self-caring.

Our nurses do a lot through health education. ..... We need patients to be involved more now, especially when dealing with the side effects of radiotherapy. (Nurse_2.10)

Patients also recognised the importance of information which provided opportunities for them to take care of themselves.

... she [the primary nurse] said I should drink more water, because I was thirsty. She taught me to wash my mouth with the gargle in the morning and evening. And also I had to brush my teeth, otherwise it would be inflamed. (Patient_5.103)

6.3.1.1.2 Self-knowledge transmitted from patients to clinicians

As well as the utility of transmitting knowledge of disease, disease progression and treatment held by clinicians, there was recognition of the value of the knowledge held by patients about their own bodies, their psychological status and their physiological responses to illness and treatment. The ‘self-knowledge’ transmitted by patients can be specifically about their symptom experience and responses or can be in the form of reminders and feedback for clinicians about their personal treatment plans.

i) Reporting symptoms in order to obtain treatment

Self-knowledge refers to subjective information about patients’ own symptoms or discomfort. Patient participation was understood by the clinician and patient interviewees as patients disclosing their symptom experience in order to inform treatment.

Patient: My understanding? It’s just to participate in my own situation.
Interviewer: What do you mean to participate in your own situation?

Patient: As I came here to see the doctor, I must tell the doctor and nurse about my symptoms and then ask them what I should do.

(Patient_5.56)

Doctors and nurses considered one of the characteristics of patients having a more active preference for participation was to report their symptoms and initiate questioning about their symptoms in order to obtain treatment.

In terms of patient participation, it is an interactive [activity] with patients. For example, if a patient has some distress or symptoms, he can tell us and then we respond to the problems in time...

(Doctor_1.56)

ii) Patient providing information as a reminder or feedback

Some perceived patients’ contribution in the clinical interaction as providing information to clinicians as a reminder or feedback. These reminders included information such as medication history, changes to medication prescriptions, planned investigations or results of investigations and so on.

Doctors asked for patients’ feedback of treatment effects and nurses asked patients to restate instructions to show whether the information delivered from nurses was understood by patients. The example below was provided by a nurse talking about a patient who she felt wanted to participate by reminding clinicians of his treatment and tests.

...... Whether patients want to participate, normally speaking, most [of the patients] want to be involved. For example......If the patient knows he has an injection or treatment [scheduled], he will ask us “Why haven’t you come to give me the injection? Why
hasn’t my blood test been taken? They actually know everything. (Nurse_2.4)

One patient described the important contribution in reporting their experience of care and treatment to clinicians:

Giving the example of drug administration, it is an interactive activity. The doctor and nurse should at least know the effects of the medicine such as the effects on pain control. As a patient, I should tell them I am sensitive to this medicine. Therefore it is a mutual interaction (Patient_5.153)

iii) Patients are the best source of knowledge of their subjective experience

Patients’ reports of symptoms or personal experience were regarded as a fundamental or even exclusive form of knowledge, as patients are the best source of knowledge of subjective experiences.

... We are not patients and we can’t really understand how hard it is to overcome any of their suffering, such as dry mouth or sore throat. (Nurse_2.10)

To participate in care, first of all, patients should speak out ...some things are impossible for the doctor to know, such as pain which is known by the patient himself. So the patient should cooperate with the doctor through speaking out (about his symptom or effectiveness of symptom treatment). (Patient_5.153)
6.3.1.1.3 Information sought by patients from sources other than clinicians

Although the primary source of information for patients was their doctors and nurses, patients also sought information about their illness and treatment from other sources.

i) Patients access multiple sources of information

Many patients talked about seeking information about their care and treatment and did so using a variety of different sources. Patients read instructions in the medication packing box when their medication was first dispensed to them (patients in this case study self-administered their medications during their admission). Some patients obtained information and skills from health brochures and posters in the hospital, read articles in books or magazines, or searched related information from the Internet. A few patients searched papers in academic journals, however, these patients often had a medical background. In addition to written sources, many patients sought information from others who had a similar illness experience or simply overheard patient examinations and discussions during their hospitalisation. When there was someone in the family or their social circle working as a health professional, patients asked for help from these family members or friends.

Patient: I think communication among patients is also very important. Like what drugs to take and what are the potential reactions to treatment

Interviewer: Do you mean the communication among patients?
Patient: Yes. They are involved in the process. I think it is also very important to know which kind of medicine they take when we have the same symptoms. (Patient_5.76)

...if I don’t know this, I would search it on the website which is a way to get knowledge or listen to other patients who have the same disease as me and ask them whether they have experienced it [a symptom]. (Patient_5.153).

Doctors and nurses acknowledged the utility of other sources and this information seeking behaviour was part of their understanding of patient participation.

If the patient considers himself to be a person with a sense of [personal] responsibility and to be very important for his family, he tries his best to look for a lot of information to read from the web, journals, books and any other kinds of media. (Nurse_2.10)

ii) Problems related to the use of other sources relate to the quality of available information

Seeking information from other sources was not always viewed positively by doctors and nurses who identified problems with the use of other sources that were related to the variable quality of the available information.

So I think Chinese patients have too little knowledge about this (medicine). Even if they read a lot on the web, the information online is not very accurate, is it? There are very few authoritative websites (in China) that could provide scientific knowledge to patients while there are some in foreign countries which are designed specifically to educate health professionals or patients. (Doctor_1.2)
In addition, other sources of information were also seen as a potential reason for increased demands by patients and potential for conflict.

*Those who want to be involved are likely to have more complaints and demands. They come to ask us for particular treatments, or come to consult us with data searched on the net, or elsewhere.*

*(Doctor_1.15)*

### 6.3.1.2 Negotiated decision-making can be achieved in various ways

Negotiated decision-making refers to decisions made through discussions between clinicians and patients. Decision-making was seen as another key activity during interactions that constituted participation. Clinicians and patients explained their understanding of participation in terms of the relative contribution from clinicians and patients in the process of decision-making. Four subthemes emerged: knowing options to make informed decisions, knowing professional opinions, knowing patients’ preferences, and making decisions.

#### 6.3.1.2.1 Knowing options to make informed decisions

To be involved in decisions relating to treatment and nursing care, patients need to be aware of available options. The majority of doctors and nurses stated that they would introduce to patients all the available treatments to create an opportunity for patients to make an informed decision. Over half of the patients expressed their desire to know the options available along with the advantage and disadvantage of each treatment.

*In most cases, patients are involved in......the discussion about their situations and their treatments, and involved in the choices*
of the treatments......and then there is discussion with them about some treatment options because sometimes there are several treatment options available. (Doctor_1.02)

... everyone’s situation is different... I would like to look for the one suitable to me. If there is more than one method, they might explain to me what the side effects of each are, and then I ...... according to my situation [made a decision].-(Patient_5.119)

6.3.1.2.2 Knowing professional opinions

Being aware of professional opinions was perceived as a form of participation in their treatment or care. The perception that clinicians have a role to present their professional advice for patients to consider was common among doctors and patients and some nurse interviewees mentioned the importance of presenting professional opinions. Professionals’ knowledge and experience–based advice was generally valued by participants.

I think that participation is important. But it doesn’t mean I know more than the doctor nor that they should obey me. What I mean is that they should share their knowledge with me. ... The doctor and nurse still play the main role. They should give me some suggestions and let me have the chance to make a choice. That’s what I want. (Patient_5.145)

I think, in terms of the treatment, patients might be able to participate in symptom care activities caused by the treatment
like radiotherapy. As to the cancer-related symptoms, it depends...... such as pain, for example, this kind of simple symptom. From my experience, I definitely always talk with them, in a way like “Does your pain influence your daily life, such as your sleeping. If not, that means your pain is slight, so I suggest you not take any medicine. But if you are in too much pain to fall asleep, then you have to consider whether to have painkillers.” (Doctor_1.15)

We talk to patients every day. During the communication, we get to know their current symptoms, like dry mouth, lack of appetite, nausea and vomiting, and we tell them the methods to deal with these symptoms. Some patients are glad to hear the advice while some refuse to follow the advice because they think all of the medications have side effects. So we tell them there are medications available to treat their symptoms and the doctors prescribe the medications according to the symptoms patients have during the ward rounds. (Doctor_2.10)

6.3.1.2.3 Knowing patients’ preferences

Patients, nurses and doctors all acknowledged that patients have a role in the management of their symptoms. They acknowledged both the positive and negative aspects associated with knowing patients’ preference for participation.

i) Patients’ preferences are important

Patients were perceived to be involved in their treatment or care when they presented their views and opinions to clinicians. Patients and clinicians
acknowledged patients’ rights and the need to value and respect patients’ preferences and views.

*Be sure to consider the patients’ views. When the patients propose [their opinions], the doctors should think over whether the patients’ opinions could be adopted.* (Patient_5.87)

It’s mainly because today, patients have a right to know. We are not able to replace their opinion... everybody has different opinions. The one (option) that you may think is good for you is not necessarily good for someone else. Some patients think surgery is a good option while others don’t want surgery. Some patients pay more attention to quality of life while others to the effects of treatment. Everyone is different... Therefore, different patients have different needs and expectations. You provide the treatments suitable to the patients (Doctor 1.2)

ii) Patients do not have the requisite knowledge to have a preference

Despite the value placed on patients’ preferences, there was also a shared belief that patients do not necessarily have the requisite knowledge or ability to have a preference.

*Yes. I took the doctor’s advice, and I did not have any opinions. Patients cannot have any opinions... I have no opinions about this. Since I am in hospital, everything is determined by doctors.* (Patient_5.1)

... if a patient has some knowledge about some aspects, he then might propose an opinion. The doctor might adopt the suggestion if it’s correct or feasible. If this opinion is incorrect, then the doctor should give some explanation to the patient. (patient_5.153)
The plan for his radiotherapy was a standard one which should last for six weeks. But he said, “No, I want to go home earlier. Can you please reduce the number of radiation treatments because my cancer is mild, could the amount of radiation be lower?” Therefore, his desire for participation is not scientific, just based on his own preference. We can’t respond to this kind of participation. (Doctor_1.15)

iii) Clinicians’ concerns with the consequences of patient participation

Nurses expressed concerns that patient participation may adversely influence clinicians’ judgements.

In terms of the treatment, I think patients should not participate too much. Because excessive participation could lead to interference with doctors’ decisions. .... Patients’ requests would obviously have an impact on a doctor’s judgement. For example, a doctor may have planned to prescribe a gargle [for mouth sores] but the patient said he wanted a [intravenous] drip, then the doctor might change his prescription. (Nurse_2.1)

Some nurses were less accepting of patients’ refusal to comply with advice or instructions. Two nurses in particular, talked about patients refusing clinicians’ prescriptions or suggestions, or not complying fully with their treatment or care. When nurses were asked about their attitudes towards patients’ refusal or less compliant behaviours, they acknowledged this may be a kind of patient participation, but appeared to disapprove of it.
Interviewer: Do you support this kind of participation in refusing advice?

Nurse: From my opinion, it is good for him to recognize his own current situation. But what we, doctors and nurses, hope is the same as the hope of patients, that is to say we all hope to improve their rehabilitation and relieve the side effects of radiotherapy and chemotherapy. (Nurse_2.10)

Interviewer: Is this a kind of participation when patients think it over then decide not to cooperate with you?

Nurse: ......I suppose it is participation. (Nurse_2.26)

6.3.1.2.4 Making decisions

There was recognition that making decisions is a normal part of the care and treatment trajectory for patients with a diagnosis of cancer. The nature, timing and person(s) responsible for making decisions described by participants were variable.

i) Patients are responsible for making their own decisions

Doctors and nurses reported the activity of decision-making as a significant attribute of patient participation. They stated that patients’ involvement could be in decisions about treatment methods or whether a medication or nursing intervention was needed. Some patients expressed the view that an ideal state of participation was that patients make the final decision after being properly informed. The following quotes are examples of ways patients can participate in decision making:
Doctors, anyway, are responsible for the treatment, but still have to let patients make the decision if there are options of treatment available. At least I never replace patients in making the decision. What I do is give patients advice, like which one is more suitable for them if there are two options. I tell them which one I think is better but it’s up to them and it is the patients who make the final decision. (Doctor_1.2)

Firstly, from the beginning of his admission, [patient participation] means a patient should be involved in knowing his situation overall. After some relevant examinations have been done, he can be involved in some way to make decisions about the choice of treatment methods (Nurse_2.10)

He (the doctor) might tell me there are several treatment methods available for me to choose and what results can be achieved with each method. After being told, I think over the options to decide which one I’d like to choose. The doctor might say each one is possible for me but the final decision should be left to me. (Patient_5.145)

Similarly but more strongly,

This is my own life. The only thing doctors can do is help me rather than make decisions for me. It is I who should make the decisions, just like I should be responsible for my health rather than the doctors… I believe when I am sick, the doctors can give me professional advice. Therefore, I think I should listen to their suggestions but leave the decisions to myself. (Patient_5.92)

ii) Who is eligible to make the final decision?
The context for this theme emerged largely, but not exclusively, in relation to decisions about treatment for cancer overall but provides an interesting perspective on the degree of participation during decision making where patients are considered competent to make decisions. Although patient involvement in decision making was acknowledged as a part of patient participation, there was conjecture about whether patients have the ability to make the so-called ‘final decision’ about treatment. Patients and clinicians often felt that once a decision was made to have their cancer treated, then the type of treatment and the treatment plan was essentially up to clinicians and, in relation to certain pharmaceutical products, there were few available choices in China. From nurses’ perspective, patients’ participation in decision-making was mostly about consenting to treatment rather than deciding which treatment to have.

Well, for example, I don’t know whether it is a correct example, the decision making of taking medication or not. This is the most basic one, isn’t it? To decide whether to take medication when there is a symptom occurring. But there is probably no way for patients to decide what medication to choose. (Doctor_1.15)

... a patient should be involved to get the knowledge of his comprehensive situation. ..., when we provide our nursing care, we are required to obtain the patient’s informed consent, including consent for a venepuncture which is traumatic or for an intravenous cannulation for medication administration. All of these kinds of procedures need consent [of patients] after our detailed introduction, which is one of the ways of participation. (Nurse_2.10)
The context in which care is delivered can remove treatment options simply because choices are not available.

(Sometimes) there is nothing they (patients) can decide because there are not many medications available to choose from in this hospital... there may be only one medication available ...one or two for each stage...there is nothing to choose. So patients usually follow their doctors’ orders. (Doctor 1.2)

Some patients were keen to present their opinions, however some indicated that they were more concerned with having the opportunity to have their opinions heard than actually having their views adhered to in a final decision. Many patients believed that it was beyond their capability to be involved in treatment decisions. Instead, patients held the belief that complying well with clinicians was the best way to participate.

In terms of symptom care, I think even if I participate in it, I am not sure my opinion is correct. The doctor might think what I can see is less than what he can see. I think the doctor’s opinion should be right. What I do is just provide my opinion.

Interviewer: So you want to take part in the discussion rather than the decision making?

Patient: Yes, only discussion. The decisions should be left to the doctors. (Patient_5.111)

Some patients however, when considering the medication management of their symptoms are less cautious about their role in decision making. The following examples relate to medication administration such as whether to take symptom-control medicine or what dose to take. Again, it’s important to
remember that patients in this case study were responsible for the self-management of all oral and topical medications.

*If I have constipation, I take it. When the problem is addressed, then I won’t take it the next day. I can make the adjustment by myself. Even though the doctor doesn’t tell me (to stop it), I’ll stop it because the goal has been achieved. Is that right? (Patient_5.145)*

*It might be too strict if the nurses dispense the medicines every time. They did it that way when I was in the hospital in Wuxi. The nurses did this three or four times a day. Sometimes the doctors prescribed more medicine than we needed. They prescribed more just in case. If I can administer it, then I can control the dose. I can decide by myself. There are instructions on the box. It’s I who have the symptoms and I have the personal experience. So I can make a small modification with more or less of the dose. (Patient_5.123)*

The role of family members was identified by clinicians in particular, to play a significant role in treatment decision-making.

*In China mostly...I am told by some family members that they are afraid to have any negative effects on the patient’s mood by telling the patient [about his/her malignant diagnosis or pessimistic prognosis], especially to those older people who were never told. (Doctor_1.2)*

*Nurse: We generally tell more to the families than patients, sometimes, especially to those families of patients who are very sick.*
Interviewer: In this case, was the patient happy for the family member to be involved in their symptom management?

Nurse: The situation in China is different [from western countries]. It's the Chinese family members who make the decision about whether the patients should know (their prognosis) rather than whether the patient wants to know (their diagnosis)…. They [patients] know they have got cancer but they are kept from the severity [stage of the cancer]. This is especially for patients whose cancer has metastasized. They are not informed of the truth. (Nurse_2.10)

6.3.1.3 Patients’ self-management is perceived as patient involvement

While patients and clinicians acknowledged patients’ unique role in self-care based on their knowledge of their own bodies and circumstances, patients were clear and keen to take charge of aspects of their care that they felt was their responsibility.

6.3.1.3.1 Patients responsible for their psychological status

As well as symptom treatments and care, there were other areas where patients were recognized as having an important role. In particular, they regarded managing psychological distress as a personal responsibility. They talked about the necessity to adjust mentally and adapt to the many changes associated with being diagnosed with their disease.

They (psychological problems) are private, in the mind, and something that can be regulated by myself. (Patient_5.87)

Patients’ psychological status was also raised by doctors. The discussion during the interviews, however, indicated that the doctors did not always have
the time to address patients’ psychological issues thereby making the patient responsible for managing this as the following conversation highlights:

Doctor: What is lacking here is social workers who can chat with the patient to improve his emotional symptoms. We doctors have the ability to judge what causes his symptoms, whether that is really related to his disease or treatments, or any other mental factors. However, we can’t pay much attention to the mental-related symptoms and we can’t give them enough explanations because there are indeed too many patients suffering from mental distress in real life.

Interviewer: Do you mean there are too many patients with this problem to pay attention to?

Doctor: Yes, too many indeed. And if you explain to him once, then he will have another problem because he can’t get rid of his anxiety and panic.

6.3.1.3.2 Patients are in control of their own diet or life style

When asked what activities patients could participate in, some patients indicated that they were keen to participate in the activities related to healthy diet and life style. Some patients emphasized choosing what to eat was in the scope of their own control when they were admitted to hospital.

My understanding of patient participation, I think, I have the ability to participate in my diet…….For example, a patient gets the symptom of losing taste, that he feels no taste when eating. Then he tries to eat something with a heavy taste for breakfast. We will lack energy if we don’t eat anything. Man is iron and food is steel. (It’s a popular Chinese saying.) I agree with that. (Patient_5.111)
One doctor and four nurses shared the importance of nutritional diet and recognized through daily communication that patients were mostly concerned with what they could eat.

*The question asked most [by patients on the ward] is, “Can I eat this? Can I eat that?” (Doctor-1.15)*

*When patients have symptoms like vomiting or nausea, they or family could participate in the care related to diet. Patients are mostly lacking in good nutrition during chemotherapy or radiotherapy. If they participate [in their diet care], they become responsible for eating something with more nutrition... diet is the aspect patients most desire to be involved in. (Nurse_2.01)*

### 6.3.1.4 Summary

What emerged through the analyses is the shared understanding that patients and clinicians have mutual and distinctive roles in symptom care and treatment. Both patients and clinicians considered information exchange was key to patient involvement, in which professional knowledge and patients’ self-knowledge is transmitted and that patients have access to information from sources other than clinicians. Patients could be involved in negotiated decision-making by being informed of options, knowing professional opinions, presenting their preference and making decisions. Other self-management activities, such as adjusting psychological status and controlling their own diet or life style, were also perceived as ways of patient involvement. Patients, as well as doctors, expressed concerns that patients may not have the requisite medical knowledge to present a preference. Nurses in particular held concerns of the consequences of patient
participation in that participation might interfere with clinicians’ work. Most of the nurses and patients believed that participation meant patients comply with treatment and care whereas doctors seldom mentioned compliance *per se*. Despite the general consensus that patients should be responsible for making their own decisions, there were shared views that patients may not have the requisite knowledge to make final decisions in areas related to treatment and symptom management.

### 6.3.2 Reasons given by patients for their preferred roles

In the previous section, patients’ understanding of and attitudes towards participation were explored. In this section the rationales that patients provided to explain the reasoning behind their most preferred control preference, explored during the semi-structured interview are presented in order to expand our understanding of participation. Responses to this question were analysed through content analysis. The three themes identified were: the importance of information exchange, the importance of negotiated decision-making and personal/professional role expectations. These themes were largely congruent with patients’ understandings and attitudes towards patient participation presented in the previous section. The new theme that emerged from this analysis related to who is responsible and accountable for making decisions.

The content analysis of the reasons identified by patients according to the number of patients within each preference group are displayed in Table 6.5. While there were small numbers in each group, for the purpose of this
analysis, a reason was considered to be shared by most of the patients with a certain preference when all or almost all (90% or more) of the patients in the group reported a particular reason for their control preference. The numbers in categories where the shared understanding threshold was considered to have been reached are in bold.

Table 6.5 Patients’ reasons for selecting a particular control preference according to control preference group (n=41)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub Theme</th>
<th>Control Preference</th>
</tr>
</thead>
<tbody>
<tr>
<td>The importance of information exchange</td>
<td>Professional knowledge transmitted from clinicians to patients</td>
<td>10 20 5 1 0</td>
</tr>
<tr>
<td></td>
<td>Self-knowledge transmitted from patients to clinicians</td>
<td>6 20 5 2 1</td>
</tr>
<tr>
<td>Decision-making is a process that involves both patients and clinicians</td>
<td>Knowing options</td>
<td>0 6 2 0 0</td>
</tr>
<tr>
<td></td>
<td>Knowing professional opinions</td>
<td>2 7 2 0 0</td>
</tr>
<tr>
<td></td>
<td>Knowing patient preferences</td>
<td>2 22 4 2 0</td>
</tr>
<tr>
<td>Who is responsible and accountable for making decisions?</td>
<td>Doctors take responsibility for decisions made</td>
<td>10 6 1 1 0</td>
</tr>
<tr>
<td></td>
<td>This is my life</td>
<td>0 4 2 1 1</td>
</tr>
</tbody>
</table>

The exchange of professional medical-technical knowledge from clinicians with patients’ knowledge of themselves was viewed by the majority patients,
irrespective of control preference, as important. Patients described clinicians as being qualified, having the professional knowledge and the responsibility for all their treatments and care. While patients did also comment on their self-knowledge in making decisions it is important to note that patients who selected a passive Control Preference appeared to put more emphasis on professional knowledge than their own knowledge when making decisions about their symptom management. For example,

_Well, I think I have no knowledge about the treatment he gave to me and I am not the authority on it, I have not learned about it before._ (Patient_5.76, Passive preference)

Patients with a passive-shared or collaborative preference appeared to weight their knowledge of self and clinicians’ knowledge more equally. Patients with these preferences also talked about the decision-making process as involving both patients and doctors. Patients in these two preference groups acknowledged that although clinicians had more professional knowledge they (clinicians) also valued their (the patient’s) own knowledge. The preference of expressing their own opinions was emphasized when they explained their reasons for their control preference.

_I think I might talk with the doctors about my situation. After our talking, he could... prescribe me some medications or something else......Doctors are certain (about their decisions), so as a patient, we should listen to the doctors’ suggestions mostly._ (Patient_5.131, passive-shared preference)
The doctors and we consider both opinions and have a discussion together... A negotiation should be made according to everyone’s situation. What I can do is to negotiate because I have no knowledge how to deal with it and what the result is going to be. (Patient_5.145, collaborative preference)

The distribution of patient responses presented in Table 6.5 together with the reasons patients expressed for choosing a particular control preference support the data about understandings of and attitudes towards patient participation that were presented in Section 6.3.1. The notion of responsibility and accountability for decisions also emerged from the analysis of data regarding why patients selected a particular Control Preference. Patients’ responses that support this theme indicate that it may be a key motivator driving patient preference for participation. The following quotes provide examples of how patients with a passive, active-shared and active preference described the notion of responsibility and accountability in decision making:

Since [I chose to come] to the hospital, everything should be up to the doctor. (Patient 5.76 Passive)

This is my own life. What the doctors can do is only help me rather than making decisions for me. It is I who should make the decisions, just like I should be responsible for my health rather than the doctors. I believe when I am sick, the doctors can give me professional advice. Therefore I think I should listen
to their suggestions but leave the decisions to myself. (Patient_5.92, active-shared preference)

I prefer to make the decision by myself because there is no one else I can rely on in this hospital. (Patient_5.70, active preference)

Patients shared rationale for selecting a particular control preference even though they preferred different participatory roles. These rationales were related to information exchange, negotiated decision-making or role expectation. There were, however, differences in the proportion of patients in each Control Preference group who described particular reasons for their preference; some reasons appeared to only be identified by patients with certain preferences although the numbers in each group are small. Patients who expressed a passive control preference talked about their dependence on health professionals and this was quite different to the way patients in the other preference groups expressed their rationales for their preferences. Those who wanted to be involved in their treatment and care (passive-shared, collaborative) shared the belief that they not only valued the knowledge and opinions of health professionals’ but also their own knowledge and preferences. Despite the very small number of patients in the active-shared or active preference group, the three patients valued their own knowledge and opinions and believed that they had responsibility for their own lives.
In summary, the data suggest congruence between patients in their understandings of and attitudes towards participation in terms of information exchange and decision-making. A new theme related to who should be responsible and accountable in decision-making emerged in these data. This finding provides insights into how patients may understand their role during an episode of admission.

6.3.3 Factors influencing patients’ participation in symptom management

In this chapter, findings related to patient, doctor and nurse perceptions of and attitudes towards patient participation together with patients’ reasons for selecting a particular Control Preference have been presented. The analyses thus far has revealed similarity and variability both within and between each participant group and that the way participants describe participation is congruent both in descriptions of their understanding of participation and when discussing reasons for selecting their most preferred role.

The purpose of the next section is to explore what participants perceived were factors that impacted on patients’ actual participation in symptom management. These factors were investigated in the patient survey as well as in more detail in the semi-structured interviews with patients, nurses and doctors. In the survey, patients were asked what, if anything, made their participation in symptom management difficult or easy. Patients were given
four possible response options as well as the ability to write about anything not listed.

During the individual interviews, the factors patients, doctors and nurses perceived made it either easier or more difficult for patients to participate in their symptom management in the acute care setting were explored. Doctors and nurses were further asked their awareness of family members’ involvement and of any organisational policies regarding patient participation. There were not specific questions related to families’ involvement in the patient interview guide, however if patients talked about their families in this context, they were asked further questions about their preference for their families’ involvement.

Forty-six out of 140 patients (32.9%) in the survey reported they had experienced difficulty in participating in symptom management. Table 6.6 presents the number of patients who identified barriers or facilitators to their participation. This was a multi-response question because it is possible that more than one of the options influenced patients’ ability to participate. Time available with clinicians was considered by many patients (n=96, 68.6%) as a factor influencing their participation. Only two patients recorded a factor other than the four listed. Both factors were barriers to participation. More specifically, one was related to their perceived communication ability ("I’d like to communicate but there are many things I don’t know how to ask.") and the other was familiarity with the ward ("Not familiar with the ward surrounding").
Table 6.6 Patient reported factors impacting on their ability to participate in symptom management in the patient survey (n=140)

<table>
<thead>
<tr>
<th>Factors (multiple response)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not enough time with clinicians</td>
<td>96</td>
<td>68.6</td>
</tr>
<tr>
<td>Information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having sufficient information</td>
<td>64</td>
<td>45.7</td>
</tr>
<tr>
<td>Memory</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to remember information provided</td>
<td>30</td>
<td>21.4</td>
</tr>
<tr>
<td>Perception of how well they feel</td>
<td>47</td>
<td>33.6</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>1.4</td>
</tr>
</tbody>
</table>

The five themes and related categories of the factors identified in participants’ perceptions of patient participation derived from the semi-structured interviews are presented in Table 6.7. The data supporting each theme are presented in the following five sections according to theme.

Table 6.7 Themes, subthemes and categories of patients’ and clinicians’ perceptions of patient participation in symptom management

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication-related factors</td>
<td>Comprehension</td>
<td>Comprehending medical information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Comprehending language -Impact of dialects</td>
</tr>
<tr>
<td></td>
<td>Opportunity for communication</td>
<td>Time available for communication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Characteristics of clinicians’ Available time/energy of clinicians</td>
</tr>
<tr>
<td>Symptom severe</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Establishment of rapport</td>
<td></td>
<td>Empathy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Concern</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encouragement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Familiarity</td>
</tr>
<tr>
<td>Decision-related</td>
<td>Patients’ medical-</td>
<td></td>
</tr>
</tbody>
</table>
### Factors Related to Technical Knowledge

| Role expectations | Trust in clinicians  
|                   | Patients are responsible for themselves  
|                   | Fear of bothering clinicians  
|                   | Fear of challenging clinicians’ expertise  
| Symptom severity |  
| Availability and provision of options |  

### Family-related Factors

| Family roles | Family as Spokespersons  
|             | Family as care providers  
| Preference for family involvement can vary |  

### Peers-related Factors

| Sources of information |  
| Patient activators |  
| Promote self-management |  

### Organizational Policies

| Informed consent |  
| Patient education |  
| Self-care monitoring |  

### 6.3.3.1 Communication-related factors

Communication-related factors were viewed by patients, nurses and doctors as potential barriers or facilitators to participation. Four key subthemes emerged from the analysis: comprehension, opportunity for communication, symptom severity and rapport.
6.3.3.1.1 Comprehension

When talking about communication between patients and clinicians during treatment and care, patients’ capability to understand the information that was communicated to them was acknowledged by doctors, nurses and patients as a barrier to information exchange. Patients’ limited comprehension was one of the most commonly reported barriers by doctors, nurses, and patients. Doctors reported that they tended to provide more information to those patients whom they perceived to have the ability to understand the information.

*The patient stood beside me and he tried to repeat what I told him only five minutes earlier. I heard the wrong meaning from him. ……To some patients, the more you tell them, the more confused they are. So I’d rather speak as little as possible (to them). (Doctor_1.02)*

*They [doctors] just gave us a few words [treatment or disease information]. It might be due to our limited capability of understanding because some professional knowledge was beyond our understanding. (Patient_5.145)*

Patients in the case study were from various parts of China. Clinicians found some patients, especially older patients, could only speak their local dialect and some could not understand Mandarin, which is China’s official language. This created a barrier to communication between patients and clinicians. Patients also expressed concerns about the impact that dialect can have on understanding medical information.
Language [dialect] could also be a barrier [to communication]. It could be. [Some patients] don’t speak Mandarin. We don’t know their dialect and they don’t understand ours either. (Nurse_2.16)

The difference between dialects and Mandarin could lead to some misunderstandings. (Patient_5.123)

6.3.3.1.2 Opportunity for communication

Opportunities for patients to communicate with nurses and doctors was identified as a precondition for participation. Doctors and nurses also described their efforts to provide opportunities to talk or discuss care with patients in clinical practice. Medical or nursing ward rounds in the morning were identified as the most important occasion for communication, especially with doctors, however due to the nature of nursing work patients had greater opportunities to communicate with nurses through hourly rounding and the monthly patient education seminar held on the ward.

Patient engagement can be facilitated in some occasions. One is the enquiry of patients’ medical history during the morning ward rounds and another one is the conversation before or after a treatment during the admission. Before we start a specific treatment, we always have a special (formal) conversation to inform them. All these activities contribute to the active involvement of patients. (Doctor_1.56)
I think the seminars... might have an effect on symptom relief because some health education on the ward can be provided to patients through them (Doctor 1.5)

First of all, I usually go into a patient’s room for the purpose of an inspection, and then...I ask my patients whether they have had any reactions after the treatment, including effects on their sleeping, diet and any other possible side effects. Then these patients are willing to tell me all of the problems they have. So I think ward rounds in the morning are very essential. Even though some patients don’t have any symptoms, I still show my concern to them. I asked a patient, “Did you sleep well last night?” “Have you had your breakfast? What did you eat?” Then the patient told me he was good except for a little bit of dry mouth. (Nurse_2.10)

Patients also acknowledged the frequent enquiries from clinicians, especially during the morning ward round. Most of the patients said they would report to clinicians directly about their discomfort when they were asked.

If we have any symptoms, they would ask us and we also would tell them. (Patient_5.118)

When the clinicians were asked what prevented them from helping patients to be involved, some nurses admitted they were not always happy to talk with patients. For example, two nurses reported that they were not always in the frame of mind to interact with their patients. In these circumstances, they would have as little contact with their patients as possible.

Sometimes, it’s impossible for me to keep an enthusiastic mood every weekday. When there was something influencing my mood, I had to slow down that day and tried to keep myself away from
communicating (with my patients). I wore a gauze mask because of my unhappy facial expression. When the patients asked me any questions, I told them I had a sore throat. That day, I tried my best to communicate with patients as little as possible.
(Nurse_2.10)

Patients also acknowledged that not every clinician had the patience to talk with them. Some could perceive that a clinician may be unhappy or perhaps reluctant to communicate and this reluctance could be a characteristic of a clinician’s personality. However, most patients attributed poor communication to the few opportunities available for them to talk with clinicians, especially with doctors.

I wish that we could have the chance to talk to our doctors not only during the ward rounds. I wish they could come more frequently to (ask about our situation), (now) having a ward round only once a day (is not enough) (Patient 5.84)

Clinicians’ responses to questions or information volunteered by patients were capable of stopping any further inquiry. Any iteration of a clinicians’ response such as “that symptom/problem is normal” was seen as a way of immediately putting an end to an interaction. As one patient said:

The nurse told me to have more rest and eat more red food [Red bean and peanut skin have the effect of increasing erythrocyte count] but the doctor answered me in a very general way. So I had no opportunity to ask more. He used one sentence to keep you away. It would be the same if in a situation when I say I want to come in [into the doctor’s office] he were to say, “No, you can’t.” Then there is no reason for me to ask about getting in again...(Patient_5.111)
Lack of time and/or energy were considered by both clinicians and patients as factors that limited clinicians’ availability for patient-clinician communication. The phrases “lack of energy”, “feel too tired” or “feel exhausted” were reported in the interviews.

_Honestly, doctors currently don’t have much patience. I used to try to spend longer times talking with patients, but I felt too tired. If I spend half an hour or 40mins to talk with each patient, no one could not understand it (an explanation), as long as you give him enough explanation. I could do nothing indeed when facing such a large number of patients. Sometimes it’s just to say... sometimes... it’s too hard for me. I once gave a consultation to a surgical patient. After I spent more than an hour to talk with him, he finally got a very clear understanding. But I did feel exhausted after spending so much time with such a patient. …… Generally speaking, I spend less than 10 mins on an explanation or communication._ (Doctor_1.5)

Nurses also reported the need to prioritise due to their workload giving priority to tasks such as intravenous or subcutaneous medication administration or other nursing duties which reduced the time available to communicate with patients.

_Because I think there is not much time for us to spend in the ward room. We have to stay here (in the Nursing Station) dealing with medical orders and reading documents._ (Nurse_2.12)

Patients also recognized the heavy workload of clinicians and showed their understanding.

_Because they are too busy. I have been to their office several times and found they were not in._ (Patient_5.16)
But you have to understand the fact that there are too many patients and it’s impossible (for clinicians) to give an explanation to everyone, isn’t it? It’s impossible indeed. (Patient_5.89)

6.3.3.1.3 Symptom severity

Doctors, nurses and patients all recognised that patients did not report all the symptoms they experienced to clinicians. Patients’ experience of a symptom, specifically, its severity, was deemed to be a factor that influenced whether it would be reported.

When a patient has the problem of diarrhoea with the frequency of four times a day, he might think it doesn’t matter even though the symptom is not a normal one. But when he has diarrhoea ten times a day, he then would report it to his doctor. So I think their participation has something to do with the severity of their problems. (Nurse_2.23)

Another reason is the severity. If it is slight, we would not suggest that the doctor should deal with it. But when I have a severe pain, I might (ask for) a painkiller. (Patient_5.124)

6.3.3.1.4 Establishment of rapport

Rapport between patients and clinicians was described as a facilitator to patient participation in their care. Rapport was often described as being built by clinicians showing empathy and concern to their patients.

If you valued him (a patient), he would pay more attention to himself. (Nurse_2.10)
This perspective was confirmed by some patients. One patient reported that her doctor was “a good doctor” after experiencing what she described as “empathy and encouragement” (Patient_5.92). Another patient appreciated clinicians’ seriousness and commitment and defined this characteristic as one of the elements of “cooperation” (Patient_5.123). A number of patients did however, describe experiencing what they considered was a lack of care or concern from their doctors and nurses. Some patients indicated when they reported a symptom to their doctor but got no response, they were not confident enough to report it again. 

_I think... I find it seems doctors and nurses don’t care much about my symptoms. Is that because this kind of symptom always comes with radiotherapy? For example, all of my discomfort is considered by them as a normal reaction. I don’t’ think they care about it. I guess they will not pay attention to us unless we keep on telling them we feel uncomfortable._ (Patient_5.133)

Some patients found it difficult to build rapport with their clinicians because they did not know which RMO or primary nurse was responsible for their care due to the high frequency of doctors’ rotation and nurses’ shift changes. This lack of familiarity or knowledge of who to contact acted as a barrier to patients’ willingness and opportunity to participate. This was confirmed by a doctor and a nurse who recognised that familiarity with the staff and ward surrounding could influence patients’ involvement in their treatment or care.

_I’m just thinking it’s too rough sometimes... I am not familiar with this place and I don’t know the doctors well, so sometimes I don’t dare to speak out, and don’t want to say._ (Patient_5.131)
As to the facilitators, after the policy of ‘resident doctor in charge’ was implemented, it is easier for patients to ask questions to their residents ... whether patients can find the doctor (who is in charge of their care) is a key factor. Because there are interns, training doctors, it’s hard (for patients) to know who is responsible for them. (Doctor_1.34)

6.3.3.2 Decision-related factors

Making decisions or choices is one of the most commonly understood components of patient participation in healthcare. Four key categories that impact on participation in decision-making were identified. These were: patients’ medical technical knowledge, role expectations, symptom severity, and availability and provision of options.

6.3.3.2.1 Patients’ medical-technical knowledge

From patients’ perspectives, a lack of medical-technical knowledge was the largest barrier to participating in decision-making. Previous experience with health care was perceived to make participation and sharing their opinions during conversations with clinicians easier for patients, with the inverse also being true.

Interviewer: In the case of the injection to increase your white blood cell (WBC) count, you would prefer to be involved in it because you have a little knowledge about it?

Patient: Not only a little. It is because I have received the injection many times and I am quite familiar with the side effects after the injection. During the chemotherapy, there was a longer time between two courses for all the WBC to recover. For me the WBC
count would increase gradually when I had some dietary supplements at home. (Patient_5.118)

Taking the example of medication treatment or symptom control, what I know is surely not enough. I have no ability to make a decision, (because) I don’t know what I should do. Therefore, the degree I want to participate is not the same as the degree I actually participate. (Patient_5.60)

From clinicians’ perspective, they felt that many patients were not able to participate in treatment decisions because they lacked medical-technical knowledge or they were not sufficiently or accurately informed.

It is because most of the patients don’t have professional knowledge on this aspect. They have no idea. [Even though] we would explain to them about the treatment, they usually have low degree of participation. They actually don’t know. What they can do is only tell doctors how they feel, however as to the specific treatment…. (Doctor_1.56)

The explanation provided by doctors about his illness and the education provided by our nurses [both have an effect on a patients’ participation]. In the example of Hirudoid, if I didn’t explain it to him adequately, his level of involvement might be affected. He would have no knowledge about the cream and would keep on leaving it aside. (Nurse_2.23)

I think the patients in China have no ability to do this, (because) they have little medical knowledge. Sometimes I talk to them a
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lot and then let them repeat it right back. I find what they say is not what I told them. They misunderstand it. (Doctor_1.2)

6.3.3.2.2 Role expectations

There was variability in patients’ attitude towards and understanding of who had the ultimate responsibility for making treatment and care decisions. This expectation of who is responsible influenced patients’ perceived role in decision making. Trust of clinicians’ expertise and patients’ desire to take responsibility for their health were both described.

Almost half of the patients expressed their trust in clinicians. They believed it was clinicians’ role or duty to deal with their problems and to make decisions for them not only because of clinicians’ medical knowledge but also because of their professional commitment. One of the patients who espoused this belief said:

(I would like to leave all decisions to doctors) It’s because I think I should hand myself over to the doctors and trust them, since I am here. (Patient_5.103)

A minority of patients also discussed their preference for taking responsibility for their own health and health outcomes. One patient’s response:

This is my own life. What the doctors can do is only help me rather than making decisions for me. It is I who should make the decisions, just like I should be responsible for my health rather than the doctors. (Patient_5.92)
Fear of bothering clinicians was expressed. Patients were concerned that their demands would trouble doctors or nurses and as a consequence of this belief their willingness to report symptoms was impacted.

*Interviewer:* When the pain occurred to you, what did you do? Did you tell your doctors or nurses immediately?

*Patient:* No, I didn’t. I tried not to bother them.

*Interviewer:* Do you understand why you have to take this medicine? Why did the doctors prescribe you the anaesthetic sedative agents rather than a general painkiller?

*Patient:* The doctors must have more experience in this field. Since some do not like to say more, why should I have to ask them more questions? (Patient_5.44)

*Interviewer:* Did you talk with your doctor about your withdrawal [stopped self-administering a medicine]?

*Patient:* No, I didn’t. Since I got well, why did I need to talk with them? I didn’t have to. If I had said something, they would have found it troublesome. (Patient_5.123)

Nurses also acknowledged that patients were reluctant to report symptoms so that they did not bother the doctors as highlighted in the following quote:

*[When a patient had diarrhoea] There might be one or two times in the morning. It probably happened before. So he did not think he had to report it to the doctor. He thought this [reporting his slight diarrheal] would trouble the doctor. He thought he must not trouble the doctor. If he did, the doctor would dislike him. If (the doctor) disliked him, he would be in trouble. The patient would think like that. Probably it is not exactly the same, but I understand patients would have such a thought. (Nurse_2.56)*
Some patients also described a reluctance to talk with doctors about their symptom or treatment because they did not want their opinions to be regarded as a challenge of their doctor’s expertise.

_Interviewer:_ Why did you finally follow your doctor’s advice?

_Patient:_ “...it is difficult to communicate with the doctor. As he is the doctor in charge of me, there are many things I can’t talk to him about, because [if I do], I am challenging his authority. But I think I can discuss things with other doctors [who are residents or interns].” (Patient_5.102)

6.3.3.2.3 Symptom severity

Symptom severity again was a potential barrier to decision making. Both doctors and nurses indicated that when patients are acutely unwell they may prefer not to participate. There was also the perception that patients who are too sick might not be capable of making sound decisions. In these circumstances doctors and the patients’ family members would make medical decisions for them.

_I think, most of them, if their situation is not stable [they are in an advanced stage or have severe symptoms], do not want to participate, because many patients are very negative (in mood)._ (Doctor_1.15)

_When a patient can’t eat food (because of lack of appetite or difficulty swallowing), if this symptom is not very severe and the outcomes of examinations are not bad, we would follow her preference [the patient might not want to get any additional_
nutraceutical]. If her nutrition indicators, like albumin count are very low, we definitely would not listen to her [follow her opinion].

Interviewer: What do you mean “not listen to her”?

Doctor: It means if she is obviously suffering from malnutrition and can’t eat anything, she must have an intravenous infusion (for diet supplements).

Interviewer: Even when the patient doesn’t want to?

Doctor: She still has to. (Doctor_1.34)

Especially when they [patients] get severe side effects during the treatment of chemotherapy or radiotherapy, they need more time to rest. For example, the patients got tired or irritable when we asked them to conduct the nasal douche or talked with them a bit more [the patients would not be willing to talk or administer the self-care]. Yes, the symptoms they get are one of the factors (of their participation). (Nurse_2.10)

6.3.3.2.4 Availability of options

During patient and clinician interactions, the availability of more than one option and the communication of all options by clinicians were described as factors that facilitated opportunities for patients to participate in making decisions.

The doctors stated that before a decision was made they should inform patients as much as possible and give patients opportunities to express their preference or opinion. When there was only one option then clinicians
Chapter 6 Perceptions of patient participation in symptom management (Part II)

described making the decision on behalf of the patient. Patients described the same scenario.

*Interviewer: Do you generally provide the options to patients?*

*Doctor: Yes, we …… we do. Yes. Unless in the case where there are no more options available, we tell patients (about the treatment) directly. If there are options available, we should definitely tell them.* (Doctor_1.2)

*B because there is only one treatment method, I have no way to choose. If there are several methods available, I definitely want to participate in the decision. But now there is only one.* (Patient_5.119)

Some patients indicated that even when more than one option was available, their doctors did not give them the opportunity to choose between them. Instead, the decisions were made by doctors according to the treatment routine in the hospital and doctors’ own preference or experience. One patient talked about choosing a skin protection medication:

*There must be some [options of skin protection methods to use]. However, we [patients in this patient’s room], have no choice. Other patients [in other rooms of the ward] all use this kind of ointment. Before I came here for radiotherapy, the doctor in my own hospital recommended some ointment to me. A nurse here also mentioned this ointment during their health education. However, the doctor who is currently responsible for my care and treatment thinks it’s ineffective, so she never prescribes this ointment to her patients.* (Patient_5.70)
6.3.3.3 Family-related factors

Chinese cultural influences and the need for family/friend support during an inpatient admission meant that it was important to explore family related barriers and facilitators to patient participation. The data in this section includes patients’ responses to the survey component as well as in-depth responses elicited from patients, nurses and doctors during the semi-structured interviews.

In the survey, patients were asked about their preference for and actual involvement in symptom management of their support persons and the findings are displayed in Table 6.8. Four questions were asked. One hundred and eleven (76.7%) patients preferred to discuss decisions with their family members prior to making them. Partners who were husbands or wives were the persons who most of the patients (n=92, 87.6%) wanted to discuss decisions with. Approximately one-third of patients indicated that the absence of family members when decisions needed to be made was a barrier to participation. Three patients described reasons other than those listed as their experience with support persons in decision making: Families could not help at all because the doctor had said the symptoms were a normal reaction; the carer was busy with his job, housework and child caring; and there were differing opinions between the couple.
Table 6.8 Patients who preferred involvement of support persons in decision making (n=145)

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>(%)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patients who wanted to discuss decisions about their symptom management with a family member/friend prior to making a decision.</td>
<td>111</td>
<td>(76.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Who did the patient want to involve (multiple response)(^{\wedge})</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partner</td>
<td>92</td>
<td>(63.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>24</td>
<td>(16.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>17</td>
<td>(11.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other*</td>
<td>11</td>
<td>(7.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Was the patient able to involve their support person as much as they wanted?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>2</td>
<td>(1.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>14</td>
<td>(9.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most of the time</td>
<td>20</td>
<td>(13.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>As much as I wanted</td>
<td>75</td>
<td>(51.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. What factors impacted on the patient’s ability to involve their support person as much as they wanted? (multiple response)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) ‘Support person’ not present during medical rounds</td>
<td>30</td>
<td>(33.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) ‘Support person’ not present when decisions need to be made</td>
<td>33</td>
<td>(37.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Not being able to remember all the information to tell the ‘Support person’</td>
<td>35</td>
<td>(39.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Having to make quick decisions</td>
<td>30</td>
<td>(33.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Not being given the opportunity to discuss the decision in private with your ‘Support person’</td>
<td>13</td>
<td>(14.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Other</td>
<td>3</td>
<td>(3.4)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Other included friend, grandson, maternal uncle, niece, daughter in law, brother in law

According to the responses in interviews, almost all of the doctors and nurses acknowledged family members’ roles in interactions between patients and clinicians and in making decisions. Clinicians found families played an active
role as patients’ spokespersons during information exchange and helped patients with their daily care.

Some patients might feel itching on their body which is probably a side effect of the medication. Patients might not be able to see their body rashes but their family members can. Then families and patients can report the symptom. Patients talked about their subjective feelings, like the degree of itching and families supplemented the information by talking about the rash site, broken skin or flaking skin. (Doctor_1.56)

There is an example in Bed 18 ... the patient who has a colostomy and metastases to his lumbar, brain and cervical vertebra. He has to lie in bed all the time and is taken care of by his wife 24/7. ......The patient has to have an infusion of a biological target medicine every week and bone inhibition medicine once a month. Because these medicines are all out-of-pocket, and are bought by his wife outside the hospital and brought to us, the doctor always forgets to prescribe them. So his wife reminds me and the doctor actively every week. She also reminds us of the time of her husband’s PICC (Peripherally Inserted Central Catheter) maintenance. (Nurse_2.23)

Some doctors and nurses described their practice of informing families of their patients’ diagnoses or illness situations and involving families in making decisions together with patients. Clinicians also discussed circumstances whereby families kept bad news, such as the cancer diagnosis and/or the stage of the disease including presence of metastases, from the patients. When families received disease and or treatment related information it was up to family members whether they disclosed this information. Clinicians
perceived that most patients accepted the involvement of their family members.

_Interviewer: Did patients realize their family members made many decisions for them?_

_Doctor: Yes, they knew._

_Interviewer: Were they happy with that?_

_Doctor: Generally, they were happy with that, at least they accept it (that family members made decisions for them). Because these family members usually are direct relatives who mostly take care of the patients all the time or are already the person making decisions in the family. (Doctor_1.56)_

_In the example of the patient in Bed 12, the patient was diagnosed with brain metastasis. When I got the result of the MRI, I talked to his wife instead of the patient himself, because I didn’t know whether his wife would tell him the truth and I was afraid to place too much stress on the patient. So on this occasion, we talked to the family member first and it was up to her whether to tell the patient. (Nurse_2.23)_

One nurse noted that families’ involvement was not always approved of by patients as sometimes patients and their families had different opinions related to symptom treatment.

_There was a patient who was unhappy with his family member’s involvement. His family member told me the patient had some symptoms and asked me to give the patient some medicines, but the patient said he was fine and he did not want to take that medicine. (Nurse_2.25)
While clinicians accepted the role of families and did not appear to challenge the decisions they made about disclosing information to the patient, there were some patients who reported not wanting their family members to be involved in care or decision-making. Patients talked about wanting to make their own decisions and not wanting to trouble family members with symptom issues.

*Patient:* I was afraid... that I would not have a reconstruction, or something else. So I hoped to make the decision by myself. I didn’t let my husband and cousin know of my surgery before I signed.

*Interviewer:* So if you have a symptom, you will report it.

*Patient:* Yes. I might not tell my family or friends, but I absolutely tell my doctors. I hope I am the first person who gets the answer. (Patient_5.92)

*Interviewer:* Was your family member involved?

*Patient:* No, my family member... didn’t have to.

*Interviewer:* You said your son was a doctor, wasn’t he?

*Patient:* Yes, but these things... these things [deal with symptoms] he did not participate in, I didn’t want him to participate in these things. (Patient_5.1)

**6.3.3.4 Peer-related factors**

The influence of peers on patient participation was a clear theme that emerged from the responses of both nurses and patients. Patients in the same room or neighbouring rooms usually had the same cancer type and similar treatment regimens, hence they usually experienced similar symptoms. Some patients stated they actually had more communication
with their peers from whom they got to know more about the cancer or symptom treatment than clinicians. The previous experience of peers could motivate patients to participate by encouraging them to report their problems more actively to clinicians. This was most frequently motivated by a desire to influence the doctors to prescribe the same medication as one of their peers.

*I felt itching and always wanted to lift my hand to scratch it. But I was told by the other patient before that we should not scratch it and if the skin was broken we might get infection. So I reported to the doctor and he asked me how itchy it was and whether I wanted to apply any medication.* (Patient_5.118)

Nurses also described how patient-to-patient conversations influenced participation highlighting that this was often to attain prescriptions to treat symptoms. Nurses also made use of peer impact to help patients encourage each other and be more active in their self-care activities.

*I think peer impact is very critical. If a patient sees other patients’ symptoms are relieved with a medication, he will want the medication because he believes it will also work on him. I always tell my patients about the cases of previous patients who have recovered from the disease, and sometimes show some photos [of these patients] to them.* (Nurse_2.10)

### 6.3.3.5 Organisational policies

The culture of an organisation and behaviour of clinicians can be influenced by organisational policies. During the semi-structured interviews both nurses and doctors were asked explicitly if they were aware of any policies that specifically referred to patient participation. Doctors’ initial response to this
question was that there were no special policies directed towards the role of patients in their care. They said, “have no idea”, “can’t remember any of them”, “very few” etc. When these doctors were questioned in more detail, they recalled some policies. Doctors indicated that patient participation was enabled through the policy of informed consent prior to surgery or procedures, that doctors are required to inform patients before beginning cancer treatment or at the beginning of an admission to hospital.

As to the policies related to patient participation, patients are required to sign on some inpatient consent documents about the ward regulations, or other [treatment] information. It’s possible (kind of policies related to patient participation), because patients always ask questions before they sign their names on the documents. They usually ask about the content in the document......Then we would give some explanation. (Doctor_1.34)

Nurses however, based on their responses, appeared to have higher awareness of organisational policies than the doctors. Nurses also, more frequently described patient education activities that were carried out for the purpose of delivering timely and comprehensive information and achieving high quality patient outcomes. As a ward initiated intervention, they prepared education sheets, wrote examination plans on the white boards in each room, displayed the daily blood test results at the Nurses’ Station where patients could access their results and nurses also organised a patient education seminar monthly. Nurses also described how they
orientated patients to the ward and care plan and the ongoing review of patient satisfaction using the information provided.

*High-Quality Nursing Promotion which is strongly advocated currently emphasises a lot of patient education from nurses. We are required to enter the ward room frequently and our Head Nurse often asks patients for their feedback (of the information we give).* (Nurse_2.23)

One of the key organisational policies that the nurses described was their role in monitoring compliance with patient self-administration of oral and external medications as well as the effectiveness of the medications.

*There are policies related to quality (of care) management. Prescriptions of narcotic analgesics, (oral) chemotherapy medications, psychiatric medications like hypnotics, must be documented on our daily sheet. Nurses are required to assess patients’ medication administration every shift or according to administration frequency. As to analgesics, after administration, we must assess the degree of pain relief, which is our duty.* (Nurse_2.16)

**6.3.3.6 Summary**

Multiple factors facilitating or impeding patients’ participation in symptom management were identified. Communication-related factors, such as comprehension, opportunities for patient-clinician interactions, symptom severity and established rapport between patients and clinicians, were considered to have an impact on the motivation for, and quality of, information exchange. Organisational policies, through the requirement for informed consent, can also facilitate communication. Factors such as
patients’ medical-technical knowledge, their role expectations, symptom severity and available options had an impact on decision-making. The involvement of family members could enhance communication and self-care but could also be perceived as a barrier to communication between patients and their clinicians. Peers, described as patients who were undergoing similar experiences and treatments can be a source of information and motivation for patients to question their care or seek further treatment.

### 6.4 Discussion

The purpose of the analyses presented in this chapter was to further explore how patient participation in symptom management was perceived by doctors, nurses and patients. The analyses focused on uncovering patients’, nurses’ and doctors’ understanding of and attitudes towards patient participation in symptom management; the reasons provided by patients for their control preference; and, factors that were identified as barriers or facilitators to patient participation in symptom management. The findings offer insights into the motivations behind patients’ and clinicians’ behaviours.

#### 6.4.1 Perceptions of the meanings and preferred roles in patient participation in symptom management

Patient participation in symptom management was perceived as a mutual interaction between patients and clinicians, within which patients could be involved through information exchange, negotiated decision-making and self-management. These findings indicated both patients and clinicians
shared the understanding that patient participation has a richer meaning than simply limited to decision-making. This perception is in line with Brownlea’s broad definition of patient participation where “participation means getting involved or being allowed to become involved in a decision-making process or the delivery of a service or even simply to become one of a number of people consulted on an issue or a matter” (1987, p. 605). Eldh (2010) also suggested that patient participation is sharing responsibility for care rather than simply partaking in decision making.

Information exchange was understood as a key attribute of patient participation. This perception is consistent with findings in previous studies (Frank, Asp, & Dahlberg, 2009b; Höglund et al., 2010; Heggland, & Hausken, 2013). In Eldh’s investigation of 362 Swedish patients designed to elicit their understanding of participation, the top seven descriptors of participation were all related to information exchange, including “the staff listen to me”, “to get explanations to my symptom/problem”, “to tell about my symptom/problem” (Eldh, Ekman, & Ehnfors, 2010). The notion of patients’ self-knowledge transmitted from patients to clinicians was emphasised by patients and clinicians as a way to participate and to some patients, it was described as the only way they could contribute to symptom management.

The importance placed on information exchange is consistent with the survey findings presented in Chapter 5 where reporting symptoms or problems was rated by over 90% of patients as important, making it the most commonly cited participatory activity. This notion of reporting symptoms as
the meaning of patient participation was also found in Ekdahl’s (2010) study of 15 fragile-elderly, Swedish patients who defined their participation as communication with health professionals about personal experiences of symptoms and illness. As this study focused on patient participation in symptom management, patients’ description of their role in symptom assessment (Dodd et al., 2001), a key component of symptom management, is not unexpected.

One of the key aspects of information exchange that emerged from the analyses, particularly from patients and nurses, was its function in promoting positive patient compliance with treatment and care. The notion of compliance has not been reported in quantitative studies exploring patients’ understanding of participation. It was however identified by Soleimani et al who through a grounded theory approach, found that the lowest form of interaction between patients and nurses was that patients followed professional advice without doing anything else (Soleimani, Rafii, & Seyedfatemi, 2010). Kolovos et al (Kolovos et al., 2014b) investigated nursing staff’s perceptions of patient participation in Greece and found compliance with staff’s orders was perceived by nurses as a core component of the meaning of patient participation. Tobiano et al (2015b) in a study exploring 20 Australian medical patients’ perceptions of participating in nursing care, concluded that a power imbalance exists between patients and clinicians and this imbalance is both implicit and explicit. Patients recognise the imbalance and have no choice other than to adhere to instructions and this was seen as a barrier to patient participation. In the study reported in this thesis,
patients’ views of compliance were not necessarily an outcome of perceived power imbalance but more in line with the recognition that having sought expert care and accepted a particular treatment approach, compliance was in their best interests. Receiving adequate information was a means of ensuring that patients could adhere and participate in their treatment goals. Understanding the plan of care therefore was perceived by nurses and patients as being fundamental to positive compliance. Understanding was perceived as different to simply being given information. Again, this is consistent with Eldh’s (2010) findings where patients focused on having knowledge rather than simply being informed.

Both patients and clinicians described subtleties in the processes of decision-making that involved both sharing advice and voicing opinions. Patients’ capacity to make independent decisions was perceived as limited by both patients and clinicians. While it was recognised by patients, nurses and doctors that patients could be involved in different stages of the decision making process, there was a clear emphasis, particularly from patients, on the value of their involvement in discussions rather than in making final decisions. The survey findings support this notion where although activities related to decision-making were rated highly, both patients and clinicians placed less value on participation in decision-making than on information exchange.

Beaver et al in their study of 41 patients with colorectal cancer in England found that being involved did not necessarily mean patients wanted to make
decisions; instead, being fully informed and being kept up to date with what was happening to them were perceived as patient participation (Beaver et al., 2005). Eldh et al (2010) also reported that patients described their participation as interacting with health professionals. Therefore, the perception of participating in a negotiated process rather than making decisions suggests that definitions of participation that limit it to decision making are not adequate in this context. The findings reinforce the importance of communication between patients and clinicians about decisions related to their care so that patients have the opportunity to receive advice and share their preferences and opinions about what matters to them.

Patients described their role in symptom management in terms of their involvement in self-management by adjusting their mental status, diet or lifestyle whereas nurses emphasised patients’ responsibility to be involved in nursing activities such as mouth care and nasal lavage. Performing self-care activities, such as making dietary adjustments, was considered an important participatory behaviour by 75% of respondents in the survey component of the current study. Although self-care was not rated as highly as the activities related to information exchange this may have been due to patient perceptions of their current situation in hospital where the focus was treatment rather than lifestyle and wellbeing. Similar perceptions were found in previous studies both from the perspective of patients’ (McInnes et al., 2014; Seale et al., 2015; Thyssen, & Beck, 2014; Wåhlin,Ek, & Idvall, 2006) and nurses’ (Löfman,Häggman-Laitila, & Pietilä, 2008; Sahlsten et al., 2009).
Chapter 6 Perceptions of patient participation in symptom management (Part II)

It is not unreasonable to assume that perceived patient roles are influenced by clinicians’ role, experience and organisational context.

Nursing care is usually provided by nurses in acute care settings and when patients are involved in administering that care themselves, it is likely that nurses perceive this to be indicative of patient involvement in their care. Kvangarsnes, in a study in Great Britain, also found that patient involvement in nursing care and administration of medical treatments influenced nurses’ perception of the extent that patients were participating in their care (Kvangarsnes et al., 2013).

Concerns about the extent to which patients should participate in their care and decisions were raised by both nurses and doctors. Doctors were concerned that patients may make incorrect decisions while nurses described the potential for participation to interfere with the care patients receive. This qualitative finding explained the survey findings where both doctors and nurses were more likely than patients to perceive patient involvement as a hindrance to care delivery. Holding these views of patient participation may impact on the extent to which doctors and nurses encourage or facilitate participation by patients (Löfman, Häggman-Laitila, & Pietilä, 2008; Larsson et al., 2011a; Lever, O’Reilly, & Pryor, 2008; Li, Ye, & Jiang, 2012; Sahlsten et al., 2005a).
6.4.2 Reasons for preferred roles in decision making in symptom management

The motivation behind the selection of patients’ most preferred role in symptom management was explored through content analysis. The themes that emerged were: the importance of information exchange; decision-making is a process that involves both patients and clinicians; and understandings of who is responsible and accountable for making decisions. The discussions of role preferences and behaviours reinforced the interpretations of the patients’ perceptions of participation. Patients who preferred clinicians to make final decisions reported that a lack of professional medical knowledge and high levels of trust in professionals’ expertise was key to their choice. These two reasons for a passive preference are consistent with findings of previous studies (Beaver et al., 2005; Ekdahl, Andersson, & Friedrichsen, 2010; Lewin, & Piper, 2007; Vestala, & Frisman, 2013). In both the present and previous studies, healthcare professionals agreed that lack of professional knowledge was a barrier for patients to be involved in medical decision-making or hospital care (Heldal, & Steinsbakk, 2009; Kolovos et al., 2014b).

Distinct from the patients with an absolute passive preferred role, patients who selected one of the other four preferences emphasized their own role in symptom management. Patients with an active control preference valued their self-knowledge and right to express their own opinions. Patients who wanted to make decisions themselves placed emphasis on their own
responsibility. Interestingly, patients described similar reasons for selecting their role even when their preferred levels were not the same. This is consistent with Entwistle’s (2001) findings where patients used similar descriptions for different role preferences in participation. To date, a focus of research has been to explain why patient preference for participation is often passive (Lewin, & Piper, 2007; Seale et al., 2015; Vestala, & Frisman, 2013), it is perhaps more important to explore what motivates patients to be involved, because this knowledge is essential to developing interventions and models of care to engage patients as participants in their care.

6.4.3 Factors influencing patient participation in symptom management

Facilitators and barriers related to patient participation in symptom management were assessed in the survey with both multi-choice and open-ended questions. They were also explored in more depth in the individual semi-structured interviews. All of the multi-choice factors listed in the survey: time with clinicians, adequacy of information, how well they are feeling were described in more detail, without prompting, by patients, nurses and doctors in the semi-structured interview. The ability of patients to remember the information they had been provided was rarely mentioned.

Identified communication-related factors such as comprehension, opportunities for communication, symptom severity and establishment of rapport were identified as potential barriers or facilitators to participation and have been widely reported in previous studies as linked to patients’
ability to participate. More specifically, patients’ capability to comprehend information or situations (Löfman, Häggman-Laitila, & Pietilä, 2008; Penney, & Wellard, 2007; Swenne, & Skytt, 2014) and lack of encouragement, respect, and trust (Eldh, Ekman, & Ehnfors, 2006, 2008; Larsson et al., 2011a, 2011b) have been found to be barriers to effective communication between patients and clinicians.

Opportunity was identified as a key factor influencing information exchange between patients and clinicians and thus patients’ capability of participating in their care and in discussions and decisions. The opportunity to communicate with clinicians was often influenced not only by the nature of clinicians’ recognition and acceptance of a collaborative model which has previously been reported in the literature (Löfman, Häggman-Laitila, & Pietilä, 2008; Larsson et al., 2011a), but also on the workload of clinicians. These factors influencing opportunity were identified by patients, nurses and doctors. Again this finding is supported by responses to the survey where the availability of clinicians was the most common factor in patients’ perceived ability to be involved in their care. The notion of workload and impact of the clinical environment in providing patients with opportunities to participate have been reported previously (Lever, O’Reilly, & Pryor, 2008; Malmgren, To¨rnvall, & Jansson, 2014).

Symptom severity was an influencing factor in both determining whether patients actually reported symptoms to their clinicians and their ability to participate. Patients acknowledged that when they perceived that a
symptom was not severe then they did not report it. Not disclosing symptoms has the potential to influence treatment outcomes, however, many patients who described not reporting their symptoms qualified their response by stating that they could handle the problem themselves through self-management or did not want to bother clinicians. The self-administration policies in the case study site are fairly unique, however, it is possible that because patients had responsibility for self-administration of symptom management medications they did not require additional medical or nursing interventions to manage minor symptoms. When they were unable to control a symptom or it was a new or troublesome symptom then they were more likely to ask clinicians for help.

Both doctors and nurses considered the severity of symptoms as factors influencing patients’ decision-making capacity. In cases where a doctor or nurse perceived a patient’s symptom to be severe then they would make treatment decisions without involving the patient. This perception that symptom burden is a barrier to participation in care decisions was identified in an Australian study (Cohen, & Botti, 2015). Symptom severity not only influences patients’ willingness to report a symptom but also the opportunity that patients are given to participate in symptom management.

Professional knowledge was regarded as a key factor in decision-making and is also one of the most commonly reported factors in other research (Cohen, & Botti, 2015; Eldh, Ekman, & Ehnfors, 2008; Höglund et al., 2010; Löfman, Häggman-Laitila, & Pietilä, 2008; Larsson et al., 2011a; Rainey et al.,
2013; Vestala, & Frisman, 2013). In this study, the majority of the patients had been diagnosed in the previous 12 months. Additionally, the majority of patients had no previous experience with healthcare and there was a strong shared perception that they did not have the knowledge to equip them to make decisions about their treatment. Patients who have experienced long term chronic illness on the other hand, are expected to have the requisite knowledge or experience to participate in decision making (Vestala, & Frisman, 2013). Role expectations in terms of who should make decisions was variable.

For some patients, trust in clinicians and respect for their knowledge and experience were reasons given for a passive control preference. Trust and respect have been widely reported as influencing participation irrespective of clinical and cultural contexts (Cohen, & Botti, 2015; Lever, O’Reilly, & Pryor, 2008). When patients perceived that they held responsibility for making final decisions, they were more likely to express their preferences and opinions to clinicians about treatment and care. In the survey findings, patients were considered to hold responsibility for self-care by most patients (80%), 97.4% of doctors and 100% of nurses however professional medical knowledge and opportunity for communication were recognised barriers to patients’ ability and/or willingness to take responsibility for their treatment decisions. Lever’s et al (Lever, O’Reilly, & Pryor, 2008) and Tobiano’s et al (2015b) findings were similar. Perceived understanding and opportunities for patients to take a more active role are fundamental to patient participation during their hospitalization.
Lack of resources and consequently limited available options for treatment was a context specific, but important factor in clinician motivation for involving patients. Survey data indicated that 40% of patients reported that they did not receive any information about symptom treatment options and only 21% of patients were involved in discussing examinations or treatment. That patients were not provided with options was consistent in both the survey and interview findings. Doctors did not perceive that patients were capable of making choices between different medications; they did, however espouse the belief that patients should make decisions about cancer treatment modalities when there was more than one option available. So in the case study context, lack of options was a significant factor in whether doctors considered involving patients.

Patient interactions with their family members and other patients during their admission influenced patient participation. Most of the patients preferred that their family members were involved in their symptom-related decision-making. Interestingly however, clinicians described providing diagnosis and treatment information to patient families and leaving the decisions regarding treatment, care and how much of this information was conveyed to patients, up to the family. In China the role of the family in decision-making is a cultural norm. In addition to health-care professionals dominating medical decision-making, Li, et al (2014a) summarized three main modes of decision making which are patients’ autonomous decision-making, family decision-making and patient and family co-determination. Importantly the first mode, patients’ autonomous decision making was
Chapter 6 Perceptions of patient participation in symptom management (Part II)

noted as most commonly occurring in the outpatient care setting where decisions regarding diagnosis and treatments are discussed. The other two modes of decision making appeared to be more prevalent where patients were diagnosed with major diseases or were in critical care. Henoch et al (2012) in Sweden also found that family members’ opinions were used as a proxy to make care decisions when lung cancer patients were unable to communicate their preferences.

The results from the patient survey component found family members’ absence did not adversely impact patients’ ability to have family members’ involved in their care. This was because over 70% of patients had family members providing care for them during their hospitalization and 41.4% of family members were present in patients’ rooms for more than 12 hours each day. It is important to note that not every patient preferred their family members to be involved in their care and decision-making. The reasons provided by these patients included their desire to be autonomous in their decision-making, the symptom issues they were experiencing were not bothersome enough to trouble their families, or that they held differing opinions to their family members about treatment. Although family members have been involved by clinicians in practice or research (Jiang, Liu, & Wang, 2007; Zhou, Huang, & Zhang, 2012), there are very few studies that have explored patients’ preferences for their family members’ involvement and related reasons. Li (2009) investigated 120 inpatients in a Chinese cancer hospital and found they preferred their families to participate in decisions related to lifestyle or selecting doctors rather than in decisions related to
examinations and treatments. Li’s findings indicated patients’ preference for family involvement in medical decision-making differed according to the type of decision that was being made. These findings are important because the data from both nurses and doctors indicated that they had no reservation in providing families with information and decision-making responsibility without necessarily knowing patients’ preferences for family involvement. In China, where family involvement in care provision in hospital is the norm, a better understanding is needed to ensure family members’ involvement is aligned with patients’ preferences.

Other patients in the ward were identified in this study to have some impact on patients’ actual experience of participation and as key motivators to patients’ actual participation. The specialty nature of the case hospital meant that most patients admitted to one of the two wards were likely to have similar types of cancer or were receiving similar treatment. Further, the layout of the wards where data were collected meant that most patient rooms were shared by four patients which is characteristic of most public hospitals in China. This ward design facilitates patient-to-patient communication and also means that patients can hear interactions between other patients and clinicians. Patients shared their stories and experience with each other. Nurses in particular identified the utility of using peer patients to educate other patients and to reassure patients who were anxious about treatment or side-effects. This was also evident in the findings of a Finnish study of orthopaedic patients and their nurses, where peers
were recognized as a facilitator for patient participation (Löfman, Häggman-Laitila, & Pietilä, 2008).

The interviews with both doctors and nurses indicated that they were not aware of any specific organisational policies that provided guidance for patient or family participation in their treatment and care. Nurses were aware of policies that facilitated or directed patient education, informed consent and self-administration of medications or nursing care because these policies related to their care provision and quality indicators. These policies motivated information provision, informed decision-making and patients’ self-management. Doctors were less likely to be aware of hospital directives regarding patient involvement other than those related to informed consent for treatment. This suggests that if patient or family care policies or procedures existed in the case study organisation, these were not a communication priority for medical staff.

6.5 Conclusions

There was substantial agreement between the findings derived from the interviews reported in this chapter and the survey findings reported in Chapter 5. There was a shared understanding that patients and clinicians have mutual roles in symptom care and treatment. Information exchange was acknowledged as being key to patient involvement and the processes of negotiated decision-making were described as being achievable in various ways. Patients’ self-management was perceived as a method of patient involvement and was described as psychological, functional and dietary
maintenance as well as self-administration of medications. However nurses had a different perception of self-care that was more focused on activities of daily living and specific treatments such as nasal lavage. Patients’ roles in negotiated decision-making were generally perceived by patients, doctors and nurses as limited. In addition, doctors were concerned that patients would make poor choices and nurses were concerned that decisions would interfere with care.

Some of the reasons patients gave for particular role preferences were similar irrespective of role preference. Patients who wanted a more active role however were more likely to talk about the salience of self-knowledge, responsibility for self and the right to express opinions. Factors thought to influence participation related to capability such as communication, knowledge and symptom severity, and opportunity that refers to accessibility to clinicians and willingness of clinicians to involve patients.

In next chapter, findings from the naturalistic observation are presented for the purpose of exploring patients’ and clinicians’ behaviours during interactions related to symptom management to enable the phenomenon of patient participation in symptom management to be reviewed from another perspective.
CHAPTER SEVEN

Interactions between clinicians and patients
in symptom management

The perceptions of patient participation from both patients’ and clinicians’ perspectives obtained from the self-report survey and individual interviews were reported in the previous chapters. Perceived roles in participation were predominately in information exchange and more limited in negotiated decision-making. Patient participation is a complex, multifaceted phenomenon and perceptions of participation provide particular insights, however it is important to examine how participation is actually enacted in clinical practice.

The findings reported in this chapter, address Aim 2 of this research program, to explore patients’ and clinicians’ behaviours during interactions related to symptom management.

Using naturalistic observation and survey methods, the related objectives were to:

1. Describe how and under what circumstances patients communicate with clinicians during interactions related to symptom management;

2. Identify clinicians’ communication behaviours that facilitate or impede patient participation during interactions related to symptom management;
3. Analyse the congruence between clinicians’ and patients’ perceptions of preferred and actual participation in symptom-management related decision-making.

7.1 Methods

The full description of the data collection and analysis methods appear in Chapter 3 Section 3.4.1. The naturalistic observations were conducted in the first phase of the program in order to reduce the possibility that participants may be influenced by the surveys and interview questions and alter their behaviours.

Doctor-patient dyads and nurse-patient dyads were recruited through consecutive sampling. For the doctor-patient observations, medical teams were observed during the medical morning ward rounds. Primary nurses were observed during nursing morning ward rounds and nursing working hours.

An observation checklist was used concurrently with field notes of observed conversations and behaviours. The checklist data were analysed using descriptive statistics. The conversation and observation notes were analysed through qualitative content analysis. Although the interaction data were collected first, the analyses were informed by the three main themes of participation in symptom management that emerged from the patients’, doctors and nurses’ perceptions of patient participation. These were: information exchange, negotiated decision-making and self-care.
Chapter 7 interactions between clinicians and patients in symptom management

7.2 Findings

The findings are presented in five sections. The characteristics of the participants observed are presented in the first section, followed in the next two sections by a description of the doctor-patient and nurse-patient interactions related to symptom management. Communication behaviours of clinicians and family members that appeared to facilitate or block patient participation in symptom management are described next, and, in the final section, patients’ preferred and actual experienced roles of participation when interacting with doctors and nurses are compared and discussed.

7.2.1 Characteristics of the observed participants

The observations of doctor-patient interactions were conducted between 6 Aug and 16 Aug, 2013. The observations of nurse-patient interactions were conducted between 27 Aug and 15 Oct, 2013. Patients involved in the observations were recruited one day before each observation. Of the eligible doctors and nurses (outlined in Chapter 4, Section 4.2.1), 67.9% of doctors and 100% of nurses were recruited. There were 91 patients eligible for the observations of doctor-patient interactions and 81 consented to participate, with a response rate of 89%. All the patients eligible for the observations of nurse-patient interactions consented to participate (n=112).
7.2.1.1 Demographic and illness-related characteristics of the observed patients

The characteristics of the observed patients in both doctor-patient and nurse-patient cohorts are presented in Table 7.1. In the 81 doctor-patient dyads, patients’ average age was 50.1 years (SD=11.0); 55.6% (n=45) were males. Patients were mostly from the cities surrounding Shanghai. Just under half (48.1%, n=39) the patients were diagnosed with head and neck cancer. In the 112 nurse-patient dyads, patient participants had an average age of 49.6 years (SD=11.9); 59.8% (n=67) were males.

To identify whether patients participating in the observation and survey cohorts were from the same patient population, comparisons were made across the three groups in regards to the demographic and diagnosis variables. These characteristics are shown in Table 7.1. The mean ages of the three cohorts were all approximately 50 years (F=1.74, P=0.177). Chi-square test was used to compare the distribution of sex and province of residence and no significant differences were found (sex: $X^2=3.80$, P=0.149, residence: $X^2=15.07$, P=0.130).
In Phase 1 (naturalistic observation), close to 90% of patients invited in the doctor-patient dyads and 100% in the nurse-patient dyads agreed to participate. While in Phase 2 (survey and interview), which occurred four weeks later, 54% of patients invited to take part in the survey accepted.
When comparing the characteristics of participants and non-participants in Phase 2, as presented in Chapter 4 Section 4.3.2, two-thirds of patients with breast cancer or lymphoma consented to participate while nearly half of the patients with head and neck cancer refused. This is the primary reason for the different distribution of cancer types between the three cohorts. As type of cancer was found to have no predictive effects on patients’ preference for participation in the ordinal logistic regression analysis, the different distribution of cancer types in the two phases of this research was not considered to have had a substantial influence on the findings, therefore the cohorts can be considered to be from the same population.

7.2.1.2 Demographic characteristics of the observed clinicians

During medical ward round observations, every patient participant had a conversation with the chief or consultant doctor who led the ward round and/or the resident medical officer (RMO) in charge of the patient’s care. There were 29 doctors involved in the observation phase and 20 were RMOs. The average age of the doctors overall, was 33.6 (SD=5.7) years, ranging from 27 to 51 years. Fifteen doctors were male. The average age of RMOs was 31.3 (SD=3.1, min-max: 27-36) years and 11 were males.

Nine primary nurses were involved in the observation of nurse-patient interactions. All were female with an average age of 30 (SD=4.3, min-max: 24-36) years.
7.2.2 Interactions between doctors and patients.

7.2.2.1 Context of the doctor-patient interactions

Doctor-patient interactions were observed in eight morning medical ward rounds involving five doctor teams. Each doctor team was in charge of the care of 17 to 26 patients. An average of 10.1 (SD=3.37, min=5, max=16) patients participated on each observation day and an average of seven doctors were present in one medical round (SD=1.15, min=5, max=9). There were no nurses or allied health staff present other than one research assistant nurse. Conversations occurred between doctors and patients for the purpose of performing daily medical reviews.

Of the 81 observed interactions between doctors and patients, 75 (92.6%) involved some discussion of symptom management, of which 93.3% (n=70) were related to assessment of symptom status. One patient had a tracheotomy so he had difficulty in speaking; therefore no conversation occurred between him and the doctors. All the patients were admitted in a four-bed shared room and the conversations occurred in the patients’ rooms.

![Figure 7.1 The distribution of the duration of doctor-patient interactions](image-url)
Twenty-one (25.9%) patients had their family members present. The distribution of average duration of doctors’ discussions of patient cases with the team, with or without patient involvement is presented in Figure 7.1. The average duration of doctors’ engagement with each patient’s case was 52 (SD=33) seconds with the duration ranging from approximately two seconds to three minutes.

### 7.2.2.2 Initiation of symptom discussions in doctor-patient interactions

Doctors initiated questioning about symptoms in 72.2% (n=52) of interactions whereas patients volunteered their symptoms in 26.4% (n=19) of interactions. One family member reported a patient symptom.

All the symptoms discussed during observed interactions between patients and doctors were counted and are listed in Table 7.2 according to the frequency of patients who experienced them. There were 75 symptoms identified; 14 patients did not discuss any symptoms with their doctors. Gastrointestinal symptoms were the most common symptom group discussed (n=26, 34.7%). Sore throat, changes in skin, leukopenia and mouth sores were discussed with five or more patients. A psychological/moodrelated symptom was disclosed once in patient-doctor conversations.
Table 7.2 Symptoms identified in the observed interactions with nurses and doctors

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Dr-Pt interactions</th>
<th>Nr-Pt interactions</th>
<th>Symptoms</th>
<th>Dr-Pt interactions</th>
<th>Nr-Pt interactions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gastrointestinal System</strong></td>
<td></td>
<td></td>
<td>Peripheral Tissue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of appetite</td>
<td>4</td>
<td></td>
<td>Changes in skin</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>3</td>
<td></td>
<td>Itching</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Mouth sores</td>
<td>5</td>
<td></td>
<td>Changes in sensation</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Constipation</td>
<td>3</td>
<td></td>
<td>Swelling</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>2</td>
<td></td>
<td>Numbness in hands or feet</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty swallowing</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reflux</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rectal bleeding</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Central Nervous System</strong></td>
<td>7</td>
<td></td>
<td><strong>Psychological/Mood</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>3</td>
<td></td>
<td>Feeling sad</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>1</td>
<td></td>
<td>Irritable</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Dizziness</td>
<td>0</td>
<td></td>
<td>Worrying</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Fever</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sweats</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Respiratory System</strong></td>
<td>11</td>
<td></td>
<td><strong>Others</strong></td>
<td>14</td>
<td>9</td>
</tr>
<tr>
<td>Sore throat</td>
<td>6</td>
<td></td>
<td>Leukopenia</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Nasal problems</td>
<td>3</td>
<td></td>
<td>Lack of energy</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Cough</td>
<td>1</td>
<td></td>
<td>Thrombopenia</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>1</td>
<td></td>
<td>Weight loss</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Fatigue</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Total</strong></td>
<td>75</td>
<td>71</td>
</tr>
</tbody>
</table>
7.2.2.3 Doctor-patient interactions related to symptom management

Interactions between doctors and patients were analysed to identify whether patients had opportunities to participate in information exchange and decision-making. Figure 7.2 displays doctor-patient interactions related to patient participation in symptom management.

![Diagram of doctor-patient interactions related to symptom management](image)

Figure 7.2 Doctor-patient interactions related to patient participation in symptom management
7.2.2.3.1 Interactions involving Information exchange

In the 75 interactions related to symptom management, all the patients were involved in information exchange. However, in some cases (n=27, 36%) patients were asked by doctors about their symptoms or problems or doctors talked about patients’ symptoms without patients’ contribution. The exchanges were brief and very little additional information was provided by doctors or patients. In these conversations, information was delivered in one direction only. For example:

**Patient_3.76:** Do I need more courses of radiotherapy?

**Attending:** Today is the 25th course. We will add more next Monday.

**Consultant:** Why does your neck [skin] look like it is overcooked?

(The patient laughed, without speaking)

**Consultant:** Applying ice might be helpful.

**Attending:** (patient’s name), 10 courses? Are you OK?

**Patient_3.57:** Yes, 10 courses. I feel good. I had an injection yesterday and got a pain here [arm].

**Attending:** Please have a talk with your nurse [about the arm pain].

**Patient:** OK.

**Attending:** How about your bowel movements?

**Patient:** Much better after I took the drug yesterday.

Brief exchanges between patients and doctors occurred in most of the cases (n=45, 60%). Most of these exchanges were initiated by doctors either with non-specific open-ended or specific close-ended questions. Patients reported their symptoms and then doctors gave a brief explanation of the symptoms.
Consultant: Are you all right?
Patient_3.19: Yes, but it’s painful here [her neck].
Consultant: Don’t worry. You probably have a stronger reaction [to the radiotherapy than other patients].
Patient: The skin here [neck] seems very hot.
Consultant: This is a kind of a skin reaction [to the radiotherapy].
Patient: I understand.

Attending: How are you going these days?
Patient_3.83: I’m a little deaf.
Attending: Are you? It might be related to the Oxaliplatin.
Patient: Am I still having the chemotherapy today?
Attending: Yes. Three days will be fine.

Cases in which Information was more comprehensively exchanged were observed in very few interactions (n=3, 4%) between doctors and patients. Comprehensive exchange was considered to occur when patients reported their symptoms, the symptoms were acknowledged and doctors answered patients’ questions or provided explanations to help patients understand what was happening.

Consultant: (patient’s name), are you OK?
Patient_3.10: I’m very good. I told Doctor** too yesterday I felt very good. It works [the radiotherapy works so that the symptoms have obviously been relieved]. The only problem is that I have a stomach ache when I open my bowels. The stool is a little watery and a bit black.
Consultant: It’s a bit black, right?
Patient: I am taking Spore Powder. I am not sure (whether the Spore Powder has something to do with the black stool).
Consultant: Don’t take Spore Powder.
Patient: Yes, that’s why I stopped taking it.
Consultant: Let’s prescribe some examinations for you, for example the faecal occult blood test.
Patient: OK.
Consultant: The Spore Powder is not suggested for you because it causes bleeding.
Patient: Really?
Consultant: One of the reasons is that Spore Powder causes bleeding and the other one is that it could affect your liver function.
Patient: OK. I really feel very happy these days (because I feel better). Thank you, doctor.

7.2.2.3.2 Interactions involving decision-making

In 30 (40%) interactions observed, doctors talked with their patients not only to collect or provide information, but also to make decisions about medications or further examinations or treatments. Opinions and preferences were exchanged between doctors and patients in 22 cases. In these interactions, 14 doctors initiated questions about patients’ views. In the case below, doctors were going to prescribe an intravenous infusion to provide nutrition for Patient_3.15. The patient was adamant that the infusion not be commenced. The doctors emphasised the significance of nutritional support and gave an explanation partially addressing the patient’s concern however the patient did not want to accept the treatment. Whether the patient’s preference was accepted is not known.

(Patient_3.15 is having breakfast. She seems to have difficulty swallowing)

Consultant: Do you have diabetes?
(The patient shakes her head.)
Consultant: Would you like me to prescribe a fluid infusion for you?
(The patient shakes her head.)
Consultant: You don’t have to hold out. I suggest you have an infusion if you have to take 1-2 hours to eat porridge. It will work. What are you worried about? This medication is not a big deal, it only has a little amount of nutrients.
Patient: I’d like to eat rice by myself.
Consultant: How long do you take to finish a bowl of porridge?
Patient: Half an hour.
Consultant: I advise you to take some treatment.
RMO: It’s not good [during the radiotherapy] if you don’t have enough nutrition.
Consultant: I suggest you have an infusion because support treatment is very important.
Patient: (I think) nothing is better than eating by myself. By the way, my nose is not stuffed up any more, but......
Consultant: You have to keep doing the nasal douche even though you can breathe properly. Saline does not work as......
Patient: But it will bleed after douching.
Consultant: It’s good to douche 2-3 times per day with less amount of douche. Patients usually experience the most severe side effects in the second week. (You will) have worse days in the following two days. I suggest you have the fluid infusion.
(The patient still shakes her head.)
In addition to being asked their preferences, some patients (n=8) actively expressed their preferences and exchanged views with the doctors.

Patient_3.40: Can I have the MRI examination?
Consultant: Today? I think next time [next admission for chemotherapy]. You will be discharged today.

Patient: Could you please give me a copy of the discharge summary for the last admission?

Resident: Sure.

Patient: Could you please prescribe some thrombopoietic medications for me?

Consultant: Your thrombocyte count currently is not low.

Patient: It will decrease.

Consultant: OK. Is there anything other than medication you need?

Patient: It seems enough.

However in some interactions (n=3), doctors provided an opinion or suggestion to patients according to the patients’ situation and they also asked patients whether that was acceptable however patients often did not recognise this as an invitation to provide their perspective and did not respond. In the case below, Patient_3.82 reported her symptoms but did not indicate any agreement or disagreement with the doctor’s suggestion in the interaction observed.

Attending: Have you finished (chemotherapy)?

Patient_3.82: Yes.

Attending: Let me give you a fluid infusion, with some anti-emetics.

Patient: I’m so sick.

Attending: I am going to give you a fluid infusion today and tomorrow. Is that OK?

Patient: I vomited last night.
In a few occasions, professional opinions or suggestions were provided to patients or their families however patients’ preferences or assent were not sought but implied.

Consultant: Are you unwell?
Patient_3.41: I’m OK, except a little reflux.
Consultant: You can take some omeprazole. It protects your stomach and inhibits gastric acid.
Patient: OK.
Consultant: You lack energy, don’t you?
Patient’s family: Yes, he does.
Consultant: When did the chemotherapy pump finish?
Patient’s family: 10 o’clock last night.

Consultant turned to the resident: Please prescribe some leucocyte-stimulating agents.
Consultant to family: We are using some leucocyte-stimulating agents. He might feel sick (after the agent) for approximately 3 days. (It’s normal) The leucocytes are low.

As in the case above, when family members were present or interacted, doctors would refer to the family member rather than the patient. Family members would then participate in decision-making on behalf of patients.

Patient_3.79: I finished my chemotherapy yesterday?
Attending: Are you feeling good?
Family member: Yes, not bad. And the skin on the neck is also not bad.
Attending: Yes. 23 lights.
Family member: Please prescribe some gargles for us.
Attending: OK. Two bottles? Everything is OK?
(The patient and family smiled.)
Chapter 7 Interactions between clinicians and patients in symptom management

Family member: Has all the chemotherapy been completed?
Attending: Yes.
Consultant: Let’s decide (whether to have more chemotherapy) after the radiotherapy is over.

7.2.2.4 Summary

Conversations during the morning ward rounds occurred between a group of doctors and patients with or without family members present for the purpose of performing daily medical reviews. These interactions with each patient were very brief; most lasted less than one minute. Approximately 75% of the conversations related to symptom assessment were initiated by doctors. All except one of the 75 symptoms discussed were physical symptoms. Most often, information exchange between doctors and patients was brief, and 40% of the conversations related to symptom management involved some form of decision making. In these situations, most of the patients (24/30) were given an opportunity to provide their opinion or preference about treatment or at least to state their agreement, however some patients were either not given the opportunity or did not take the opportunity to express their preferences. Although family members were present in 26% of interactions observed, they participated in only three interactions. However, when family members did participate, they became the focus of the interaction and would make decisions on behalf of patients.
7.2.3 Interactions between nurses and patients

7.2.3.1 Context of nurse-patient interactions

Primary nurses were responsible for the care of 12 to 16 patients in three or four rooms on the designated wards. In the over 46 hours of nurse-patient observations during the morning nursing ward rounds and the following nursing working hours from 8:30 to 10:30 in the morning and 1:30 to 3:30 in the afternoon, a total of 290 interactions were observed, in which 273 nurse-patient interactions occurred in the morning with an average of 2.4 times per patient (SD=1.5, min=1, max=9). Two primary nurses who were observed in the morning continued to be observed in their afternoon shifts. Seventeen interactions in the afternoon were observed involving 10 patients with a mean of less than one interaction per person (mean=0.8, SD=1.25, min=0, max=5).

More than half of the interactions (n=158, 54.5%) lasted less than one minute. Ten (4.5%) long interactions (>10 minutes) were observed when nurses performed maintenance of a peripherally inserted central catheter (PICC) or patient education. In 8.3% (n=24) of interactions, no conversation was observed between patients and their primary nurses as the primary nurses performed a very brief ward round or review. In these cases, nurses entered patients’ rooms, observed whether their patients were in the rooms and then signed their names on the review sheet which was hung on the wall by the bed. During these reviews, the nurses did not talk to their patients at
all or provided a general greeting to everyone in the room without any individual conversations.

As to the location, 94.8% (n=275) of the interactions occurred in the patients’ rooms. Six (2.1%) interactions were at the Nurses’ Station and five (1.8%) were in the corridors. Two (0.7%) patients entered other patients’ rooms and talked to their primary nurses and two (0.7%) patients who left their ward during the observation period were spoken to by their primary nurses by phone.

Aside from 150 (51.7%) interactions in which the primary nurses interacted with the patients alone, 140 (48.3%) interactions occurred in the presence of two to four nursing assistants or students. Family members were present for 96 (85.7%) of the patients observed.

The nurse-patient interactions occurred for four main purposes. Of all the interactions, more than half (n=163, 56.2%) were related to nursing ward rounds at the beginning of a morning shift or reviews of patients every hour. Approximately one-fifth of the interactions (n=62, 21.4%) were initiated for the purpose of providing information including patient education. Other occasions where nurses interacted with patients were to perform nursing treatments (n=55, 19.0%) such as fluid infusions, vital sign assessment or blood sugar testing or maintenance of PICC lines. In addition, medication administration was observed in 10 interactions (3.4%).

Conversations involving symptom management were observed 159 (54.8%) times, in which symptom assessment was performed in 79 interactions.
Other interactions were related to cancer treatment such as radiotherapy or chemotherapy.

### 7.2.3.2 Initiation of symptom discussions in nurse-patient interactions

Primary nurses initiated questioning about symptoms in 75% (66) of interactions and patients volunteered their symptoms to their nurses in 19 (21.6%) interactions. Three family members who were present initiated a report of the patients’ symptoms to nurses. As shown in Table 7.3, no significant difference was found between doctor-patient interactions and nurse-patient interactions in terms of who initiated symptom assessment conversations ($x^2=0.41$, $P=0.523$).

<table>
<thead>
<tr>
<th>Clinicians and patients who initiated symptom-associated interactions</th>
<th>Doctor-patient interactions (n=72)</th>
<th>Nurse-patient interactions (n=88)</th>
<th>$x^2$</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors or nurses</td>
<td>52 (72.2)</td>
<td>66 (75.0)</td>
<td>0.41</td>
<td>0.523</td>
</tr>
<tr>
<td>Patients</td>
<td>19 (26.4)</td>
<td>19 (21.6)</td>
<td>0.41</td>
<td>0.523</td>
</tr>
<tr>
<td>Family members</td>
<td>1 (1.4)</td>
<td>3 (3.4)</td>
<td>0.41</td>
<td>0.523</td>
</tr>
</tbody>
</table>

In Table 7.2 displayed in Section 7.2.2.2, the 71 symptoms discussed in the observed nurse-patient interactions are presented. Two patients did not discuss any symptoms with their primary nurses. Lack of appetite (n=11) and nausea and vomiting (n=8) were the most common symptoms in the discussions. Dizziness, changes in skin and itching were also common,
discussed in five patients’ conversations. Two of the 71 symptoms were related to patients’ mood or psychological problems.

7.2.3.3 Nurse-patient interactions related to symptom management

Of the 159 nurse-patient interactions related to symptom management, information exchange, decision-making and self-care were three types of activities in which patients were involved. Interactions between nurses and patients were analysed to identify whether patients had opportunities to participate and how they participated in these activities. Figure 7.3 shows the activities in the nurse-patient interactions related to symptom management.

7.2.3.3.1 Interactions involving information exchange

Information exchange, especially during the nursing ward rounds, was frequently in the form of one-way information delivery from patients or nurses. In the case below, the patient answered the nurse’s questions about his nasal hygiene. The nurse received the information but did not give any substantial feedback.

(7:43am, Nursing ward round for Patient_4.090)

Nurse: Good morning. I am the primary nurse in charge of your care today. Have you done the nasal washes? Was there bleeding?
Patient: Yes, there was.
Nurse: What was the amount of bleeding?
Patient: There was blood in the washing fluid.
Nurse: Please tell your doctor [about this problem]. [Let me] have a look at your PICC line.
Patient: Sure.
Nurse: Did you use the Nasal Cleaner (for your nasal wash)?
Patient: Yes, I did.

Figure 7.3 Nurse-patient interactions related to patient participation symptom management

Information was often delivered from the nurse to the patient without significant patient involvement. In the case below, the patient received brief instructions about his chemotherapy from the nurse.

(9:20am, Patient_4.100 was undergoing chemotherapy that day. His primary nurse entered the room for education.)

Nurse: We will come to check you every hour.
Patient: OK.

Nurse: Do you know the chemotherapy instructions?
Patient: No, I don’t know.

Nurse: Drink more water. Have a light diet.
On most occasions (n=76, 47.8%), patients and their primary nurses exchanged information but very briefly. Usually patients responded to nurses’ greeting or assessment questions by reporting their current symptoms or problems and then nurses gave feedback to the problems or answered patients’ questions. In the example below, the primary nurse provided a very brief explanation of the cause of the patient’s sore gums. It seemed the patient had received medication for this symptom but did not know what this medication was for. The nurse answered the patient’s question briefly with no further explanation.

(7:43am, Nursing ward rounds for Patient_4.86)

Nurse: Good morning, I’m your primary nurse today. Are you OK?
Patient: My gums are very sore.
Nurse: Your reaction [to the radiotherapy] is starting.
Patient: What medicine is this? [the patient took out a bottle of medicine from his bedside cabinet and asked.]
Nurse: This is mouth-wash.

Full exchange of information between patients and nurses was only observed in four cases in which nurses gave detailed explanations of the cause of symptoms and the treatment procedure or reactions. For example:

(9:20 A primary nurse and nurse assistant entered Patient_4.7’s room to administer an injection of a blood cell stimulating factor.)
Nurse assistant: (the patient’s name), it’s time for your injection.
Please go back to your bed.
Patient: Injection?
Nurse assistant: Yes.
Patient: My son has gone to buy the blood.
Nurse assistant: You still have to get the injection even if the blood is bought. After the blood transfusion...
Primary nurse: There are two high quality injections for you this morning. Here is the first. The second is the one bought by yourself and it will be administered in a while. The third injection in the afternoon is an ordinary one [a domestic medication]. (The nurse helped the patient to lie on the bed)
Nurse assistant: I am going to inject the first and second both in one arm and the third in the other arm.
Patient: I am having backache.
Primary nurse: It’s great. It means your white blood cells are growing.
(The nurse assistant checks the patient’s name and inpatient ID number)
Primary nurse: The first injection is the most expensive one. It’s to grow blood platelets. Are you ok?
Patient: Yes, I’m fine.
Primary nurse: The next one is to grow red blood cells. It’s to treat your anemia. It’s a good sign when you feel backache. The ache means the blood cells are growing.
Nurse assistant: Do you know how long to press?
Patient: 10mins.

7.2.3.3.2 Interactions involving decision making

Activities related to decision making usually occurred after information exchange. There were not many decisions made within the observed nurse-patient interactions. Ten nurses, in 12 interactions, provided opportunities for patients by asking patients’ preference after they presented options or professional opinions. In response to these opportunities, six patients
presented their preference or opinions or deferred decisions for discussion with family members. The patient in the case below delayed making the decision to accept a PICC line in the first two interactions observed, because she was waiting for her sister to come in so she could discuss it further. After discussion with her sister, she decided not to have a PICC line inserted.

(9:56am, Primary nurse entered Patient_4.84’s room to discuss the PICC line)

Nurse: I have asked your doctor. He said you can have a PICC line. Now it’s time for your decision. As I said before, the advantage of a PICC is that you don’t have to have the venipuncture (after the PICC line is inserted) and the disadvantage is the line needs to be maintained (periodically). Where do you live?

Patient: Changning District.

Nurse: Since you live in Shanghai, PICC maintenance will not be a problem for you.

Patient: Is there a maintenance service in second level hospitals?

Nurse: Yes, there is.

Patient: I see.

(The nurse noted that the patient had an allergy alert on her arm band.)

Nurse: You might get an allergy with the 12 yuan dressing.

Patient: I definitely will. I even get flushing on the skin at the back of my neck if I don’t get rid of labels on the collar.

Nurse: There is a better dressing, costing 20 yuan. No one has had an allergy with this dressing so far.

Patient: I see.

Nurse: We have given you the information. You can make a choice or discuss it with your sister.

Patient: She will come soon.
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Nurse: Then you have to have the venipuncture for today’s infusion (because the patient can’t decide right now).
Nurse: Your doctor suggested you have the PICC line. The doctor did not suggest it for the patient in Bed *, because she only gets the infusion once a week. So it varies from person to person.
Patient: OK. I’d like to discuss it with my sister.

However, in the other five interactions, patients did not make decisions or present their preferences to their primary nurses, accepting the treatment offered.

(9:04am, A primary nurse entered Patient_ 4.79’s room for the hourly review)
Patient: When will I get the infusion today?
Nurse: Not yet. The medication will not be delivered [to our ward] until noon. I have reported [your fever] to your resident medical officer who suggested you drink more water.
Patient: You did?
Nurse: Your temperature was 37.6 °C yesterday. It is always around 37.5 or 37.4. Drink more water, please. Do you need an ice bag?
Patient: No, thanks.
Nurse: OK. Then more water and rest. Don’t fall.

In seven interactions, patients were observed to initiate discussions about their preferred treatment with their primary nurses. They either asked for medications such as sedatives or agreed or disagreed with the nurses’ suggestions.

Patient_4.20: Can I get some sleeping pills? I have lost 2kg [because of poor sleep].
Nurse: Do you have difficulty in sleeping?
Patient: Yes.

Nurse: I will have a look whether the consultant is in the office [to ask for a prescription]. Sleeping pills are a special prescription drug that cannot be prescribed by the RMO.

Patient: OK. Thank you.

Another patient expressed her preference when her primary nurse entered her room to change her infusion bag.

(9am, A primary nurse entered Patient_4.34’s room to change the infusion bag)

Nurse: Here I am. It’s [the infusion bag] empty.

(The nurse checks the patient’s name, then hangs another bag.)

Nurse: This is the last day for this, so it’s the small bag. You will only get the nutrition medication for infusion tomorrow. Understand?

Patient: Yes.

Nurse: Do you think it [the nutrition medication] works?

Patient: So-so. Is it you who told the doctor (to prescribe the nutrition medication)?

Nurse: No, it was prescribed by the doctor.

Patient: Could you please tell the doctor I’d like to keep this bag only [the one that is on now]. I don’t need the nutrition medication. Can he add some more medication in this bag and stop that nutrition bag? Is that OK?

Nurse: I will deliver your preference to your doctor. But I don’t think you will get enough nutrition when you have such a poor appetite. So you must eat more.

Patient: It [the mouth mucosa] is so painful. I don’t want to eat. Can the doctor add other medication (in the bag)?

Nurse: We usually add potassium chloride only.

Patient: Can glucose be in?

Nurse: It is already there. And there is Soluvit in this bag.
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Patient: Is there any other medication that can be added?
Nurse: It’s up to the doctor.

Patient: I’d like to get more medication in one bag. I don’t like the bag of nutrition medication. It takes too long to finish.
Nurse: I can ask the doctor for you.

This patient in the above case communicated her preference. Her doctor came to talk with her five minutes later and stopped the prescription of the nutritional infusion.

Family members were also observed to present opinions or preference to nurses. As the family members were at the bedside with the patients, they were often spokespersons by expressing the patients’ preferences. Nurses however did address patients in responding to symptom information or requests.

(In the morning nursing ward round, nurses entered Patient_4.56’s room. The primary nurse checked whether their patients were in the room and checked patients’ nails for hygiene and safety.)

Primary nurse: Good morning. It’s still me in charge of this room. My surname is...... (To Patient_4.056) This is your third day of chemotherapy. Do you feel good?
Family member: She lacks appetite. I see there are a lot of infusions these days. Can she get a PICC line?
Primary nurse (to the patient): For this course? You didn’t have a PICC in your last course. Your chemotherapy course is every 21 days.

Nurse 2: Did you have the chemotherapy in the outpatient department?
Patient: Yes, at outpatients.
Nurse 2: The doctor said your course period is long, so you don’t have to insert a PICC line.

Primary nurse: But you can ask your doctor in a while [during the medical ward round] to decide whether you need it or not.

7.2.3.3.3 Interactions involving self-care

Within interactions between nurses and patients, primary nurses discussed the performance of self-care such as medication self-administration, proper diet during treatment, protection of skin in the radiotherapy site, fall prevention, functional exercise, and nasal washes etc. Nurses were observed in 21 interactions to provide patients with information about how and what to do to care for themselves and encouraged patients to adhere to treatment plans. An example of a nurse checking in on patients’ self-care is as follows:

(7:42, Nursing ward round for Patient_4.102)

Nurse: Good morning. Do you wash your nose (every day)?

Patient: Yes, I do. I bought a nasal wash device online. It was only 40RMB.

Nurse: Good. Where does the water wash out?

Patient: From my mouth. Can I put some salt in the wash water?

Nurse: Yes, you can put in a little.

Nurses also monitored or reminded patients to perform self-care by asking patients whether their medication had been taken or whether the patients with nasopharyngeal cancer had performed nasal care.

(A primary nurse talked to Patient_4.86 during the hourly review)

Nurse: Did you administer the spray?

Patient: Yes, I did.

Nurse: And rinse your mouth (with the gargle)?

Patient: Yes.
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Nurse: How often do you administer the spray?
Patient: Twice.
Nurse: That’s not enough. It can be done 4-5 times (a day).

Instructions were often very instrumental with very little questioning about patients’ understanding. Patients were not often asked if they had other concerns or questions. The following example of an interaction regarding discharge planning illustrates a focused explanation of diet without checking the patient’s understanding or concerns.

(10:50am, A primary nurse entered Patient_4.15’s room for discharge education)

Nurse: Today you are being discharged. I am here to give you some information about what to do after discharge. You should have a high protein diet. Do you know what kind of food has much protein?
Patient: Yes, I do. Like fish, prawns.
Nurse: Correct. Drink more water and keep your mouth clean. You might find some changes in taste. Don’t eat pan-fried or deep-fried food and eat less sticky rice. It’s best if you do not go outside in the daytime to avoid ultraviolet radiation. Keep the skin of the radiotherapy site away from soap or facial cream.
Patient: OK, I got it.
Nurse: Have a light diet, such as steamed......
Patient: Pardon?
Nurse: Steamed fish. That’s all.
Patient: Thank you.

7.2.3.4 Summary

Apart from the nursing ward rounds in the mornings, primary nurses entered patients’ rooms during hourly reviews (rounding) or to provide patient
education, information or perform nursing treatments. However, interactions with primary nurses were still low frequency and low duration for most of the patients observed. Similar to the interactions between doctors and patients, primary nurses initiated questions about symptoms more frequently than patients volunteered this information. Of the 71 symptoms identified within nurse-patient interactions, psychological problems were a minority. Nurses seemed to be most concerned with symptoms associated with appetite or fatigue. In interactions related to information exchange, dialogue was generally brief or one-way with few observed attempts to engage patients in the exchange. Although there were relatively few decisions made between nurses and patients, in those interactions patients were given opportunities to express their preferences or opinions. Nurses involved patients in their self-care by monitoring, providing information or encouraging patients to participate with their treatment plans.

7.2.4 Communication behaviours influencing patients' participation in symptom management

Through the analysis of the patient-clinician conversation transcriptions, clinicians' behaviours that facilitated or impeded patients to participate in symptom-related communication and decision-making were identified. The behaviours described were identified at least once during the observation periods.
7.2.4.1 Clinicians’ communication behaviours facilitating patient participation

Facilitating behaviours could be categorised into three themes: establishing rapport and providing emotional support, facilitating information exchange and facilitating negotiated decision-making. The frequencies of specific behaviours in each theme are listed in Table 7.4 according to clinicians involved.

<table>
<thead>
<tr>
<th>Behaviours</th>
<th>Frequency (number of interactions)</th>
<th>Clinicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establishing rapport and providing emotional support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-introduction</td>
<td>46</td>
<td>Nurse</td>
</tr>
<tr>
<td>Encouragement</td>
<td>17</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Consolation</td>
<td>11</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Facilitating information exchange</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Checking own understanding</td>
<td>46</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Assessing patient’s understanding</td>
<td>35</td>
<td>Nurse</td>
</tr>
<tr>
<td>Obtaining additional information or concerns</td>
<td>12</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Following up cues</td>
<td>10</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Using assessment tools</td>
<td>1</td>
<td>Nurse</td>
</tr>
<tr>
<td>Facilitating negotiated decision-making</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explaining clinical issue</td>
<td>49</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Clarifying patient’s agreement or preference</td>
<td>41</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Discussing uncertainty</td>
<td>20</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Analysing the pros and cons</td>
<td>7</td>
<td>Doctor, nurse</td>
</tr>
</tbody>
</table>
7.2.4.1.1 Establishing rapport and supporting emotionally

During interactions, clinicians were observed to establish rapport with their patients or support patients emotionally through self-introduction, encouragement or consolation.

Nurses generally introduced themselves at the beginning of interactions if they were not known to the patient, however doctors did not introduce themselves, their teams or the purpose of their visit in any of the observed interactions.

Encouragement from clinicians was observed where doctors gave hope to patients by telling them their symptoms would be alleviated soon or that their symptoms were not unusual given the treatment they were receiving. Nurses encouraged their patients to participate in various activities such as listening carefully during patient education, to report symptoms as soon as possible, self-administer medications and maintain a diet rich in nutrition and so on. Nurses often encouraged patients by noticing their self-management and commenting on its effectiveness.

(8:38am, hourly review of Patient_4.53)

Nurse: Are you administering Biafine (Trolamine Cream)?

Patient: Yes, I do. I have had 13 courses.

Nurse: Your skin [on the radiotherapy site] looks very good.

Nurses used positive and negative examples of other patients to encourage patients to continue.
(Patient_4.76 was exercising her arm when the primary nurse entered the room.)

Nurse: You are exercising, aren’t you? Keep doing it. The patient in Bed* has difficulty in straightening her arm so that she can’t have radiotherapy right now. It is because she didn’t exercise her arm (after her surgery).

Patient: I see. (That’s why) I keep doing it.

Consoling behaviours by doctors and nurses were observed in the way they communicated with patients, using comforting words to reduce anxiety during nursing procedures or explaining why patients were experiencing particular symptoms. Again comparing patients’ experience with those of others was a common way of comforting patients who were experiencing symptom distress. One nurse comforted her patient in the following way:

(8:36am, hourly review of Patient_4.83)

Patient: (I’m) bloated, and it’s difficult for me to pass stools.

Nurse: Difficulty in passing stool is a side effect of the radiotherapy. You have only two lights left. (You are lucky… this symptom has occurred much later than for others’.

Doctors more commonly used explanation and rationale for symptoms to reduce patient anxiety.

Attending Physician: Are you being discharged (today)?

Patient: Yes. Doctor, can I ask you a question? Why do I have an abnormal sensation in my throat?

Attending: (The mucosa in your throat) is probably breaking down. It’s a kind of reaction to the radiotherapy. It’s impossible to have something bad (organisms) growing. Please don’t worry.

Patient: I see.
Attending: Please come back here for review in three months.
Protect you skin when you are at home. Keep (the site of radiotherapy) away from water (Patient_3.32).

7.2.4.1.2 Facilitating information exchange

During the interactions observed, clinicians used different skills to facilitate information exchange with patients. The behaviours identified included checking their understanding of patients’ concerns, assessing patients’ understanding of what was relayed to them, obtaining additional information, picking-up cues and using assessment tools.

Both doctors and nurses checked their own understanding to ensure they understood what patients wanted to express. This was achieved by repeating or realigning what they heard, as the following conversation illustrates:

Patient_3.7: These days it seems I am feeling that my legs (the discomfort of my legs) are getting worse.
Consultant: Getting worse?
Patient_3.7: Yes.
Consultant: You will get well gradually later. But it might be impossible for you to recover completely.
Patient_3.7: I see.
Consultant: Do you feel the numbness in your feet is getting better?
Patient_3.7: Still the same.
Consultant: Not worse?
Patient_3.7: No.

Nurses’ identification of patients’ understanding was achieved by asking patients whether they understood or asking them to repeat what they were
told. Doctors were rarely observed to check patients’ understanding of interactions because the ward rounds were so brief.

(8:37am, Patient_4.17 asked her Primary nurse how to administer a medication on her bedside table during the morning nursing ward round. The nurse came back to provide the explanation.)

Nurse: This medication is a gargling liquid. It should be used after meals, for example right now. Before you administer it, you should wash your mouth with warm water. Keep it for 10-15 minutes and then gargle in small amounts.

Patient’s family member: Gargle slowly.
Nurse: Correct. 3-5 times. Got it?
Patient: Got it.

Patient’s family member: What’s the amount each time?
Nurse: One mouthful, like 5-10ml. Do you understand?
Patient: Yes, I do.

Obtaining additional information or concerns included inquiries such as “Anything else?” or “OK?”. Patients were encouraged to ask if they needed assistance (“Please ask me when you need to”), or to use the call bell.

Clinicians often noted patient problems or symptoms through observation or picking up cues from patients or their families and would inquire about them without prompting from patients.

(Patient_4.97 was due to have chemotherapy on the observation day. The nurse noted the reddened skin on the patient’s hand during the morning ward round and commented.)

Patient’s family member: Can we apply any ointment on it?
Nurse: Yes, you can. Is it itching?
Patient: Yes, itching.
Nurse: Try not to scratch it.

Assessment tools were rarely used to explore patient symptoms. There was one occasion observed where the primary nurse asked the patient to score his pain using the Visual Analogue Scale (VAS) available on each patient’s bedside. No other assessment tools were observed to be used.

7.2.4.1.3 Facilitating negotiated decision-making

During interactions that involved some form of decision-making, four categories of facilitating behaviours were identified. These were: explaining the clinical issue, clarifying patients’ agreement or preference, discussing uncertainties and analysing the pros and cons of a treatment.

Both doctors and nurses were observed to provide clear explanations of clinical issues or concerns to clarify what was being decided upon and to provide their view of the problem. In these conversations, the reasons for a suggested option were explained. For example, in the case below the doctor explained the possible reason for a patient’s problem and the plan going forward.

Consultant: (Patient_3.10’s name), are you OK?

Patient: I’m very good. I told Doctor** too yesterday I felt very good. It works [the radiotherapy works so that the symptoms have obviously been relieved]. The only problem is that I have a stomach ache when I [open my bowels]. The stool is a little watery and a bit black.

Consultant: It’s a bit black, right?

Patient: I am taking Spore Powder. I am not sure (whether the Spore Powder has something to do with the black stool).
Consultant: Don’t take Spore Powder.
Patient: Yes, that’s why I stopped taking it.
Consultant: Let’s prescribe some examinations for you, for example the faecal occult blood Test.
Patient: OK.
Consultant: The Spore Powder is not suggested for you because it causes bleeding.
Patient: Really?
Consultant: One of the reasons is that Spore Powder causes bleeding and the other one is that it could affect your liver function.
Patient: OK. I really feel very happy these days (because I feel better). Thank you, doctor.

In discussions of clinical issues or symptoms, clinicians would suggest treatments in a way to elicit their patients’ preference or agreement with suggestions by providing them opportunities to express their opinions. One such example is illustrated below:

Patient_4.28’s daughter: It (my father’s skin on the neck) is becoming red here.
Nurse: Yes.
Patient’s daughter: How about the back (skin on the back of the neck)?
Nurse: Red too. Would you like me to prescribe something for you?
Patient_4.28: I have a sore throat.
Nurse: Would you like the Kangfuxin (a Chinese traditional medicine for treating ulcerous mucous membranes).
Patient’s daughter: Do you mean this? (daughter takes out a bottle of liquid medicine and shows it to the nurse.)
Nurse: Yes.
Sometimes the way forward for treating symptoms or identifying the source of a problem was uncertain. For example, when it was difficult for clinicians to clearly identify the cause of a symptom or recommend a medication that would be beneficial, there was discussion about the uncertainty so that patients were informed of the issues. Further, clinicians sometimes communicated the factors that would be considered when making a decision. In the example provided here, the patient had a raised temperature and he wanted to know whether he could still have radiotherapy that day:

*Nurse: I’ve asked the doctor. He didn’t say definitely that you could not have the radiation. It depends. When did you have the radiotherapy yesterday?*

*Patient_4.79’s family member: In the evening.*

*Nurse: Let’s measure the temperature at 6pm. If it’s above 38.5, I don’t think you can have radiotherapy.*

When a symptom treatment was offered, some clinicians provided information about the pros and cons of different options. In the example illustrated below, the relative value of two topical products to soothe the discomfort of radiation burns included disclosure of the cost to the patient.

*Nurse: Do you apply the Trolamine every day?*

*Patient_4.29: No, I don’t.*

*Nurse: Do you want to? There is another agent, a spray. It costs 1,000-2,000 RMB for each radiotherapy course and can be applied before, during or after the radiotherapy. However the Trolamine can only be applied when your skin feels burned. The cost of the spray is out of your pocket. I’ve introduced both of them to you but it’s up to you to decide which one to choose.*
7.2.4.2 Clinicians’ communication behaviours impeding patient participation

Clinicians’ behaviours that hindered patient participation in symptom management were those that were indicative of discordant relationships between patients and clinicians and poor communication affecting information exchange. The frequencies of the characteristics of these behaviours are summarised in Table 7.5 according to the clinicians involved.

Table 7.5 Clinicians’ communication behaviours impeding patient participation

<table>
<thead>
<tr>
<th>Behaviours</th>
<th>Frequency (number of interactions)</th>
<th>Clinicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discordant relationships between patients and clinicians</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denying patients’ feelings</td>
<td>2</td>
<td>Nurse</td>
</tr>
<tr>
<td>Criticising patients</td>
<td>1</td>
<td>Doctor</td>
</tr>
<tr>
<td>Poor communication affecting information exchange</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changing topic or ignoring concerns</td>
<td>22</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Using professional language</td>
<td>16</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Giving normalised responses</td>
<td>12</td>
<td>Doctor, nurse</td>
</tr>
<tr>
<td>Brief responses</td>
<td>4</td>
<td>Nurse</td>
</tr>
<tr>
<td>Interrupting</td>
<td>2</td>
<td>Doctor</td>
</tr>
</tbody>
</table>

7.2.4.2.1 Discordant relationships between patients and clinicians

Opposed to behaviours establishing rapport, discordant relationships occurred when patients’ feelings were denied or patients were criticised. Although these behaviours were uncommon during the observations they
were present. An example is the response from a nurse to a patient’s comments about feeling unwell. The nurse’s response implied that it was not possible to have this symptom experience before the specific medication is administered without considering other possible factors that may contribute to the symptoms.

(Nurse_2.13 was administering a subcutaneous injection for Patient_4.20)

Nurse: This injection is to facilitate the growth of leucocytes – white blood cells.
Patient: OK.

Nurse: You might get a low fever, but just around 37.5, and feel sore and ache all over.
Patient: I am feeling sore in my throat now.
Nurse: I haven’t even administered the injection.
Patient: I am probably weak. The chemotherapy reaction is very severe.

The following interaction occurred during the daily doctors’ ward round and was heard by other patients, family members, doctors and nurses. The patient was visibly embarrassed by this exchange. The criticism was related to the patient’s delay in seeking treatment for bowel cancer.

(Patient 3.3 talked with his doctor about blood in his stool)
Consultant: How long have you had this problem with your stool?
You didn’t come to the hospital until the tumour was sufficiently big.
Patient: (I didn’t notice it until) I felt there was something pressing down (in my anus).
Attending: Could it be touched?
Consultant: This is a problem with the media that tells the public that a lot of advanced patients have been cured by doctors. Therefore, many patients think they can be cured no matter how advanced their disease is. (Turned to other doctors at the bedside). This is like a pupil who has extremely poor grades in school. Is it possible for the pupil to get better grades even he goes to a good school?

7.2.4.2.2 Poor communication affecting information exchange

Barriers to efficient information exchange were identified when clinicians exhibited communication behaviours such as: changing topic or ignoring a patient’s comments, using professional language (or jargon), normalising patients concerns, providing brief responses or interrupting patients.

The most frequent blocking behaviour identified in the observations was changing topic or ignoring a patient’s concerns. In these situations, when patients reported a symptom or problem to their doctors or nurses, they did not receive any response. This behaviour was observed in both doctors’ and nurses’ interactions. The conversation below is an example of this failure to respond to a patient’s concerns expressed to his primary nurse.

Nurse: How do you usually perform those exercises?
(Patient 4.25 showed the motion)
Nurse: Great. You need to drink more.
Patient: It’s hard to swallow.
(The nurse did not respond to the swallowing symptom, and proceeded with the education)
Nurse: (Pointing to a sign on the wall). This is a sign about prevention of falls. And there are armrests and non-slip mats in the bathroom.
Clinicians sometimes used professional terms which patients had difficulty in understanding. Terms, such as “Irritable Bowel Syndrome”, “support treatment”, “ER (estrogen receptors)” and “PR (progesterone receptors)”, or specific medication names were often used in conversations with patients without checking patients’ familiarity with the terms.

One type of response to patients’ concerns was categorised as ‘normalising’ symptom experience. This referred to comments by clinicians that a patient’s symptoms were ‘normal’ side effects of their cancer treatment rather than engaging with the patient to determine symptom distress or providing further explanation. While these symptoms were indeed very common side effects of radiotherapy or chemotherapy and almost inevitable, statements such as the one illustrated below appeared to close off any further discussion about this particular symptom.

**Consultant: Are you OK?**

**Patient 3.1:** I’m fine but I have pain and itching in my anus.

**Consultant:** There always are some side effects of radiotherapy. It’s normal.

Very brief responses to patients’ concerns were observed to end interactions that could potentially have been used to engage patients in their care. Brief responses or explanations did not provide sufficient information.

**Patient_4.20:** My main problem is the low white blood cell count.

**Nurse:** Yes, it is. The count will increase quickly if you eat more.

**Patient:** I have no appetite.

**Nurse:** You can have frequent and small meals.
In this case, the nurse neither gave the reason why eating more could increase the blood count, nor explained how to achieve frequent and small meals.

Interrupting patients when they were describing symptoms was another potential barrier to effective communication. In these cases, patients were not given the opportunity to express their concerns fully.

*Patient_3.15:* By the way, my nose is not stuffed up any more, but...... *(interrupted by the consultant)*

*Consultant:* You have to keep the nasal douche even though you can breathe properly. Saline does not work as well.

*Patient:* But it will bleed after douching.

*Consultant:* It’s good to douche 2-3 times per day with less of the liquor.

### 7.2.4.3 Family and patient peer influences on patient participation

In addition to clinicians’ communication behaviours, other factors found to have some impact on the involvement of patients were the presence of family members and other patients in shared-rooms.

Some family members accompanying patients were involved in conversations with clinicians. Family members reported patients’ symptoms or problems, asked or answered questions, and expressed opinions or suggestions. The following is a conversation between two doctors and a 75-year-old patient and his daughter.

*Consultant:* Grandpa, you had the radiotherapy yesterday, didn’t you?
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Patient_3.5: Yes.
Consultant: The chemotherapy was administered?
Patient’s daughter: Yes.
Consultant: Do you feel unwell?
Patient: I’m fine.
Consultant: Nothing bad?
Patient: (shook his head)
Consultant: That’s fine. Do you have......any other medical diseases? Hypertension, heart disease?
RMO: No.
Patient_3.5’s daughter: He doesn’t have any other diseases. ...... I’m a little worried that he isn’t getting enough nutrition.
Consultant: You need to eat more. No diabetes? Eat more. I can’t prescribe any preventive medicine. It is prohibited to prescribe it.
Patient’s daughter: There was a suggestion by Doctor*. Is there any nutrient solution he can have?
Consultant: No intravenous drip. He has to eat by himself. There is no indication to prescribe an intravenous drip. Otherwise we’ll be criticized.
(The patient and his daughter Laughed.)

Some conversations were observed to only occur between clinicians and patients’ relatives without any involvement of patients themselves. And in other conversations, the clinicians changed their focus to relatives, preventing patients from participating in the conversation. A nurse talked to her patient (Patient_4.79) through the call bell:

** (Patient_4.79’s name), I’ve got your blood test results. Your white blood cell counts are lower (than normal value), and platelet counts are lower......Your daughter is coming. I’ll talk to her.
(The nurse closed the call before the patient said anything.)
The wards did not provide for a separate, private space for patients to discuss symptoms or concerns. All the patient rooms in the observation were shared by four patients who mostly had similar diagnoses. When there was a conversation between a patient and his/her doctor or nurse, other patients sometimes took part in it to help the patient report symptoms or ask their own questions. Patients nearby communicated and influenced each other occasionally. There were instances when one patient was taking a medication that appeared to be effective so other patients in the room asked for that medication from their doctors or nurses. An example is illustrated below:

*Patient_3.58:* I have a sore throat.

*Attending:* It is possible if the radiation reached your throat.

*Attending said to Patient_3.58’s RMO:* Prescribe some Kangfuxin for him.

*Patient:* (Other) patient said this medication is good (pointing to the medication on the bedside table of a neighbouring patient).

*Attending:* This is Kangfuxin (I just prescribed it for you).

### 7.2.4.4 Summary

A range of doctors’ and nurses’ behaviours that facilitated or impeded patients to participate in the communication and decision-making related to symptom management were identified. Facilitating behaviours of doctors and nurses involved establishing rapport and providing support, facilitating information exchange and negotiated decision making. Behaviours that impeded participation were predominately related to poor communication
affecting information exchange. Although not common, discordant relationships between patients and clinicians blocked participation.

7.2.5 Patients’ preferred and experienced roles of participation when interacting with doctors/nurses

After each observation, patients and their doctors (RMO) or patients and their primary nurses were asked to report their perceptions of patients’ preferred and actual participatory roles during the observation period. The findings regarding patients’ participatory roles are presented from the perspectives of patients and doctors/nurses, respectively, in this section.

7.2.5.1 Patients’ preferred and experienced participation when interacting with doctors/nurses

The distribution of patients’ self-reported preference and actual experience of participation in decision-making about symptom management within doctor-patient interactions is displayed in Figure 7.4. When asked about the
role statement they preferred when interacting with their doctors, over half of the patients (n=43, 53.1%) preferred their doctors to decide for them after considering patients’ opinions and 21 patients (25.9%) did not want to leave all decisions to their doctors. None of the 81 patients preferred to make the final decisions independently. In terms of the distribution of actual participation, the number of patients in Passive (n=29, 35.8%) and Passive-shared (n=46, 56.8%) roles was slightly higher than the number who preferred those categories, and less patients (n=2, 2.5%) reported that their actual participation in decisions were made in collaboration with doctors than would have preferred. Based on the weighted Kappa analysis, patients’ actual participation level moderately agreed with their preference (Kw: 0.53, SE: 0.10, 95%CI: 0.32 to 0.73).

When interacting with nurses, many patients preferred decisions about symptom management be made in collaboration with nurses. The role statements of passive-shared, collaborative and active-shared were the preferred roles of 39.3% (n=44), 32.1% (n=36) and 17% (n=19) of patients respectively. Patients who preferred absolute passive roles (n=12, 10.7%) outnumbered those who preferred an absolute active role (n=1, 0.9%). Four patients did not report their actual experienced roles because they felt that they had not had interactions with nurses related to symptom management.

The roles patients experienced most were the passive-shared (n=47, 43.5%), collaborative (n=26, 24.1%) and active-shared (n=18, 16.7%) roles (See Figure 7.5). A substantial agreement was identified (Kw: 0.75, SE: 7.85, 95%CI: 0.56 to 0.94).
As shown in Table 7.6, the median of patients’ preferred participation roles in interactions with doctors were not the same as their preference for interactions with nurses (P<0.001). A significant difference was also found when comparing patients’ actual experience of participation in doctor-patient interactions and nurse-patient interactions (P<0.001). The findings indicated that patients had a more active preference and actually experienced more active participation when they interacted with nurses than with doctors.
Table 7.6 Comparison of patients’ reported level of participation in interactions with doctors and nurses

<table>
<thead>
<tr>
<th></th>
<th>Preference for participation</th>
<th>Actual participation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median $(P_{25}, P_{75})$</td>
<td>P</td>
</tr>
<tr>
<td>With doctors</td>
<td>2 (1,2)</td>
<td>0.000*</td>
</tr>
<tr>
<td>With nurses</td>
<td>2.5 (2,3)</td>
<td></td>
</tr>
</tbody>
</table>

*P<0.001

7.2.5.2 Doctors’/nurses’ perceptions of patients’ preferred and experienced roles in participation

The distribution of RMO reports regarding their patients’ preferred and actual roles of participation is displayed in Figure 7.6. Thirty-three (41.8%) patients were estimated to hold a passive-shared role preference. Only one patient (1.3%) was thought to prefer an active role. In terms of the perceived level of actual participation, the largest category was still of the passive-shared group (n=30, 38%), followed by the collaborative group (n=26, 32.9%).

![Figure 7.6 Patients’ preferred and experienced roles in participation from doctors’ perspective](image-url)
No patient was considered by doctors to actually make decisions completely by themselves. Substantial agreement was identified in doctors’ estimates of preferred and actual participation, with the coefficient of Kw 0.69 (SE: 0.11, 95%CI: 0.47-0.91).

Figure 7.7 displays, from the nurses’ perspectives, the distribution of patients’ preferred and actual participation in symptom management. Nurses’ perceived that most patients preferred a collaborative (n=32, 28.6%) or active-shared role (n=33, 29.5%). Nine (8%) patients were thought to prefer an active role. Regarding nurses’ perceptions of patients’ actual participation level, the numbers in each role statement category were similar except for the numbers in the passive group which decreased from 16 (14.3%) preferred to 7 (6.3%) actual. The coefficient of Kw was 0.70 (SE: 7.52, 95%CI: 0.52 to 0.89), indicating substantial agreement in nurses’ estimates of preferred and actual participation.

![Figure 7.7 Patients’ preferred and actual level of participation from nurses’ perspectives](image-url)
7.2.5.3 Agreement between patients’ and clinicians’ responses to patients’ participatory role

The responses of patients and clinicians regarding patients’ preference for and actual experience of participation in symptom management were compared to examine whether doctors and nurses could estimate their patients’ preference correctly and had similar perceptions of their patients’ actual participation as patients themselves. The weighted kappa coefficients are displayed in Figure 7.9. In terms of patients’ preference, the level of agreement was found to be poor in the comparisons between patients’ and doctors’ responses (Kw: -0.09, SE: 0.11, 95%CI: -0.30 to 0.13) and slight in the comparison between patients’ and nurses’ responses (Kw: 0.12, SE: 1.37, 95%CI: -0.05 to 0.29). The strength of Kw implied that nurses were closer at estimating patients’ preferences than doctors, however the 95% CIs of the two Kw coefficients overlapped which means the difference between the Kw values was not significant. In terms of patients’ actual participation experience, the responses of patients were quite different from the responses of their doctors (Kw: -0.23, SE: 0.09, 95%CI: -0.40 to -0.05) and their nurses (Kw: -0.06, SE: 0.08, 95%CI: -0.22 to 0.10). The Kw values were indicative of poor agreement.
Figure 7.9 Agreement between patients’ and clinicians’ responses

More detailed data in the comparisons between patients’ and clinicians’ responses in respect to patients’ level of participation are displayed in Figure 7.8. Examination of the contrasts shows that in estimations of preferred and actual participation, the majority of clinicians perceived patients to be more

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<table>
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<th>Actual participation: Patients Vs Nurses</th>
<th>Clinicians perceived more active than patients reported</th>
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<td>Preference: Patients Vs Nurses</td>
<td>Clinicians’ and patients’ responses agreed</td>
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<td>Actual participation: Patients Vs Doctors</td>
<td>Clinicians perceived less active than patients reported</td>
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Figure 7.8 Comparison between patients' and clinicians' responses regarding patients' preferred and experienced participation
active than patients themselves reported. The results indicated that both doctors and nurses tended to overestimate their patients’ participatory preference and actual level of participation.

7.2.5.4 Summary

Patients preferred more active participation with nurses than with doctors and they reported that they did experience more participation in nurse interactions. Patients’ participatory preferences and actual level of participation were overestimated by both doctors and nurses and there was poor agreement between patients’ preferences and experience and doctors’/nurses’ estimations.

7.3 Discussion

The nature of patient and clinician interactions were examined to identify the frequency of symptom conversations, who initiated these conversations and opportunities for patient participation in exchange of information and expression of preferences in relation to decisions for treatment. Symptom management was clearly a care priority, observed in 92.6% of doctor-patient interactions and 55% of nurse-patient interactions. The high percentage of interactions related to symptom management highlighted the importance of exploring patients’ roles in this activity. Doctors and nurses initiated symptom conversations in approximately 75% of symptom related interactions.

The naturalistic observations uncovered the low-frequency, low-duration nature of conversations that occurred in clinician interactions overall, both
with doctors and nurses. Most interactions lasted less than one minute providing limited opportunity for comprehensive exchange of information and identification of patient preferences in relation to treatment decisions. The limitations associated with the context of interactions were evident in the almost exclusive focus on physical symptoms virtually to the exclusion of symptoms related to psychological or mood related problems. Further, the limited time available provided few opportunities for comprehensive exchange of information between patients and clinicians. Nevertheless, in interactions related to decisions for treatment the majority of patients had the opportunity to state their preferences or at least agreement with the treatment offered. A minority of patients chose not to offer their opinions.

7.3.1 Characteristics of patient-clinician interactions

The finding that doctors and nurses initiated the majority of symptom discussions is not consistent with the findings from the patients’ self-report survey in Phase 2 where 68% (n=100) of patients indicated they usually took the initiative to report their symptoms rather than wait until they were asked. It is understandable that during the morning ward rounds clinicians were usually the dominant persons who started conversations with questions about patients’ conditions. Patients may not want to initiate discussions because of the brevity of the rounds and the number of people attending. It should also be noted that only medical rounds were observed in exploring doctor-patient interactions in this case study, however patients could find their doctors on the wards at other times if they needed to. Doctors in the
individual interviews also confirmed that patients could speak to them in their offices after the morning ward rounds. Another possible explanation for the low number of observed patient-initiated symptom discussions, is that according to the patient interviews, patients tended to initiate symptom discussions when their symptoms were severe and therefore in the context of the brief ward rounds, patients may not have felt comfortable discussing symptoms that were less severe. It is less clear why so few patients initiated symptom discussions with nurses. Patients were seeing nurses on morning nursing rounds and at least hourly during patient rounding, yet only approximately 25% of patients initiated symptom discussions. Again, the brevity of these interactions may have been a significant factor.

As well as the relatively low number of patient-initiated symptom discussions, was the finding that physical symptoms appeared to be the focus of discussions with nurses and doctors. Gastrointestinal and respiratory symptoms were the most commonly discussed symptoms and nurses were more likely to interact with patients about diet and rest. Given the low duration of interactions, it is not surprising that psychological or mood problems were rarely discussed. This finding is not unique to the Chinese context. In an Australian study, Cohen observed cancer patients in nursing interactions and also found that symptom assessment involved clinicians asking patients specific questions and symptom discussions were limited to identifying the presence of physical symptoms for which treatments were readily available (Cohen, 2012). Limited symptom assessment is a barrier for the comprehensive understanding of patients’ symptoms and effective
symptom management (Kirkova et al., 2006). The risk is that patient symptoms will go unrecognised if reliance is on clinicians asking patients about specific symptoms. In a recent study by Casey et al. (2016), 53% of symptoms identified by cancer patients as important to them were not documented by their clinicians, and a positive relationship was found between symptoms that were documented and those treated.

The majority of interactions between nurses and patients were focused on monitoring patient progress through rounds and review, performing nursing treatments or medication administration. Approximately 21% of interactions were initiated for the purpose of providing information or education. Nurses supported patients in the provision of self-care and medication self-administration through monitoring and reminders although the relative number of activities related to support of self-care was low; 21 of the 290 interactions observed were related to self-care. Indeed, self-care in activities of daily living are recognised as a form of patient participation (Kvangarsnes et al., 2013; Latimer, Chaboyer, & Gillespie, 2014; McInnes et al., 2014; Thyssen, & Beck, 2014). Nurses clearly played a different role to doctors in relation to supporting patient participation. During nurse-patient interactions, 85.7% of patients had family members present. There was however little difference between doctors and nurses in the frequency in which patients initiated symptom interactions or the relative proportion of physical versus psychological symptoms discussed. This was unexpected because the primary nursing model of care in the case study wards and length of stay of patients in the wards would suggest opportunity for patients
to report symptoms and seek and receive psychosocial care. The findings that in 54.5% of interactions nurses spent less than one minute with patients and in 8% of interactions there was no conversation between nurses and patients provides some explanation. Further, when nurses engaged in symptom discussions with patients, the dialogue tended to be unidirectional, explanations were brief with few attempts to engage patients in the exchange.

Formal ward rounds and nurse rounding serve an important function for sharing information between patients and clinicians, however the brevity of the rounds, the tendency for many patients to report their symptoms only in response to doctors’ or nurses’ inquiries, and the generally brief explanations received from clinicians has implications for participation. Flow of information between health professionals and patients is recognised as a fundamental aspect of participation (Kolovos et al., 2014b; Sahlsten et al., 2008; Sahlsten et al., 2005b; Sahlsten et al., 2009) and doctors’ ward rounds and nurses’ hourly rounding are the main opportunities patients have to exchange information. For example, Weber (2007) found that medical information exchange was the main topic of interactions in a study of 71 ward-rounds on two internal medicine wards in Switzerland. Interviews with 14 Swedish inpatients also revealed that exchanging information was one of the main themes relating to patients’ experience of ward rounds (Swenne, & Skytt, 2014).
Decisions related to symptom management were made in approximately 40% of patient-doctor interactions, but in less than 12% of nurse-patient interactions. In making decisions about symptom treatment, doctors and nurses mostly sought patients’ opinion about the decision or at least some form of assent. Patients’ responses were variable; not all patients offered their preferences or opinions to clinicians when given the opportunity to do so. There are several potential explanations for the variability in patients’ responses to opportunities to participate. In the majority of interactions where decisions were made, clinicians would make a recommendation for treatment and seek patients’ opinion. It can be difficult for patients to provide an alternative to clinicians’ recommendations. Frongillo (2013) found that when clinicians made specific recommendations for treatment to patients with breast cancer, patients reported lower levels of participation in decision making than those who did not receive clinicians views first.

Checking patients’ agreement can be regarded as a way of involving patients in decision making however it is a low level of participation. Frongillo (2013) suggested that more negotiation is needed that includes the discussion of pros and cons of different treatments and eliciting patients’ goals and treatment preferences. The survey and interview findings identified that for some patients, participation in decisions relating to their management is difficult or not their preferred option. Patients’ perceived lack of medical knowledge is a known barrier to participation in decision-making (Larsson et al., 2011a; Rainey et al., 2013; Vestala, & Frisman, 2013), as is lack of understanding of what is being asked (Ekdahl et al., 2011;
Malmgren, To¨rnvall, & Jansson, 2014) (Cohen, & Botti, 2015). Facilitation of participation requires that clinicians recognise patient-perceived barriers to participation and provide opportunities for patients to participate, but this would require substantial changes to the processes of interactions observed.

### 7.3.2 Facilitators and barriers to patient participation in symptom management

Data related to the facilitators and barriers to participation in symptom management were derived from analyses of the context of interactions and the communication behaviours of clinicians during interactions. The brevity of observed interactions affected the depth of information exchange and the overall opportunity for patients to participate fully in their symptom management. Doctors and nurses conducted morning ward rounds separately and nurses did not attend the doctors’ rounds therefore there were few observed opportunities for patients and their families to interact with the health care team as a whole. The finding in this study of low-frequency and low-duration of interactions between patients and clinicians seemed to be more pronounced than reported in Australian studies (Cohen, 2012; McTier, Botti, & Duke, 2014). In McTier’s study, nurses in a cardiothoracic surgical ward interacted with their patients an average of 3.8 minutes per patient in a 2-hour observation period during which clinical handover and double staffing occurred. Cohen reported doctors spent a median of 4.1 minutes and nurses spent a median duration of 2.1 minutes
per interaction with their patients during a 2-hour observation period in an oncology/haematology ward.

Clinicians’ work load might be a reason for the different frequency and duration reported between China and Australia. The average number of patients cared for by each nurse per shift was 3 (SD, 0.5; range, 2 to 4) in McTieer’s study although the patients were in the postoperative period after cardiothoracic surgery. In contrast, primary nurses in the current study were responsible for 12 to 16 patients and every doctor team had 17 to 26 patients. Given the apparent higher clinical workload in the Chinese hospital context, it might be not feasible for clinicians to spend more time with their patients in one interaction. Time pressures are known to result in brief interactions with clinicians (Cohen, & Botti, 2015) and patients find it difficult to play an active role in brief ward rounds (Swenne, & Skytt, 2014). Whether longer interactions alone improve symptom communication is not known and needs to be researched further.

There was evidence that clinicians attempted to establish rapport and provide support for patients during interactions. These were apparent when clinicians introduced themselves, provided encouragement and consolation for patients experiencing symptom distress. Knowing who clinicians are and their role in patients’ care is essential for patients to be able to communicate effectively (Ekdahl, Andersson, & Friedrichsen, 2010; Larsson et al., 2011a). Nurses tended to introduce themselves and their role as a matter of routine because it was a quality and safety requirement of the case hospital. Doctors
did not introduce themselves most likely because patients had been in the hospital for at least 7 days and treating doctors were known to them. The Phase 2 survey data confirmed that 90% of patients had received information about the doctors and nurses responsible for their care. Providing encouragement and consolation were considered facilitators for patient participation because these behaviours improve rapport between patients and clinicians (Eldh, Ekman, & Ehnfors, 2006, 2008; Larsson et al., 2011a, 2011b; Ye, 2011; Zhang et al., 2008).

Relatively uncommon were behaviours that created discordant relationships. These were evident when clinicians denied patients’ feelings or were critical of patients indicating lack of respect and minimising trust. The importance of respect and trust in clinical relationships in term of clinicians’ behaviours is prevalent in the western literature (Eldh, Ekman, & Ehnfors, 2010; Sahlsten et al., 2009), however the emphasis in the Chinese literature is on patients’ obligations to show respect to clinicians. For example, a grounded theory study conducted in China examined the relationships between patients’ trust in hospitals and health professionals as facilitators for patient participation in safety (Ye, 2011). In another study, patients’ trust in clinicians, as a mediator between patient participation and treatment outcomes, was shown to have positive effects on participation and treatment outcomes (Shen, 2010). This notion of unidirectional respect and trust has been influenced by Confucianism which regards benevolence and care as its core values; doctors who abide by high moral principles, are owed a fiduciary trust (Hou, & Xiao, 2012).
Chapter 7 Interactions between clinicians and patients in symptom management

The presence of family members and other patients impacted on patient-clinician interactions. Family members were present with 25.9% of patients in doctor-patient interactions and 85.7% of patients in nurse-patient interactions. The high prevalence of attendance by family members is both a function of the nursing shortage in hospitals in China and Chinese traditional culture where family members usually take part in patient care (Chang, 2001; Hui, Wenqin, & Yan, 2013). Clinician interactions with family members were not common however when they did occur, family members either helped patients communicate their symptoms or spoke on behalf of patients, sometimes depriving patients the opportunity to talk directly with clinicians. Li (2014a) outlined three basic clinical decision-making modes for medical decision-making in China. These are patients' autonomous decision-making mode, family decision mode and patient and family codetermination. Family member involvement provides support for patients, enhances information exchange and decision making, however family decisions can exclude patients and not account for their wishes or preferences (Li et al., 2014a; Xu, 2013). There was evidence in the few interactions observed with family members that clinicians, doctors in particular, tended to interact with family members to the exclusion of patients.

Communication behaviours that emerged as facilitators and barriers to information exchange and decision making were about the effectiveness of applying skills in listening, questioning and clarifying patients’ understanding of their situation and the information provided. When decisions were made about symptom treatments there were evident attempts to explain the
clinical issue, clarify patients’ agreement or preference, discuss uncertainty and examine the benefits of particular plan. Nurses more so than doctors would assess patients’ understanding and ask patients to repeat back information to ensure that they had understood. Time pressures however, seemed to play a part in the effectiveness of clinicians’ communication. The behaviours exhibited included changing topic, interrupting, ignoring patients’ concerns or normalising particular symptoms so that they could be dismissed. These behaviours are effective in blocking further conversation, removing opportunities for patients to contribute their experience, ask questions and participate in decision-making.

Patient participation is elicited through effective communication. Recognised barriers to effective communication by nurses include ward culture, lack of knowledge and experience and resource issues such as time constraints and staff shortages (Charlton et al., 2008; McCabe, 2004). Time constraints also affect communication by doctors (Li, Ye, & Jiang, 2012; Zhang et al., 2006; Zhang et al., 2008). It does take time to establish relationships with patients, explain medical/technical information, listen to patients’ and families’ experience and concerns and collaborate in setting treatment plans however, Chan et al. (2011) challenge the notion that effective interactions require ‘long and attentive communication’ (p. 1174). They argued that informal communication that is sequential, cemented through successive encounters can establish positive nurse-patient relationships and opportunity for therapeutic communication. Hagerty and Patusky (Hagerty, & Patusky, 2003) identified the importance of each interaction patients have
with nurses no matter how brief, as steps towards building a therapeutic relationship.

In summary, the overall impression of the analyses of interactions between patients and clinicians was one of paternalism, where paternalism is defined as “a system under which an authority undertakes to supply needs or regulate conduct of those under its control in matters affecting them as individuals as well as in their relations to authority and to each other.” (Paternalism, n.d.). This was most pronounced in interactions between doctors and patients during morning ward rounds where the intent was highly task focused, that is, to perform a brief review of patients’ progress so that treatment could continue however, it was also evident in nurse-patient interactions. There was a tendency by both nurses and doctors to monopolise conversations without providing opportunities for patients to participate and many nurses performed task only interactions. Paternalistic interactions are not uncommon in clinical practice where patients feel that opportunities for participation are restricted (Tobiano et al., 2015b) or that clinicians make decisions and reject patients’ views (Larsson et al., 2011b).

### 7.3.3 Congruence between patients’ and clinicians’ perceptions of preferred and experienced participation

The findings of the post-observation survey of preferred and actual participation identified that 64% of patients in doctor-patient interactions and 56% of patients in nurse-patient interactions preferred their doctors or nurses to make decisions for them. There was a significantly higher
preference for passive interactions with doctors than with nurses. Indeed, patients reported more passive experienced participation with doctors than with nurses and moderately achieved their preferred participation with doctors but substantially achieved their preferred participation with nurses. Nurses and doctors however, overestimated their patients’ participatory preference and actual level of participation during the symptom management interactions.

The passive preference by patients for participation in interactions with doctors and nurses was consistent with the findings in the survey in Phase 2. Patients in both phases perceived that they had achieved their preferred level of participation. The findings suggest that a clinician dominant model is acceptable to patients and this is consistent with the findings of Chinese studies focused on patients with colorectal cancer (Hou et al., 2014) and with chronic hepatitis (Zhang et al., 2011).

That patients preferred, and achieved, a relatively less passive role when they interacted with nurses than with doctors is an important finding in this study. Analyses of data of the naturalistic observations and individual interviews provide some insights for understanding this.

Patients’ preference for participation might be influenced by the types of decisions required. As observed in doctor-patient interactions, patients often faced decisions related to medical examinations or treatments, while in nurse-patient interactions, patients mostly dealt with decisions about nursing care, medication self-administration or self-care activities. Both
patients and clinicians stated, in the individual interviews, that interactions with doctors about medical decisions required professional knowledge and this may inhibit patients from active participation. Doherty (2005) also found that patients wanted more involvement in decision-making with nurses than with doctors stating that nurses were easier to access and that decisions involving nurses often related to issues such as self-care in which patients preferred more involvement. Nurses’ greater accessibility than doctors was confirmed in Swenne & Skytt’s study of patients’ experience and perceived barriers to participation in ward rounds (Swenne, & Skytt, 2014). Quantitative comparisons of patients’ preferences for participation in their interactions with doctors and nurses have seldom been reported in previous studies with the exception of one study in Finland which identified a significant difference between the perceived importance of participation in decisions about cancer treatment and nursing care (Sainio, & Lauri, 2003), again with a preference for more participation in nursing care.

In addition, during the interviews, patients stated that they engaged in more communication with nurses than with doctors. The findings of the naturalistic observations provided evidence that patients were given opportunities to express their preferences or opinions in nurse-patient interactions, although there were relatively few decisions observed to be made between nurses and patients. Hence, opportunity and nurses’ communication style might contribute to patients’ more active perceived participation in nurse-patient interactions. Supporting this was Mohsin-Shaikh’s (2014) and Davis’ (2012) findings that nurses were more likely than
doctors, to involve patients in medication safety by supporting them to ask questions.

This study identified that both doctors and nurses tended to overestimate their patients’ participatory preference and experience again, in accordance with previous, although limited, studies comparing patients’ and clinicians’ perceptions of patients’ preferences for participation in decision-making. Wilkinson (2008), in an investigation of 152 acute medical inpatients and their doctors, found there was little agreement between patients’ preferences and their doctors’ predictions of those preferences. Overestimation was found in 48.7% of pairs and underestimation in 28.9% of pairs. Similarly, in Florin’s study (2006a), comparing patients’ with their RN's perceptions, patients preferred to be more passive in decision making regarding general nursing needs as well as physical and psychological needs than RNs expected. In terms of patients’ actual level of participation, clinicians also perceived their patients were more active than patients’ themselves experienced. Again, Timonen and Sihvonen (2000) also found that nurses reported patients took a more active part in bedside reporting than patients experienced.

This lack of congruence between patients’ reported preferences and experience and those estimated by their clinicians may be explained in several ways. Preference for participation is not an explicit assessment for hospitalised patients and there are few validated tools or methods for clinicians to use in order to assess patients’ participatory roles. Patients need
to be asked directly and frequently about their preferences (Wilkinson et al., 2008); (Florin, Ehrenberg, & Ehnfors, 2006a) because patients’ preferences may vary depending on the context and issue.

Inaccuracies in clinicians’ perceptions of patients’ actual participatory experience are congruent with the survey findings in Phase 2 where doctors and nurses thought they motivated their patients to participate in treatment and care more than patients had experienced. This might be because patient participation is not understood exactly in the same way by patients and clinicians. For instance, patients in previous studies have described participation as having knowledge and understanding rather than simply being informed (Eldh, Ekman, & Ehnfors, 2010). Clinicians may hold a more narrow perception of patient participation and therefore be unaware that patients are not achieving their participation preference (Elkin et al., 2007). For example, in Pieterse’s study (Pieterse et al., 2008), and the current study, some clinicians understood patient participation as associated with informed consent procedures. If the notion of participation is narrowly defined, clinicians may believe that they have involved their patients by providing information about treatment or nursing care while patients may not recognize this as an opportunity to participate.

7.4 Conclusions

The naturalistic observations identified low frequency and low duration doctor-patient and nurse-patient communication during the morning ward rounds and nurses’ working hours. Doctors and nurses tended to dominate
interactions and initiated questions about symptoms more frequently than patients volunteered their symptoms. Gastrointestinal symptoms were the most common symptom group discussed by doctors and nurses whereas discussion of psychological symptoms were rarely initiated by clinicians or patients. In interactions related to information exchange, dialogue was generally brief or one-way with few observed attempts to engage patients in the exchange. In interactions related to decision making, patients were often given opportunities to express their preferences or opinions to nurses whereas this was less evident in doctor-patient interactions and patients missed opportunities to participate. Nurses involved patients in their self-care by monitoring, providing information or encouraging patients to participate with their treatment plans. A small number of family members were observed to participate in self-care discussions and made decisions on behalf of patients.

Doctors’ and nurses’ behaviours facilitating patient participation during interactions involved establishing rapport and providing support, facilitating information exchange and negotiated decision making. Behaviours that impeded participation were predominately related to poor communication affecting information exchange. Discordant relationships between patients and clinicians also blocked patients’ participation.

More than half of the patients in the doctor-patient interactions and nurse-patient interactions preferred to leave decisions to their doctors or nurses, but patients displayed less passive preference when they interacted with nurses. Most of the patients achieved their preference for participation, with a moderate agreement in doctor-patient interactions and a substantial
agreement in nurse-patient interactions. Both doctors and nurses tended to overestimate their patients’ participatory preference and actual level of participation during the symptom management interactions.

This is the final chapter reporting of the analyses conducted. In Chapter 8, integration of the findings reported in the four findings chapters, implications for clinical practice, strengths and limitations, and suggestions for future studies are presented.
CHAPTER EIGHT

Integration and conclusions

This purpose of this research was to advance our understanding of the enablers and barriers to patient participation in symptom management in acute cancer care environments. It focused on exploring the synergies between patients’ and clinicians’ perceptions of patient participation in a Chinese acute cancer care setting.

A mixed-methods, single case study (one institutional) design was used. Surveys and semi-structured interviews explored patients’ and clinicians’ perceptions of patient participation in symptom management; naturalistic observation was employed to describe patients’ and clinicians’ behaviours during interactions related to symptom management. The study findings provide a comprehensive insight into the phenomenon of patient participation within a specific clinical setting from both the patients’ and clinicians’ perspectives.

This final chapter provides an integrated discussion of the findings and begins with a brief synopsis of the science gap addressed, followed by the key findings of the research and an integrative interpretation of these findings. The implications of the findings for clinical practice are discussed. The strengths and limitations and the suggested future research agenda are presented in the final two sections.
8.1 Synopsis of the science gap

Review of recent literature of patient participation in acute care settings reveals participation as a kind of respectful and partnering relationship where clinicians surrender power in decision-making, patients obtain knowledge and are involved in healthcare activities (Sahlsten et al., 2008). Evolving literature suggests that patients may not perceive their role in decision-making as highly as their role in information exchange (Höglund et al., 2010) and that while clinicians recognize patients’ role in decision-making they have concerns about patients’ capacity to undertake this role (Heggland, & Hausken, 2013; Macdonald et al., 2014). Variability in patients’ preferred level of participation in care decisions have been reported in previous studies conducted mostly in western countries (McTier, Botti, & Duke, 2015; Mohsin-Shaikh, Garfield, & Franklin, 2014; Vestala, & Frisman, 2013). There is limited evidence that patients do not achieve their preferred participation (Florin, Ehrenberg, & Ehnfors, 2006a; Ramfelt, Lützen, & Nordström, 2005) and clinicians tend to overestimate the amount of participation that patients prefer (Florin, Ehrenberg, & Ehnfors, 2006a; Mohsin-Shaikh, Garfield, & Franklin, 2014; Wilkinson et al., 2008). Identified factors associated with patients’ preferred level of participation include age (Chung et al., 2012; Uldry et al., 2013), gender (Arnetz, & Arnetz, 2009; Chung et al., 2012), level of education (Chung et al., 2012; Hamann et al., 2011), physical status (Löfman, Häggman-Laitila, & Pietilä, 2008; Silva et al., 2012) and psychological status (Shepherd, Butow, & Tattersall, 2011), although the
effects of these factors are not consistent. The enactment of patient participation in health care is multifaceted, influenced by patient (Rainey et al., 2013; Vestala, & Frisman, 2013), clinician (Löfman, Häggman-Laitila, & Pietilä, 2008; Lever, O’Reilly, & Pryor, 2008) and context related factors (Cohen, & Botti, 2015; Drach-Zahavy, & Shilman, 2015).

In China, there is evolving interest in the study of patient participation in acute care settings (Guo, 2013; Jiang, Liu, & Wang, 2007). However perceptions of patient participation in China has been explored in very few studies and these have focused on patient safety (Li, Ye, & Jiang, 2012; Ye, Liu, & Liu, 2013) or general participation (Yu, 2014). Chinese patients’ preference for and actual participation in treatment and nursing care are few (Hou et al., 2014; Zhang et al., 2011) and researcher-designed tools have been used (Yu, 2014; Yue, 2014) making it difficult to compare findings with those conducted in western countries. Limitations in our knowledge of patients’ and clinicians’ understanding and experience of patient participation in acute care prevent innovation in strategies to promote participation (Li, 2014; Wan, & Wan, 2013; Zhou, Huang, & Zhang, 2012).

Although research in western countries has provided some insights into patient participation in acute care settings, the perceptions and enactment of patient participation in Chinese acute care settings, especially in the field of oncological symptom management, are less known. For this multifactorial construct, clinical and cultural contexts need to be considered. Emerging research in western countries indicates that there is a discrepancy between
patients and clinicians in how patient participation is perceived. There is needed a comprehensive exploration of patient participation in symptom management in China that integrates both patients’ and clinicians’ perceptions.

8.2 Summary of key findings

The research reported in this thesis is the first comprehensive assessment of the synergies between patients’ and clinicians’ perceptions of patient participation in symptom management in an oncological acute care setting. Both patients’ and clinicians’ self-report perceptions and their behaviours in actual interactions were explored through multiple methods.

Through survey method, five key findings were identified. First, in terms of the importance of participatory activities in symptom management, the findings were that patients, doctors and nurses shared the perception that the exchange of symptom information is the most important aspect of patient involvement in symptom management. Although rated highly overall, the importance of patients participating in decision-making for symptom treatment and care was rated lowest uniformly. Nurses were more likely to rate the importance of patient involvement higher than patients, however nurses as well as doctors were more likely than patients to consider patient involvement as a hindrance to care delivery because of the time required of clinicians and implications for increased workload.

Second, regarding actual participation rate, both doctors and nurses thought they provided patients with more symptom information than patients
perceived. Nurses perceived they met their patients’ needs to a greater degree than experienced by patients. Doctors and nurses thought they motivated their patients to participate in treatment and care more than patients experienced.

Third, over 80% of patients in the acute care setting preferred their doctors and nurses to make decisions for them and 64.8% of patients in the sample achieved their control preference while 24.5% experienced a more passive role than they preferred.

Fourth, this study confirmed predictors of patients’ preference for participation. Patients who were single, female, employed, undergoing radiotherapy or had higher levels of health literacy regarding the ability to appraise information critically and to find health information, tended to prefer more active participation in their symptom care.

Fifth, when patients’ actual experience agreed with their preference, patients were more likely to perceive that they had received higher quality of care than those who had not achieved their preferred participation. However, patients’ preference for participation and their actual experience of participation in symptom management was not found to be correlated with patients’ satisfaction with care delivery during symptom management.

In addition to the surveys, perceptions of patient participation in symptom management were explored through semi-structured interviews. The three key findings identified largely supported the findings of the survey component. First, patients, doctors and nurses shared many of the
understandings of patient participation. Information exchange was considered key to patient involvement; patients could also be involved in negotiated decision-making and other self-management activities, such as adjusting psychological status and controlling their diet or lifestyle. However, whether patients have the requisite knowledge to present opinions and make final decisions were concerns shared by both patients and clinicians. In addition, nurses expressed concerns that patients’ participation in decision-making might interfere with clinicians’ work. Most of the nurses and patients believed that participation meant that patients comply with treatment and care whereas doctors seldom mentioned compliance *per se*.

Second, the exploration of reasons perceived for preferred participatory roles indicated that information exchange, negotiated decision-making and role expectations were shared by patients irrespective of control preference. The trend in the findings suggested that the more active role patients preferred, the higher they perceived responsibility for their own health outcomes.

Third, factors facilitating or impeding patients’ participation in symptom management were identified. Activities related to information exchange were perceived to be influenced by communication competence, communication opportunity, patients’ symptom severity and established rapport between patients and clinicians. Patients’ participation in decision-making can be impacted by factors like patients’ professional knowledge, role expectations, and availability of treatment options. The involvement of
family members, peers and existing organizational policies were also perceived as possible factors impacting on patient participation in their symptom treatment and care.

In addition to the self-reported perceptions of patient participation, the observation of patients’ and clinicians’ behaviours during interactions related to symptom management added to the richness of the data. Low-frequency and low duration of interactions between patients and clinicians were a significant finding. Symptom discussions were usually initiated by doctors and nurses during the morning ward rounds and nurses’ working hours. Doctors and nurses were most concerned with physical symptoms related to the cancer diagnosis and cancer treatments with very little discussion of patients’ mood or psychological problems. Doctors and nurses held brief exchanges about symptom information with their patients. During interactions between patients and doctors, some patients were either not given the opportunity or did not take the opportunity to express their opinions; whereas most patients had opportunities to express their preferences or opinions to their primary nurses. Nurses were more likely to involve patients in self-care by providing information or encouraging patients to comply with treatment plans.

Common facilitating behaviours by doctors’ and nurses’ involved explaining clinical issues, checking their own understanding of patients’ concerns and clarifying patients’ agreement or preference with a treatment plan. Facilitating behaviours such as self-introduction, assessing a patient’s
understanding and monitoring and reminding were more frequently observed in nurse-patient interactions than those of patients and doctors. Blocking behaviours observed in both doctor and nurse interactions with patients were task focused interactions, changing topic or ignoring, using professional language and normalising comments.

Exploration of patients’, doctors’ and nurses’ perceptions of patients’ preferred and actual participation in symptom-management related decision-making during interactions observed, revealed that patients had a higher preference for participation in nursing activities than in medical treatment and they achieved this preference. Both doctors and nurses tended to overestimate patients’ participatory preference for, and actual achieved participation in interactions.

8.3 Integration of findings

Integrated analyses of these findings inform the enablers and barriers to patient participation in symptom management in the Chinese acute cancer care setting.

8.3.1 Enablers of patient participation

8.3.1.1 Recognizing patients’ active role in symptom management

Recognition of patients’ roles in symptom management was found to be mostly consistent between patients and clinicians and was identified from different sources of data. In both patients’ and clinicians’ survey responses, all the participatory activities were rated as important by the majority of
patients, doctors and nurses, indicating a high level of recognition of the necessity for patient participation in symptom management. The high value placed on information exchange was emphasized when patients and clinicians explained their understandings of patient participation. Meanwhile, symptom assessment and patient education were the main activities observed in the patient-clinician interactions in symptom management.

The positive expressed attitudes towards patient participation are in agreement with the findings in previous studies which reported patients’ and/or clinicians’ high perceived importance of patient participation in healthcare delivery, in Greece (Kolovos et al., 2014a), Denmark (Abrahamsen, Draborg, & Nørgaard, 2014), Australia (McMurray et al., 2011; Tobiano et al., 2015a, 2015b) and China as well (Ma, & He, 2005; Ming, & Zhao, 2011; Ming et al., 2010; Zhang et al., 2014). Information delivery as a way of participation was especially emphasized in some of the above literature (Abrahamsen, Draborg, & Nørgaard, 2014; Tobiano et al., 2015b). This positive recognition is an important prerequisite for the success of patients’ attempts to participate in their care.

8.3.1.2 Raising patients’ active preference for participation in symptom management

Although passive preference for participation in decision-making was dominant in the Chinese patient sample, the current study identified that patients tended to have an active preference for participation in symptom-related decision making when they were single, female, employed and
undergoing radiotherapy. In addition, higher levels of health literacy, especially when patients had the ability to appraise information critically and to find health information, was positively associated with patients’ active preference. Consistently, both patients’ and clinicians’ responses in the individual interviews indicated symptom severity and comprehension competence could influence patients’ of participation experience overall.

Preference is a predisposition in favour of something. To enable patients’ participation in symptom management, patients’ preference needs to be addressed. Illness-related factors associated with patients’ preference for participation have been explored in previous studies (Arnetz, & Arnetz, 2009; Chung et al., 2012; Florin, Ehrenberg, & Ehnfors, 2008). Health literacy can influence patients’ ability to take responsibility for their own healthcare and have been identified as potential predictors of patients’ preference for participation (Ekdahl et al., 2011; Larsson et al., 2011a; Naik et al., 2011). These findings suggest that preference is potentially modifiable and impacted on by factors such as physical performance, understanding and knowledge and, if addressed, can facilitate patients’ participation in their own healthcare activities.

8.3.1.3 Providing patients with opportunities to participate

Whether patients had opportunities to be involved in their symptom management was identified as an important factor in facilitating patient participation. This conclusion is derived from the interview findings where the availability of clinicians for communication and discussion of options for
symptom treatment were seen as enablers. Specific behaviours by clinicians such as inquiring if patients wanted additional information or had concerns, explaining clinical issues, clarifying patients’ agreement or preference for treatment, discussing uncertainty, examining barriers and analysing the pros and cons were also observed to facilitate participation. Previous studies have found that patients felt their opportunities for participation were restricted (Larsson et al., 2011b; Tobiano et al., 2015b). Understanding the explicit behaviours that provide patients with opportunities to participate is important for bringing about changes in the way clinicians interact with their patients and inform strategies for providing clinicians with the skills to facilitate participation.

8.3.2 Barriers to patient participation

8.3.2.1 Patients’ and clinicians’ concerns related to patients’ participation in decision-making

Negotiated decision-making was perceived generally as one of the activities patients should participate in during the process of symptom management, however there was unease about the capability of patients to participate in symptom-related decision-making and this was evident in multiple dimensions of the findings. The importance of patients participating in decision-making for symptom treatment and care was rated lowest among all the participatory activities by both patients and clinicians. More clinicians perceived patient participation as a hindrance to their work than patients did. Patients were also concerned about their lack of knowledge about disease and treatment. Ambivalence about patient participation in decision making
was further evidenced in the responses’ of nurses who worried that patients’ ill-informed opinions or suggestions might influence clinicians’ judgements. Although the divergence between patients’ and clinicians’ concerns about patient participation in decision making needs to be confirmed in further research, these findings suggest a potential barrier to involving patients in their treatment or care.

The finding of the control preference survey, that over 80% of patients preferred their doctors and nurses to make decisions for them, reflected the value patients’ placed on clinicians’ roles in decision-making. Further exploration of patients’ perceived reasons for their participatory preference revealed that patients with a passive preference mostly believed that clinicians held professional knowledge and were responsible for treatments and care. How much patients could contribute depended on their perceived ability, knowledge and sense of responsibility for their own outcomes.

Lack of confidence and passive preference for participation in decision making expressed by patients, and clinicians’ concerns about patients’ ability to make decisions, suggests a very narrow interpretation of what it means for patients to be involved in decision-making. Limited recognition of patients’ ability to participate in decision-making is not unique to this study (Abrahamsen, Draborg, & Nørgaard, 2014; Seale et al., 2015; Tobiano et al., 2015a). Tobiano for example, identified that regulations and safety of care were factors that concerned nurses when they decided whether to involve patients in their care. Although decision-making is not the only aspect of care
that patients can be involved in, it is regarded as the highest level of patient participation (Soleimani, Rafii, & Seyedfatemi, 2010). However, participation in decision-making does not require patients to have the level of knowledge that clinicians hold. Rather, it requires that patients are fully informed of the treatment options available to them, their implications, the pros and cons of treatment, and that this information is made available in a way that they can access and understand so that ultimately, they can decide to accept and participate in treatment.

8.3.2.2 Clinicians’ strategies in involving patients

Findings from various sources of data suggested that clinicians lacked strategies or were reluctant to involve patients in their daily practice. This was evident in failure to assess patients’ preference for participation. It was identified in the CPS survey that neither doctors’ nor nurses’ perceptions of patients’ preference for participation in symptom management-related decision-making was congruent with patients’ perceptions. Paradoxically, both doctors and nurses thought their patients had a more active preference than patients reported. Based on the clinicians’ responses in the interviews, clinicians acknowledged that they did not assess patients’ preference in their daily practice and their judgement of whether a patient wanted to participate in treatment or care was usually based on their subjective assessments. Clinicians’ overestimation of patients’ preference for participation is in line with the findings reported in literature
(Florin, Ehrenberg, & Ehnfors, 2006a; Mohsin-Shaikh, Garfield, & Franklin, 2014; Wilkinson et al., 2008).

This lack of congruence between clinicians and patients in their estimation of participation can be explained in part by the data. The survey data identified that both doctors and nurses thought they provided symptom information and motivated patients to participate to a greater degree than patients experienced. Nurses were more likely than patients, to perceive they met their patients’ needs. These different perceptions were most evident in relation to aspects of participation in discussions or decision-making in symptom treatment and care. Similar disparities in perceptions were reported in Kullberg’s study in information exchange and information provision between health care professionals and patients related to changes in medication and fall risk assessment (Kullberg et al., 2015), and in Papastavrou’s study in which nurses reported higher degree of information provision and patient participation in decision-making concerning care than patients’ had experienced (Papastavrou et al., 2015).

Common blocking behaviours identified through the naturalistic observation of patient/clinician interactions included task only interactions, changing topic or ignoring, using professional language, giving normalized comments and monopolising. These blocking behaviours impacted on relationships and information exchange. However, in the individual interviews, these blocking behaviours were not spoken about by clinicians who perceived barriers to participation were mainly related to patient characteristics or the clinical
context rather than their personal behaviours or skills. Clinicians, especially
doctors, perceived lack of time and energy to provide more opportunity for
patients to participate as an important barrier to patient participation.
Clinician behaviours identified have been reported previously in Australian
cancer care settings (Butow et al., 2008; Cohen, 2012). When these
behaviours occurred patients were deprived of opportunities to participate
but clinicians did not appear to recognise that they were exhibiting these
behaviours in their interactions with patients.

8.3.3 Status of patient participation in the case study

Patient participation in symptom management in the case study setting was
predominately in relation to aspects of exchanging information and self-
management of care. There was very little evidence of patients engaging in
negotiated decision-making. In terms of perceptions of experience, close to
70 percent of patients stated that they would report their symptoms and the
majority of patients had received information about their symptoms and
treatments; however less than 25 percent of patients felt that they had been
given the opportunity of being involved in discussions or decision-making
about their treatment and care during their hospitalization.

The naturalistic observations confirmed patients’ perceptions of few
opportunities to engage in decision-making; clinicians tended to dominate
patient-clinician interactions. Less than 20 percent of interactions involved
patients expressing their own opinions about their preference for symptom
treatment or examinations to doctors or nurses.
A consistent finding was that more than 80 percent of the patients preferred to leave their symptom-related decisions to doctors and nurses with or without considering patients’ own opinions and 90 percent of patients experienced passive or passive-shared roles.

The survey and naturalistic observation data indicated the limited recognition and enactment of patient participation in symptom management. The findings are in accordance with those in Cohen’s study that explored patient participation in symptom management in an acute cancer care setting in Australia, although a smaller proportion of patients reported a passive and passive-shared preference in Cohen’ study (Cohen, 2012). Tobiano et al also found knowledge sharing was a way of participation among hospitalised medical patients in Australia while limited opportunities for participation in decision-making were perceived by patients (Tobiano et al., 2015b). Patients’ poor participation in symptom management therefore, is not unique to the Chinese setting, rather, the data suggest that it is a widespread issue regardless of health care system and cultural setting.
Figure 8.1 Integrated findings of patient participation in symptom management in the acute cancer care setting
8.4 Implications for clinical practice

The findings of this multi-methods study confirmed the significant problem of enacting patient participation in care and the potential impact on patients’ perceived quality of care if patients are not provided opportunities to participate. Participation in their care is perceived by patients as a component of quality care (Schröder, Ahlström, & Larsson, 2006) and the positive effects of patient participation in improving care quality has been identified in the literature (Gascoigne, & Watson, 2009; Jangland et al., 2012; Weingart et al., 2011). This was further evidenced in the current research where patients who achieved their preference for participation in their care perceived higher quality of care than those whose preference was not achieved. This finding suggests that supporting patients to achieve their preferred level of participation may be more important than focusing activities on encouraging higher preference for participation for the purpose of achieving improved satisfaction with care. Professionals need to recognize each patient’s unique knowledge and respect the individual’s description of his or her situation in order to provide opportunities for true patient participation (Eldh, Ekman, & Ehnfors, 2006; Larsson et al., 2011b). This is consistent with the notion of patient-centred care where the patient is a respected and autonomous individual and a patient’s individual needs should be embodied in care planning (Kitson et al., 2013). However, patients’ preference for participation can be influenced by their perceived knowledge and competence to participate and this can be facilitated by clinicians.
The findings in this Chinese case study suggest that patient participation is recognized by patients and clinicians as an important component of cancer care but the enacted roles were limited and predominately within the lower level of participation. Patients’ and clinicians’ attitudes about the relative roles and contributions relating to decision-making influence interactions or communication between them (Entwistle, & Watt, 2006). Therefore, a wide range of participatory activities should be made explicit and advocated in related hospital policies and included in professional education and patient education. Positive perceptions of patients’ roles in their care may raise patients’ preference for participation in the activities they value and encourage them to participate if they have confidence in their ability to do so. For clinicians, explicit policies and processes would encourage them to value patients’ roles in their treatment and care and to develop skills and strategies for involving patients.

The findings of this research suggest that patient participation in acute treatment and ongoing care is recognized by clinicians in the Chinese health care system and culturally by the recipients of care. Further, the findings suggest that the issues faced in enacting participation are similar to those in western countries although there are some differences that need to be considered. Patients’ preference for participation in symptom management in the Chinese case study appeared to be more passive than reported in research conducted in an Australia acute cancer care setting (Cohen, 2012). These findings suggest that introducing participation interventions into the Chinese context that are successful in other countries may not be advisable.
A recurring finding in the case study data was the poor recognition by clinicians of their patients’ preference for, and actual participation. Overestimation of patients’ preference and actual participation indicates that individual assessment of patients’ preference did not occur in clinical practice and doctors and nurses were not fully responsive to patients’ preferred participation. Patients’ and clinicians’ understanding of patient participation encompassed a range of activities including not only decision-making but information exchange and self-care activities. The overestimation of patients’ preferred participation suggests that clinicians were making subjective judgements of patients’ preferences however, patients need to be asked directly to determine individual patient preferences (Wilkinson et al., 2008).

The facilitating and blocking behaviours observed during patient-clinician interactions suggest the need for a greater focus on communication skills training. Behaviours observed included task-based or monopolising that inhibited patient initiated conversations about concerns or preferences. Facilitating behaviours included explaining clinical issues, analysing pros and cons, clarifying patients’ agreement or preference, discussing uncertainty, and examining barriers. In addition, Wilkinson suggests other facilitating behaviours such as open questions, encouragement, reflection, and consultation about the plan of action (Wilkinson, 1991). Assessing patients’ understanding of the information provided was exhibited in some interactions. The use of recall and feedback is an effective method for assessing patients’ understanding (Kemp et al., 2008; Watermeyer, Kanji, &
Mlambo, 2015). This approach was observed in nurses’ interactions but seldom by doctors and may have been due to the time they had available to interact with patients. Indeed in the interviews with doctors, time and fatigue were factors that mitigated against the sort of communication some doctors understood to be necessary for effective patient participation. Whether clinicians are unaware of blocking behaviours or if they adopt them in response to the time constraints they face is important to determine because any interventions to improve communication needs to encompass the context in which communication occurs.

The findings of this case study have highlighted the complexity of enacting patient participation in care in particular within the cancer care environment. Motivation has been reported as a key factor in the successful implementation of patient participation in shared decision-making in clinical practice (Legare et al., 2008). Providing opportunities for patients to participate in their treatment and care requires skill, recognition of its value and trust in the ability of patients to contribute to decisions that affect them. Most clinicians in this case study believed that they had involved their patients through information provision and motivating patients to participate however, many patients did not perceive that this had occurred. Indeed, over half of the doctors and nurses were observed, in the interactions involving decision-making, to ask their patients’ opinions although not all patients responded. Facilitating participation is not only dependent on clinicians’ awareness of providing opportunity but also on the
clarity in which that opportunity is provided, the context in which it occurs and concurrent behaviours that accompany invitations to participate.

8.5 Strengths and limitations

The research program presented in the thesis is a novel exploration of the phenomenon of patient participation in symptom management in a Chinese oncological acute care setting. The findings contribute to the evolving knowledge of patient participation in this specific clinical and cultural context. Its design is characterised by a number of strengths:

First, the case study design has the advantage of exploring phenomena within ‘real-world’ practice (Yin, 2009). This case presented an analysis of typical everyday patient-clinician interactions. The single case study provided a framework for the comprehensive exploration of whether and how patients are involved in the process of symptom management.

Second, the concurrent, mixed-methods design compensated for the deficiencies of single methods (Polit, & Beck, 2012). Given the multifaceted nature of the patient participation phenomenon, the triangulation of self-report survey, individual interview and naturalistic observation provided a comprehensive understanding and insights, by combining the knowledge of subjective perception and objective behaviours. Triangulation during data analyses allowed deductive and inductive interpretations and conclusions, beneficial to the development of an integrative framework of patient participation in symptom management.
Third, data collection from multiple participant groups embodied the interactive characteristic of patient participation. In addition to the recruitment of patients who were the main participants in previous studies, this study involved doctors and nurses as they interacted with patients in managing symptoms in the clinical context. Inclusion of multiple participant groups contributes to our knowledge of the similarity and difference in patients’ and clinicians’ perceptions of patient participation in symptom management.

Fourth, consecutive sampling adopted in the survey and observation phases decreased the possibility of selection bias that is the risk associated with convenience sampling. Purposive sampling of clinicians in the interview phase captured data from doctors and nurses with differing experiential backgrounds. Stratified sampling of patients based on their control preference in patient interviews enabled the exploration of patients’ understanding of the meanings underpinning control preference.

The limitations of this research are related to external validity or transferability of the findings, and considerations of internal validity or credibility. Single case study design has limitations relating to external validity and generalizability (Yin, 2009). This study identified limited perceptions of patients’ participatory roles in symptom management and overall passive preference for participation in decision-making by patients and these findings may not be generalizable to the Chinese population nationwide. The intention of this research was as a primary exploration of
patient participation in symptom management within a Chinese context and the findings contribute to existing knowledge in this area, identify potential areas of concern and can be compared to the findings of other studies conducted in China and worldwide to determine complementarity or divergence.

In the survey phase, five of 343 admitted patients were excluded because of physical disability and 73 of 300 eligible patients were not willing to participate due to feeling unwell or unwillingness to participate. It is possible that patients who were experiencing higher symptom distress may not have been included. Age, sex and cancer type was found to differ between the participants and nonparticipants; this kind of potential bias is not uncommon in cancer clinical studies (Cohen, 2012; Murthy, Krumholz, & Gross, 2004) but needs to be acknowledged.

The PPSM Questionnaire took patients approximately 15-20 minutes to complete. Fatigue in cancer patient populations is well recognized and 13 patients (8.5%) did not complete the PPSM questionnaire. In order to reduce participant burden, after consenting patients they were left a copy of the questionnaire to self-complete. This enabled patients to manage their fatigue by completing the survey in smaller sections over a 24 hour period. The researcher also assisted some patients to complete the survey to reduce burden whilst increasing the representativeness of the data collected.

Data obtained in the naturalistic observations and surveys were not from the same patient sample because the phases were conducted sequentially due
to the constraints of the PhD program and consequently a single data collector. This limitation weakens the comparisons between the multifactorial data. There were however, no differences in demographic characteristics of age, sex and place of residence between the patient samples in the observation and survey phases. There was a difference in the distribution of cancer type however type of cancer was not found to be associated with patients’ control preference in this research. Therefore, the samples in the observation and survey phases can be considered to be from the same population.

Conversations between patients and clinicians were recorded by handwritten notes because most of the clinician participants refused to be audio recorded during interactions with patients. Every attempt was made to record conversation content as accurately as possible but it was not always possible to record verbatim.

The observations of doctor-patient interactions occurred during the medical ward rounds which lasted less than three minutes per patient. Both the survey and interview data indicated that there were other opportunities for patients to talk to their doctors. For example, patients could go to their doctors’ office to report symptoms they felt were severe. Hence, this study did not capture all potential interactions between patients and doctors about patients’ symptoms. The observation of nurse-patient interactions included mainly nursing working hours in the morning and, although longer than the doctor-patient interactions, were still a snapshot of care. Two
afternoon nursing working periods were observed and the average number of interactions in the afternoon \( (0.8 \pm 1.25) \) were lower than those in the morning \( (2.4 \pm 1.5) \). The aim of the design was to capture the period with high intensive interactions and this was achieved. It is possible that lengthier interactions between nurses and patients occur in the less busy afternoon periods but this was not evident in the data.

### 8.6 Future studies

This research has identified the important shared role patients and clinicians have in successfully enacting patient participation and future exploratory and intervention research needs to continue to incorporate this relationship.

More research is needed to provide assessment tools and strategies for determining patients’ preferences for participation in multiple activities. The Control Preference Scale used in the current research was developed to assess patients’ preference for control roles in decision-making and is limited in assessing ongoing care. The Views and Behaviours about Patient Involvement in Care assesses a wider range of activities, however it investigates patients’ perceptions of the importance of these activities rather than preference for participation. It was evident in this research that even those patients who indicated high perceived importance in participation in decision making preferred to leave final decisions to doctors and nurses. Clearly, preference for participation is not the same as perceived importance.

The current research identified ambivalence by both patients and clinicians about the competence and ability of patients to participate in higher order
activities related to decision making and the potential implications of patient participation on workload and the quality of decisions made. Further research is needed to address ways to explicate patients’ roles in symptom management and encourage perceived self-efficacy during an episode of hospitalization. The reasons given for patients’ different preferred roles identified in the current research have provided insight for future interventions.

As well as future interventions to raise awareness of patients’ potential roles in their care there are needed strategies that can be adopted by clinicians and patients to improve patients’ participation. This research has identified the complexity of enacting patient participation within the current care context. Whether improving patient participation is beneficial to patients’ symptom outcomes also needs to be examined. Suggested interventions in the literature to facilitate patient participation include information delivery through e-health platforms (Post et al., 2013; Stanton et al., 2013), interventions encouraging patients to initiate symptom reporting (Jangland et al., 2012; See et al., 2014), and decision aid interventions (Vodermaier et al., 2009), et al. Whether these interventions are acceptable and feasible within Chinese acute settings needs to be investigated.

8.7 Conclusions

The purpose of the research program reported in this thesis was to explore the synergies between patients’ and clinicians’ perceptions of patient participation in symptom management to advance our knowledge of the
enablers and barriers to patient participation in symptom management within the Chinese acute cancer care environment. The case study design provided insight into the complexity of patient participation embedded in everyday clinical interactions. The concurrent, mixed methods design explored this phenomenon from various perspectives and dimensions to achieve a comprehensive understanding of the issue. Synergies were identified between patients and clinicians with respect to their understanding of patient participation and their perceptions of the importance of various participatory activities. Differences identified related to clinicians’ perceptions of how participation can interfere with clinicians’ judgements and impact on workload, how well clinicians motivate patients to participate and overestimation by clinicians of patients preference for, and actual participation. Patients were prevented from fully participating in care and decision making when patients and clinicians had concerns of patients’ knowledge and ability to participate in decision-making and clinicians lacked strategies to engage patients. In summary, these factors contributed to the limited participation in symptom management observed within the Chinese acute care setting studied. Future research is needed that is focused on interventions directed towards patients and clinicians to enhance interactions that facilitate patient participation in their care, and these interventions need to be investigated within the Chinese acute cancer care context.
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## Appendix 1: Summary of the studies related to patients’ perceptions of the meaning of participation in acute care (n=14)

<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Participants</th>
<th>Topic</th>
<th>Methods</th>
<th>Attributes of patient participation identified</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tobiano et al., 2015b</td>
<td>Australia</td>
<td>Maximum variation sample of 20 patients on four medical wards, in two hospitals 60% female, aged from 30 to 92</td>
<td>Patients’ perceptions of participating in nursing care, including the barriers and facilitators for this activity</td>
<td>Individual interviews</td>
<td>“Exchanging intelligence”: patients seeking knowledge and sharing knowledge with nurses</td>
<td>Power imbalance (barrier): complying with nurses, interpreting nurses’ approaches</td>
</tr>
<tr>
<td>Thyssen &amp; Beck, 2014</td>
<td>United Kingdom</td>
<td>Purposeful sample of 8 patients admitted to Intestinal Failure (IF) Unit 5 females, aged 18-59</td>
<td>How patients with IF experience their hospital surroundings in relation to pp</td>
<td>Individual semi-structured interviews</td>
<td>Getting and seeking information</td>
<td>Enablers: Ample space to move around for daily activities  Having “your own space”: feeling of relaxation and privacy. A feeling of independence, reassurance, normality, control, responsibility, and confidence</td>
</tr>
<tr>
<td>McInnes et al., 2014</td>
<td>Australia</td>
<td>Convenience sample of 51 English speaking patients admitted to orthopaedic &amp; neurology wards in two co-located metro hospitals. Mean age 65 (SD 16.6), 55% female. 74% surgical</td>
<td>Patients’ understanding of pressure injury prevention (PIP), their perceived roles, and factors that enable or inhibit PP in PIP</td>
<td>Researchers self-developed questionnaire with 18 close ended and 5 open-ended questions.</td>
<td>“work together”</td>
<td>“ongoing PI education”</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>“keep skin healthy” Skin care “listening to your body” Mobility and repositioning “Looking after the inside” Nutrition and hydration</td>
<td></td>
</tr>
<tr>
<td>Author(s)</td>
<td>Country</td>
<td>Methodology</td>
<td>Sample Characteristics</td>
<td>Focus</td>
<td>Data Collection Method</td>
<td>Findings</td>
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<tr>
<td>Latimer, Chaboyer &amp; Gillespie, 2014</td>
<td>Australia</td>
<td>Purposive sampling, using maximal variation of 20 patients in two metropolitan hospitals</td>
<td>65% females, median age: 65.5 (P25-P75: 56.5–68.7) years, 50% having current or past pressure injury (PI)</td>
<td>Patients' perceptions of their current and future role in (PI) prevention</td>
<td>Individual semistructured interviews</td>
<td>“Enabling me to participate”: nurses’ supportive behaviours.</td>
</tr>
<tr>
<td>McMurray et al., 2011</td>
<td>Australia</td>
<td>Convenience sample of 10 inpatients 6 females, aging from 52 to 74 years (median 68 years)</td>
<td>Patients’ perspectives of participation in shift-to-shift bedside nursing handover</td>
<td>A descriptive case study with individual interview</td>
<td>Acknowledging patients as partners. Patients perceiving that the inclusive approach of handover as nurse—patient interaction</td>
<td>Nurses’ sharing professional information, recognizing that patients were knowledgeable and had a legitimate right to information on their condition</td>
</tr>
<tr>
<td>Soleiman i, Rafii &amp; Seyedfate mi, 2010</td>
<td>Iran</td>
<td>Purposive and theoretical sampling of 9 patients with chronic illness, 8 nurses, and 5 family members, recruited from the medical wards. Mean age: patients 50 years, nurses 34 years</td>
<td>To identify the factors relevant to patient participation and the nature of that participation, as experienced by chronically ill patients and nurses</td>
<td>Grounded theory with individual interview Participate in care Observation</td>
<td>Participation is an interactive process between nurses, patients, and family members in the caregiving context “convergence of the caring agents” working together.</td>
<td>True participation (express views, and make decisions)</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Sample Characteristics</td>
<td>Methodology</td>
<td>Themes</td>
<td>Findings</td>
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<tr>
<td>Eklund, Ekman &amp; Enhfors, 2010</td>
<td>Sweden</td>
<td>362 inpatients and outpatients 58% female 48% 30-59 years</td>
<td>To depict patients’ description of PP</td>
<td>Having fruitful communication based on respect; being treated as an individual with disease; being respected as a person with a requirement to understand and make decisions; being able to ask questions or concerns</td>
<td>Taking part in planning Setting own goals Having control over healthcare contact, making own plan, disease “Comprehending and taking actions based on knowledge” (4,3,11) “Being confident” (1,2) “Being in control” (6,10)</td>
<td></td>
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<tr>
<td>Ekdahl, Andersson &amp; Friedrichsen, 2010</td>
<td>Sweden</td>
<td>15 patients Mean age: 84 years, 10 females</td>
<td>Frail elderly patients’ preferences for participation in medical decision making during acute hospitalization</td>
<td>Semi-structured interviews</td>
<td>Receiving information and good communication: 1) Wanting information about their illnesses and planned investigations, results of their investigations, and the doctors’ diagnostic considerations. 2) Patients expressing their thoughts and feelings about their symptoms and illnesses</td>
<td>The hospital an institution of power Barriers to communication: Aging and being too ill; many doctors involving in medical decisions; Linguistic problems (ascent) Variable degree of preference for participation For frail elderly patients participation means information, not the wish to participate in decisions about their medical treatments</td>
</tr>
<tr>
<td>Frank, Asp &amp; Dahlberg, 2009a</td>
<td>Sweden</td>
<td>Purposive sampling with maximal variation, 9 patients in emergency department</td>
<td>To describe patients’ different conceptions of patient</td>
<td>&quot;Having a clear space&quot;: Patients consider themselves to be ED staff as an initiator to give patients information relevant to their circumstances and</td>
<td>Being acknowledged: being noticed through eye and/or verbal contact when the patient’s condition so demands, PP means being acknowledged</td>
<td></td>
</tr>
<tr>
<td>Authors and Year</td>
<td>Country</td>
<td>Participants</td>
<td>Setting</td>
<td>Methodology</td>
<td>Data Collection</td>
<td>Framework/Phenomenological Approach</td>
</tr>
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<tr>
<td>Larsson et al., 2007</td>
<td>Sweden</td>
<td>26 patients in somatic inpatient care as well as discharged from such a setting 8 females time spent in hospital ranged from 4d to 7months age range: 32-87yrs</td>
<td>To explore the meaning of PP in nursing care</td>
<td>Grounded theory with 6 focus group interviews</td>
<td>Insight through consideration constitutes the dynamic nurse-patient interaction process. &quot;Obvious atmosphere&quot;: recognition, equality, adequate time; adaptability: consistency in care; invitation to speak. &quot;Concordance&quot;: &quot;Rights&quot;: &quot;Will&quot;, a &quot;Dialogue process&quot;, &quot;Support&quot;</td>
<td>“Concordance”: “Written agreement” “Rights”: “Growth of knowledge”, “Rights”: Information</td>
</tr>
<tr>
<td>Wåhlin, Ek &amp; Idvall, 2006</td>
<td>Sweden</td>
<td>Purposeful sample of 11 patients in intensive care unit, varied diagnoses, ages (28-83 yrs), days in ICU (4-35d) and gender (5 females)</td>
<td>To describe patient empowerment in intensive care</td>
<td>Phenomenological approach Individual interviews</td>
<td>Strengthening and stimulating patients own inherent joy of life and will to fight. A positive environment that acknowledged feelings of value (acknowledgement) and motivation and in which the patient felt safe, received additional care and participated as he/she wished had a positive influence (patients being taken seriously and listened).</td>
<td>Information contributed to safety if it provided answers to questions or wonders, facilitated comprehension of symptoms, treatment or coherence, or prepared for coming changes.</td>
</tr>
</tbody>
</table>
### (Li, Zhang & Yang, 2014)

**China**

- **266 patients recruited from urban healthcare institutions**
  - 56.8% female, varied age group (≥50 yes, 48.5%)

**Purpose**: To explore the dimensions and motivations of patients' participation behaviors.

**Method**: Survey with self-designed questionnaire.

**Data Analysis**: Exploratory factor analysis.

**Key Findings**:
- "to communicate with doctors"
- "doctors glad to answer my questions"

**Compliance with doctors to conduct investigations, treatment, medication administration**

### (Liu, 2012)

**China**

- **15 patients interviewed, varied age (30-50yrs 66.7%), 40% females**
- 324 inpatients surveyed, 44.1% females, mostly between 20-50yrs (70.4%)

**Purpose**: To build a model of patients' participation competence and current status in the Chinese context.

**Method**: Literature review, interview, survey with self-designed tool.

**Data Analysis**: Communication competence (Accumulated Variance Contribution Rate, AVCR: 55%)

**Key Findings**:
- Communication exchange
- Motivations for PP: to increase the psychological control of medical service processes and results, reduce medical risk, to ensure medical efficacy, to enhance ability to safeguard their rights

### (Ye, 2011)

**China**

- **Purposeful sampling and theoretical sampling of 34 inpatients and outpatients in medical, surgical, and orthopedic units from 6 hospitals on varied level in Shanghai**
  - 65% females, aged between 20-81yrs

**Purpose**: To explore the perception and knowledge of patients about the safety of hospital care.

**Method**: Grounded theory with individual interviews and media reports analysis.

**Key Findings**:
- "Decisive involvement": Decision of going to a doctor (choosing hospital, choosing healthcare staff) and motivation of going to see a doctor.
- Participation in diagnosis and treatment (decision of surgery, being involved in planning and implementation, investment and willingness of participation).

**Caretaking involvement**:
- "Complaining involvements": explaining safety errors, complaining through different ways.

Core category: interactive involvement in patient safety. Enables: patient-provider trust, medical information support, impropts communication between patient and professionals, and support both from family and professionals.
Appendix 2: Summary of the studies related to clinicians’ perceptions of the meaning of participation in acute care (n=7)

<table>
<thead>
<tr>
<th>Author Date</th>
<th>Country</th>
<th>Participants</th>
<th>Topic</th>
<th>Methods</th>
<th>Attributes of patient participation identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kolovos et al., 2014b</td>
<td>Greece</td>
<td>181 nurses working in med/surg wards in 3 Greek hospitals</td>
<td>To investigate nursing staff’s perceptions related to PP and the parameters affecting it during nursing care</td>
<td>A cross-sectional study with both a quantitative and qualitative orientation</td>
<td>Relationships established: &quot;ability to influence and responsibility&quot;; provided alternatives communicating preference; Information shared: &quot;information providing&quot;; communication of symptoms by patients; Asking questions; Compliance with staff’s orders*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>95% females, mean age 36.7yrs</td>
<td></td>
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<tr>
<td>Tobiano et al., 2015a</td>
<td>Australia</td>
<td>20 nurses in 4 medical wards</td>
<td>Explore nurses’ understanding of PP in nursing care and the barriers and facilitators.</td>
<td>Semi-structured interview</td>
<td>Motivating patients to make decisions promote independence &quot;encouraging independence&quot;; Providing information to patients; Patient participation in clinical communication with particular focus on providing rationale for care activities; Participate verbally (reporting symptoms, asking questions, during handover, reporting back on what other clinicians have said); Activities of daily living (ADLs); Patient willingness; Patients can participate in two ways: physically (ADLs, self-medication and monitoring of meds);</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 in private (n=10), two in public (n=10) in two different states. Median age: 28yrs 75% females</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kvangasse et al., 2013</td>
<td>Norway</td>
<td>17 ICU nurses, repeatedly sampled from two hospitals in western Norway</td>
<td>To explore ICU nurses’ perceptions of patient participation in the acute phase of COPD exacerbation</td>
<td>3 Focus group interviews</td>
<td>Emotional reciprocity: helping patients cope with anxiety and fear; Emotional reciprocity: Keeping sense of control, making deals; Low level of patient power and participation; Reading body language; Communicating with the next of kin, as indirect practice of PP; Corrines with treatment, e.g. a patient making effort to obtain the necessary moisture during mask treatment; PP as life or death situations; Other areas of PP: time and extent of care, meals, activity, visits, and administration of medical treatment;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>All females between 41-62yrs, &gt;10yrs of nursing experience</td>
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</tr>
<tr>
<td>Author(s)</td>
<td>Country</td>
<td>Method</td>
<td>Participants</td>
<td>Data Collection</td>
<td>Findings</td>
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<tr>
<td>Sahlsten, 2009</td>
<td>Sweden</td>
<td>16 Registered nurses providing inpatient care, were recruited from three hospitals in West Sweden. All females, years after registration: mean 32.5, range 0.5–39.5.</td>
<td>To explore RNs' strategies to stimulate and optimise patient participation in nursing care. To identify ward nurses' supporting practices.</td>
<td>3 focus group interviews.</td>
<td>Building close cooperation: creating confidence (trust and honesty), showing respect (support patients in voicing their own opinions and experiences), showing courage (not determine the topic of conversation), creating engagement (showing genuine interest in patients' own experience of the situation).</td>
</tr>
<tr>
<td>Frank, Asp &amp; Dahlberg, 2009b</td>
<td>Sweden</td>
<td>11 nurses &amp; physicians in an ED, 3 physicians, 4 nurses and 4 auxiliary nurses, working for 2-23 months in the ED.</td>
<td>To describe caregivers' conceptions of patient participation in an emergency care unit.</td>
<td>Individual interviews.</td>
<td>Mutual participation: Caregivers showing genuine interest and encouragement.</td>
</tr>
<tr>
<td>Appendix</td>
<td>Country</td>
<td>Design</td>
<td>Methods</td>
<td>Study Details</td>
<td>Findings</td>
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<tr>
<td>(Sahlsten et al., 2005)</td>
<td>Sweden</td>
<td>31 nurses providing inpatient care, recruited from five hospitals in west Sweden</td>
<td>Grounded theory, 7 focus group interviews</td>
<td>To clarify registered nurses' understanding of patient participation in nursing care by investigating nurses' interpretation of the elements of PP and its implementation</td>
<td>Mutuality in negotiation: Interpersonal processes (interplay, invite, confirm) Therapeutic relationship (reassurance, empathy, professional distance, self-knowledge) Information requirements for choice Patient right of self-determination, responsibility</td>
</tr>
<tr>
<td>(Zeng &amp; Yan, 2014)</td>
<td>China</td>
<td>17 experts with over 10 yrs of work experience</td>
<td>Delphi Technique</td>
<td>The draft mode was formulated based on literature review and analysis of chemotherapy adverse events, combined with the existing strategies of patients in patient safety.</td>
<td>“Decisive support” (doctors support): mutual trust and encouragement, listening to patients, suitable communication methods “caring support” (nurses support)</td>
</tr>
</tbody>
</table>
Appendix 3: Summary of the studies related to patients’ and clinicians’ perceptions of the meaning of participation in acute care (n=7)

<table>
<thead>
<tr>
<th>Author Date</th>
<th>Country</th>
<th>Participants</th>
<th>Topic</th>
<th>Methods</th>
<th>Attributes of patient participation identified</th>
<th>Activity engagement</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Macdonald et al., 2014)</td>
<td>Canada</td>
<td>Convenience sample. 24 English speaking patients taking multiple meds and living with a chronic illness 1-2 weeks post discharge from a gen med unit of one of three hospitals (2 tertiary ref, one com) and 17 (RNs) and 9 (LPNs) in same units where pts were recruited.</td>
<td>Patients’ and nursing staff’s perceptions and experiences of medication administration and what fosters or impedes the patient voice</td>
<td>Constructivist grounded theory Individual semi-structured interview Analysed with exploratory factor analysis</td>
<td>Relationships established: Based on RN perception of patient capacity Power surrendered: RNs talked about being committed to patient education Information shared: Engaging in the medication administration process Activity engagement: Both RNs and patients see the role of the patient in ‘confirming delivery of the right medication’ Patients saw their role as ranging from confirming the meds to questioning the RNs about their meds. RNs talked about assessing patients’ mental status to determine capacity for and interest in participating.</td>
<td>Independent analysis. Pt and RN asked same questions. Perceptions compared. Limited by time constraints.</td>
<td></td>
</tr>
<tr>
<td>(Kolovos et al., 2014a)</td>
<td>Greek</td>
<td>Convenience sample of medical and surgical patients ($n = 300$, mean age: 55.4yrs, ranging 18-96yrs, 38.7% females) and the nursing staff ($n = 118$, mean age 36.7 years) working in the respective wards in three general hospitals.</td>
<td>To describe patient participation in decision making during nursing care from patients' and nursing staff perspectives</td>
<td>Survey using a questionnaire designed by Staino and Lauri (2003) to identify the extent to which cancer patients participate in decision making about their treatment &amp; nursing care</td>
<td>Interpersonal interaction supported by both groups. Collaboration was patients' perception while a more paternalistic attitude was evident in nurses' perception in relation to nursing care planning. A supportive framework was identified by both groups</td>
<td>&quot;I make my own decisions&quot; was the only item scored by more than half of the patients as not at all important. The mean values of importance and realization of PP in DM for patients and nurses were reported slightly different, but it was not known whether they were different significantly.</td>
<td>Schedule and treatment were identified factors in both groups</td>
</tr>
<tr>
<td>(Hegeland &amp; Hausken, 2013)</td>
<td>Norway</td>
<td>4 physicians (1 female) 7 nurses (all female, mostly 40-60yrs) and 7 patients (4 female, mostly 60-65yrs) in surgical unit (such as Tob., orthopaedic, urologic, gastrologic).</td>
<td>To identify how health care professionals and patients experience patient participation in decision-making processes in hospitals</td>
<td>Semi-structured Individual interviews</td>
<td>Integration of information: Asking and answering questions to integrate information, rank options and assess alternatives. (Communication difficulties and lack of opportunities to talk with physicians were perceived as barriers. Nurses found it difficult</td>
<td>Information dissemination: Acquisition and dissemination of knowledge, giving and receiving information, communication skills, dialogue between participants (both clinicians and patients agreed that PP in DM depends on accurate information about</td>
<td>As a group, health care professionals were more positive than patients. Both agreed on information dissemination but were partly divergent on control. Perceived barriers were mostly about</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Sample Details</td>
<td>Methods</td>
<td>Findings</td>
<td>Implications</td>
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<tr>
<td>Höglund et al. (2010)</td>
<td>Sweden</td>
<td>8 patients (3 females, 40-74yrs) recently discharged from hospital after MI. 17 doctors and nurses (12 females, 25-60yrs, 3-32 yrs work experience).</td>
<td>To explore and describe patient and clinicians’ perceptions of PP in care processes and decision-making in hospital with MI. 5 focus group interviews</td>
<td>Clinicians: Active involvement in medical decision-making or obtaining informed consent. Less emphasis by patients. Both staff and patients viewed patient participation primarily as information.</td>
<td>Hindrances were lack of time, staff, and patients’ lack of medical knowledge. Patient characteristics could also influence the level of participation. Patients perceived participation increased one’s personal commitment while clinicians perceived it increased patients’ feelings of security, control and influence.</td>
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<tr>
<td>(Bolster &amp; Manias, 2010)</td>
<td>Australia</td>
<td>11 nurses (9 females, average age 27 yrs) and 25 patients (6 females, average age 59 yrs, 18-91 yrs) in acute care wards with a collaboratively developed philosophy of person-centered care, in an Australian metropolitan hospital</td>
<td>To examine nurse-patient interactions during medication activities</td>
<td>Individual interviews and naturalistic observation</td>
<td>All nurses emphasized providing individualized care to patients while none of the patients indicated they had established a relationship with an individual nurse.</td>
<td>Nurses accentuated participation and collaboration to empower patients to make choices while a minority of patients described being involved in medication activities.</td>
<td>Nurses emphasized the importance of providing medication information and most patients felt they had got comprehensive information.</td>
</tr>
</tbody>
</table>
| (Löfman, Häggman-Lahti, & Pietilä, 2008) | Finland | 39 patients with rheumatoid arthritis and 36 nurses participated in the initial phase of evaluation phase | To describe the content and development of a model to promote self-determination (SD) of patients with rheumatoid arthritis from view of patients and nurses. | Action research designed with initial assessment phase to evaluate the level of SD, planning phase to develop a model, application phase and | Mutual decision making, freedom to express themselves (attention was paid to patients, and nurses respect patients’ views) (perceived by patients as preconditions) | Patients’ own decision making Independent choices (stressed by both patients and nurses) Nurses described independent choice about nursing care, linked to making choices and the right to refuse treatment: Influence on care decisions | Expertise of patients – respect patients’ knowledge and wishes Patients’ courage, knowledge and extensive professional nursing skills (perceived by nurses as preconditions) | Activity: participate in own nursing care | Impediments to SD: Insufficient staff resources, high turnover of nurses, patients’ lack of courage, (perceived by both groups) Shyness, kindness, fear of being stigmatized as a bad patient, trust in nurses as authorities (perceived by patients) Patients’ mobility, state of health and shyness (perceived by nurses) Promoting factors:
| (Tutton, 2005) | UK | 19 older patients with multiple diagnoses aged 60yrs in a ward with patients with high levels of nursing needs, requiring slow-stream rehabilitation or having complex discharge requirements. 24 nurses providing care on the ward. | To explore the meaning of participation for older people in hospital and their health care workers and ways in which staff can enhance patient participation in their care. | Action research, Focus group and individual interview. | Participation is a dynamic process that is integral to the work of nurses and carers. Emotional work (Acceptance, using emotions in a positive way, strong emotions). Partnership: respect, trust, negotiation. | Nature of participation: decision making, Negotiating care: a dynamic process of communication, evaluation and change. | Understanding the person: personal history, connecting with the person understanding illness/dependence. | Difficulties of promoting participation: caring for patients with inability to communicate verbally, time constraints, limited teamwork, and the ward environment. Comparisons between patients and nurses were not presented clearly. |
Appendix 4: Patient Participation in Symptom Management – Patient Questionnaire

Patient Participation in Symptom Management – Patient Questionnaire

Thank you for agreeing to complete this questionnaire. Your involvement and answers are important to us. Your answers will be kept confidential.

This questionnaire is designed to help us better understand your role in the discussions and decisions with the doctors and nurses about the care of your symptoms while you are in hospital.

There are no right or wrong answers, so please answer the questions based on your own experience and what aspects of care are important to you.

Please read every page carefully and answer all of the questions. If you unsure about how to respond to a particular question we are happy to help so please talk to the researcher when she returns to collect the survey.

Thank you again for completing this questionnaire.
### Appendices

Date of survey _______ (Day/ Month)  
Time of survey _________ am/pm

#### Section 1: Demographic and Cancer Information

**Instruction:** For the following questions please check the box.

<table>
<thead>
<tr>
<th>1 Date of birth:</th>
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<tbody>
<tr>
<td>_<em><strong><strong>/</strong></strong></em></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>(month/year)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2 Sex:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Male</td>
<td>☐ Female</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>3 Province of residence:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>______ (Province or Municipality City)</td>
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</table>

<table>
<thead>
<tr>
<th>4 Marital status:</th>
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</thead>
<tbody>
<tr>
<td>☐ Single</td>
<td>☐ Married</td>
<td>☐ De facto</td>
<td>☐ Divorced</td>
</tr>
<tr>
<td>☐ Widowed</td>
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<table>
<thead>
<tr>
<th>5 What is the highest level of education you have completed:</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>☐ Primary school</td>
<td>☐ Junior high school</td>
<td>☐ Senior high school</td>
</tr>
<tr>
<td>☐ Undergraduate</td>
<td>☐ Postgraduate</td>
<td></td>
</tr>
</tbody>
</table>

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<tr>
<th>6 Current work status:</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>☐ Occupied (still working)</td>
<td>☐ Occupied (on leave e.g. sick leave)</td>
<td>☐ Retired</td>
<td></td>
</tr>
<tr>
<td>☐ Non-occupied</td>
<td>☐ Studying</td>
<td>☐ Other (please specify)</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>6a What is your usual occupation (including the occupation before you retired or became non-occupied)?</th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>☐ Peasant</td>
<td>☐ Worker</td>
<td>☐ Company employee</td>
</tr>
<tr>
<td>☐ Civil servant</td>
<td>☐ Healthcare provider</td>
<td>☐ Service worker</td>
</tr>
<tr>
<td>☐ Student</td>
<td>☐ Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7 Your income level per month (Yuan):</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ ≤1,000</td>
<td>☐ 1,001-3,000</td>
<td>☐ 3,001-6,000</td>
<td>☐ 6,001-10,000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8 Access to medical insurance:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Yes</td>
<td>☐ No</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>1.8a If yes, the type of your major medical insurance:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Government Medical Insurance</td>
<td>☐ Social Medical Insurance</td>
<td></td>
</tr>
<tr>
<td>☐ Private Medical Insurance</td>
<td>☐ Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>
Appendices

9 Type of cancer:
- ☐ Lung cancer
- ☐ Bowel cancer
- ☐ Breast cancer
- ☐ Prostate cancer
- ☐ Gastric cancer
- ☐ Oesophageal cancer
- ☐ Head and neck cancer (please specify)
- ☒ Lymphoma
- ☐ Other (please specify)

10. Date of diagnosis: _____/____ (month/year)

11. Past treatment related to cancer (You may choose more than one option):
- ☐ Surgery
- ☐ Chemotherapy
- ☐ Radiotherapy
- ☐ Endocrine therapy
- ☐ Traditional Chinese medicine
- ☐ Other (please specify)

12. Purpose for this admission (You may choose more than one option):
- ☒ Chemotherapy
- ☐ Radiotherapy
- ☐ Other (please specify)

13. Other medical history (You may choose more than one option):
Do you have a chronic pain condition? ☐ Yes ☐ No
If yes, please list all:

Do you have a condition that limits your mobility? ☐ Yes ☐ No
If yes, please list all:

Have you ever been treated for anxiety in the past? ☐ Yes ☐ No
If yes, please list all:

Do you have a condition that impacts your breathing? ☐ Yes ☐ No
If yes, please list all:

Do you have a condition that impacts your bowel function? ☐ Yes ☐ No
If yes, please list all:

Have you ever been treated for depression in the past? ☐ Yes ☐ No
If yes, please list all:

Do you have any other conditions?

14. Do you have any family members or friends who are providing care for you while in hospital?
- ☐ Yes
- ☐ No
If yes, how long do they spend with you in hospital (If there are more than one care givers, please report the total length they spend)
- ☐ ≤ 2 hrs
- ☐ 2-4 hrs
- ☐ 4-8 hrs
- ☐ 8-12 hrs
- ☐ >12 hrs

15. Have you had a patient care assistant during this admission to hospital?
- ☐ Yes
- ☐ No
If yes, have you had a patient care assistant in the previous 24 hours?
- ☐ Yes
- ☐ No
## Memorial Symptom Assessment Scale

### Part 1

**INSTRUCTIONS:** We have listed 26 symptoms below. Please read each one carefully. If you have had the symptom during the past 24 hours, let us know how often you had it, how severe it was usually, how much it distressed or bothered you, and whether your doctor or nurse knows it by making a "✓" in the corresponding box. If you did not have the symptom, make an "✓" in the box marked DID NOT HAVE.

<table>
<thead>
<tr>
<th>DURING THE PAST 24 HOURS</th>
<th>DID NOT HAVE</th>
<th>IF YES HOW OFTEN did you have it?</th>
<th>IF YES How SEVERE was it usually?</th>
<th>IF YES How much did it DISTRESS or BOTHER you?</th>
<th>IF YES Does your doctor or nurse KNOW that you have this symptom?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you have any of the following symptoms?</td>
<td>Rarely</td>
<td>Occasionally</td>
<td>Frequently</td>
<td>Almost constantly</td>
<td>Slight</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cough</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling nervous</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dry mouth</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Feeling drowsy</td>
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<tr>
<td>Numbness/tingling in hands/feet</td>
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<td>Difficulty sleeping</td>
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<td>Feeling bloated</td>
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<td>Problems with urination</td>
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<tr>
<td>Vomiting</td>
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<td>Shortness of breath</td>
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<td>Diarrhoea</td>
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<td>Feeling sad</td>
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<td>Sweats</td>
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<tr>
<td>Worrying</td>
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<tr>
<td>Itching</td>
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<tr>
<td>Lack of appetite</td>
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<tr>
<td>Reflux</td>
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<td>Dizziness</td>
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<td>Difficulty swallowing</td>
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<tr>
<td>Feeling Irritable</td>
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<tr>
<td>Fatigue</td>
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<tr>
<td>Fever</td>
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</tbody>
</table>
### Part 2

**INSTRUCTIONS:** We have listed 8 symptoms below. Please read each one carefully. If you have had the symptom during the past 7 days, let us know how SEVERE it was usually, how much it DISTRESSED or BOthered you and whether your doctor or nurse knows it by making a “✓” in the corresponding box. If you DID NOT HAVE the symptom, make an “✗” in the box marked DID NOT HAVE. If you have mouth sores or constipation during the past week please tell us if these have also been present during the past 24 hours by making a “✓” in the corresponding box.

#### DURING THE PAST 7 DAYS

<table>
<thead>
<tr>
<th>DID NOT HAVE</th>
<th>IF YES</th>
<th>How SEVERE was it usually?</th>
<th>IF YES</th>
<th>How much did it DISTRESS or BOTHER you?</th>
<th>IF YES</th>
<th>Does your doctor or nurse KNOW that you have this symptom?</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

- **Mouth sores**
- **Constipation**
- **Change in the way food tastes**
- **Weight loss**
- **Hair loss**
- **Swelling of arms or legs**
- **"I don't look like myself"**

**Changes in skin**

**IF YOU HAVE HAD ANY OTHER SYMPTOMS DURING THE PAST WEEK, PLEASE LIST BELOW AND LET US KNOW HOW MUCH THE SYMPTOM HAS DISTRESSED OR BOthered YOU.**

- **Other:**
- **Other:**
- **Other:**
- **Other:**
Appendices

Hospital Anxiety and Depression Scale (HADS)

Name: __________________________ Date: __________________

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don’t take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

**I feel tense or ‘wound up’**
- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

**I still enjoy the things I used to enjoy**
- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

**I get a sort of frightened feeling as if something awful is about to happen**
- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn’t worry me
- Not at all

**I can laugh and see the funny side of things**
- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

**Worrying thoughts go through my mind**
- A great deal of the time
- A lot of the time
- Not too often
- Very little

**I feel cheerful**
- Never
- Not often
- Sometimes
- Most of the time

**I can sit at ease and feel relaxed**
- Definitely
- Usually
- Not often
- Not at all

**I feel as if I am slowed down**
- Nearly all the time
- Very often
- Sometimes
- Not at all

**I get a sort of frightened feeling like ‘butterflies’ in the stomach**
- Not at all
- Occasionally
- Quite often
- Very often

**I have lost interest in my appearance**
- Definitely
- I don’t take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

**I feel restless as if I have to be on the move**
- Very much indeed
- Quite a lot
- Not very much
- Not at all

**I look forward with enjoyment to things**
- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

**I get sudden feelings of panic**
- Very often indeed
- Quite often
- Not very often
- Not at all

**I can enjoy a good book or radio or television programme**
- Often
- Sometimes
- Not often
- Very seldom

Now check that you have answered all the questions.

This form is printed in green. Any other colour is an unauthorised photocopy.


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Cl. Assessment is part of the Cenatrpa Group

Printed in Great Britain

W.L(UK)
Eastern Cooperative Oncology Group (ECOG) Performance Status

In the following question we are interested in finding out how the impact of your current health condition is affecting your daily living activities. There are 5 different options to select from. Please select the statement that most accurately reflects your activity *over the past week*.

<table>
<thead>
<tr>
<th>Grade</th>
<th>ECOG</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction.</td>
</tr>
<tr>
<td>1</td>
<td>Restriction in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work.</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours.</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours.</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair.</td>
</tr>
</tbody>
</table>
Section 2: Participation

Symptom information and patient communication behaviours

1. In the past 24 hours, did a doctor or nurse make it clear to you that they consider treatment of symptoms very important and that you should tell them when you are experiencing a symptom?
   - Yes
   - No

2. Has the information provided about symptoms been presented to you using language/terms that you understand?
   - Yes
   - No

3. Do you usually report your symptoms to the doctors and nurses or wait until you are asked?
   - Report
   - Wait

4. Using the following scale please indicate whether you would press your patient call bell to report a symptom?
   - Never
   - Rarely (<10% of the time)
   - Sometimes (50% of the time)
   - Usually (75% of the time)
   - Always (100% of the time)

5. Have you received any information about your symptom treatment options?
   - Yes (Proceed to question 6)
   - No (Please proceed to question 7)

6. How helpful was this information?
   (If 0 is equal to ‘not at all helpful’ and 10 is equal to ‘extremely helpful’ please tell me a number that best represents how helpful the information was)
   - Not at all helpful
   - Extremely helpful

7. Have you refused symptom management medication that is prescribed on a regular basis in the past 24 hours?
   - Yes
   - No

a) If yes to question 7, please explain what medication you refused and why:

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
Section 2: Participation

Symptom information and patient communication behaviours

1. In the past 24 hours, did a doctor or nurse make it clear to you that they consider treatment of symptoms very important and that you should tell them when you are experiencing a symptom?
   □ Yes  □ No

2. Has the information provided about symptoms been presented to you using language/terms that you understand?
   □ Yes  □ No

3. Do you usually report your symptoms to the doctors and nurses or wait until you are asked?
   □ Report  □ Wait

4. Using the following scale please indicate whether you would press your patient call bell to report a symptom?
   □ Never  □ Rarely (<10% of the time)
   □ Sometimes (50% of the time)  □ Usually (75% of the time)
   □ Always (100% of the time)

5. Have you received any information about your symptom treatment options?
   □ Yes  (Proceed to question 6)
   □ No (Please proceed to question 7)

6. How helpful was this information?
   (If 0 is equal to ‘not at all helpful’ and 10 is equal to ‘extremely helpful’ please tell me a number that best represents how helpful the information was)
   Not at all helpful  Extremely helpful
   0  1  2  3  4  5  6  7  8  9  10

7. Have you refused symptom management medication that is prescribed on a regular basis in the past 24 hours?
   □ Yes  □ No

   a) If yes to question 7, please explain what medication you refused and why:
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
10. Have you been allowed to include your ‘support person’ in decisions about your symptom treatment as much as you wanted during this admission?

11. What factors do you believe have impacted on your ability to involve your ‘support person’ when making decisions about your symptom management? (please tick all that apply)

- ‘Support person’ not present during medical rounds
- ‘Support person’ not present when decisions need to be made about symptom management
- Not being about to remember all the information to tell the ‘support person’ so that they can be involved in the decision making
- Having to make quick decisions
- Not being given the opportunity to discuss the decision in private with your ‘support person’
- Other (please specify)
Patients' Views and Behaviours about involvement in care (modified)

**INSTRUCTION:** The following questions are designed to find out, from your perspective, what degree you agree with, and usually receive care related to your symptoms. For each question please give the answer that best describes your attitudes or experience during this admission.

<table>
<thead>
<tr>
<th>To what degree do you agree that the following aspects are important: The patient</th>
<th>Agree completely</th>
<th>Agree somewhat</th>
<th>Don't agree very much</th>
<th>Don't agree at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 gets clear information</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
</tr>
<tr>
<td>2 Ask questions about their symptoms</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
</tr>
<tr>
<td>3 expresses his/her views</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
</tr>
<tr>
<td>4 is involved in discussions about his/her symptom care and treatment</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
</tr>
<tr>
<td>5 is involved in making decisions about my symptom care and treatment</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
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<tr>
<td>6 bear the main responsibility for his/her future health</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
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</tbody>
</table>

**Did you receive the information you wanted about the following:**

<table>
<thead>
<tr>
<th>Did you receive the information you wanted about the following:</th>
<th>To a very great degree</th>
<th>To a fairly great degree</th>
<th>To a certain degree</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 Your symptom(s) and their course?</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
</tr>
<tr>
<td>8 Why specific examinations/treatments are done?</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
</tr>
<tr>
<td>9 How examinations/treatments are done?</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
</tr>
<tr>
<td>10 Possible pain/discomfort that can develop in conjunction with examinations/treatments?</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
</tr>
<tr>
<td>11 What will occur during the acute phase?</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
<td>😄</td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>To a very great degree</td>
<td>To a fairly great degree</td>
<td>To a certain degree</td>
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<td>12</td>
<td>Did you have the opportunity to ask questions about your symptoms?</td>
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<tr>
<td>13</td>
<td>Did you understand the information you received?</td>
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<td>14</td>
<td>Were the doctors and nurses sensitive to your special needs/requests?</td>
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<td>15</td>
<td>Are you worried about your symptoms?</td>
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<tr>
<td>16</td>
<td>Were you treated with respect?</td>
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<tr>
<td>17</td>
<td>Did you receive the information you wanted about the results of examinations/treatments?</td>
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<tr>
<td>18</td>
<td>Did you receive the information you wanted about your medications?</td>
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<tr>
<td>19</td>
<td>Do you want the opportunity to ask questions before you are discharged?</td>
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<tr>
<td>20</td>
<td>Did you take part in discussing your examinations/treatment with your doctors and nurses?</td>
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<tr>
<td>21</td>
<td>Have you been involved in making decisions about symptom care and treatment with the doctors and nurses?</td>
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<tr>
<td>22</td>
<td>Did you discuss the goals of your symptom care and treatment with the doctors and nurses?</td>
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<tr>
<td>23</td>
<td>Have doctors/nurses motivated you to take responsibility for your future health?</td>
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<tr>
<td>24</td>
<td>Do you want to take part in planning your follow-up care i.e. what would happen after you are discharged from hospital?</td>
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</tbody>
</table>

**To what degree do you agree with following:**

<table>
<thead>
<tr>
<th></th>
<th>Agree completely</th>
<th>Agree somewhat</th>
<th>Don’t agree very much</th>
<th>Don’t agree at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>25</td>
<td>Patients who want to be involved in their care can create problems for clinicians in their work</td>
<td></td>
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<tr>
<td>26</td>
<td>Patients who are involved in their care take clinicians’ time away from other patients</td>
<td></td>
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<tr>
<td>27</td>
<td>Patients who are involved in their care increase clinicians’ workload</td>
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</table>
Barriers and facilitators to patient participation in symptom management

Still thinking about this admission I would like to find out about what things you believe have made it easy or hard for you to be involved in your symptom management.

1. Have you found it difficult to participate in care decisions about your symptoms?

☐ Yes  ☐ No

a) If yes, why was it difficult? (please tick all that apply)
Not enough time with clinicians ☐
Not enough information ☐
Difficulty remember information ☐
Feeling unwell ☐
Other (Please specify) ☐

2. What, if anything do you believe has made it easier for you to participate in the care of your symptoms during the past 24 hours?

Having enough time with clinicians ☐
Having enough information ☐
Being able to remember information ☐
Feeling well ☐
Other (please specify) ☐
### Section 3: Satisfaction with Symptom Management

**INSTRUCTION:** Please read each of the statements below and mark an “✓” in the box which best indicates how satisfied or dissatisfied you are with the care you have received for your symptoms since you have been in hospital.

<table>
<thead>
<tr>
<th>How satisfied or dissatisfied are you with:</th>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Slightly dissatisfied</th>
<th>Slightly satisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>the results of your symptom treatment overall in the past 24 hours</td>
<td></td>
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<tr>
<td>the way your doctors responded to your reports of symptoms in the past 24 hours</td>
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<tr>
<td>the way your nurses responded to your reports of symptoms in the past 24 hours</td>
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<tr>
<td>the information that you have been provided with relating to your symptoms</td>
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<tr>
<td>the information that you have been provided with relating to the treatment of your symptoms</td>
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</table>

If you are not satisfied with the treatment of your symptoms or the information you have been provided about your symptoms in any way, please explain why.

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--------------------------------------------------------------
Section 4: Understanding Health
Understanding Health and Healthcare Questionnaire

Understanding Health and Healthcare Questionnaire

In this questionnaire, please consider healthcare providers as doctors, nurses and any other health professional.

Unit Record Number (UR): ______________
Example:

Please indicate how strongly you disagree or agree with the following statements by crossing the response that best describes you now.

Ms. Jane Citizen has answered these questions in the following way:

*Check a box by crossing it:*

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1. I am doing some of my hobbies</td>
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<tr>
<td>2. I have a plan to do some physical activity</td>
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</tbody>
</table>

Question 1. Jane’s answer shows that right now she agrees that she has been doing some of her hobbies.

Question 2. Jane disagrees with the statement that right now she has a plan to do some physical activity.

Please indicate how strongly you disagree or agree with the following statements by crossing the response that best describes you now.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel I have good information about health</td>
<td></td>
<td></td>
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<tr>
<td>2. I have at least one healthcare provider who knows me well</td>
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<tr>
<td>3. I can get access to several people who understand and support me</td>
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<tr>
<td>4. I compare health information from different sources</td>
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<tr>
<td>5. When I feel ill, the people around me really understand what I am going through</td>
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<tr>
<td>6. I spend quite a lot of time actively managing my health</td>
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<tr>
<td>7. When I see new information about health, I check up on whether it is true or not</td>
<td></td>
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</tr>
</tbody>
</table>
Please indicate how strongly you disagree or agree with the following statements by crossing the response that best describes you now.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
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<td>15</td>
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<td>22</td>
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<tr>
<td>23</td>
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</tbody>
</table>
Appendices

Example:

Please indicate how easy or difficult the following tasks are for you to do now.

Ms. Jane Citizen has answered these questions in the following way:

*Check a box by crossing it:*

<table>
<thead>
<tr>
<th>Task</th>
<th>Cannot do</th>
<th>Very difficult</th>
<th>Quite difficult</th>
<th>Quite easy</th>
<th>Very easy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Drive a car</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Read a book</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Question 1, Jane’s answer shows that right now she cannot drive a car. Question 2, Jane shows that right now she can read a book quite easily.

---

Please indicate how easy or difficult the following tasks are for you to do now.

<table>
<thead>
<tr>
<th>Task</th>
<th>Cannot do</th>
<th>Very difficult</th>
<th>Quite difficult</th>
<th>Quite easy</th>
<th>Very easy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Find the right health care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Make sure that healthcare providers understand your problems properly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Find information about health problems</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>4 Feel able to discuss your health concerns with a healthcare provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>5 Confidently fill medical forms in the correct way</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6 Find health information from several different places</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Have good discussions about your health with doctors</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>8 Get to see the healthcare providers I need to</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Accurately follow the instructions from healthcare providers</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>10 Get information about health so you are up to date with the best information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Decide which healthcare provider you need to see</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Read and understand written health information</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>13 Make sure you find the right place to get the health care you need</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Task</td>
<td>Cannot do</td>
<td>Very difficult</td>
<td>Quite difficult</td>
<td>Quite easy</td>
<td>Very easy</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-----------</td>
<td>----------------</td>
<td>-----------------</td>
<td>------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Get health information in words you understand</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Discuss things with healthcare providers until you understand all</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>you need to</td>
<td></td>
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</tr>
<tr>
<td>Find out what healthcare services you are entitled to</td>
<td></td>
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<tr>
<td>Read and understand all the information on medication labels</td>
<td></td>
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<tr>
<td>Get health information by yourself</td>
<td></td>
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</tr>
<tr>
<td>Work out what is the best care for you</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Ask healthcare providers questions to get the health information you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>need</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand what healthcare providers are asking you to do</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section 5: Quality care

Quality from the patient’s perspective-Short form

**INSTRUCTION:** The following questions are designed to find out, from patient’s perspective, how important different types of care are to you as well as what you have actually experienced. For each question please give the answer that best describes the care you received during this admission to the radiotherapy ward. Please fill in both A and B for each question.

<table>
<thead>
<tr>
<th>A. This is how important it is to me</th>
<th>B. This is what I experienced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Of the very highest importance</td>
<td>Fully agree</td>
</tr>
<tr>
<td>Of high importance</td>
<td>Mostly agree</td>
</tr>
<tr>
<td>Of some importance</td>
<td>Party agree</td>
</tr>
<tr>
<td>Of little or no importance</td>
<td>Do not agree at all</td>
</tr>
<tr>
<td>Not applicable</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>

**I receive useful information on**

1. How symptom assessments and treatments take place
   - A: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5
   - B: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5

2. The results of symptom assessments and treatments
   - A: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5
   - B: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5

3. Self-care; “how I should take care of myself?”
   - A: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5
   - B: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5

4. Which doctor is responsible for my medical care
   - A: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5
   - B: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5

5. Which nurse is responsible for my nursing care
   - A: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5
   - B: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5

**I receive**

6. The best possible physical care; e.g. help to take care of my personal hygiene
   - A: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5
   - B: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5

7. The best possible symptom care (as far as I can tell)
   - A: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5
   - B: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5

8. Effective pain relief
   - A: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5
   - B: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5

9. Symptom assessments and treatments within acceptable waiting times
   - A: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5
   - B: [ ] 1  [ ] 2  [ ] 3  [ ] 4  [ ] 5
| | A. This is how important it is to me | B. This is what I experienced |
|---|---|---|---|---|---|---|---|---|
| The doctors | Of the very highest importance | Of high importance | Of some importance | Of little or no importance | Not applicable | Fully agree | Mostly agree | Partly agree | Do not agree at all | Not applicable |
| 1 | Seem to understand how I experience my situation |  |  |  |  |  |  |  |  |  |
| 1 | are respectful towards me |  |  |  |  |  |  |  |  |  |
| 2 | Show commitment; 'care about me' |  |  |  |  |  |  |  |  |  |
| The nurses | Of the very highest importance | Of high importance | Of some importance | Of little or no importance | Not applicable | Fully agree | Mostly agree | Partly agree | Do not agree at all | Not applicable |
| 1 | Seem to understand how I experience my situation |  |  |  |  |  |  |  |  |  |
| 1 | are respectful towards me |  |  |  |  |  |  |  |  |  |
| 1 | Show commitment; 'care about me' |  |  |  |  |  |  |  |  |  |
| I talk to | Of the very highest importance | Of high importance | Of some importance | Of little or no importance | Not applicable | Fully agree | Mostly agree | Partly agree | Do not agree at all | Not applicable |
| 1 | The doctors in private when I want to |  |  |  |  |  |  |  |  |  |
| 1 | The nurses in private when I want to |  |  |  |  |  |  |  |  |  |
| I have a good opportunity | Of the very highest importance | Of high importance | Of some importance | Of little or no importance | Not applicable | Fully agree | Mostly agree | Partly agree | Do not agree at all | Not applicable |
| 1 | To participate in decisions that apply to my symptom treatment and care |  |  |  |  |  |  |  |  |  |
| My symptom treatment and care | Of the very highest importance | Of high importance | Of some importance | Of little or no importance | Not applicable | Fully agree | Mostly agree | Partly agree | Do not agree at all | Not applicable |
| 1 | Are determined by my own requests and needs rather than the staff's procedures/routines |  |  |  |  |  |  |  |  |  |
| My relatives and friends | Of the very highest importance | Of high importance | Of some importance | Of little or no importance | Not applicable | Fully agree | Mostly agree | Partly agree | Do not agree at all | Not applicable |
| 1 | are treated well |  |  |  |  |  |  |  |  |  |
| There is | Of the very highest importance | Of high importance | Of some importance | Of little or no importance | Not applicable | Fully agree | Mostly agree | Partly agree | Do not agree at all | Not applicable |
| 1 | A pleasant atmosphere on the ward |  |  |  |  |  |  |  |  |  |
Appendix 5: Patient Participation in Symptom management –Doctor Questionnaire

Thank you for agreeing to complete this questionnaire. Your participation and answers are important to us. Your answers will be kept confidential.

This questionnaire is designed to help us better understand your role in the discussions and decisions with patients about the management of their symptoms while they are in hospital.

There are no right or wrong answers. For each question please give the answer that best describes your attitudes or performance.

Please read every page carefully and answer all of the questions. If you are unsure how to respond to a particular question please ask Cen Lin.

Thank you for completing this questionnaire.
# Section 1: Demographic Information

**Instruction:** For the following questions please check the box.

<table>
<thead>
<tr>
<th>1. Age group:</th>
<th>□ 18-20</th>
<th>□ 21-30</th>
<th>□ 31-40</th>
<th>□ 41-50</th>
<th>□ 51-60</th>
<th>□ 61-70</th>
<th>□ 70+</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Sex:</td>
<td>□ Male</td>
<td>□ Female</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Medical education:</td>
<td>□ Bachelor Degree</td>
<td>□ Master</td>
<td>□ PhD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Have you undergone any specialty oncology training?</td>
<td>□ Yes</td>
<td>□ No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| If yes, what was this training? | .................................................................
| | .................................................................
| 5. Job title: | □ Doctor | □ Attending Doctor |
| | □ Associate Professor/Chief | □ Professor/Chief |
| 6. Role in ward: | □ Resident | □ Attending | □ Consultant | □ Chief |
| | □ Other (please specify) | | |
| 7. Length of employment in this radiotherapy unit: | ........... (Please specify either months or years) |
| 8. Length of oncological experience: | ........... (Please specify either months or years) |
Section 2: Views and behaviour

Clinicians’ Views and Behaviours about Patient Involvement in care (modified)

**INSTRUCTION:** The following questions are designed to find out, from your perspective, what degree you agree with, and usually perform, the following types of patient care. For each question please give the answer that best describes your attitudes and performance.

<table>
<thead>
<tr>
<th>To what degree do you agree that the following aspects are important: The patient</th>
<th>Agree completely</th>
<th>Agree somewhat</th>
<th>Don’t agree very much</th>
<th>Don’t agree at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 gets clear information</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2 asks questions about his/her symptoms</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3 expresses his/her views</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>4 is involved in discussions about his/her symptom care and treatment</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>5 is involved in making decisions about his/her symptom care and treatment</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>6 bears the main responsibility for his/her future health</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>To what degree do you usually inform the patient about:</th>
<th>To a very great degree</th>
<th>To a fairly great degree</th>
<th>To a certain degree</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 The patient’s symptom(s) and their course</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>8 Why specific examinations/treatments are done</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>9 How examinations/treatments are done</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>10 Possible pain/discomfort that can develop in conjunction with examinations/treatments</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>11 What will occur during the acute phase</td>
<td>□, □</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>To what degree do you usually ask whether the patient:</td>
<td>To a very great degree</td>
<td>To a fairly great degree</td>
<td>To a certain degree</td>
<td>Not at all</td>
</tr>
<tr>
<td>------------------------------------------------------</td>
<td>----------------------</td>
<td>-------------------------</td>
<td>-------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>12 Has questions</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>13 Has understood the information he/she has received</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>14 Has special needs/requests</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>15 Is worried about his/her symptoms</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>To what degree do you usually:</th>
<th>To a very great degree</th>
<th>To a fairly great degree</th>
<th>To a certain degree</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>16 Treat the patient with respect</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>17 Inform the patient about results from examinations/treatments</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>18 Inform the patient about his/her medications</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>19 Provide the patient with the opportunity to ask questions before they are discharged</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>20 Involve the patient in discussing his/her examinations/treatments</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>21 Make decisions about symptom care and treatment together with the patient</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>22 Discuss the goals of symptom care and treatment with the patient</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>23 Try to motivate the patient to take responsibility for his/her future health</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>24 Involve the patient in planning his/her follow up care i.e. what happens after he/she is discharged from hospital?</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>To what degree do you agree with the following:</th>
<th>Agree completely</th>
<th>Agree somewhat</th>
<th>Don’t agree very much</th>
<th>Don’t agree at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>25 An involved patient’s demands can create problems for me in my work</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>26 An involved patient takes my time away from other patients</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
<tr>
<td>27 An involved patient increases my workload</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
<td>☐,</td>
</tr>
</tbody>
</table>
Appendices

Appendix 6: Control Preference Scale

Control Preference Scale – Observation – Doctor’s complete

1 Patient PREFERENCE for participation in symptom management

Instructions:
We are interested in finding out about patients’ preference for being involved in their symptom management while they are in hospital. We are also interested in finding out about doctors and nurses’ perceptions of patient’s preferences for involvement and actual involvement in their symptom care. The following five statements describe how much a patient might want to be involved with the doctors in making decisions about his/her symptoms and symptom treatment. I would like you to read each statement and mark a “√” in the box that most closely aligns with your perception of ______ patient’s preference for being involved in making decisions about the treatment of his/her symptoms.

The patient prefers that I make all decisions regarding treatment(s) of his/her symptoms.

The patient prefers that I make the final decision about which treatment(s) will be used to treat his/her symptoms, but only after I seriously consider his/her opinion.

The patient prefers to share responsibility with me for deciding which symptom treatment(s) is best for him/her.

The patient prefers to make the final decision about their symptom treatment(s) after seriously considering my opinion.

The patient prefers to make the final decision about which treatment(s) he/she will receive for his/her symptoms.
Appendices

2 Patients ACTUAL role in making decisions about their symptom management

Instructions:

In this question I would like you to think about the patient’s actual involvement in his/her symptom management. The same five roles that you used to answer the previous questions are written below, however, they are written to reflect the actual involvement. Please look at these roles and mark a “✓” in the box next to the role that most closely reflects the way that the patient is involved in the decisions made about his/her symptoms.

I make all decisions regarding treatment(s) of the patient’s symptoms.

I make the final decision about which treatment(s) will be used to treat the patient’s symptoms, but seriously consider the patient’s opinion.

The patient and I share responsibility for deciding which symptom treatment(s) is best for him/her with me.

The patient makes the final decision about his/her symptom treatment(s) after seriously considering my opinion.

The patient makes the final decision about which treatment(s) he/she will receive for his/her symptoms.
Control Preference Scale – Observation – Patient-doctor interaction
Patient’s complete

Date of birth: ____/____ Year/Mon

Sex: Male □  Female □

Province of Residence: ____/____ (Province/city)

1. Patient PREFERENCE for participation in symptom management

Instructions:

I have 5 different cards. Each card contains a role statement that describes how much you might want to be involved in making decisions about your symptoms and symptom treatment with your doctors. I would like you to read each card and pick the statement that best reflects your preference for being involved with your doctors in deciding your symptom treatment.

I prefer to leave all decisions regarding treatment(s) of my symptoms to my doctors.

I prefer that my doctors make the final decisions about which treatment(s) will be used to treat my symptoms, but seriously consider my opinion.

I prefer that the doctors and I share responsibility for deciding which symptom treatment(s) is best for me.

I prefer to make the final decision about my symptom treatment(s) after seriously considering my doctor’s opinion.

I prefer to make the final decision about which treatment(s) I will receive for my symptoms.
2. Patients ACTUAL role in making decisions about their symptom management

Instructions:

You’ve just told me the role you would prefer in making decisions about your symptoms is (repeat patient preference). Please think about the way your symptoms have been managed today or recently. There are another five cards that contain the same roles as the cards you have just used to answer the previous questions, however they are written to reflect your actual dealings with your nurses about your symptoms. Please look at these cards and tell me which role is closest to the way decisions about your symptoms are made."

My nurses make all decisions regarding treatment(s) of my symptoms.

My nurses make the final decision about treatment(s) for my symptoms, after they seriously consider my opinion.

My nurses and I share responsibility for deciding which symptom treatment(s) is best for me.

I make the final decision about my symptom treatment(s) after seriously considering my nurse’s opinion.

I make the final decision about my treatment(s) for my symptoms.
Control Preferences Scale Phase 2/Stage 1

Patient Survey

1. Control Preference Scale (Rating)

Instructions: I have 5 different cards. Each card contains a role statement that describes how much you might want to be involved in making decisions about your symptoms and symptom treatment with your doctors and nurses. I will read you each statement separately. After I read a statement I would like you to please think about your symptom(s) today and decide how much you that statement reflects your preference on a scale of 1 to 5, where 1 is NOT PREFERRED and 5 is PREFERRED.

NOTE: Patients will need to provide their answer to each statement before moving on to the next statement.

DO NOT change a patient’s responses to a previous role statement. If a patient wants to change an answer please tell them they will have the opportunity to rank their preferences in the next question.

The numbers (1-5) do not have to be different for each role statement.

After reading each statement ask the patient “How much does that statement reflect your preference?”

Not Preferred Preferred

I prefer to leave all decisions regarding treatment(s) of my symptoms to my doctors and nurses.

I prefer that my doctors and nurses make the final decisions about which treatment(s) will be used to treat my symptoms, but seriously consider my opinion.

I prefer that the doctors, nurses and I share responsibility for deciding which symptom treatment(s) is best for me.

I prefer to make the final decision about my symptom treatment(s) after seriously considering my doctor’s and nurse’s opinions.

I prefer to make the final decision about which treatment(s)
2. Control Preference Scale (Ranking)

Instructions: Please rank the cards in order from your most preferred role statement (5) to your least preferred role statement (1). In this question no two role statements can have the same rank. There are no wrong answers.

I prefer to leave all decisions regarding treatment(s) of my symptoms to my doctors and nurses.

I prefer that my doctors and nurses make the final decision about which treatment(s) will be used to treat my symptoms, but seriously consider my opinion.

I prefer that the doctors, nurses and I share responsibility for deciding which symptom treatment(s) is best for me.

I prefer to make the final decision about my symptom treatment(s) after seriously considering my doctor's and nurse's opinion.

I prefer to make the final decision about which treatment(s) I will receive for my symptoms.
3. Actual Role Achieved

**Instruction:** You’ve just told me the role you would prefer in making decisions about your symptoms is (repeat patient preference). Please think about the way yours symptoms have been managed today or recently. There are another five cards that contain the same roles as the cards you have just used to answer the previous questions, however they are written to reflect today, or your most recent dealings with your doctors and nurses about your symptoms. Please look at these cards and tell me which role is closest to the way decisions about your symptoms have been made.

*My doctors and nurses made all decisions regarding treatment(s) of my symptoms.*

*My doctors and nurses made the final decision about treatment(s) for my symptoms after they seriously considered my opinion.*

*The doctors, nurses and I shared responsibility for deciding which symptom treatment(s) was best for me.*

*I made the final decision about my symptom treatment(s) after seriously considering my doctor’s and nurse’s opinions.*

*I made the final decision about my treatment(s) for my symptoms.*
## Appendix 7: Interview guide

### Guide for patient interview

<table>
<thead>
<tr>
<th>Topic</th>
<th>Main themes</th>
<th>Questions</th>
<th>Potential patient responses/discussion points</th>
<th>Additional probes according to patient response</th>
</tr>
</thead>
<tbody>
<tr>
<td>When patients select a control preference what does it mean to them?</td>
<td>Reason for preference</td>
<td>Can you tell me why this is your most preferred role?</td>
<td>If patients talk about past experience of participation or hospitalization or symptoms that have influenced their preference please explore.</td>
<td>Could you tell me a little bit more about how this experience has influenced your preference for participation?</td>
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<td>Can you tell me about why being (specify patients role preference e.g. making decisions about your symptom management) is important to you?</td>
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<td></td>
<td>What type of care activities related to your symptoms do you participate in given your preference for (specify patient’s role preference)?</td>
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<tr>
<td>What types of care activities related to symptoms have patients participated in during their current admission?</td>
<td>Symptom communication</td>
<td>How do you think the doctors and nurses should find out about the symptoms you are experiencing?</td>
<td></td>
<td>You might use one of the symptoms that the patient has already reported to guide them with this question. For example, how do you think the doctors and nurses should find</td>
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<tr>
<td>Patient experience in participating in symptom treatment</td>
<td>Thinking about this admission, how has the treatment for your symptom been decided?</td>
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<tr>
<td>If you have a symptom and do not report it, what do you think will happen?</td>
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<tr>
<td>Can you think of any situations where you might not tell the doctors and nurses about a symptom that you are experiencing?</td>
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<tr>
<td>Can you tell me a little bit about your experience(s) of participation in symptom management during your stay in hospital?</td>
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</tbody>
</table>

**For patients who achieved their preferred level of participation:**

Question: Can you tell me a little bit about the things that made it possible for you to be able to participate at your preferred level?

**For patients who did not achieve their preferred level of participation:**

Question: Can you tell me a little bit about your
<table>
<thead>
<tr>
<th>How do you think a patient with your preference for participation should engage with the doctors and nurses about their symptoms?</th>
<th>Can you describe any particular types of behaviours that you think are characteristic of someone with this preference?</th>
</tr>
</thead>
<tbody>
<tr>
<td>[If the patient’s preference is NOT active] Can you provide me with any examples of behaviours that you think a patient who prefers to make the final decision about which treatment they will receive for their symptoms might engage in during their hospital admission?</td>
<td>Let’s take for example &lt;insert symptom here&gt;. If you were a patient who wanted to make the final decision in the management of their &lt;insert symptom here&gt;, and you felt this symptom right now, what would you do?</td>
</tr>
<tr>
<td>Can you think of any examples where you have been involved in making the final decision about your symptoms?</td>
<td>If patient is unable to think of anything provide an example: You have been constipated in</td>
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<tr>
<td>Question</td>
<td>Answer</td>
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<tr>
<td><strong>[If the patient’s preference is active] Can you provide me with any examples of behavior that you think a patient who prefers to collaborate with the doctors and nurses about which treatment they will receive for their symptoms might engage in during their hospital admission?</strong></td>
<td><strong>Let’s take for example &lt;insert symptom here&gt;. If you were a patient who wanted to collaborate with the doctors and nurses about the management of their &lt;insert symptom here&gt;, and you felt this symptom right now, what would you do?</strong></td>
</tr>
<tr>
<td><strong>How do you think the doctors and nurses should find out about which symptom treatment is best for you?</strong></td>
<td><strong>If the patient responds that they leave it to the experts</strong>&lt;br&gt;<strong>Question:</strong> Do the doctor and nurses speak to you about the different treatments (medications)?**</td>
</tr>
<tr>
<td>Satisfaction with participation</td>
<td>Would you like to have more to do with how your symptoms are being managed while you are in hospital?</td>
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<td>Have you ever worried about how your symptoms are being treated while you are in hospital?</td>
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<tr>
<td>What are patient perceived barriers and facilitators to patient participation in acute care?</td>
<td>What are the types of things that a doctor or a nurse has to do in order for you to be able to participate in the management of your symptoms?</td>
</tr>
</tbody>
</table>
## Guide for doctor and nurse interview

<table>
<thead>
<tr>
<th>Overall topic</th>
<th>Main theme</th>
<th>Guiding questions</th>
<th>Discussion point</th>
<th>Potential probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do clinicians think about patient participation generally?</td>
<td>Clinicians’ understanding and attitudes towards patient participation</td>
<td>Tell me what you think about patients being involved in their care on your ward?</td>
<td>What do they think patients being involved means?</td>
<td></td>
</tr>
<tr>
<td>What do clinicians think about patient participation in symptom management?</td>
<td>Clinicians’ attitudes and perceptions of patients participating in their symptom management</td>
<td>Tell me what you think about patients being involved in the management of their symptoms while they are in hospital?</td>
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<td></td>
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<td>What sorts of symptom care processes do you think that patients could participate in?</td>
<td>If the clinicians provide examples</td>
<td>How do you think patient involvement in these things might influence their symptom outcomes?</td>
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<td>What do you think of the idea of patients deciding about the treatment of their symptoms while they are in hospital?</td>
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<td>Do you think patients should be able to treat their own symptoms i.e. administer their own medication?</td>
<td>If clinicians say yes</td>
<td>What sorts of things would have to happen on the ward to make it possible for patients to be able to administer their own medication?</td>
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<td></td>
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<td>If clinicians say no</td>
<td>Can you please tell me why you think that patients should not be able to administer their own medications?</td>
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<tr>
<td>Overall topic</td>
<td>Main theme</td>
<td>Guiding questions</td>
<td>Discussion point</td>
<td>Potential probes</td>
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<tr>
<td>Clinicians’ perceptions of patients’ preference for participating in their symptom management</td>
<td>In your everyday practice how do you know if patients want to be involved?</td>
<td>If the clinicians are able to provide examples</td>
<td>Do you ask patients how much they want to be involved?</td>
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<td></td>
<td>What sorts of behaviours do you think are characteristic of patients who want to be involved?</td>
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<tr>
<td></td>
<td>What sorts of behaviours do you think are characteristic of patients who do not want to be involved?</td>
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<tr>
<td>Family participation</td>
<td>Can you give me some examples of when a patient’s family member has been involved or wanted to be involved in symptom management?</td>
<td>If the clinicians can provide examples</td>
<td>Was the patient aware of their illness?</td>
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<td>Was the patient happy for the family member to be involved in their symptom management?</td>
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<td>Was the patient aware of the decisions that their family member was making for them?</td>
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<tr>
<td>Overall topic</td>
<td>Main theme</td>
<td>Guiding questions</td>
<td>Discussion point</td>
<td>Potential probes</td>
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<tr>
<td>What are the barriers and facilitators of patient participation in symptom management on the ward?</td>
<td>Hospital or ward policies</td>
<td>Are you aware of any hospital or ward policies regarding patient participation?</td>
<td>If they are aware of policies</td>
<td>Can you tell me a little bit more about these?</td>
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<td>What do you think about these policies?</td>
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<td></td>
<td>Do these policies help you involve patients in their care?</td>
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<tr>
<td>Patients’ capacity to participate</td>
<td>What sorts of things might influence a patient’s ability to participate in their symptom management on the ward?</td>
<td>If the clinicians talk about patient knowledge/understanding of illness</td>
<td>Do you think if patients had more knowledge that they might want to participate more?</td>
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<tr>
<td></td>
<td></td>
<td>Respect for the expertise of the doctors and nurses</td>
<td>What sorts of things do you think patients might do to manage their symptoms if they were not in hospital?</td>
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<td>If the clinicians mention that the patients are too sick to participate</td>
<td>When the patients are very sick, how do you get their inform consent?</td>
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<td></td>
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<td>Do you think the type of decision might influence patients’ willingness to be involved?</td>
<td>If clinicians say yes</td>
<td>What type of decision do patients prefer to be involved?</td>
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<td></td>
<td>Do you think that patients’ experience with a particular symptom might influence their preference for being involved in symptom management?</td>
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<tr>
<td>Overall topic</td>
<td>Main theme</td>
<td>Guiding questions</td>
<td>Discussion point</td>
<td>Potential probes</td>
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<tr>
<td>Symptom</td>
<td>Let’s think about the ward routines, how do you find out about patient symptoms?</td>
<td>If the clinicians talk about asking the patient about their symptoms</td>
<td>How do you decide which symptoms you should ask patients about? How often would you ask patients about their symptoms?</td>
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<td></td>
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<td>If the clinicians talk about patients volunteering their symptoms</td>
<td>Do you think the type of symptom might influence patients reporting?</td>
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<tr>
<td>Context of</td>
<td>Is there anything that you do in your daily care that enables patients to be involved?</td>
<td>If yes</td>
<td>Could you please tell me a little bit more about these? What are they?</td>
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<td>care</td>
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<td>Are you able to do these every day?</td>
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<td>What sorts of things might prevent you from helping patients be involved?</td>
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<td>If no</td>
<td>Could you please tell me a little bit about this? E.g. are you too busy?</td>
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<td></td>
<td>Hospital wards are very busy and cancer patients can be complex. Still thinking about the ward, what sorts of things might have to be modified in order for patients to be able to participate in their care?</td>
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</table>
Appendices

Appendix 8: Observation notes

<table>
<thead>
<tr>
<th>Date ______</th>
<th>Time commenced ______</th>
<th>Time completed ______</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor ID____</td>
<td>Patient ID____ ______</td>
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</table>

<table>
<thead>
<tr>
<th><strong>OBSERVATION NOTES</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DOCTOR WARD ROUNDS</strong></td>
</tr>
</tbody>
</table>

Researchers to complete during naturalistic observation of Physician ward rounds. A separate tool should be completed for each patient seen on the ward round.

**Clinicians on the round**

- Medical □
  - Resident □
  - Attending □
  - Consultant/Chief □
  - Cover (HMO) □
  - Other ______

- Nurse □
  - Primary RN □
  - Assistant nurse □
  - Student RN □
  - Nurse unit Manager □
  - Research assistant (Nurse) □
  - Other ______

- Allied health □
  - Physiotherapy □
  - Occupational Therapist □
  - Dietician □
  - Speech pathologist □
  - Social worker □
  - Other ______

**Activity**

Purpose ____________________________________________________________

Length of the interaction ________________

**Context**

Location ____________________________

Family member present  Yes □  No □

**Comments**
Appendices

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<table>
<thead>
<tr>
<th>Date</th>
<th>Nurse ID</th>
<th>Patient ID</th>
</tr>
</thead>
</table>

### OBSERVATION NOTES

**PRIMARY NURSES**

Researcher to complete during naturalistic observation with nurses, every time there is patient/nurse activity of any nature.

### Activity

**Purpose**

- Symptom management
- Other

**Time commenced**

**Length of interaction**

### Context

**Location**

**First interaction for the shift**

- Yes
- No

**How initiated**

- Patient uses call bell
- RN enters room and patient initiates interaction
- RN initiates interaction
- Nurse assistant contacts PN
- Student RN contacts PN

**Family member present**

- Yes
- No

**Nursing assistant present**

- Yes
- No

### Comments
Appendix 9: Ethics approval letter

Ethics approval letter from Deakin University

Memorandum
To: Prof Mari Botti
School of Nursing & Midwifery

B

From: Deakin University Human Research Ethics Committee (DUHREC)

Date: 27 June, 2013

Subject: 2013-135

Patient participation in symptom management in a Chinese acute cancer care setting

Please quote this project number in all future communications

The application for this project was considered at the DU-HREC meeting held on 17/06/2013.

Approval has been given for Ms Cen Lin, under the supervision of Prof Mari Botti, School of Nursing & Midwifery, to undertake this project from 27/06/2013 to 27/06/2017.

The approval given by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the approval. It is your responsibility to contact the Human Research Ethics Unit immediately should any of the following occur:

- Serious or unexpected adverse effects on the participants
- Any proposed changes to the protocol, including extensions of time.
- Any events which might affect the continuing ethical acceptability of the project.
- The project is discontinued before the expected date of completion.
- Modifications are requested by other HRECs.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

DUHREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research (2007).

Human Research Ethics Unit
research-ethics@deakin.edu.au
Telephone: 03 9251 7123
伦理编号: 1306122-9

审查日期: 2013.6.3
审查会议地点: 2号楼5楼第五会议室
研究项目名称: 住院肿瘤患者参与症状管理的案例研究

审查文件:
- 相关文件: 原件必需盖章、复印件需签名
- 国家食品药品监督管理局批件: _
- 方案、版本号: 2013.5.2
- 项目: 题号: _
- 药品生产许可证及检验报告/医疗器械注册证及检验报告
- 研究者简历、临床研究经历
- 其他(请说明): 研究者调查问卷(患者参与意愿和实际参与情况调查;研究者用):
- 患者参与症状管理调查问卷;患者参与症状管理调查问卷。

研究科室: 护理部
主要研究者: 张晓莉
申办者: 研究者发起
伦理审查方式: 会议审查

投票结果:
应到人数: 16人 实到人数: 10人
回避委员: 无

审查意见:
复旦大学附属肿瘤医院医学伦理委员会于2013年6月3日会议审查了护理部张晓莉递交的“住院肿瘤患者参与症状管理的案例研究”方案及知情同意书等研究资料。

本次会议应到人数16人，实到人数10人。审查结果：研究方案: 同意;知情同意书: 同意;伦理审查意见：2013年6月3日，向伦理委员会提交伦理审查意见的回复及02版(2013.6.17)知情同意书，经审查确认，本研究方案主体内容及伦理方案已从该机构已预期的伦理委员会。经审查确认，同意方案即日起不进行更新。该伦理委员会已回复该机构。

附件: 伦理委员会签署及保密协议、伦理委员会组成人员名单。