This is the author’s final peer reviewed version of the item published as:


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Seeking the views of health professionals on translating chronic disease self-management models into practice

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Abstract

Few studies have investigated the views of health professionals with respect to their use of chronic disease self-management (CDSM) in the workplace.

Objective: This qualitative study, conducted in an Australian health care setting, examined health professional’s formal self-management (SM) training and their views and experiences on the use of SM techniques when working with people living with a chronic illness.

Methods: Purposive sample of 31 health care professionals from a range of service types participated in semi-structured interviews.

Results: The majority of participants (65%) had received no formal training in SM techniques. Participants reported a preference for an eclectic approach to SM, relying primarily on 5 elements: collaborative care, self-responsibility, client’s individual situation, structured support and linking with community agencies. Problems with CDSM centred on medication management, complex measuring devices and limited efficacy with some patient groups.

Conclusion: This study provides valuable information with respect to the use of CDSM within the workplace from the unique perspective of a range of healthcare providers within an Australian health care setting.

Practice Implications: Training implications, with respect to CDSM and patient care, are discussed, together with how these findings contribute to the debate concerning how SM principles are translated into healthcare settings.

Keywords: chronic disease; self-management; translation; health professionals
1. **Introduction**

Chronic disease (CD) is estimated to account for almost 80% of the total burden of disease and injury in Western countries [1-3]. Active partnership between health professionals and health service users have been associated with patients’ adherence to and satisfaction with treatment, and is seen as the central tenet of the management of CD [4]. In particular, an emphasis on self-management (SM), individual empowerment and patient-professional partnering in chronic illness management, has resulted in the development of a variety of generic and disease-specific SM models aimed to reduce health related costs and assist patients to develop skills and techniques to enhance their self-care, thereby improving patient outcomes (see [5-7] for recent reviews).

The SM models differ in a number of ways, such as mode of participant recruitment, delivery format, location, therapeutic approach and facilitator. In addition to traditional models of CDSM such as the Stanford Chronic Disease Self Management Program (CDSMP) [8], more recent initiatives include individual-focussed strategies such as telephone coaching, health coaching and motivational interviewing [9, 10]. Alternative strategies that encompass both individual and group formats include internet based disease-specific CDSM courses, such as those promoted by the NSW Arthritis Foundation [11] and more recently by the National Health Service Expert Patients Program (EPP) [12]. Regardless of their design, common principles shared by the majority of SM approaches include linkage with community based resources, a client-centred collaborative approach, structured patient support such as goal setting and care plans, disease information and educational materials [13].
Evidence for the efficacy of SM models is mixed. A number of clinical trials have reported positive results [8, 14, 15]. For example, Lorig and colleagues [8] reported on findings from a Randomised Controlled Trial (RCT) of the CDSMP, which found significant improvements in self-reported health, amount of exercise and a reduction in hospitalisations. However, patients reported no differences in pain/physical discomfort, shortness of breath or psychological wellbeing compared to wait-list control subjects. Despite the positive findings reported by some clinical trials, questions remain regarding the efficacy of CDSM programs when adopted in everyday clinical practice [16-20]. For instance, in their recent 12-month RCT of an arthritis lay-led SM program, Buszewicz and colleagues found an increase in patient self-efficacy, but no significant reduction in health care utilisation, health related quality of life, or psychological health [16]. In addition, Kennedy and colleagues reported the findings of a national evaluation of the EPP, which again demonstrated modest gains in self-efficacy, but no significant reduction in health service utilisation [21]. Results such as these have led researchers to question the effectiveness of SM programs and their sustainability when translated into everyday practice [6, 16].

**Contemporary Issues: The use of self-management principles in clinical practice**

When efficacy studies have demonstrated evidence-based success, but failed to effectively replicate those results in clinical practice, concerns have been raised regarding program translation and external validity [22-27]. It has been argued that disease specific clinical trials commonly focus on the experiences and outcomes of the service user, usually concerned with only one chronic condition; rather than the reality of significant co-morbidities, regularly faced by patients and health professionals [28, 29]. When adapting to primary care settings, SM programs have
faced setbacks and required various trade-offs sometimes resulting in “inadequate integration into primary care”[6, p.84], leading to the recommendation that decisions regarding future study design be made in the context of patient, clinician and clinic preferences [30, 31].

Relatively little work specifically considers the views of clinicians and other health professionals with respect to the use of CDSM in their practice across a full range of chronic illnesses and yet, such perspectives are vital to the successful integration of CDSM programs into the workplace. Some studies have been conducted in the US and UK, either focusing on a specific chronic illness [32, 33] or professional discipline [34-36]. For instance, Blakeman and colleagues interviewed 16 British General Practitioners (GPs) regarding their perspectives on their involvement in the facilitation of CDSM [34]. They found that although GPs valued increased patient involvement, they were not convinced of the efficacy or applicability of CDSM programs, expressing a general reticence to refer patients; a major impediment to the successful inclusion of CDSM in patient care. Even fewer studies have focussed on the relevant issue of training and how this may influence the way in which SM models are applied in clinical practice [37, 38].

In summary, adequate translation of CDSM programs to the broader health care system requires a multidisciplinary approach, co-ordination of multiple health care services and engagement of both patients and health service professionals. Currently, few studies, and none in Australia, have examined the views and experiences of a broad range of professionals involved in the provision of CDSM assistance and advice, in the workplace. This qualitative study aims to address this gap in the current
literature and contribute to the translation debate by asking health workers, who are either directly involved with, or manage staff who work with, patients with a broad range of chronic illnesses, specific questions about what elements of SM they use in their clinical practice, whether or not the clinicians had received formal SM training and what elements of CDSM were not considered useful.

2. Methods

2.1 Study setting and recruitment of participants

This Australian study was conducted within the State of Victoria’s largest metropolitan health care service provider, which supports a greater population of 1.235 million people. The organisation was undergoing a large-scale health system re-design known then as Hospital Admission Risk Program Chronic Disease Management (HARP CDM). The major focus of HARP CDM was to “develop preventive models of care involving hospitals and community agencies which focused on people with chronic and complex conditions and gave priority to high volume and/or frequent users of the acute public hospital system” [39, ¶1]. This qualitative study was conducted alongside a broader evaluation of the design phase of HARP CDM, with the intent of capturing the views of the stakeholders who had been involved in this system re-design. All stakeholders were involved in the care of individuals with a CD across a range of professional disciplines (i.e., medical specialists, general practitioners, nurses, psychologists) and health service settings (i.e., emergency department, hospital outpatient care, community health services, primary care).
Approval to conduct the study was provided by the relevant university and hospital ethics committees. The investigators were provided with a list of 48 health care professionals all of whom were involved in the initial design process and who would be closely involved in the subsequent implementation and embedding phases of HARP CDM. These individuals were invited to participate. Participation was purely voluntary and all provided informed consent.

2.2 Data Collection

The aim of this study was to elicit health professionals’ views on their use of SM techniques in their workplace and to consider the influence of formal SM training on clinicians’ practice. The authors developed semi-structured interview schedules in conjunction with the HARP CDM Management Group. Interviews were conducted in both individual and group format, ranging from 30-60 minutes and 1.5-2 hours duration, respectively. All interviews were audio taped and professionally transcribed and subsequent transcripts were assigned a code number to ensure anonymity. Consistent with qualitative research methods, the interview schedule incorporated a number of open-ended questions regarding SM, such as how the health professionals used SM techniques and principles when working with individuals with CD; which techniques or principles were considered helpful, and which were not. The interview process was flexible allowing for discussion on these issues.

2.3 Data Analysis
Thematic analysis [40] was conducted, utilising strategies from grounded theory [41], to identify themes from the data. Authors AL & PS independently read the transcripts, utilising open coding techniques whereby text was broken down and coded according to its meaning [41]. Emergent categories and themes were compared and contrasted. Consensus was achieved through discussion between the authors. Interview tapes were consulted if responses or interpretation required clarification. The process was recursive in nature, with the authors moving back and forth between the stages of data familiarisation and development of concepts [42], until the final themes were agreed. During data analysis, the authors adopted an inductive approach, choosing not to engage closely with the CDSM literature. This approach was considered appropriate, as an investigation of a range of health professionals’ views on CDSM had not previously been conducted, and the authors wished to maintain a broad analytic field of vision, thereby allowing the potential for development of innovative themes [40]. In order to enhance the trustworthiness of the findings, a number of standards of rigour were utilised. Participant’s language was used at all levels of coding, how and why participants were selected was clearly specified, and the literature pertaining to each theme was discussed. These factors, in combination with the multidisciplinary nature of the study, enhance the probability that the research findings have meaning in similar situations [43].

3. Results

3.1 Response rates and characteristics of participants

Of the original 48 participants approached, 8 could not be contacted or were on leave, 5 refused to participate (1 cited work commitments, the remainder gave no reason) and 2 were no longer in the relevant role. Thirty-three individuals agreed to
participate and provided informed consent, although 2 failed to arrive for interview and could not be re-booked, resulting in 31 interviewees (65% participation rate).

The majority of the participants were female (81%, see Table 1), within the 40-60 year age range (71%). Participants represented a range of health service settings, broadly categorised as Outpatients/Ambulatory services (42%), Acute Medical specialists (29%), Community Health Services (CHS: 19%) and Emergency Department (ED: 9%), with an average 3.5 years spent in their current role. The distribution of gender and service setting for non-participants was similar to the rest of the sample.

3.2 Self-management training

Thirty-five percent (n=11) of the participants had received formal training in CDSM. The majority of those who had received training had been trained in the ‘Flinders Model’ of Chronic Condition SM (n=5); of the remainder, 2 had been trained in the CDSMP, 2 had disease specific training in management of arthritis, and 2 participants did not specify. Interestingly, the majority of CHS and ED staff had not received any formal training in SM, although approximately half of the outpatient staff and medical specialists had received formal SM training. Indeed, the quotes below highlight the importance of formal training, and the concerns some clinicians have regarding their lack of an appropriate skill base in SM.

What I have found really useful is that the (SM) packages that are developed for the client population are probably just as helpful to the professional
population because we assume a knowledge base around SM that is not there (AL_02).

Self-management is meant to be a big part of my job, but I don't feel like I am doing it. Don't officially know how to go about it, so working in the dark (SL_04).

3.3 Elements of SM that were regularly used when working with people living with a chronic illness.

Rather than giving preference to specific SM models, clinicians reported utilising an “informed eclecticism”, relying on elements and principles gained from their experience and training, drawing on the diversity of SM techniques available. These elements, combined with the clinician’s subjective assessment of the client’s individual needs, formed the basis for the decision on the most appropriate approach for the patient.

You probably have a variety of strategies that you have to use and you may have to use them at different times. So just trying to hang your hat on one thing isn’t going to work (JB_17).

...aware of the Flinders model and those sort of tools or processes of self-management and I suppose just being a bit more eclectic (JB_03).

Five major themes emerged with respect to the way in which health professionals’ utilised SM in their workplace: collaborative care i.e., working in partnership with
the client; an emphasis on self-responsibility; a strong focus on the client’s individual situation and factors; the value of structured support materials in the form of care plans, educational material and goal setting; and linkage with related community/health care services.

3.3.1 Collaborative care
The contemporary paradigm of the professional-patient working alliance appears to have been wholly adopted by the clinicians involved in the study. In particular, GPs and outpatient health care workers emphasised partnership as an important element in the therapeutic relationship.

…it is about engaging with the person ….. It is more about having an equal footing with the client and what will be of benefit and working together in the journey (JB_03).

3.3.2 Self-responsibility
Clinicians acknowledged the essential role of patient self-responsibility in management of their chronic illness and modification of health behaviours. Clinicians reported that they promoted the value of self-responsibility from their first meeting with the patient, hoping to integrate it into the patient’s lifestyle.

We talk about self-management from their very first appointment, and I guess we introduce elements of self-management and again not just about the physical side of it, but about how you can manage your own condition and contribute to your own well-being (JB_01).

3.3.3 Individual situation and factors
Clinicians reported that successful CDSM required recognition that there was no “one size fits all” approach, and asserted a preference for addressing the individual social, emotional and psychological needs of the patient. Their subjective assessment of the biopsychosocial characteristics of the patient influenced the choice of SM tools, requiring a broad range of techniques to choose from.

...an individual approach, looking at the stages of change and allowing for an individual program. Having different strategies and different interventions is important (JB_09).

I use a combination of eclectic approaches. I use the Flinders tool when appropriate, .... Lots of action planning and short term goal setting (JB_07).

3.3.4 Structured approach and structured support materials

Clinicians from all professions and service types described the value of structured support materials in the form of care plans, educational material and goal setting, in their relationship with the patient. Respondents suggested that not only did it give the patients a tangible reference to take home, but it gave clinicians an opportunity for comparison during the long term clinical relationship.

Written action plans, because it is something that people can go to....and alter their own management accordingly. The people who do this well, we don’t ever see them in the hospital emergency departments, so they are looking after themselves very well (AL_02).

It (SM) has got to be acknowledged, it has to be written, it has to be clear and it has to be do-able (AL_01).
Education material, so they are looking for specific things in their illness (JB_18).

3.3.5 Linkage with related community/health care services

General practitioners, as the key providers of patient care, have direct contact with patients at a primary care level. In addition, they act as gatekeepers to other health services and in consequence, can affect the sustainability of disease management programs. Interestingly, the medical professionals in this study reported a strong reliance on community health services to deliver and reinforce the messages of CDSM.

Referring to the local community health services, which they sort of slot them into those sort of (SM) programs....someone else to provide the services or the information about that. Having agencies to refer to is useful for me (JB_05).

In addition, clinicians across all service types emphasised the importance of clear linkages between services (primary, secondary and specialist care), both to ensure consistent information, as well link patients living with chronic illness with available support services and programs to manage their condition.

The main thing that we try and do is commence early the education of these clients so that they improve their understanding of their conditions...but we do rely a lot on getting these people back out to the community organisations who have better skills than us in self-management (JB_04).
3.4 Elements of self-management that were not considered “useful” when working with the target population.

There was less agreement amongst the health professionals interviewed on the aspects of SM that they did not find useful. Many of the issues raised related to disease specific concerns. Two predominant themes emerged: difficulties associated with devices designed to assist or measure symptom management, including risks associated with medication management; and the influence of individual factors on a patient’s capacity to undertake CDSM.

The majority of chronic illness care is undertaken by the patients themselves, or their carers, in their own home. Within these circumstances, health professionals cited inappropriate or complex measuring devices as potentially problematic.

*There are certain trends that are measuring devices that aren’t that useful that are pushed. For example, for someone who has emphysema to be given a peak-flow meter…is a waste of time (AL_01).*

Correct management of medication was raised by a number of clinicians as a risk factor. Concerns regarding complex medication regimens highlighted an area of conflict between health professional’s support for the principles of patient self-responsibility and their feelings of professional responsibility for the delivery of patient care. Respondents were concerned that medications were not fully understood or were being taken incorrectly.

*One of the important issues with this client group would be medication management…. (JB_13).*
Surprisingly, some clinicians felt that, dependent on individual factors; some patients were deemed to have limited capacity for CDSM. Cognitive impairment, complex conditions, dysfunctional family situations and cultural context were all cited as barriers to successful CDSM, and were reported to influence clinician’s decisions to select out some patients from SM opportunities.

*If you are saying “go and do this” and they are experiencing financial hardship, or they are in a family violence situation and can’t possibly contribute (JB_03).*

4. **Discussion and Conclusion**

4.1 Discussion

The current qualitative study provides valuable insights from a multidisciplinary group of health professionals on using CDSM in the workplace. Clinicians in the current study reported using CDSM techniques in an eclectic fashion, focussing on five key elements: collaborative care; self-responsibility; individual situation; structured support, and linkage with health care networks. The findings have implications for training of health professionals and how evidence based practice translates to community and clinical settings.

The current study is the first to investigate the views of a broad range of health professionals who not only work with patients with CD across a range of service systems but each of whom played an important role in the redesign and implementation of a large CDSM program, across an entire health care network. Interestingly, the majority of health professionals interviewed had not received any formal SM training, a circumstance which has been argued to impede the
dissemination of SM education [44]. Not surprisingly some participants expressed
concern that they were “working in the dark” and would like further training in the
area. These sentiments are consistent with findings from a number of recent studies in
the UK which focussed on nurses, reporting that they lacked confidence, skills and
resources beyond experience and intuition when facilitating CDSM [35, 36, 38].
Together these studies raise the important issue of further training and education, and
indeed Pruitt & Epping-Jordan in their discussion on training needs for the global
health care workforce, argue that the current workforce is ill-prepared to care for
patients with ongoing health issues, and that reform in both training and tertiary
institutions is critical to deliver “21st century health care for 21st century health
problems” [45; p.639].

Respondents indicated that they relied predominantly on their experience and
intuition, utilising an “informed eclecticism” when making decisions regarding their
choice of SM strategies rather than adopting a standard model. Although previous
studies have acknowledged the value of a broad range of tools when catering for the
individual needs and circumstances of people living with a chronic illness [46] an
eclectic approach to SM has not been tested in effectiveness trials in the community.
Indeed, a growing body of research has highlighted the “voltage drop” of treatment
efficacy that occurs when translating clinically proven programs into community
settings [27]. Whilst it is not unexpected to find that clinicians adopt an eclectic
approach to SM practice, findings from this study make a strong case for health
services to implement a number of program fidelity measures. For example, we argue
for a graduated approach towards application of clinically proven strategies into non-
research settings, whereby the “elements of both efficacy and effectiveness research
are combined into successively more complex designs” [30, p.327]. A complementary approach would be to conduct future effectiveness research directly within primary care practices [31]. Both options present an opportunity to ground CDSM research within the complexities of primary care concerns and home-based CD management issues, of which a reduction in departure from evidence-based guidelines is the desired outcome.

Elements of CDSM that were commonly cited as useful by health professionals constituted five themes: working in partnership with the client (ie: collaborative care); an emphasis on patient self-responsibility; importance of structured support in the form of care plans, educational material and goal setting; consideration of an client’s individual situation, and clear linkages with related community and healthcare services. Respondents, especially GPs and those working in outpatients/ambulatory care, embraced the concept of working collaboratively with patients to manage their chronic illness. This position is supported by the literature, which suggests that a strong working alliance between clinician and patient is associated with both improved patient understanding of their illness and adherence to treatment [4, 34]. In addition, the role of the patient in taking responsibility for management of their illness and associated behaviour change was also acknowledged by respondents as an essential element of CDSM. Clinicians reported that they promoted the critical value of self-responsibility from their first contact with the patient, hoping to integrate the concept from the outset. Use of structured materials and care plans gave clinicians a format by which to explain results, and an opportunity for comparison during the long term relationship. Conversely, patients were provided with a tangible reference to take home, giving the patient the confidence to manage treatment themselves. This
position was advocated both by the study respondents, and supported by the literature [34].

A key component of a productive working alliance was consideration of the individual social, emotional and cognitive needs of the patient, a point correspondingly emphasised by patients in a recent study by Gordon, Smith and Dhillon [47]. Some clinicians in the current study reported that, dependent upon their subjective assessment, various aspects of SM were not emphasised if the patient was considered unable to manage the requisite tasks. However, exclusion of patients is not recommended and a diverse range of programs, designed to accommodate various chronic conditions and individual patient needs, are available to the well-informed health care professional [8-12]. Finally, consistent with the literature, respondents across all service types emphasised the value of clear linkages and productive interaction between services [48]. Although GPs are recognised as the key providers of patient care, Blakeman and colleagues [34] reported that a poor knowledge of public health care services impacted on GPs ability to facilitate patients to engage in self care. Findings from the current study suggest that his conclusion applies to other health professionals as well.

Although feedback from health professionals on the subject of “what didn’t work” varied somewhat, two main themes emerged: difficulties associated with symptom management devices and medication management; and factors affecting the capacity of an individual to undertake CDSM in the home. Clinicians clearly expressed concern about the challenges faced by patients when managing measuring devices or medication regimes outside the health service environment. Previous literature has
demonstrated a strong theoretical and empirical link between adherence self-efficacy and actual adherence to SM regimes [4], which has in turn been associated with improved outcomes [49]. Therefore, the patient must feel prepared and capable of meeting the required tasks for SM to be successful. This finding has important implications for medication regimes, as well as the design and operation of disease-specific measuring devices, all of which must be as user friendly, affordable and as impervious to mismanagement and abuse as possible.

Finally, there was recognition that despite best intentions, standard SM strategies were not for everyone. Clinician utilisation of various SM elements appeared to be dependent upon their subjective assessment of the individual circumstances of patients. However, this practice, without the aid of specific screening or decision making tools, results in a circumstance that contradicts the aim of evidence based CDSM programs: to “de-emphasise the role of intuition an unsystematic clinical decision making” [50, p. 481]. Rather than professionals relying on their own discretion, the authors advocate that health services develop clear guidelines and assessment tools which can assist health professionals to identify individuals who may encounter difficulties with CDSM programs or tasks, and direct them to more appropriate options. Further, the authors argue that the lack of awareness that was exhibited by many of the participants of the diverse range of available CDSM interventions, potentially disadvantages patients who may not be offered interventions appropriate to their chronic condition or individual circumstances.

The value of a qualitative study such as this, is in providing the rich insights into the challenges and trade-offs that health professionals experience within a complex
system. It is intended that these insights inform future direction in both the development of CDSM programs and in the training and engagement of the health professionals who will promote and use them.

4.2 Conclusion
A particular strength of this study was access to the unique range of health professionals who dealt with a variety of chronic illnesses and co-morbidities on a daily basis, or managed those who did. Their views and experiences provide insight into the successful principles of SM utilised by a broad range of health professionals within in clinical and community settings. Due to the multidisciplinary nature of the study, the results are transferable and meaningful in similar settings [43]. Further work is needed to explore the service system linkages and constraints that impact on clinician’s ability to assist patients in their self care.

4.3 Practice Implications
This study raises two important implications with respect to training in CDSM and how it is translated in the workplace. Health professionals across a range of service types reported utilising many of the key elements of SM and yet the majority had received no formal SM training. Respondents reported dependence upon their intuition and experience when working with patients. Those who had received formal training in SM models appeared to utilise only certain elements they deemed useful rather than delivering a complete package. Whilst it has been shown that health professionals commonly utilise key elements of SM when working with patients, the paper raises questions about the level of training in SM. There is clearly a strong need for further skills and knowledge training in CDSM which should occur in
tertiary settings, and following this, as part of professional development within health services. It is expected that enhanced CDSM training to a broad range of health professionals would increase general awareness of the nature, availability and efficacy of a range of CDSM programs.

The second aspect relates to the complex issue of translating best practice into the workplace. A range of RCT and other methodologies examining the efficacy of SM programs and strategies report positive outcomes [8, 15, 28], yet few studies examine the effectiveness of SM in community settings and even fewer studies report on exactly how health professionals utilise SM in the workplace. This study suggests that in the absence of structured translation approaches such as reported by Francis, Feyer & Smith in their evaluation of the Sharing Health Care Initiative [46] and Lahdensuo [51], and in the absence of clear fidelity guidelines, we cannot be confident that the current eclectic approach is as effective as other approaches reported in efficacy trials [23, 27].

Acknowledgements

The authors would like to thank Greg Young, Christine Jones and the HARP CDM Management Group for their support of the study, as well as the individuals who kindly agreed to be interviewed. The authors also thank the following Deakin University staff: Judy Buckingham, Sophia Liddy and Gay Magilton for their assistance with data collection. The views expressed in this paper are the views of the authors and not that of the health care provider.

Conflict of interest

The authors state that there are no conflicts of interest.
I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.
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