PROTOCOL

Engaging patients and families in communication across transitions of care: an integrative review protocol

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Abstract

Aim. To describe an integrative review protocol to analyse and synthesize peerreviewed research evidence in relation to engagement of patients and their families in communication during transitions of care to, in and from acute care settings.

Background. Communication at transitions of care in acute care settings can be complex and challenging, with important information about patients not always clearly transferred between responsible healthcare providers. Involving patients and their families in communication during transitions of care may improve the transfer of clinical information and patient outcomes and prevent adverse events during hospitalization and following discharge. Recently, optimizing patient and family participation during care transitions has been acknowledged as central to the implementation of patient-centred care.

Design. Integrative review with potential for meta-analysis and application of framework synthesis.

Review method. The review will evaluate and synthesize qualitative and quantitative research evidence identified through a systematic search. Primary studies will be selected according to inclusion criteria. Data collection, quality appraisal and analysis of the evidence will be conducted by at least two authors. Nine electronic databases (including CINAHL and Medline) will be searched. The search will be restricted to 10 years up to December 2013. Data analysis will include content and thematic analysis.

Discussion. The review will seek to identify all types of patient engagement activities employed during transitions of care communication. The review will identify enablers for and barriers to engagement for patients, families and health professionals. Key strategies and tools for improving patient engagement, clinical communication and promoting patient-centred care will be recommended based on findings.

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Introduction

Patients who actively participate in healthcare decisionmaking have been found to have better health outcomes (Rachmani et al. 2002, Arnetz et al. 2004, 2010, Coleman et al. 2004, 2006, Weingart et al. 2011) and more positive experiences of care (Weingart et al. 2011). Key national and international health agencies have emphasized patient engagement during healthcare delivery as central to promoting safe care [Joint Commission of Accreditation in Healthcare Organizations (JCAHO) 2003, World Health Organisation (WHO) 2007, Australian Commission on Safety and Quality in Health Care (ACSQHC) 2011], with the importance of patient-centred care affirmed in the landmark report Crossing the Quality Chasm (Institute of Medicine (IOM) 2001). Communication breakdown between health professionals during transitions of responsibility and accountability for care is a major safety concern (Thomas

Keywords: acute care, clinical decision-making, communication, integrative review, nursing, patient-centred care, patient engagement, transitions of care

Why this review is needed?

- Active engagement of patients in healthcare acts as a safety buffer and potentially reduces preventative adverse events related to communication breakdown. Yet, the best approaches and the barriers and enablers for engaging patients and their families in communication during transitions of care remain unknown.
- This integrative review will address the gaps in knowledge by analysing and synthesizing research and evaluating the quality of evidence in relation to patient and family engagement in communication during transitions of care.
- This integrative review will identify effective strategies and tools to promote engagement.

et al. 2013). Omissions in information are reported to adversely affect patient safety and the quality of care (McMillan et al. 2006, Kripalani et al. 2007). Described as a 'safety buffer' (Davis et al. 2007, Scott et al. 2011), patients' active engagement in health care offers a potential bridge to clearer communication between health professionals and agencies (Jenkinson et al. 2014). Active engagement enables health professionals to identify and be responsive to patient preferences, values and care needs (IOM 2001, Rathert et al. 2013), thereby offering the potential for improving patient safety and quality during transitions of care. However, the role of patients and their families in all forms of communication during transitions has not been clearly defined. There is uncertainty about how to promote patient engagement during communication to improve the quality and safety of care. Examination of relevant research will provide evidence to inform health policy development, clinical practice, education of health professionals and future research.

Background

Patient-centred care (PCC) has been defined as '...health care that is respectful of and responsive to, the preferences, needs and values of patients and consumers' (ACSQHC 2011, p.1). PCC, a term used interchangeably with personcentred care, has been operationalized in many healthcare agencies [Institute of Medicine (IOM) 2001, Rathert *et al.* 2013, Australian Commission on Safety and Quality in Health Care (ACSQHC) 2011], using the principles of PCC defined by the Picker Institute (Picker Institute 2013).

These principles include coordination and integration of care; information, communication and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; transition and continuity and access to care, in addition to the central premise of respect for patients' values, preferences and expressed needs (Institute of Medicine (IOM) 2001, Picker Institute 2013, Rathert et al. 2013). Development of these principles was initially informed by research conducted by Gerteis et al. (1993) exploring patient experiences. More recently, the International Alliance of Patients' Organisations (IAPO) has recommended five principles of respect; choice and empowerment; patient involvement in health policy; access and support and information for organizations to practise and achieve patient-centred health care (IAPO 2006). These principles form the basis from which to evaluate current practice (IAPO 2012). However, different stakeholders in health care emphasize different dimensions or elements of PCC (Salzburg Global Seminar participants 2011, Kitson et al. 2013). These differences may contribute to definitions of patient participation, engagement and/or involvement in the PCC movement having different meanings, depending on the context where it is enacted (Gallivan et al. 2012).

Much progress has been made in bringing about change towards more patient-centred healthcare systems (National Health Service (NHS) Commissioning Board 2012, ACSQHC 2012). Nonetheless, implementing PCC in an organization requires more than guiding principles and/or quality frameworks (Groene *et al.* 2009, Kitson *et al.* 2013). Several organizational factors may need to be aligned for success, including committed senior leadership and strategic vision; sustained staff satisfaction; feedback reporting; resources; a culture supportive of change and importantly the engagement of patients and families at all levels (Shaller 2007, Luxford *et al.* 2011).

Patient engagement involves participation in decision-making and other aspects of care (Wellard *et al.* 2003, Longtin *et al.* 2010), including patients monitoring their progress and effects of care and providing suggestions for improving care (Iedema *et al.* 2011, Rathert *et al.* 2011). A concept analysis by Sahlsten *et al.* (2008) identified four attributes of patient participation in a nursing context. These attributes were an established relationship; the nurse surrendering some power and control; shared information and knowledge and active mutual engagement in intellectual and/or physical activities (Sahlsten *et al.* 2008). Similar descriptions about the necessity of health professionals actively enabling or activating patient participation for PCC to work are found elsewhere (Hibbard & Greene 2013,

Pelletier & Stichler 2014). However, patient willingness to participate, their condition and differences in expectations were identified as barriers to patient participation in a recent integrative review of patient participation in medical units (Tobiano et al. 2015). Nonetheless, Tobiano and investigators (2015) found that barriers and promoters in their findings resonated with Sahlsten et al.'s patient participation attributes. A recent controlled before-and-after study of PCC for hospitalized chronic heart failure patients found PCC may reduce the length of stay and preserve functional performance without increasing the risk of readmission (Ekman et al. 2012). Improvements in the quality of care, including shared information, were interpreted as a contributing factor to these findings (Ekman et al. 2012). Patient engagement is a key element of health reforms (Hibbard & Greene 2013, Pelletier & Stichler 2014), with partnering 'with' patients rather than providing services 'to' them, advocated as a way to improve patient safety and quality of care.

Nonetheless, transitions in care between clinicians and/ or clinical settings are particularly susceptible to fragmentation of care and services (Coleman 2003, Geary & Schumacher 2012). These transitions may seriously compromise the quality and safety of patient care, due to poor communication and inadvertent information loss (Forster et al. 2003, Kripalani et al. 2007, Parrish et al. 2009). Preventable adverse events during transitions in care include medication error, missed diagnosis, postoperative wound infections (Forster et al. 2003) and falls (Paniagua et al. 2006). Medication errors during transitions are often significant events (Coleman 2003), with approximately 30% of all adverse drug events (ADEs) being preventable and most ADEs occurring during the ordering phase of medication management in acute care settings (Bates et al. 1995, Aljadhey et al. 2013). The incomplete or incorrect transfer of medication information during transitions of care to, in and from acute care settings has led many organizations to advocate for medication reconciliation at admission and discharge (The Joint Commission 2006, Accreditation Canada 2013, WHO 2013), as well as the development of computerized decision supports to avoid these preventable ADEs (Barber 2004). Furthermore, tools have been developed to engage patients in medication reconciliation to improve patient safety (Heyworth et al. 2014). Weingart and investigators (2011) reported an inverse relationship between patient participation and adverse events and concluded that patient participation may prevent lapses in care.

Globally, the importance of partnering with patients to meet their needs and improve patient safety (WHO 2004)

has led to the development of major health policies, which acknowledge the paradigm shift and potential impact of PCC for reducing preventable adverse events during hospitalization (ICAHO 2003, WHO 2007, National Health and Hospitals Reform Commission 2009, Australian Commission on Safety and Quality in Health Care (ACSQHC) 2011). Government health agencies have established healthcare rights and/or charters that reinforce the patient's right to be included in decisions and choice about their health care and the right to be respected (ACSQHC 2008, The Joint Commission 2012, Department of Health 2013). More recently, the Australian Safety and Quality Health Service Standards require all health services to demonstrate a system-wide PCC focus and approach, to ensure that organizations are actively partnering with patients (Australian Commission on Safety and Quality in Health Care (ACSQHC) 2011). Other international policy documents also promote PCC in organizational standards (National Institute for Health and Care Excellence (NICE) 2012, US Department of Health & Human Services 2015).

Despite these policies, there is a paucity of empirical evidence about the role and experiences of patients and families' when participating in health care. Little is known about how patients and families engage during transitions in care or the role or willingness of health professionals to promote patient participation in acute health contexts. It is also not known whether some strategies and processes may be better than others for promoting patient engagement, particularly during times of transition when clinical communication errors have been shown to be most prevalent (Botti et al. 2009, Thomas et al. 2013). Without reviewing evidence, patient safety approaches and programmes to optimize patient engagement are at risk of being misdirected and achieving suboptimal quality and patient safety outcomes. This integrative review is part of a larger project to inform development of resources to assist clinicians, patients and their families to engage in communication during transitions of care to, in and from acute care settings (ACSQHC 2015).

The protocol

Aim

The aim of this integrative review is to analyse and synthesize the peer-reviewed research evidence in relation to engagement of patients and their families in communication during transitions of care to, in and from acute care settings.

Research question

What are the enablers for and barriers to, engaging patients in communication during transitions of care to, in and from acute care settings; and what are the strategies, tools and resources that enable patient engagement in communication during transitions of care?

Design

An integrative review will be undertaken. An integrative review of evidence includes identification of the problem, literature search, data evaluation and data analysis, which includes verification of data and drawing conclusions based on analysis (Whittemore & Knafl 2005). These steps are similar to those used for systematic reviews, as described in the reporting standards of systematic reviews (Moher et al. 2009). However, integrative reviews accommodate diverse data sources, with the type of study design not restricted in the review (Soares et al. 2014). Furthermore, synthesis may combine both quantitative and qualitative data if there are similarities and involves a more flexible analytic approach compared with systematic reviews (Whittemore & Knafl 2005, Joanna Briggs Institute 2014, Soares et al. 2014). Integrative reviews are useful when the scope of the topic is complex and uncertain.

The SPICE framework, developed in social sciences (Booth 2004), will be used to develop the review question and scope of the review, including the inclusion criteria. Components of the SPICE framework are described in Figure 1.

Inclusion criteria

Studies will be included if they describe patient, family or caregiver engagement in communication with healthcare providers during transitions of care to, in and from acute care settings, with all forms of communication (verbal, behavioural and written) eligible for inclusion. Limits to study design will not be applied. Eligible studies will include quantitative, qualitative and mixed method studies. Studies published over a 10-year period ending 2013 will be eligible for inclusion. The setting, perspective, intervention/phenomenon of interest and evaluation/outcomes for inclusion are described below.

Setting

Studies located in an acute care setting and studies describing the transition of care to and from acute care settings will be included. An acute care setting is defined as a hospital or other specialty facility that receives patients with an

acute (new onset) illness, disease, condition or problem for cure or symptom management and/or support (Hirshon et al. 2013).

Perspective/participants

Studies that include patients (adults, children) who are able to communicate their wishes, needs, goals and concerns will be eligible for inclusion. Also, studies including patients who involve a family member in communication processes on their behalf will be eligible for inclusion.

Intervention/phenomenon of interest

Studies that describe communication (verbal, behavioural, written exchange of information) of care needs, assessments and evaluations during transition of care to, in and from an acute care setting will be eligible for inclusion. These studies will need to describe patient and/or family engagement in the transition of care communication. Particular focus will be on engagement during handover. Key terms are defined below:

- The transition of care is defined as the movement of a patient from one setting of care to another or the transfer of the responsibility of care from one healthcare provider to another (Ma *et al.* 2004, National Transitions of Care Coalition (NTOCC) (2008–2015). Transitional care is defined as a 'set of actions designed to ensure the coordination and continuity of care as patients transfer between different locations or different levels of care within the same location' (Coleman *et al.* 2005, p. 246).
- Communication process includes any form of communication strategy or process for communicating care needs, assessments and evaluations. However, the particular focus will be on verbal or written communication of care, that is, the handover.
- Patient engagement encompasses activities (verbal, behavioural, written) to enhance patients' and families/carers' understanding of their condition, treatments and care plans, partnership and involvement in decision-making and evaluation of care outcomes.

Evaluation/outcomes

Factors (enablers and barriers) influencing patient and family engagement (involvement, participation) in communication during transitions of care, the perceived benefits and patient outcomes will be examined as outcomes of interest. Attempts to measure engagement behaviours will also be included. In addition, the review will identify the strategies, tools and techniques used to facilitate patient and their families' engagement in communication at transitions.

Exclusion criteria

Studies including patients who are unable to explicitly engage in transitional processes, for example, neonates, infants and unconscious patients, will be excluded. Non-English studies and reports that describe a quality improvement project without a research methodology and grey literature sources, except for academic doctoral theses retrieved through electronic databases or hand searching, will be excluded.

Search methods

Using the elements specified in the SPICE framework, a search strategy will be developed. Search terms will include the following keywords and their synonyms: communication, patients, adults, children, acute care, general practice, residential aged care, community care, primary care, transitions of care, transfer, continuity of care, health provider, and engagement. A healthcare librarian will be consulted to help refine the search strategy.

We will systematically search the following electronic bibliographic databases: The Cochrane Central Register of Controlled Trials (CENTRAL) (The Cochrane Library), Web of ScienceTM Core Collection and Current Contents Connect (Thomson Reuters), Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete (Ebscohost), Medline (Ebscohost), PsycInfo (Ebscohost), EMBASE (with Medline deselected under advanced search) and Sociological Abstracts (ProQuest). Search dates in each database will be limited from 2003 to 2013. Subject headings and keywords will be adapted according to the nuances of each database. In addition, the search coordinator of the Cochrane Effective Practice and Organisation of Care Group's trials register will be consulted for other trial sources. We will hand search the reference lists of studies selected for eligibility assessment to identify additional relevant references.

Screening and selection process

A reference management system will be used, with duplicate sources removed. Two members of the research team will screen all titles and abstracts retrieved. Consensus by two independent reviewers will determine the selection of potentially relevant reports for eligibility assessment. All potentially relevant reports will be retrieved in full text. Titles and abstracts with insufficient information to make a judgement about relevance will have the full text retrieved to confirm its relevance or not. Using predetermined inclusion and exclusion criteria, one reviewer will assess the eligibility of

selected reports for inclusion in the review. A second reviewer will then verify selection for inclusion. Disagreements will be resolved through consensus; a third-person arbiter will be used if agreement cannot be reached. Publications reporting on the same study will be counted as a single study with findings reported under the primary reference. A flow diagram adapted from PRISMA (Figure 2) will illustrate the results of the search, screening and selection processes for identifying studies for inclusion in the review.

Quality appraisal

The Mixed Methods Appraisal Tool (MMAT) version 2011 (Pluye et al. 2011) will be used to assess the methodological quality of studies. The advantages of MMAT include comprehensive guidelines and simplicity for summarizing overall quality across a range of study designs. Critical appraisal using the MMAT tool is determined by the type of study design: quantitative, qualitative or mixed empirical methods. The criteria are specific to each type of study, with four domains apportioned to qualitative studies and quantitative studies subdivided into randomized controlled, non-randomized and descriptive studies. Each study will be assigned an overall quality score, using asterisks representing the quality appraisal of each study. Scores vary from 25% (*) when one criterion is met to 100% (****) when all criteria are met. For mixed methods studies, there are three criteria specific to mixed method methodology and the scores will vary from 50% (**) when one criterion is met to 100% (****) when all three criteria are met. Concomitant appraisal of qualitative and quantitative aspects of each mixed method study is required in the MMAT tool, with the overall score not exceeding the lowest component score.

Evidence to support the validity and reliability of different methodological quality tools for assessing studies in

mixed study integrative reviews is equivocal (Sanderson et al. 2007, Crowe & Sheppard 2011). Using different quality scoring systems and scales for the purpose of measuring methodological quality has been found to lead to inconsistent findings and recommendations (Armijo-Olivo et al. 2015). This is particularly so when these tools are used for making judgements about whether a study is included or excluded from the analysis. There is no consensus about which quality assessment tools and scales are best for mixed methodologies, because most tools with or without scoring systems lack rigour (Crowe & Sheppard 2011). Currently, the recommended approach for assessing quality is for quality domains/items to be evaluated separately with the impact of methodological limitations on findings explored (Whiting et al. 2005, Wisdom et al. 2012). Reporting of methodological quality judgements ensures the transparency of decisions (Wisdom et al. 2012).

The data extraction form will incorporate the criteria for critical appraisal obtained from the Cochrane Handbook for Systematic Reviews of Interventions (Higgins & Green 2011) and supplement for qualitative studies (Hannes 2011) into the data extraction form. Data extraction will include evidence of credibility, transferability, dependability and confirmability for qualitative studies. Data extraction from quantitative studies will include assessment of the risk of bias including selection, attrition (withdrawal), performance, detection and reporting in addition to generalizability. In addition, each study will have these quality domains/items extracted and evidential data used to complete the MMAT criteria. In the review, MMAT will be used as a summarizing tool, with methodology taken into account when grouping findings. The MMAT score will not be used for exclusion decisions. All studies will be included with aspects of their methodological quality, including limitations, highlighted and the strength of the evidence summarized.

Setting: Transitions of care to, within, and from acute care settings.

Perspective: Adults, children, patients, families, and health professionals who are engaged in communication during transitions of care.

Intervention/Phenomenon of interest: The participation of patients in the communication of transition processes from home/residence/clinic to hospital, throughout hospitalisation, and return to the community.

Comparison: Any communication process used to engage patients at transitions of care related to acute care settings. A comparison group is not required for studies to be included.

Evaluation: Synthesis of individual peer-reviewed studies¹. Identification of enablers for, and barriers to engaging patients and their families in communication during transitions of care.

Figure 1 Application of the SPICE framework for review question, inclusion criteria and search strategy for the integrative review. ¹Evaluation in the SPICE framework was refined prior to data collection, with other types of documents removed.

Data extraction

All relevant data will be extracted into a Microsoft Excel spreadsheet (Microsoft[®] Office, Redmond, Washington) using a predetermined form which will include the study purpose, participant and trial characteristics, results and supporting data for critical appraisal. One member of the research team will perform the data extraction with a second member of the team double checking the extracted data for accuracy and completeness. Disagreements in the data collected will be resolved by discussion, with reference to the original publication for clarification and a third team member involved as arbiter if required. A preliminary *a priori* analytical framework will be developed by the research team to inform data analysis and synthesis.

Synthesis

The 'Framework' synthesis approach will be used to analyse and synthesize the data (Ritchie & Spencer 1994). The five analytical stages in the Framework approach include the following:

- 1 Familiarization becoming familiar with the content of
- 2 Identification of a thematic framework identifying key issues, concepts and themes.
- 3 Indexing systematically applying the thematic framework to the data.
- 4 Charting rearranging the data according to the appropriate thematic reference.
- 5 Mapping and interpretation identifying the key characteristics of the data.

Full-text reports of included studies and data populated in the Excel spreadsheet will be provided to all team members to enable familiarization and coding of data according to key issues, concepts and themes. Extracted data will be examined for outcomes and practices including strategies, processes and tools for patient engagement in communication during transitions of care. The enabling factors and barriers associated with patient engagement during care transitions to, in and from acute care settings will be identified. Both inductive and deductive processes will be used to code data and provide organizing themes, with familiarization and coding conducted independently. Research team members will then compare and discuss the organizing themes derived from the coded data, to generate an a priori analytic framework of broader themes and categories. One member of the research team will proceed with indexing and charting individual study data under the broader themes and categories. The team will review this evidence in terms of what works for whom and under what circumstances (Rycroft-Malone et al. 2012, McCormack et al. 2013). This process includes mapping and interpreting the key characteristics of the data, and the resulting findings will be reviewed by all members of the research team for accuracy and relevance. Integrative review methodology (Whittemore & Knafl 2005) describes grouping similar study designs and characteristics prior to sequential synthesis of data from qualitative designs, non-randomized studies followed by randomized interventional studies. However, this integrative review is explorative in nature with a broad scope for identify relevant studies (see SPICE framework); therefore, analysis and synthesis based on design will be conducted concurrently (Heyvaert et al. 2013). For randomized studies, with two or more studies of similar trial characteristics and outcomes of interest, data may be pooled using appropriate computer software, such as Review Manager Version 5.3, to enable an estimate of a summary effect for reporting and evaluating this type of evidence. The 'Framework' method will provide an overarching approach to analysis and synthesis of the evidence (Ritchie & Spencer 1994) and will incorporate all study designs. Presentation of the findings will include an overview of the methodological quality of the studies and the strength of the evidence. Findings from the 'Framework' synthesis will be reported narratively and the current state of knowledge in the field discussed along with implications for health policy, education, clinical practice and future research.

Discussion

This integrative review will seek to comprehensively synthesize the existing body of research related to engaging patients and their families in communication during transitions of care. The background for this protocol provides clear identification of the problem and purpose of gathering the data. The method clearly describes the process of study selection and identifies the steps to gather, code and aggregate results from individual studies and to evaluate the evidence in a way that is sufficiently robust to enable a meaningful outcome and replicable review. The protocol specifies the inclusion criteria without limiting the types of studies for inclusion or types of communication processes and/or transitions of care. By considering quantitative, qualitative and mixed method studies, we aim to produce a comprehensive review and recommendations that are relevant for policy makers and healthcare professionals. As an emerging field of study, insights into all perspectives help build a body of knowledge to inform practice. The findings from this integrative review will have important implications for health policy, education and clinical practice. We envisage that strategies and tools to

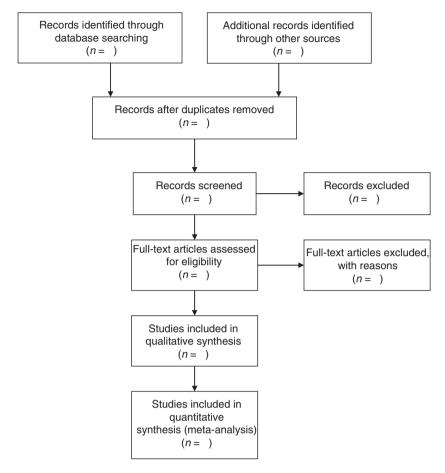


Figure 2 Flow diagram of the search, screening and selection processes. PRISMA 2009 Flow Diagram (Moher et al. 2009).

facilitate PCC during transitions may be identified through this explicit and systematic approach to synthesizing evidence. In addition, gaps in knowledge will be identified and be instructive for future research. Finally, this integrative review will raise awareness about the immense complexity of patient engagement in transitions of care.

Limitations

There are potential limitations in the study design. The integrative review may not identify all patient engagement activities, because non-English reports are excluded. The search dates are restricted, as patient engagement in health care has only recently gained momentum in research; therefore, to ensure recommendations are contemporary, the search dates will be limited to a 10-year period. Appraisal of evidence when including quantitative and qualitative studies can be challenging, as very few critical appraisal tools for mixed study reviews are available (Crowe & Sheppard 2011). MMAT has content validity (Crowe & Sheppard 2011), reliability was pilot tested (Pace *et al.* 2012), but has recently

been shown to be variable (Souto *et al.* 2015). In this review, consensus discussion will follow independent appraisal to minimize discrepancies as a limitation.

Conclusion

Patient-centred care that seeks to engage patients and their families during healthcare delivery, including transitions of care, is recognized as a crucial step in ensuring patient safety and improving quality in the continuum of health care. This integrative review will identify enablers for and barriers to, patient engagement, including structures (strategies, tools), processes and outcomes found to promote patient participation in transitions of care. Based on the findings, recommendations for system-wide health service improvements (through policy and practice) and future directions for education and research will be made. A report will be prepared on behalf of the Australian Commission on Quality and Safety in Health Care to inform future development of resources to assist patients, families and health professionals to engage in communica-

tion during transitions of care to, in and from acute care settings.

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Conflict of interest

No conflicts of interest have been declared by the authors.

Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/recommendations/)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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