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What is the experience of being readmitted to hospital for people 65 years and over? A review of the literature.

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What is the experience of being readmitted to hospital for people 65 years and over? A review of the literature.

Aim: The aim of this review is to explore the experience of a readmission to hospital from the perspective of older adults. **Methods:** A systematic review with an interpretative approach was conducted. CINAHL, Embase, and Medline were consulted. The search took place during October 2016. **Results:** 6 studies with data collection between 2004 and 2013 fit the relevant criteria and included a total of 68 older adults. Two overarching themes were developed with relevant subthemes: Experience during initial hospital stay distinguished by exclusion (*Feeling powerless; Feeling disregarded; Perception of readiness for discharge*); Patients experience uncertainty following discharge (*Perception that community based services are not available or adequate; Perception that hospital is the only safe place; Difficulty in adapting to a "new normal"*). **Conclusions:** A cycle of exclusion exists during the initial hospital stay and beyond. The experience of being readmitted to hospital is challenging, mostly perceived as negative, and, existential, emotional and psychological well being is not satisfactorily addressed by healthcare professionals.

Key Words: readmission, hospital, perception, feeling, patients, discharge, uncertainty

Impact statement: This review highlights patient voices and illustrates that they experience feelings of exclusion and uncertainty throughout admission and readmission to hospital.

Introduction and background

Current evidence indicates that older adults experience a high rate of unplanned readmission to hospital within 30 days of discharge (NHS England 2015). Unplanned readmissions are associated with poor outcomes for patients (Walsh 2014), have an impact on the wider health and social care system, can cause disruption to other forms of care (King's Fund 2010) and incur significant financial costs (Conroy & Dowsing 2012). Hospital readmissions are rising despite efforts to implement preventative services (Walsh 2014) and the latest published data for England shows readmissions accounted for 12% of hospital admissions in 2011/12 (HSCIC 2015). A variety of factors have been noted to affect readmissions including increasing age (Walsh 2014) or deprivation (Purdey & Huntley 2013). Readmissions are unequally distributed across the population and rates are higher among older people (Oliver 2015). In the UK adults admitted to hospital and over the age of 65 have a 15% readmission rate, a figure that is rising (Oliver 2015) and higher than the rate for all readmissions at 11% (HSCIC 2013). There is evidence that this trend is seen internationally (Li et al 2015).

The vast majority of literature on readmissions relies on routinely collected health data such as readmission rates by age or diagnosis (Horwitz 2016). Although these factors can be measured statistically, statistics alone do not give much in-depth understanding to this phenomenon. Indeed, there continues to be a real lack of understanding of how older people themselves experience readmissions. Patient experience is considered to be one of 3 dimensions of quality healthcare (Doyle et al. 2013) with positive patient experience associated with better health outcomes (Doyle et al. 2013). Furthermore, healthcare systems such as the National Health Service (NHS) actively include patient voices in their decision making as they recognise their important value (NHS England 2015). Despite knowing that patient experience is important, healthcare professionals are not always aware of what matters to patients (Edwards et al. 2014). Thus, research undertaken from the perspective of the patient provides an enhanced understanding of their experience which may elucidate reasons for readmission and is consistent with providing and delivering quality healthcare. It is also consistent with nursing values (Knisely & Dracuker 2015, McCormack et al. 2010).

As healthcare professionals we must listen to the voices of older adults in order to improve patient care (Kings Fund 2008). Thus, this review will explore unplanned readmissions among older adults from the perspective of the patient using research that has been undertaken from a qualitative perspective.

Method

Aim

The aim of this interpretive review is to examine qualitative research papers to explore the experience of patients (aged 65 and over) who have been readmitted to a general hospital.

Search strategy

Search terms were discussed and confirmed with a specialist librarian these were: *Readmission, Rehospitali*, Re-hospitali*, Patient readmission, Reattend*, Re-attend*, Hospital readmission AND Experience*, Feel*, Perspective*, Attitude* AND Aged, Aged 80 and over, "older adult*", "old* age", Geriatrics, Geriatric*, Frail elderly, Elder*, Senior*, "old* person*", "old* people", "65 year*", "80 year*", "over 65", "over 80", Aged hospital patient, Very elderly*. Search terms and relevant thesaurus terms were used in the following databases: CINAHL, Embase, and Medline in October 2016. Title and abstract were searched in all databases.

Inclusion criteria required that articles should be written in English language, published between 1996 – 2016 and were qualitative studies focusing on the experience of readmission of people aged 65 and over to a general hospital. Articles were excluded if they assessed an intervention or new care model, included people under the age of 65, focused on readmissions to mental health or oncology services, or solely explored the discharge process from hospital to home.

Titles and abstracts were screened and those that met the inclusion criteria were read in full. 62 full text articles were obtained from which 6 were found to meet all inclusion criteria. A citation search was carried out in Web of Science™ no further articles were found via this method. The reference lists of the selected articles were searched but no further articles were identified. [Insert PRISMA near here]

Quality Appraisal

Appraising qualitative data can be undertaken in a variety of ways and there are no agreed criteria for determining good quality qualitative research. Aveyard *et al.* (2016) refer to a range of published guidelines which recommend assessing for credibility, resonance, significant contribution, ethics and coherence. The selected articles were assessed for these using the Joanna Briggs checklist (JBI 2016) and were examined to establish if there was congruity between methodology and research question, data collection, data analysis, data interpretation, and conclusions.

All of the selected articles had obtained relevant ethical approval yet some limitations were noted. Only one of the articles clearly located the researchers culturally and theoretically and addressed the influence of the researcher on the research (Dilworth *et al.* 2012). This lack of theoretical and cultural positioning could have an impact on assumptions made by the researchers thus affecting results. Congruence was noted between findings and conclusions in all selected articles. One article (Stephens *et al.* 2013) used field notes as opposed to audio-recorded data, but direct quotes from patient participants were included in the article. Yu *et*

al. (2007) article is a ‘research in brief’ as opposed to a full article and therefore contains less detail.

Analysis

The 6 articles were analysed in order to capture a rich thematic description of the data. This was done following the methods outlined in Thomas and Harden (2008) and involved line-by-line coding of the data, construction of descriptive and then analytical themes. Each article was read multiple times and reviewed to determine (i) how participants explained their readmission and (ii) what themes exist around the readmission experience. Data were extracted into tables and grouped by initial code words by the first author. These tables were then regularly reviewed and themes were generated and refined using mind-maps over the course of approximately four weeks. These themes were reviewed and agreed upon via group discussion with all the authors. [Insert Table 1 near here]

Findings [Insert table 2 near here]

Overall, there appears to be a ‘cycle of exclusion’ experienced by many of the 68 participants in these studies. This begins during their initial hospital stay and continues until readmission. This period after their hospital stay is further distinguished by a perception of uncertainty about and exclusion from healthcare system factors.

The included studies were undertaken in Australia, the United States of America, Canada and Hong Kong. Further detail, aims, and findings are summarised in Table 1. Three of the articles (Slatyer *et al.* 2013; Stephens *et al.* 2013; Vat *et al.* 2015) incorporate experiences of older adults, caregivers and healthcare professionals. There were distinct sections enabling clear data extraction of the older adult perspective.

Experience during initial hospital stay distinguished by exclusion

Participants felt that they were not involved in decision making, information was not shared or discussed and they felt excluded from the discharge process. These examples point to a ‘cycle of exclusion’ that begins during the initial hospital visit and continues into the discharge process.

Feeling powerless

Participants noted feeling uninformed about their own care and health and described feeling “powerless, unheard and disrespected” (Dilworth *et al.* 2012 p.283). Stephens *et al.* (2013) reports patients deferred power to the healthcare professionals looking after them resulting in a lack of perceived control or ownership over their care. Similar examples are seen in Dilworth *et al.’s* (2012) study with some participants not questioning medication changes that later affected their health and contributed to their readmissions. Furthermore, one patient commented they could not discuss their care with the medical team due self-perceived lack of education and understanding of medical language used in discussion. Powerlessness was also experienced through not having control over changes to plans and treatments or not receiving adequate information from which to make informed decisions. Patients noted they did not have information about what was happening to them, they had unanswered questions and, treatment changes were not explained or discussed (Dilworth *et al.* 2012). One participant stated feeling they were in a ‘no man’s land’ where a lack of information was coupled with multiple changes to plans and treatments (Dilworth *et al.* 2012).

Feeling disregarded

Patients' knowledge of themselves, their values and preferences were ignored (Dilworth *et al.* 2012). Participants reported feeling disregarded multiple times during the initial hospital stay and discharge decision making period (Dilworth *et al.* 2012). They described communication with staff where their needs and wishes were not acknowledged (Slatyer *et al.* 2013; Stephens *et al.* 2013; Uscatescu *et al.* (2014). Some noted they had limited recall of communication with healthcare staff and that the busy, stressful environment affected their understanding of their complex healthcare situations (Slatyer *et al.* 2013). A lack of information sharing and patients receiving mixed messages was also noted (Dilworth *et al.* 2012). In some instances different members of the healthcare team (doctors and nurses) provided diverse pieces of information, and sometimes included conflicting advice about treatment, discharge or care plans (Dilworth *et al.* 2012). Participants noted they did not fully understand their conditions (Slatyer *et al.* 2013), could not recall all their medication or care plan details (Stephens *et al.* 2013), or left the hospital with no explanation as to the cause of their symptoms (Uscatescu *et al.* 2014). Being disregarded led to some people feeling frustrated and let down (Dilworth *et al.* 2012) or harmed (Dilworth *et al.* 2012; Uscatescu *et al.* 2014). For example, one participant experienced renal failure when a doctor disregarded their warnings about Non-Steroidal Anti-Inflammatories and prescribed them regardless (Dilworth *et al.* 2012).

Perception of readiness for discharge

Patients did not feel ready for discharge even when positive about going home. Vat *et al.* (2015 p.3609) report participants felt they were rushed out, "discharged too soon", "definitely too early" or "not prepared to go home". These participants felt the decision to be discharged should be based on "their level of autonomy and physical capacity" and not on their length of stay (Vat *et al.* 2015 p.3609). One participant discussed he knew he was not ready for discharge (Yu *et al.* 2007). This participant immediately consulted a private doctor on discharge and was readmitted to hospital (Yu *et al.* 2007). In some instances, participants affirmed their feelings of not being fully recovered or well enough to go home were ignored (Dilworth *et al.* 2012). Two participants mentioned they had been looking forward to going home despite not having felt ready or healthy enough to go (Yu *et al.* 2007).

Not feeling ready to go home could be associated with readmissions or the fear of readmission. Vat *et al.* (2015) noted their participants came back to the hospital as they did not feel ready to go home in the first place. Elsewhere, a participant represented to hospital as they had been sent home without knowing why they were in pain (Uscatescu *et al.* 2014). Others came back to hospital after experiencing anxiety and worry about having gone home with their condition (Slatyer *et al.* 2013). Furthermore, patients felt their readmission may have been prevented if their clinical condition had been considered as opposed to their length of stay (Yu *et al.* 2007).

Patients experience uncertainty following discharge

Immediately on discharge some individuals experienced a feeling of uncertainty. Some felt they could not rely on community support, others had difficulty accessing it. For others the feeling of uncertainty appears linked to the contrast between how they felt in hospital versus home; or, their ability to manage living with the effects of a diagnosis or treatment; a "new normal". Therefore, the following subthemes were developed: *Perception that community based services are not available or adequate*; *Perception that hospital is the only safe place* and *Difficulty in adapting to a "new normal"*.

Perception that community based services are not available or adequate

Participants perceived healthcare professionals in the community could not be trusted or relied upon (Uscatescu *et al.* 2014; Vat *et al.* 2015) due to both a lack of availability and perceived competence or clinical skill. Unavailability of resources in the community setting was noted when patients could not access community services (Stephens *et al.* 2013; Vat *et al.* 2015) some could not obtain a GP or physiotherapy appointment for over two-weeks post-discharge (Dilworth *et al.* 2012). Several participants stated it took too long to be seen (Uscatescu *et al.* 2014) or spoke of doctors and community based nurses who did not show up (Vat *et al.* 2015). Others were told they would have a home assessment at an unknown point in the future (Dilworth *et al.* 2012). Some noted they were not even aware of what community based resources were available (Vat *et al.* 2015). Difficulties were also experienced when trying to make appointments or get medication (Stephens *et al.* 2013). Certain groups of patients, such as homeless or socio-economically disadvantaged individuals, also had difficulty accessing services due to an inability to pay for transport (Stephens *et al.* 2013). The absence of community based resources is also illustrated by Uscatescu *et al.* (2014) who note only 1 participant in the study was able to access a follow-up appointment, the others were readmitted before they could attend one. Similarly, Slatyer *et al.* (2013) described a patient's condition deteriorated whilst they had been waiting for a GP appointment and then had to return to hospital.

In addition, community healthcare professionals' were not trusted or relied upon due to the perception they could not manage patients' clinical conditions (Yu *et al.* 2007; Vat *et al.* 2015). Some stated their GPs did not understand their condition (Vat *et al.* 2015) or were not competent to deal with it (Uscatescu *et al.* 2014) whilst others thought their condition could not be "cured" in the community (Yu *et al.* 2007).

Perception that hospital is the only safe place

The view that hospital is a safe place in contrast to the uncertainty of home is illustrated with some participants describing doubt about their ability to manage at home. All the participants (n=3) in Dilworth *et al.*'s study (2012) described this, feeling their return to hospital was unavoidable and that they needed to return as they required help or felt unwell. Similar situations are described elsewhere (Slatyer *et al.* 2013) with individuals feeling uncertainty because they did not understand the complexity of their care or had a limited understanding of their health which contributed to feeling they could not manage (Slatyer *et al.* 2013). In some instances, participants felt hospital was a positive setting and their only lifesaver, with some noting their only resource in the face of death was to return to hospital describing this as an "obligation with no alternative" (Uscatescu *et al.* 2014 p.37). Yu *et al.* (2007) noted patients felt powerless to manage COPD after discharge and they lacked confidence in their ability to manage symptoms. Some participants reported a feeling of impending death which meant they did not feel they had any other option but to return to hospital (Yu *et al.* 2007).

Hospital as a safe social space was experienced by some patients who had formed positive and supportive bonds with healthcare professionals and other patients (Yu *et al.* 2007). This contrasted with their uncertainty over what services were available in the community and a feeling of being a burden to their families. Participants in this study stated they experienced a positive social atmosphere in hospital and did not feel lonely there (Yu *et al.* 2007).

Difficulty in adapting to a "new normal"

Uncertainty was experienced by patients in terms of expectations of themselves and their ability to adapt to their altered situation as a result of their diagnosis or treatment, which we refer to as a "new normal". There is evidence that patients are experiencing new uncertainty

that they need to learn to live with but they do not feel they have received adequate support from healthcare professionals to do so. Patients described not feeling back to normal after discharge, or feeling isolated and some experienced acute or unresolved symptoms (Uscatescu *et al.* 2014). Some patients attributed this to not receiving discharge information or instructions which meant they could not tell if their health was getting better or worse when they went home, they did not know what to expect (Vat *et al.* 2015). For others this was because they had limited recall of conversations with healthcare professionals (Slatyer *et al.* 2013) thus they did not have clarity over what to expect on discharge. A lack of confidence about how to control symptoms was also cited by some as a reason for readmission (Yu *et al.* 2007; Uscatescu *et al.* 2014). A number of patients even noted they felt anxious and scared (Slatyer *et al.* 2013).

Other participants contrasted the independence they experienced before their initial admission with how they felt on discharge; they noted this led to feelings of uncertainty and in some cases readmission (Dilworth *et al.* 2012). This was echoed in other articles, where some patients described they did not want to accept this situation or lose their independence (Slatyer *et al.* 2013). For others the “new normal” was yet another issue they needed to adapt to alongside complex life changing events, such as being a veteran, experiencing homelessness, and living with psychiatric conditions (Stephens *et al.* 2013).

Discussion

This review highlights the experiences of older adults who are readmitted to hospital. Overall, the themes in this review indicate that returning to hospital can be the consequence of a prior experience in which individuals feel excluded from decision making, are unready for discharge and perceive a lack of support at home which, paradoxically can lead to the perception that hospital is the safe place to be. This review illustrates the psychological and emotional experiences that can run alongside the physical health harms, which include readmission, as described by the Kings Fund (2014).

There is evidence in the wider nursing literature that many patients feel ill-prepared to go home, (Annema *et al.* 2009 and Kangovi *et al.* 2012). Participants in Annema *et al.*'s study (2009) did not consider they received adequate help from healthcare professionals with this transition. Not feeling prepared to go home was also found to be associated with readmissions among older adults (Annema *et al.* 2009; Coffey and McCarthy 2012). The inevitability of a return has been highlighted elsewhere (Jeffs *et al.* 2014). It therefore seems logical to argue that feeling ill-prepared to go home might increase the likelihood of a readmission.

Effective discharge planning is recognised as a factor in readmissions and patient satisfaction (Gonçalves-Bradley *et al.* 2016); however, the strength of this evidence is weak (Preyde *et al.* 2009; Gonçalves-Bradley *et al.* 2016). Nevertheless, best practice guidance for nurses on discharge planning is available (Lees 2013; NICE 2015a) and hospitals have local processes and guidelines to support nurses. Evidence from this review through the subthemes of *feeling disregarded, powerless and perception of readiness for discharge*, indicates that discharge planning can impact on readmissions. However, our review also suggests that patients do not feel included throughout the hospital stay; they describe a ‘cycle of exclusion’ that indicates that their care is not being undertaken in a holistic manner.

This review identified that many patients struggle to receive the support they need once at home. Having difficulty obtaining support in the community is also an issue observed in

other peer reviewed (Lees 2013) and organisational (Age UK 2012; Healthwatch 2015; RVS 2013) research. Adequate community support and follow-up is also deemed important by older adults themselves (RVS 2013; Healthwatch 2015). It is logical to argue that closer patient involvement in discharge planning might lead to greater awareness and perceived accessibility of community services which may help to support patients once discharged.

Context and power are essential to understanding the findings contained in these studies. For example, some respondents noted they felt powerless to manage their condition (Yu *et al.* 2007) or that they did not have the knowledge or authority to question the decisions made by healthcare professionals (Dilworth *et al.* 2012). This indicates opportunities for creating authentic and therapeutic relationships may have been missed. A respondent noted they wanted to be spoken to about their condition using lay language (Dilworth *et al.* 2012) highlighting that power can be exerted through the language we use as professionals (Kuokkanen & Leino-Kilpi 2000). This is reflected in other work that describes patients feeling like objects, with discussions controlled by healthcare professionals, use of medical language and communication being ‘about’ instead of ‘with’ them (Efrainsson *et al.* 2003).

Power can be viewed in the ability of people to exercise choice (Laverack 2016) thus having no choice is synonymous with powerlessness. This is pertinent in light of the respondents’ views that they felt powerless or disregarded in decision making throughout their stay and readmission. As nurses, it is our role to help create therapeutic relationships with patients, creating environments where equality of worth is central and where patients feel able to be active and equal participants (Kuokkanen & Leino-Kilpi 2000). By understanding all the elements of transition processes nurses can nurse patients accordingly and take their individual circumstances into account (Meleis *et al.* 2000). An example of this type of care in practice is delivered by Acute Clinical Team services run in Wales. Skilled Advance Nurse Practitioners assess, diagnose and care for older adults in the community (Griffiths & Davies 2017). Patients are considered partners in care management and initial feedback suggests this service prevents hospital admission though more evaluation is required (Griffiths & Davies 2017).

To be ill has meaning to the person with the illness (Lindburg *et al.* 2013) and addressing this meaning with patients should form part of routine nursing care. This review demonstrates this psychological and emotional care is often not addressed by health care professionals. This is not surprising as these aspects of care have been found to be some of the most commonly reported activities of care left undone with 46% of nurses sampled citing they did not have time for ‘comfort/talking with patients’ and 34% not able to develop or update nursing care plans or care (Ball *et al.* 2016). Furthermore, other research has found that older adults can rationalise the need for extra support or time in hospital but their existential needs or feelings around grief and loss are not always addressed (Lindburg *et al.* 2013). Psychological adjustment is also required by patients when they are discharged from hospital but again this element of patient care is often overlooked by healthcare providers (Lees 2013). Helping people to address existential matters and manage and understand changing expectations, of themselves as individuals and of health care services are vital and form part of delivering holistic person centred care.

One strength of this study lies in the consistent thematic findings despite heterogeneity between studies. The size, composition, geographic and clinical location all vary as do the readmission timeframes which range from 14 days to 1 year. The health care systems represented also vary. This review adds strength to the argument around the need to deliver

holistic person centred care and to value the nursing time and skill dedicated to this. It should not be seen as acceptable to rush or omit this aspect of care.

The articles selected for this review each have their own limitations thus these findings should be viewed accordingly. Only articles written in English were included, interviews took place in a hospital setting, not a setting of the participants choosing; there is a lack of noticeable diverse voices (including women, people from different black or minority ethnic groups, LGBTQ, and different socio-economic backgrounds); and a lack of data from the United Kingdom is apparent. Additionally, only half of the selected articles wholly focused on the patient experience, the others incorporated views from care givers and health professionals (Slatyer et al 2013; Stephens et al 2013; Vat et al 2014). Furthermore, a sole researcher carried out the search and analysis which could potentially bias findings.

Impact statement

There are two main outcomes from this review. Firstly, this review highlights the importance of the patients' voices that are otherwise 'silenced' (Serrant-Green 2010) in current research on readmissions to hospital. Listening to patient voices is vital for healthcare professionals and enables the provision of person-centred care (Schwind et al. 2016). Furthermore, viewing patients holistically and considering the way they describe their healthcare trajectories within and outside of hospital settings is important when we are providing care (Schwind et al. 2016).

Secondly, the themes identified in this review are important as they have not been identified in individual qualitative studies. They illustrate that patients often feel excluded and uncertain during readmission, indicating that holistic care is not always being provided. This emphasises the value and importance of human connection in nursing practice. Sharp et al (2016) have identified that this can improve patients' experience of care and that incorporating personal, emotional and spiritual elements within nursing can have a positive impact on patient empowerment and recovery. Understanding how and why patients feel excluded and uncertain at readmission is therefore of paramount importance.

Conclusion and recommendations

This review was carried out to explore the experiences of readmission to hospital among older adults. Individual themes in this review are echoed in other research. However, when taken collectively the themes synthesised illustrate a negative experience and a cycle of exclusion for many. In addition, individuals' existential, emotional and psychological wellbeing was not adequately addressed. This review highlighted the continued lack of evidence that exists on returning to hospital in the words of older people themselves. Future research should address the continued paucity of data from the perspective of older people and incorporate more diverse voices. Research should also be conducted into how to help manage patients and families expectations. It would also be interesting to consider how readmission experience could vary depending on the healthcare system in place as this can influence how care is paid for and what services are available. How a lack of resources could impact on healthcare professionals' abilities to deliver person centred care must be addressed as part of future research.

The following recommendations are made in light of the findings from this review:

- The nursing skill and time dedicated to delivering holistic person centred care must be valued by clinical, educational, research and policy organisations and prioritised in clinical settings.

- Future research should include the voices of older people themselves and ensure diversity is represented for example through participatory research methods.
- Discharge processes should incorporate adequate psychological and emotional preparation for the transition.
- Information and self-care advice should be given in a way that is relevant to people and the reality of their home life.
- Specialist services that bridge acute and community settings should be further evaluated.

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