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TITLE PAGE

Feeling let down: An exploratory study of the experiences of older people who were readmitted to hospital following a recent discharge

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FEELING LET DOWN: AN EXPLORATORY STUDY OF THE EXPERIENCES OF OLDER PEOPLE WHO WERE READMITTED TO HOSPITAL FOLLOWING A RECENT DISCHARGE

ABSTRACT

Background: Readmission of older people to hospital following a recent discharge may be an indicator of gaps in services either prior to or after discharge.

Aims and objectives: To explore the experiences of older people who have been readmitted to hospital following recent discharge to their homes.

Design: A qualitative descriptive study

Method: In-depth interviews were conducted with three older people who were discharged from a large tertiary referral hospital in NSW Australia and readmitted. Interviews were conducted within the hospital setting in a private room. An interview guide was used to explore the reasons for admission and readmission to hospital and experiences upon discharge to home. In particular the researchers were interested in the events that led to readmission. Data were analysed thematically

Results: Three main themes emerged including: *being left out, being cared for* and *feeling let down*.

Conclusion: While this study was undertaken in only one hospital with only three older people the findings provide valuable insight into their experiences. Nurses need to be proactive in ensuring and promoting a person centred approach to the care and treatment of older people.

Key words: older person, readmission to hospital, qualitative study, person-centred care

INTRODUCTION

As the population grows over the next 20 years the number of older people requiring health care will also increase concomitantly (Australian Institute of Health and Welfare (AIHW), 2008). The interaction between co-morbidities, polypharmacy, and the older person's socio-economic situation often contribute to their need for acute care and hospitalisation (Karmel, Hales, & Lloyd, 2007). Hospitalisation is a stressful and traumatic event for older people and may result in de-conditioning and poor functional outcomes which may also result in hospital readmission. Readmission to hospital following immediate discharge has been reported to be as high as 33% amongst older people (Schwarz, 2000) with mortality rates of 20% six months after initial admission (Munshi et al., 2002) with preventable readmission rates ranging from 5.5% (Miles & Lowe, 1999) to 47% (Munshi, et al., 2002). Whilst there are a range of reasons for readmission, there is little research that investigates the experiences of older people when this occurs. Given that older people are high-end users of the health care system this is acknowledged as an important area of investigation (AIHW, 2008; Hancock, Chenoweth, & Chang, 2003; Themessl-Huber, Hubbard, & Munro, 2007). This paper reports the findings of a small qualitative study which explored the experiences of older people who were readmitted to a hospital after being recently discharged.

BACKGROUND

The study was conducted within a unit that was recently opened as part of an initiative to improve patient journeys and deliver better healthcare experiences for older people and those with chronic disease (Australian Resource Centre for Health Care Innovations (ARCHI), 2001). The main philosophy espoused by the unit and the health service more broadly is one of person centred care. Person-centredness is internationally recognised as best practice in the care of older people (Dewing, 2004; McCormack, 2004; Nolan, Davies, Brown, Keady, & Nolan, 2004; Peek, Higgins, Milson-Hawke, McMillan, & Harper, 2007; Slater, 2006). Person centred care requires the formation of a therapeutic partnership that engages the person respectfully in their healthcare (Davis, Byers, & Walsh, 2008; McCormack, 2003, 2004; Nolan, et al., 2004). The facilitation of person-centred care is influenced by the context in which care is provided (McCormack, 2003, 2004) and often there is pressure to balance organisational values, professional implications and moral obligations to the patient (McCormack, 2003; Price, 2006).

Readmission and older people

There is a lack of consistency in the definitions of “readmission” and age-related criteria for “older person”. It is also not clear what readmission rates mean in terms of their usefulness for evaluating interventions or the quality of care being provided. For the purpose of this study, readmission was defined as an unplanned admission to the same hospital within 28 days after being discharged.

Readmission rates are used as an outcome measure for the effectiveness of interventions, or as a marker of poor quality treatment or an adverse event related to the first admission (Brand, Sundararajan, Jones, Hutchinson, & Campbell, 2005; Miles & Lowe, 1999; Munshi, et al., 2002). There are a range of known risk factors for readmission to hospital including; chronic illnesses, exacerbation of existing conditions, adverse drug reactions, and social factors such as no income (Almagro et al., 2006; Arbaje et al., 2008; Brand et al., 2004; Brand, et al., 2005; Chu & Pei, 1999; Dobrzanska & Newell, 2006; Lagoe, Noetscher, & Murphy, 2001; Lee, MacKenzie, Lee, & Chan, 1999; McLean, Mendis, & Canalese, 2008; Munshi, et al., 2002; Schwarz, 2000) Some of the more common disease conditions that predispose an older person to hospitalisation include congestive heart failure, active malignancy, chronic obstructive pulmonary disease, end stage renal failure, and dysphagia (Chu & Pei, 1999).

Reasons for readmissions reported in the literature include those related to health service shortcomings, poor communication and preventable adverse events. For example, Munshi et al., (2002) found that 16% of readmissions were due to “unsorted” medical or social problems and 7% were due to “complications of treatment”. Poor communication was highlighted within and among the multidisciplinary team and primary care physicians or General Practitioners (GP) as accounting for a significant number of readmissions. Miles and Lowe (1999) found that 5.5% of readmissions resulted from an adverse event with most of these

events considered to be of minor severity and highly preventable. Based on the number of bed days these readmissions used and the cost per day they calculated that preventable readmissions alone would cost over two million dollars in a year. In Munshi, et al's., study (2002) 47% of readmissions were preventable.

Pearson, et al., (2002) compared the opinions of GPs and hospital staff regarding the reasons older people are readmitted to hospital. There was agreement from both groups that relapse and complication of the initial illness were common reasons for readmission. Carer problems were also a common reason for readmission. However, GPs thought that inadequate preparation for discharge, poor health at discharge and inadequate provision of information to the GP were problems whereas hospital staff did not. The researchers note that flaws in processing discharge summaries may account for this difference in opinion and suggest that a phone call or fax to the GP on the day of discharge could address this problem. Hospital staff saw medication problems as a contributing factor whereas GPs did not.

The patient experience of readmission

There are few studies that explore the experience of readmission from the patient's perspective. Yu et al., (2007) conducted a qualitative exploratory study of patients with Chronic Obstructive Pulmonary Disease (COPD) who had multiple readmissions to hospital. Interviews were held with the patients aged between 70 and 81 years old and who had three or more readmissions in six

months. Reasons for readmission included social and emotional factors as well as disease exacerbation and lack of self management. The researchers also identified feelings of loneliness, of being a burden, guilt, insecurity and fear amongst the participants. Yu et al., (2007) suggest that the unequal power relationship between patient and doctor may impact the discharge planning process. They argue that a person-centred approach that aims to form a partnership between professional and patient may lead to improvements in practice through an increased understanding of patient attitudes, and needs.

AIMS

The aims of the study were to explore the experiences of older people who had been readmitted to hospital following discharge from hospital and to investigate the circumstances that lead to their readmission.

Specific questions related to the aims of the study were:

- What were experiences of older people from discharge to return to hospital?
- What were the perceptions of older people in relation to the reasons for their readmission?
- What were the circumstances that led to readmission?
- What are the person-centred aspects of care within this context?

- What is needed in order to enhance a person-centred approach at this time?

DESIGN

A qualitative descriptive design was selected as it places emphasis on the research context and people in the generation of knowledge that comes from the perspective of the person (Sandelowski, 2000; Taylor, Kermode, & Roberts, 2006).

METHOD

The methods used in the study included face to face, semi-structured, in depth interviews with consenting older people who met the criteria for the study. Interviews were audio-taped for transcription and concurrent analysis. This approach allowed the interviews to be framed by a person-centred philosophy by focusing on the patients and their needs, working in partnership with the older person to enable them to convey his/her experiences. An interview schedule was developed from concepts within the literature. The schedule was designed to answer the research questions discussed above. It included the questions:

Can you tell me about having come back to hospital?

Why have you come back?

How did you feel about coming back?

What was it like to go home and then come back to hospital?

Did you have any concerns before you left?

What sorts of things were arranged for you before you left?

Is there anything that could have prevented you coming back?

The interviews were conducted by allowing the flexibility of a conversational style (Morse & Field, 1995; O'Leary, 2004) so that the researcher was able to address questions of interest while providing the participant the freedom to express his or her ideas, feelings and concerns (Morse & Field, 1995).

Participants

The participants for this study were older patients, aged 65 years or over, who had been readmitted to hospital within 28 days of discharge from a large tertiary referral Hospital in Australia, who were able to speak English, able to understand the information statement, and able to give written or verbal consent.

Over a seven-week recruitment period ten people were identified as meeting the inclusion criteria. Of these, four older people were not able to give consent due to acute episodes of delirium, dementia or physical condition, and they were considered inappropriate for interview by the Nursing Unit Manager; two declined to participate and one person was discharged before the initial approach. As a result of delays with recruitment and because of the time constraints, data collection for the study ceased after three participants were recruited. This was deemed adequate to generate relevant information and quality data for a preliminary exploration of the experiences, issues and concerns. It should be noted that

sample size must also consider material and time resources as well as the number of researchers (Holloway & Wheeler, 2002). The challenges of recruiting older people in the acute care setting whilst maintaining the integrity of the research and protecting the participants' rights were also seen to justify the smaller than expected sample (Hancock, et al., 2003; Harris & Dyson, 2001).

Participants were asked to consent to an interview and to have the interview audio recorded for transcription and analysis. Interviews were recorded to avoid the risk of missing important issues. This also allowed repeated reflection from re-listening to raw data (Holloway & Wheeler, 2002). Participants were invited to nominate a family member or carer to participate in the interview if they wished. One of the participants invited his son; his primary carer to be present. The interviews took place in the hospital setting and took between 20 and 40 minutes.

Ethics

Ethics approval was granted by the relevant University and Area Health Service Ethics Review Committees. Participants were provided with detailed information regarding the study and their rights. Participants' rights were protected through ensuring informed consent, privacy and anonymity. Pseudonyms were used in reporting the findings of the study.

Data analysis

An inductive approach to the analysis of data was used as there are only fragmented data related to the phenomenon of readmission of the older person and no literature related to the experience in the particular setting (Elo & Kyngäs, 2008). Categories were derived from the data, moving from the specific to the general observing particular detail and relating to the broader description (Elo & Kyngäs, 2008; Sandelowski, 2000). The interview formed the unit of analysis. Coding of the data was undertaken by a single author (SD). Themes were discussed and agreed on by all authors. The coding of the interviews and emergent themes were reviewed by all authors.

RESULTS

The main themes that emerged from the study were *being left out*, *being cared for* and *feeling let down*.

Being left out expresses the participants' experience of not being given information, being given mixed messages and feeling unheard and disregarded. *Being cared for* describes both the care required in context of the hospital admission and additional care required at home. The third theme, *feeling let down* describes the experience of falling through the gaps in service provision and being disappointed by services and staff.

Being left out

During the experience of being in hospital the participants described an environment in which they felt powerless, unheard and

disrespected. This theme is characterised by a lack of information sharing, being disregarded, and receiving mixed messages. The lack of information sharing was described by the participants as frustrating. They were frustrated about not being told about what was happening to them, unanswered questions and treatment changes without any information or explanation.

They haven't told me ANYTHING was the matter with me as far as I know. No, I said, WHAT'S THE MATTER WITH ME? I know I am dumb but I am sure they could explain it in layman's terms. It's all I want to know what is the matter with me? Why am I getting these dizzy spells and what is causing them? I don't think it is too hard to answer.

(Oscar)

The exemplar above highlights Oscar's frustrations and he told us he wanted to understand and that he needed things explained to him in lay terms. There was an ongoing lack of information provided to or understood by Oscar. This was a strong and recurrent theme that Oscar voiced. He felt totally uninformed about his care and health.

Participants felt disregarded, having their knowledge of themselves, their values and preferences ignored. There were situations described by participants where their express wishes were disregarded. For one person in particular having their concerns overlooked resulted in potentially permanent harm, in the form of renal failure, as a result of a medication error.

Well I am a bit, you know I am bit annoyed about the anti inflammatory I was given, because I told the doctor no, no, no, no, no I can't have them and he put, he gave me some, see I wasn't aware the nurse comes along and there are loads of little tablets and they're all different colours from what I am used to, you know, and um I didn't, wasn't aware but she did say... I am sure she said indocid and thought oh she couldn't have said that because I am not having that. Anyway, so I swallowed down the tablets, well then ... I got kidney failure so, yeah, and that's why I've got this (indicates tubes inserted into neck above clavicle) this has to, oh it's a horrible thing its um the dialysis, it must be like an enormous cannula or something and um so now, oh and I hope it will only be temporary, because otherwise its dialysis for the rest of my life and that is terrible, I am just so annoyed.

(Carol)

Receiving mixed messages describes being given different information from different member of the treating team, receiving conflicting advice including changes to plans for treatment and discharge, and poor explanations about care.

Often unclear communication was the result of changes to the treating team and doctors. Participants often referred to “they”, “the doctor”, “the physio” and only one participant named their treating doctor. Participants were not only unclear about what treatment they were receiving but also who was caring for them. Oscar noted that he has seen several doctors, one who explained things well but now he felt that no one was explaining anything to him.

There was a doctor here she was quite well. She was explaining it all to me and now they have changed doctors around.

(Oscar)

Oscar was so frustrated by the discrepancy between the team’s plans that he discharged himself from hospital against medical advice. This event was an accumulation of frustrations related to ongoing lack of information and discrepancy in plans.

Being cared for

The older people in this study previously lived independently or with little assistance. They described the need for care from family or health services to manage the changes in their health since their first admission. When describing being cared for, the help that family provided meeting these new needs was recognised. All participants described feeling that their return to hospital was an unavoidable situation. Following a period of feeling unwell or an accident these people felt that their only option was to go to or

return to hospital. *Being cared for* in hospital generated mixed emotions. Each of the older people conveyed opposing negative and positive feelings about being cared for in hospital. Carol, for example, was initially admitted for one day for treatment of an infection. She reported a change to her medications on her initial discharge and during the week she was at home between admissions reported being very drowsy and “spaced out”. She was readmitted to hospital after a fall. Carol expressed gratitude for services and the feeling of reassurance at being in hospital. This is interesting as this gratitude and easy acceptance of her situation is juxtaposed with her stories of being ignored and feeling let down, as identified in the conversation below.

I am just really grateful for the hospital to be able to look after me, feed me. So to be completely looked after and accommodated in every way, it's a very reassuring feeling, so I am really happy to be here.

So it's been a positive experience? (researcher)

Absolutely, yes and I am quite happy now to sit back and wait until my back gets better and my renal thing improves, MY RENAL CONDITION (raising eyebrows).

(Carol)

Carols emphasis and the reason for the capitals is that Carol felt that the renal failure was due to her receiving the wrong medication. So

the context of her being happy about the treatment she received needs to be seen in light of this.

Positive feelings were expressed specifically, for example Walter said: "Treatment was good I had no complaints the food was good, the nurses were nice" but follows this with "naturally if you're not well it's the best place to go". Negative comments are less specific. Walter assessed the care he received was "not as good as I have had I think probably." When questioned further about this statement and asked if there is anything in particular he replied: "Probably not" and "Only because you asked me probably." Putting this into context, Walter was initially admitted with cellulitis. He had been readmitted and treated for pneumonia which had then been confirmed to actually be pulmonary emboli. Multiple changes in plans, treatments and information had left Walter and his son feeling in "no man's land", this was discussed further above in the theme *being left out*.

Feeling let down

The theme *feeling let down* describes incidences where the older person was disappointed by their encounters with the healthcare system. Lack of discharge planning left the person in vulnerable situations, in some cases arrangements are "still in the pipeline", highlighting gaps in treatment or services, in particular at the point of discharge. For example, Walter's follow up care included a GP appointment arranged by his son, which was not available for two weeks; an outpatient physiotherapy program that would commence

in two to three weeks and a home assessment by the department of veterans affairs for home modifications at an unknown point in the future. Walter needed readmission just 7 days after discharge. When describing their experience of returning home between hospital admissions and discharge there was a sense amongst the participants of not being back to full function or not being fully recovered. Unprepared and not ready for discharge, they felt they were not well enough to go home. Discharge plans had not been discussed with them and no services put in place to support them at home.

Despite having had two recent readmissions when Oscar was asked what sorts of things have been put in place to help him manage, or if any plans have been made for when he went home this time, he said:

*No, only the doctor just mentioned this afternoon,
just before you arrived he said we're thinking
about sending you home, I said "beauty". That was
that, he just examined me and ducked off ...*

(Oscar)

Unfortunately each of the participants' journeys was punctuated by notable gaps in services. In these circumstances participants experienced less than ideal outcomes as a result of oversights or errors.

The participants felt that they needed to come to hospital because they were so unwell and needed help. When looking at their experiences there is more to this than they saw. There were instances where the care they received during their first admission can be linked to their need to return to hospital. It is in their *feeling let down* that the inevitability of their return is recognised. When asked directly participants stated that there was nothing that might have been done differently to prevent readmission. However, Walter discusses a discontinuation of anticoagulant medication, while his son described a significant decrease in mobility; Carol believed “absolutely” that a change to her medications at discharge had increased her drowsiness and contributed to her fall; Oscar expressed that he was not in a position to question the methods of health professionals stating “that’s their job; my job was a brick layer so that’s all I know.”

DISCUSSION

The experience of readmission was described by participants as an inevitable event in their lives. Three themes emerged from the data analysis. The first, *being left out* encompasses sub themes related to lack of information sharing, being disregarded and receiving mixed messages. It is this theme that highlights the lack of person centred care.

These interviews in this research reveal an imbalance of power, a lack of information and knowledge sharing, no partnership, no acknowledgement of routines or previous management, or patient

concerns. The unequal relationship between patient and doctor evident in this study is also discussed by Yu et al. (2007) who explored the experience of multiple admissions for older people with chronic obstructive pulmonary disease.

Participants expressed frustration at not being heard, and being disregarded. The disregard shown to their values, anxieties, fears and needs shows disrespect of their personhood (McCormack, 2003). The trust that is based on information and knowledge sharing, and the sharing of power and decision-making (McCormack, 2003; National Ageing Research Institute, 2006; Peek, et al., 2007) that is essential in person-centred care is not present in this experience. The active involvement of patient and family promoted in person-centred care by mutuality, reciprocity and particularity is something that is not evident in the findings of this study. Instead participants and their families expressed *being left out* of their care through a lack of information sharing; being given mixed messages and being disregarded.

Lack of involvement of older people and their families in care planning along with negative attitudes towards older people are recognised in the literature (Clarke, Hanson, & Ross, 2003; Peek, et al., 2007). A person-centred approach is recommended as a way of addressing this issue.

The theme *being cared for* described the involvement of the participant's family and of health professionals. Carer strain and carer burden discussed in the literature (Schwarz, 2000; Yu, et al., 2007)

were not apparent in the recounting of the experiences of the participants. *Being cared* for in hospital generated mixed emotions. There were positive and negative experiences and feelings described as part of this experience. The literature suggested that there may be elements of enjoying the sick role (Yu et. al, 2007). In this study readmission is described as a necessity not a desirable outcome.

A link between person-centred communicative behaviours such as active listening and immediacy and patient satisfaction has been recognised (McCance, Slater, & McCormack, 2009; McCormack & McCance, 2006). However, in this study participants expressed satisfaction despite negative experiences. Therefore, it cannot be assumed that because a patient expresses satisfaction that the care they have received has met their needs or fulfilled their expectations (Coyle & Williams, 2001). The notion that the gratitude expressed may be inherent and socially desirable responses also needs consideration. The dual role of the researcher as a care provider must also be noted here (or as a limitation to the study). The theme *feeling let down* describes incidents when the participants fell through gaps, experienced disappointment, or suffered adverse outcomes as part of their experience of readmission. The literature details the use of readmission rates to measure the quality of antecedent care. This small study found that antecedent care was related to the reason for readmission for each of the three participants. Being unprepared for discharge was described by the participants as part of this experience. Premature discharge and length of stay (LOS) are issues raised in the literature

(Ashton & Wray, 1996; Gray, 2001; McLean, et al., 2008). These results indicate that in some cases the move toward shorter LOS may equate to premature or inappropriate discharge.

Limitations

Searching for participants was limited by the function of the Inpatient Information Management (IPIM) system making it difficult to identify all potential participants.

This study was conducted as part of an Honours degree by thesis as a full time student over one year. The limitations of the researcher as a novice must be recognised in considering the questions raised by the interviews. Restricted timeframes also limited the recruitment period in the light of unanticipated difficulties identifying suitable participants for the study. This meant that the target number of participants, five, was not reached. Instead, interviews were conducted with three older people. Despite this limitation the research allows important insights into the personal experiences of these three older people. The issues highlighted are significant. For these three people it is apparent that their readmission was avoidable. These results indicate that further research in this area is needed.

CONCLUSION

Participants in this study were reconciled to their future as one that was punctuated by the inevitable return of poor health and hence their inevitable return to hospital. Listening to their stories led to

the realisation that their readmission was in many instances due to oversights or errors made during their first admission. In each case the quality of care received during their initial hospitalisation can be linked to their subsequent need for readmission. The experience of readmission is characterised by instances of poor communication, lack of consultation, and poor management that impact on what happens after discharge and inevitable readmission.

IMPLICATIONS FOR PRACTICE

Development of practice that involves people in care and decision-making is indicated. Lack of involvement and feelings of being disengaged were expressed by all participants. The possibility of assessing the person's needs and expectations on admission or as part of the discharge planning process may alleviate some of these emotions and negative experiences. The development of a tool to ensure that people are informed of some of the system-related issues and standard information including what to expect when admitted to hospital and during discharge may also assist people and families to understand how they can be involved in their care. This may include addressing minimum standards of care, for example as set out in the standing nursing and midwifery advisory committee's caring for older people practice guidance document (Department of Health, 2001).

Assessments that encourage a biographical approach to care and planning may be useful in the current setting to encourage

recognition of the older person's context and enable integration of the older person's social world (McCormack, 2003, 2004).

In terms of the context of care a culture of reflective practice is a measurable activity that may be indicative of person-centred care. The importance of reflection in terms of appropriate levels of engagement are discussed by McCormack (2003). Reflective practice including clinical supervision, case review and supported reflection are used as a way of partially or fully disengaging with the partnership to ensure ethical and safe practice when patient or practitioner values are challenged. Development of and support for reflective practice as described may encourage development of a person-centred culture.

The tensions between what is expected and what is achievable in relation to a person-centred approach to care in the acute care setting must be acknowledged here. We need to ask what is ideal within the context of this resource poor, high demand environment. More research is needed to explore what a person-centred approach to care should be in this setting. A minimum expectation should be respect for the older person, the maintenance of their dignity and acknowledgement and recognition of their "voice" and right to be communicated with and heard.

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