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The 'unworthy' patient with dementia in geriatric rehabilitation hospitals

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ABSTRACT

Background: The number of people presenting to hospital with dementia is escalating worldwide. Hospitals are inadequately prepared leading to a poor patient experience.

Aim: To explore the perspectives of nurses caring for people with dementia to critically evaluate the reasons behind the widely reported poor care received by such patients. The study examined what was privileged in the care of patients with dementia in geriatric rehabilitation facilities.

Method: The study used critical ethnography. Data were obtained from interviews with 29 nurses working with patients with dementia in geriatric rehabilitation hospitals. The interviews were audio-recorded and transcribed verbatim.

Findings: The theme of the 'unworthy' patient was supported by sub-themes of people with dementia and hospital performance targets, risk, nurse workload and acute care issues.

Discussion: Hospitals have increasing pressure to conform to tight budgets and must justify all expenditure, increase patient throughput and minimise risk. Patients with dementia can have a longer hospital stay complicated by frailty, complications and social problems. The focus on rapid discharge influences the mind-set of nurses and nurse habitus. Patients with multiple chronic co-morbidities are unpopular and considered low priority and less worthy of resources. Privileging care for certain patients and tasks is supported by organisational cultural beliefs. Nurses require support to maintain empathetic caring practices in the face of managerial priorities.

Conclusion: The research found that patients with dementia were considered unworthy in the geriatric rehabilitation hospital setting. The difficulties caring for patients with dementia are considerable. Nurses need education and support to improve practice.

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1. Introduction

Globally there has been an increase in the number of people who have dementia, which is a phenomenon related to the advancing age of the population and the subsequent rise in chronic diseases (Knapp et al., 2007). It is estimated that approximately 35.6 million people across the world currently have dementia and the rate of diagnosis is accelerating, with 7.7 million new cases identified each year (WHO, 2012). In Australia it is estimated that at least 354,000 people currently have dementia although this is a conservative approximation as dementia is often unrecognised or under-reported (Australian Institute of Health and Welfare, 2016). As a consequence, the number of people presenting to hospital with dementia as a comorbidity is escalating worldwide; however

it has been demonstrated that hospitals are inadequately prepared (Prince et al., 2015). To date, addressing the specific needs of people with dementia which are related to cognition have not been a high priority of hospitals however since the turn of the century a greater focus has been directed to dementia in the United Kingdom, Scandinavia and parts of Europe (Alzheimer Europe, 2014). In Australia, clinical practice guidelines have recently be released which aim to improve the quality and consistency of care in community, residential and hospital settings (Laver et al., 2016).

The economic burden of caring for people with dementia in the community, in institutional care and in hospital is enormous with an annual worldwide cost estimated in 2012 to be US\$ 604 billion (WHO, 2012). Cost containment is a priority both globally and in Australian hospitals, where expenditure is closely monitored to ensure that maximum benefit is provided to the community (Adams & Nelson, 2009). The valid concern about the cost of hospital care has led to an intense focus on efficient service management, with the aim of reducing risk to patients, staff and the public, and

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Summary of relevance

Problem

- It has been widely reported that people with dementia often have a poor experience in hospital.

What is already known

- Cost containment is a priority for hospitals, but people with dementia require time and resources not readily available in this environment.

What this paper adds

- Evidence that nurses view patients with dementia as less worthy of care and resources than other patients as a consequence of the hospital focus on rapid discharge and budgetary restraint. Nurses require support to provide empathetic care in the fast-paced hospital environment in which cost-containment and rapid patient flow through are prioritised.

at the same time increasing patient turnover, maintaining occupancy targets and adhering to budgets (Sorensen, Paull, Magann, & Davis, 2013). However this focus has had consequences for the nurse-patient relationship which is based on caring and does not readily adapt to the rapid movement of patients through the system. People with dementia require time and nursing resources which may not be adequately provided in this fast-paced environment. Hospitals often do not provide additional resources to support nurses when there is an increase in the workload related to the cognition of the patients, leaving the nurses ill-equipped and compromising care (Edberg, Anderson, Orrung Wallin, & Bird, 2015; Sanchez, Mahmoudi, Moronne, Camonin, & Novella, 2015). There is a dichotomy between what is affordable in these circumstances and what is required by patients with dementia and the nurses caring for them.

This paper examines the findings of a study indicating that nurses view some patients are more deserving of resources, or more worthy, than others and the underlying issues which have led to this devaluation of people with dementia in hospital.

1.1. Research purpose

The purpose of the study was to explore the perspectives of nurses caring for people with dementia to critically evaluate the reasons behind the widely reported poor care received by such patients. The study examined what was privileged in the hospital care of patients with dementia in geriatric rehabilitation facilities.

2. Methods

2.1. Study design

A qualitative design makes it possible to form an understanding of the way that people recognize and construct meaning in their world (Liamputtong & Ezzy, 2005). In this study the experiences of nurses caring for patients with dementia in geriatric rehabilitation hospitals were investigated using critical ethnography in order to build a cultural critique of the contributing forces which shaped care. Ethnography shares epistemological foundations with constructionism in which people create shared meanings based on their interactions with each other (Crotty, 1998). A critical perspective takes into consideration the power relations that are inherent in hospital hierarchies (Crookes, Knight, & Brown, 2008).

2.2. Recruitment and sampling

The data were collected in five wards of two geriatric rehabilitation hospitals in metropolitan Melbourne, Australia in 2014. Ethical clearance was obtained from the human research ethics committee of the university and the two hospitals. The nurses volunteered to take part in the study in response to flyers, and each nurse formally consented before interview. Inclusion criteria included that they were registered (RN) or enrolled nurses (EN) permanently employed in the ward and willing to be interviewed for the study. In Australia, registered nurses have completed a university degree in nursing or are hospital trained, whereas enrolled nurses have at minimum a Diploma of Nursing from the Vocation Education and Training (VET) sector and there are some enrolled nurses who were trained in the now superseded hospital-based training system (AHPRA, 2016).

2.3. Data collection and analysis

Data were collected through 29 face-to-face audio-recorded conversational interviews with enrolled or registered nurses and 120 h of non-participant observation during the period May–December 2014. The nurses were interviewed during working hours in a meeting room in the workplace when they could be spared from their normal duties. The participants were asked to talk about their experiences caring for patients with dementia in that ward, and the factors deemed to be contributors to the quality of care. The interviews commenced with the broad question ‘Can you tell me about your experiences of caring for people with dementia in this ward?’

Whilst there was an aide-memoire used by the researcher to prompt conversation when necessary, in the main the participants spoke about the issues that they considered important, and the researcher encouraged them further on these topics. The aide-memoire included questions about caring for patients with dementia with behavioural symptoms in that ward, managing workload, the nurse’s preparedness for caring for people with dementia, support available for nurses in this area, and motivation for working there. Demographic information was collected before each interview commenced and all the interviews were conducted by the first author (RD) who has extensive experience as a clinician in the care of people with dementia and is an experienced qualitative health researcher. Recruitment ceased once preliminary analysis revealed that no new information was forthcoming from the interviews.

The interviews were transcribed verbatim by the first author before thematic analysis. The data in this study were analysed separately using thematic analysis as described by Braun and Clarke (2006) to identify, analyse and report patterns or themes. The data collection and the commencement of analysis occurred concurrently. The researcher listened carefully to the audio files while reading and re-reading the transcribed interviews. Interesting or frequently mentioned issues were highlighted and noted.

The initial themes were generated focusing mainly on relevance to the research question and prevalence (Braun & Clarke, 2006). This was done with the assistance of Nvivo 10 qualitative analysis software (QSR International Pty Ltd, 2012). The research team which included two independent experienced researchers (SL and AW) listened to the interviews and examined the initial themes before a consensus was reached. The focus was on understanding the viewpoint of the individuals and the power and cultural influences at play. Mind-maps were used to clarify the relationship between codes and identify themes and sub-themes.

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