



Tensions and ambiguities: A qualitative study of final year adult field nursing students' experiences of caring for people affected by advanced dementia in Wales, UK

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SUMMARY

Background: Rising dementia prevalence means that general nurses globally will encounter more people affected by advanced dementia. Advanced dementia care is profoundly complex yet there is a paucity of research exploring how general nursing students experience and thus learn to care for those affected.

Objectives: To explore final year nursing students' (adult field) experiences of caring for people affected by advanced dementia.

Design: A qualitative design was adopted.

Setting: The setting was Wales, UK.

Participants: Eleven final year nursing undergraduates (adult field).

Method: Data were collected using digitally recorded one-to-one in-depth interviews in 2013 and analysed using thematic analysis.

Results: Participants' experiences fell within three main themes: they can be quite challenging; a lot of dementia patients are seen as hazards and it's not all about doing stuff. Participants aspired to person-centred care. However, they felt insufficiently prepared for what they believed was knowledgeable work requiring interpersonal competence and confidence. Participants appreciated that many practitioners, their clinical educators, were insufficiently prepared for advanced dementia care.

Conclusions: The study provided further evidence of the complexity of caring for those with advanced dementia and associated theory, practice and policy gaps. There are important implications for education in terms of curriculum development and learning from and in practice.

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Introduction and Background

Dementia is a significant global public health concern, for its prevalence is increasing. Recent projections estimate that 48.1 million people worldwide will have dementia by 2020 (Prince et al., 2013). Presently, approximately 800,000 people in the United Kingdom (UK) live with dementia. This is predicted to rise to 840,000 by 2026 (Alzheimer's Society, 2012). Juxtaposed against ageing populations many more people will be living with and dying from dementia in the future. In advanced dementia many will require care in general hospitals or care homes. Globally these are the places where most people with advanced dementia end their lives. Yet regrettably there is credible international evidence of suboptimal care (Sampson et al., 2009; Afzal et al., 2010; Lawrence et al., 2011).

Advanced dementia care is profoundly complex. The capacity to adapt rapidly, assess and meet complex needs, handle ethical dilemmas, co-ordinate care and communicate sensitively and effectively with individuals, families, teams and other agencies demands knowledge, critical thinking and confidence. Thus there is an imperative that nurses globally are prepared to high standards to provide safe, effective person-centred care underpinned by palliative care principles. Sadly, notwithstanding governments' initiatives to enhance workforce development in dementia (Australian Government, 2013; Department of Health, 2009) and palliative care (Department of Health, 2008; Australian Government, 2010), researchers internationally have reported that general (that is, non-specialist) nurses and nursing students are insufficiently prepared to care for people across the dementia trajectory (Hsu et al., 2005; Robinson and Cubit, 2007; Chang et al., 2009; Baillie et al., 2012a; Ryan et al., 2012) and toward the end-of-life (Gillan et al., 2013).

These findings call into question whether pre-registration nurse education equips general students for the complex realities of advanced dementia and even palliative care (Watts, 2013). Certainly Pulsford et al.'s (2006) survey of English and Welsh universities found that attention to dementia in pre-registration adult nursing curricula was

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'variable, and sometimes inadequate' (p. 8). Moreover, McCann et al. (2009) noted that general nurses' mental health preparation was of global concern. More recently the wisdom underpinning general nurses' limited exposure to mental health nursing in context has been questioned (Barrett and Jackson, 2013).

Findings from international research investigating general nursing students' dementia care experiences (Robinson and Cubit, 2007; Skaalvik et al., 2010; Baillie et al., 2012a, 2012b) offer illuminative insights, notably a theory-practice gap and insufficient mental health nursing exposure. Thus, whilst recognising the real challenges in terms of mental health placement availability and capacity, there is wisdom in Barrett and Jackson's (2013) concern. Indeed, the primacy of clinical learning cannot be understated in a practice discipline. As far as we are aware how students experience caring for people affected by advanced dementia has not been investigated. Understanding this experience is vital, for given the rising dementia prevalence many general nursing students will be involved in the care of these people. Moreover, students' unique insights may inform curriculum development and implementation and ultimately contribute to enhancing care quality and policy translation.

The Study

Aims

The study sought to obtain in-depth insight into and understand final year pre-registration nursing undergraduates' (adult field) experiences of caring for people affected by advanced dementia so as to inform curriculum development and implementation.

Method

This was an exploratory study. Given the aims and the dearth of literature, a descriptive qualitative design (Bryman, 1988) using in-depth interviews and thematic analysis was apposite. A convenience sample of undergraduates (adult field) nearing degree completion ($n = 68$) in a Welsh university was approached by the Programme Director, who presented a study synopsis and distributed information sheets. Completing undergraduates were selected for they had undertaken nine placements across South Wales and England (Table 1), were at a transitional point in their professional journey and potentially could offer valuable insights into the learning experience.

Eligibility criteria included experience of caring for people affected by advanced dementia during placements. To protect anonymity those interested in participating replied directly to the researchers. Fourteen students agreed to participate.

Interviews have a long history in qualitative research. They are used extensively to generate rich data that confers insight into experiences, thoughts, feelings and interpretations (Murphy et al., 1998). In-depth one-to-one interviews conducted by experienced researchers unknown to participants took place during early 2013 in private spaces at times of participants' choice. A conversational interview style (Burgess, 1988;

Davies, 1999) aided by a loose interview guide (Table 2) derived from the literature was adopted. The guide was adapted during data collection to incorporate emergent topics identified through preliminary data analysis. Interviews lasted between 25 and 50 min and were digitally recorded. Participants' non-verbal communication during interviews was noted.

The college's research ethics committee approved the study. Written informed consent was obtained. Participants were assured of their right to withdraw and protection of their anonymity. During transcription participants were allocated pseudonyms and all identifiers were removed. Following transcription and checking digital recordings were erased. Transcriptions were stored securely.

Thematic analysis informed by Green and Thorogood (2004) was used and commenced from the point of data collection. Digital recordings were listened to following each interview and again before transcription. Interviews were fully transcribed, noting pauses, intonation and any corresponding non-verbal communication derived from interview notes. Transcriptions were read whilst simultaneously listening to recordings. This enabled the identification of transcription errors which could impact on data interpretation.

Two researchers coded and analysed transcripts independently. Transcripts were repeatedly read and coded and patterns in participants' experiences sought. Identified patterns were assembled into broad categories and themes then discussed, scrutinised for similarity and duplication, refined and reduced until agreement was reached.

Trustworthiness was enhanced by drawing on measures to achieve credibility, transferability, dependability and conformability (Lincoln and Guba, 1985). Meticulous transcription and checking of interviews and rigorous data analysis by two researchers independently contributed to credibility. Detailed descriptions of experiences aided transferability whilst an audit trail of methodological decisions ensured dependability and confirmability.

Findings

Eleven students, all female with a mean age of 35 (range 22–45) years, participated as two were lost to follow-up and one did not attend for interview. Two reported personal experience of dementia within their families. Participants' experiences were predominantly in acute settings. As first year students in other universities two had dedicated mental health placements.

Three themes captured students' experiences of advanced dementia care as being characterised by tension and ambiguity: "they can be quite challenging", "a lot of dementia patients are seen as 'hazards'" and "it's not all about doing stuff".

They can be Quite Challenging

Participants consistently revealed practical, therapeutic and behavioural challenges associated with caring for people with advanced dementia. Ethical challenges were not expressly mentioned. Yet these threaded through participants' accounts, notably in relation to dignified care, consent and treatment decision-making, as exemplified in the following extract:

[the nursing sister] said something has to be done. So they spoke to another surgeon who advised that this patient wasn't going to be having a PEG [percutaneous endoscopic gastrostomy] and that she wanted to put them [the patient] on the end-of-life [pathway]. But then the problem was that over that weekend he started to get a bit better and he's been fitted for a PEG.

[Amanda]

The practical difficulties encountered whilst nursing highly dependent, cognitively impaired people who often had concurrent chronic illnesses, whilst simultaneously protecting and promoting their dignity were frequently described. Common examples related to personal

Table 1
Loose interview guide.

Interview guide
1. Thoughts about caring for those with advanced dementia and their families.
2. Experiences as a nursing student of caring for people with advanced dementia and their families.
3. Facilitators of and barriers to care in advanced dementia.
4. Experience of challenges of care in advanced dementia.
5. Any concerns about this area of care?
6. Ways in which students' nurse education prepared/enabled them to care for these people.
7. Anything else that they think I should know about.

Clarification will be sought as necessary to enrich the descriptions.

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