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Caring for patients with dementia: An exploration of the attitudes, perceptions and experiences of third year student nurses

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Abstract

Background: As the population ages, and people live longer, the prevalence of dementia is set to rise. This will increase pressure on health services, meaning nurses must be sufficiently equipped with the skills and knowledge needed to provide good quality care to this patient group. The objective was to explore how experience of caring for people with dementia influences the attitudes and perceptions of third year student nurses.

Methods: Third year student nurses enrolled onto a BSc Nursing (Adult) undergraduate pre-registration programme. Data were collected using focus group methodology and analysed using the 'Framework' method.

Results: The attitudes and perceptions of student nurses were mainly positive, but they reported observing stigmatising and negative attitudes from others, including healthcare professionals. Respondents reported a variety of experiences, both clinical and theoretical, where they had cared for people with dementia, but felt that at times these experiences were insufficient to develop their skills. The students felt their learning needs revolved around managing the complex behavioural and psychological symptoms in those suffering with dementia, which they felt, could best be accomplished through practice-based learning.

Conclusions: In this study, students reported perceived gaps in both theory and practice in their individual experience of nurse education on dementia. It highlighted the need for fundamental skills in dementia care to be taught early in their educational programme and the need for more practice-based experiences. This study provides some insight into the effects positive experiences of caring for those with dementia care can have on the attitudes of nursing students and the confidence they have in their skills and knowledge of delivering care to this client group.

INTRODUCTION

Dementia is an umbrella term used to describe a range of progressive and terminal neurological disorders [1]. Onset most commonly occurs over the age of 65 and leads to a disturbance of multiple higher cortical functions [2] causing symptomology such as memory loss, behavioural and mood changes, communication difficulties and problems with orientation [3], known as the complex behavioural and psychological symptoms of dementia, which can result in significant impairment to personal, social and occupational functioning [4]. The most prevalent type of dementia is Alzheimer's disease but there are over one hundred types with differing aetiologies [5].

Around 1 in 79 people (around 850,000) are currently living with dementia in the United Kingdom (UK) [6]. Worldwide this figure is estimated at around 47.5 million [7]. As a consequence of the ageing population [8, 9], the epidemiology of dementia is forecast to rise at a rate often described as the impending "*dementia epidemic*". It is important to pay attention to the impact this epidemic is likely to have on healthcare services and professionals. Individuals with dementia are thought to occupy over twenty five percent (25%) of general hospital beds and are more likely to be admitted to hospital with avoidable and preventable conditions such as dehydration and pressure sores [10, 11]. Admissions to hospital environments are characterised by longer stays, the increased likeliness of readmission and higher mortality rates than their counterparts [10].

Nurse education programmes in the UK are governed and validated by the Nursing and Midwifery Council (NMC). The NMC [12] states that all registered nurses play a key role in improving and maintaining the physical and mental health and wellbeing of people who come into their care, including patients with long-term conditions such as dementia.

BACKGROUND

A scoping review of the literature revealed little research on the attitudes, perceptions and experiences of student nurses in relation to caring for those with dementia. Most studies identified were conducted outside of the UK showing the issues raised within this research are of international significance.

Ecclestone et al. (2015), uncovered a lack of knowledge of dementia amongst student nurses, including limited understanding of the life course of dementia and a failing to recognise that its progression is terminal, and the physical decline associated with this [13]. Those with a basic knowledge of dementia attributed this to portrayals of the disease in the media or personal experiences of the disease, which may lead to unhelpful perceptions [14]. Kimzey et al. (2016) showed how the thought of caring for someone with dementia could lead to fear and apprehension among student nurses [14]. These anxieties are thought to be more prominent when patients exhibit the complex behavioural and psychological symptoms such as restlessness, agitation or aggression which students feel they do not have the skills to manage [15]. Baillie et al. (2015) reported feelings of unpreparedness among students for the reality of caring for patients with dementia which they found intense and extremely "mentally draining" [16]. More senior student nurses and those who have received pre-course exposure to caring for those with dementia, such as in a familial and/or vocational setting, tend to report more positive attitudes and perceptions towards patients coupled with an inherent confidence in caring [16, 17]. Those with no pre-course exposure to dementia found that opportunities to care of patients with dementia during their training improved their knowledge of dementia significantly [13, 14, 18]. This is only the case if the placements are enriched with learning experiences and student nurses feel that they are supported to develop their skills and knowledge [15, 18].

The exploration and analysis of the impact of positive experiences of caring for patients with dementia on the attitudes and perceptions of student nurses is an important step in informing the specific content (and its timing) of nursing curricula. It has the

potential to increase awareness that some students have had no previous contact with those suffering from dementia, which may affect their confidence and practical experiences [16]. It is vital that nurse curricula adequately prepare students to care for people with dementia, including how to implement person-centred principles and deal with challenging behaviours; knowledge students will heavily rely upon in clinical placement [15, 17].

METHODS

Design

The study falls into the interpretivist paradigm as the research has a sole focus on the subjective and unique views of the student nurses [19, 20]. The study was inspired by previous quantitative research exploring the attitudes and knowledge of dementia [21, 22]. The themes from these studies were used to inform the topic guide for the current study.

Settings and Participants

The sampling frame for the study was third year student nurses enrolled onto a BSc (Hons) Nursing (Adult) undergraduate pre-registration programme at a UK university (n = 191). Third year student nurses were identified as the target population as they are at a crucial part in their nurse training where they are on the cusp of gaining their registration which allows them to embark on a career where they will be faced with the predicted "dementia epidemic". Caring for patients with dementia will be a prominent aspect of their role and they will be required to practice independently and implement the skills and knowledge they have developed during their training.

A purposive sampling method [23] was adopted to ensure all participants were towards the end of their adult nursing degree. The students were invited to take part in the study on a voluntary basis and were asked to respond to an email invitation distributed to the cohort via the university's internal mailing system.

Data collection

Two focus groups were conducted (one with three participants and one with four). Each focus group explored their attitudes, perceptions and experiences of dementia. The focus groups were conducted with neutral and open questions to encourage discussion [24] (Figure 1).

Topic Guide for Focus Groups:

Discussion Points:

"I would like to explore the different attitudes towards and perceptions of dementia"

- Can you tell me how you think individuals with dementia are regarded in general?
- What do you feel are the anticipated responses to dementia in the hospital setting?
- How do you feel about working with individuals with dementia?
- What skills do you feel would be essential when caring for people who have dementia?
    - *Do you feel sufficiently equipped with these skills?*

"I would like to explore the different experiences we have had of caring for those with dementia"

- Can we talk about those experiences?
- Can we talk about the experiences you have had of caring for those with dementia as a student nurse?
- Can we talk about the experiences you have had of caring for those with dementia outside of your role as a student nurse?
- Can we talk about the educational experiences you have received regarding dementia?
- Do you feel your attitudes and perceptions of dementia have changed following these experiences?
- Do you wish to gain more experience of caring for those with dementia?

Figure 1: Topic Guide for Focus Groups

The researchers chose to conduct focus groups over individual interviews as it was a more flexible and economic method as a large amount of data can be collected from a sample in a relatively small time [25]. The chosen format and the selection of a homogenous sample was to try to ensure that the participants felt comfortable expressing their views as they were surrounded by a group of individuals with similar backgrounds and experiences [20]. The focus groups were moderated by the lead researcher who has a similar academic profile as the participants and has familiarity with their programme of study. This was thought to address the power imbalance of the focus group and remove any potential bias. The focus groups were audio recorded and transcribed verbatim.

One factor that may have contributed to the low response rate for the study was that the student nurses were in the final year of their studies and may not have had time at their disposal to take part in research due to the pressures of academic study and undertaking clinical placements. Those who volunteered may have had a specific interest in dementia or may have extensive experience of caring for this client group. All students that volunteered for the study were female, which may be a possible limitation of the study, but may account for gender differences within the nursing profession.

Data analysis

Data were analysed using the framework method, originally developed by Ritchie and Spencer (1994) [26]. This method is a form of content analysis, aiming to identify, analyse and report patterns in qualitative data [27]. This technique was chosen as its systematic nature provides a clear audit trail from raw data to final themes [28]. The data were analysed at group level, allowing for the identification of themes and common interactions that represented the whole sample population. The framework model incorporates five key steps to sort data into themes in preparation for interpretative analysis [28, 29]:

Transcription and familiarisation: The audio-recordings were transcribed as word-processed documents. Time was spent becoming familiar with the data and generating initial ideas and subjects of interest.

Indexing/Coding: The transcripts were annotated with initial thoughts and interpretation. A "code" was then assigned to describe what the researcher interpreted in the passage as important.

Developing a working analytical framework: Similar codes were then arranged into categories creating initial themes and subthemes. Each code was given a brief description. The analytical framework was comprised of the four themes detailed in the results section.

Charting data into the framework matrix: A matrix was constructed to chart the data. The data were summarised by category from each transcript, including reference to interesting or illustrative quotations.

Interpreting the data: The matrices were then used to write the results section of the paper.

Ethical approval

Ethical approval was obtained from the host institution. Data obtained from the study were treated confidentially and anonymously. Prior to commencing the study, an information sheet was developed and distributed to potential participants detailing the aim and objective of the study. The students were informed their participation was voluntary and those who expressed an interest were asked to sign a consent form prior to taking part.

RESULTS

Attitudes and perceptions of dementia

The students recognised that stigmatising attitudes towards people with dementia are still present in society and subsequently in healthcare settings. It was thought that individuals with dementia are "*segregated and avoided*" in society and people "*thought they were different*". It was perceived that disclosing a diagnosis of dementia does not evoke the same reaction and empathy as a diagnosis of other health conditions such as cancer. With conditions such as dementia, it was thought people "*step back*" and avoid confronting the situation, which the student

nurses felt leads to discrimination and social isolation.

> *"With dementia… they don't know how to handle it and they don't know how to deal with it so it's like I don't want to say the wrong thing, I don't want to upset you, I'll just step away."*

> *"As soon as it came out that my mum had dementia her friends just went by the way side and it ended up quite a lonely and difficult time for her because people weren't tolerant of her."*

In healthcare settings, patients with dementia can sometimes be labelled by healthcare professionals as "*challenging*" and "*hard work*" which the students felt created a single homogenous identity, which was thought, "*builds a stigma on the wards*". The term dementia was described as a "*label*" which often evokes an anticipated negative response from healthcare professionals in the hospital setting and patients are often "*judged*" even before they are received by the appropriate care team. Patients with dementia are often described as a "problem", "burden" or "*bother*" which the student nurses felt was mainly attributed to the management of the complex behavioural symptoms associated with the disease, such as "*wandering*".

Changes to attitudes and perceptions of dementia

The student nurses felt that an increase in publicity on dementia has led to a better understanding and awareness of the disease, which may contribute to a reduction in stigmatising attitudes. Generally, it was thought attitudes towards those with dementia are now more empathic as opposed to discriminatory. The student nurses felt that dementia is now thought to be "*more accepted as a disease whereas before I think it was much more of just something that happens when you get older*". Some students admitted that previously they did not take dementia as seriously as other health conditions, but this perception has changed since commencing their nurse education.

> *"I didn't actually take it as seriously. So, you look at cancer, heart failure, other diseases, straight away you hear those words and you're shocked whereas dementia… you're not as shocked by it… I think since being a nurse it made me realise that it is a very serious disease and that it should be taken a lot more seriously."*

Student nurses with pre-course exposure to dementia felt their attitudes had not changed since commencing the course but it was not discussed whether their training had a significant impact on their knowledge and skills in caring for this client group. Those with no pre-course exposure to dementia disclosed fearful attitudes towards the disease and were concerned about the complex behavioural symptoms of the disease.

> *"When I first got told I was going on an elderly complex needs ward, which was going to have loads of dementia patients, I was really scared and really worried and I really didn't want go on it."*

Fearful attitudes in some cases led the student nurses becoming avoidant of individuals with dementia. However, with hindsight, when the students were exposed to patients with dementia in clinical practice, they described how they enjoyed working with them. The students felt these experiences gave them the opportunity to develop a more rounded understanding of the disease, which in turn led to a change in their attitudes and perceptions. It was perceived by the students that without this exposure, their attitudes and perceptions would not have changed as significantly.

> *"Definitely [referring to attitude change] but only because I had a placement where I saw a lot of dementia patients, I had a lot of exposure. I don't think it would have changed as much if I hadn't had that placement."*

> *"If it wasn't for the fact I'd been exposed to, like precisely to that area, then it wouldn't have changed my opinion quite as much."*

Experiences of dementia

The student nurses recalled being exposed to dementia on at least one, if not all, clinical placements, which they found surprising as they expressed that they "*didn't know the expanse of dementia*", or "*didn't realise how prevalent it was in healthcare*"

and "*didn't realise how much as adult nurses we encounter it*". The students also found the types of settings where they were exposed to dementia surprising.

> *"I've been quite surprised how much you do see it [dementia] as well and you know sort of on all the different wards so you think you're on like a renal ward… but then they've also got [patients suffering from] dementia."*

The students felt some aspects of both the theoretical and practical components of their nurse education were insufficient.

> *"I think for this adult nursing course and for what we do get exposed to out in the hospital, we don't cover enough about dementia… I think given how many people are being recognised and diagnosed with dementia, that the course should probably accommodate a bit more about that."*

The student nurses felt theoretical components of their nurse education were heavily based on the pathophysiology of dementia, which they recognised as important, but commented, "*You don't see that, you see the behaviour that's coming as a result of it*". It was perceived that "*more emphasis needs to be put on the behaviours and the types of behaviours you might see, examples of it in practice, what people did to deal with it*". The students felt this would create a "*baseline*" of fundamental skills on how to manage certain behaviours and situations they may encounter in practice.

Despite this, the students felt "*there's only a certain amount of stuff you can learn in a classroom*" and that caring for those with dementia should primarily be practice-based learning or "*learning on the job*".

> *"I don't think you can really understand dementia unless you're working with the patients."*

> *"You can't teach somebody how to deal with someone with challenging behaviours who's got dementia."*

The student nurses felt a mandatory placement in a specialised dementia setting would be "*beneficial*" and would be a way to be "*fully exposed to an environment like that and thrown in the deep end*" to facilitate the development of new skills.

The students felt that exposure to dementia, both theoretically and practically, should occur earlier on in the course. Those with no pre-course exposure to dementia found that in some cases they were not exposed to patients with dementia in clinical practice until their third year, which they found "*daunting*". Some students had to supplement their learning with self-directed study to overcome this. The students felt that an early exposure to dementia theoretically would give them a more rounded understanding of the disease and would make them more prepared for working in the clinical environment.

Quality of care for patients with dementia

Skills and attributes perceived by the student nurses to be essential when caring for patients with dementia included patience, communication, compassion, empathy, listening and understanding. The student nurses found credibility in holistic and person-centred care approaches such as life story work and were aspired to follow this care pathway. They identified the "This is Me" booklets, developed by the Alzheimer's Society (2017) [30], as an invaluable resource to facilitate this. In relation to the patients within their care, the students stated "*it is really interesting to hear about their lives*" and "*you learn so much about them*". The student nurses recognised how person-centred care and life story work respect the uniqueness of a person with dementia and have a significant positive impact on their wellbeing and quality of care, which they found rewarding. Integrating physical and mental health care environments, creating a parity of esteem between services, was perceived by the students to be a solution to improving the quality of care and making their care and treatment more manageable for healthcare professionals.

> *"I think there's a clear line between mental health and general nursing and I think that line shouldn't be as prominent as it is."*

DISCUSSION

The student nurses' observations that stigmatising attitudes and perceptions of dementia exist in society and in healthcare settings reinforces finding from other studies. Stigma is thought to be caused by a lack of knowledge, understanding and unfamiliarity of dementia leading to a fear of the disease [31]. This can accentuate and deepen the distress experienced by someone with dementia, leading to a loss of independence, role and identity, coupled with feelings of low self-esteem, value and worth [32]. Link and Phelan (2006) reasoned that not all medical conditions are treated equally in terms of social significance [33]. This may help to explain why our participants felt that a diagnosis of health conditions such as cancer might elicit a more empathic response than disclosing a diagnosis of dementia. The results are broadly consistent with the concept of labelling theory. The complex behavioural and psychological symptoms associated with dementia are often labelled as "deviant" by healthcare professionals. Behaviours such as wandering, aggression and confused states, are seen to challenge social norms, or the "norms" of the in-patient environment [34]. A label of dementia is hastily given to an individual displaying these behaviours and those with dementia are subsequently isolated into one homogenous and undifferentiated group, leading to stigma [31, 35]. Reducing stigma is thought to be a sequential process; more understanding and awareness of the personal perspective could reduce negative connotations, lead to societal empathy, reduction in fear and stigma [31]. By producing positive images of people living well with dementia, a significant demystification of the condition and a recognition that not all people with dementia are incapable of a relatively "*normal*" functioning in society, can possibly occur [36].

Policy drivers have identified that the current provision of services for people with dementia are insufficient and improvements need to be made. Improving services for patients with dementia is thought not only to enhance the quality of care experienced, but also reduce unnecessary costs [37]. According to The Royal College of Nursing (2019) report, this can be achieved through the implementation of the SPACE principles [38]:

S – Staff who are skilled and have time to care

P – Partnership working with carers

A – Assessment and early identification

C – Care that is individualised

E – Environments that are dementia friendly

The concept that the student nurses found it "*surprising*" that as trainee practitioners in the adult field they were exposed to dementia on all clinical placements may reflect that the line between physical and mental health services continues to be prominent. On reflection, the students identified the establishment of a parity of esteem between physical and mental health services would also strive to improve the quality of care for patients with dementia, a notion supported by the Government in their "No Health Without Mental Health" [39] strategy. A 'parity approach' provides a more holistic response to a person in need of care, support and treatment, with their physical and mental needs being treated equally [40]. This relationship is poor at present, such that people with mental ill health have poorer physical health outcomes and the fact that mental illness is likely to affect a patient's compliance with treatment, but also that poor physical health is linked with poor mental health [40, 41]. These issues are especially true for people with dementia due to increased incidence of the disease and the implications of progressive cognitive decline. One attempt at developing a parity of esteem is the commissioning of Mental Health Liaison teams by the Department of Health [42], supported by NICE guidelines [43] to provide consultation, training and assessment for those with suspected or known dementia in acute services, to support both patients and nursing staff. Standards produced by the Royal College of Psychiatrists (2017) [44] stated that all staff working with the liaison psychiatry model should receive training consistent with their role which includes working with old people, including the detection and management of dementia and delirium. They advise this training is planned and delivered in collaboration with key partners (for example, acute care nurse and liaison nurse providing joint training to the rest of the liaison team) [44].

The study was consistent with other literature [17, 18], in that participants felt their learning needs lie in managing the complex behavioural and psychological symptomology of dementia, something that they felt their course did not accommodate for sufficiently in comparison to their exposure to the disease on clinical placements. Interestingly, the students felt that these needs could be met through "*practice-based learning*". In previous research, it has been found that placements of this kind have been beneficial for student nurses and provided them with the opportunity to develop new insights into care provision and enhanced understandings of dementia, while also developing their skills in communication, therapeutic practices and person-centred care approaches [45, 46].

Given the influence experience of caring for those with dementia can have on the attitudes and perceptions of nursing students, this provides another reason for exposure to dementia both theoretically and practically to occur earlier in the course, preferably during the first year of study. Introducing this late can result in student nurses being left feeling fearful of dementia and finding the anticipation of working in an environment with dementia patients "*daunting*". Nurse educators should accommodate for the fact that some students have had no previous contact with individuals with dementia, which may affect their perceived competence and willingness to engage with practice placement experiences [16]. The recently published NMC standards [47] for pre-registration nurse education in the UK, provide educators with the opportunity to develop programmes which allow students to develop the knowledge and essential skills necessary to care for patients with dementia. It is important to note that the language used by the students in this study does not always appear to be person centred. For example, the students referred to "dementia patients" or to clinical teams having "a lot of dementia on the ward". The use of more appropriate and person-centred terminology may need to be addressed in nurse education.

Limitations of the study

The main limitation of the study relates to the small sample size (seven participants) and qualitative approach to data collection, which may limit the generalizability of the findings to other areas. In addition, all participants in the study were female which limits the representation of male nursing students and their attitudes, perceptions and experiences of caring for those with dementia.

CONCLUSIONS

Research into the impact of experience of caring for patients with dementia on the attitudes and perceptions of nursing students is limited. Although based on only the views of seven female students, this study does provide some insight into the effects positive experiences in dementia care can have on the attitudes of nursing students towards those suffering from dementia and the confidence they have in their skills and knowledge of caring for this client group. It is difficult to decipher whether the changes in attitudes and perceptions are solely impacted by the nursing students' experiences during their training or from other external influences such as pre-course exposure to the disease. The study reinforces the need for participation in a supportive placement specialised in the care of those with dementia to consolidate nursing student's theoretical learning and develop their confidence and competence in caring for those with dementia. As adult nursing students are being exposed to dementia in all clinical placements, theoretical components of nurse education should be delivered as early in the course as possible to ensure student nurses are prepared with the fundamental dementia awareness before going out onto placement. This helps to accommodate student nurses with no pre-course exposure to dementia.

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