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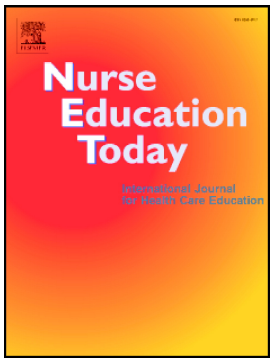

Nursing students' cultural beliefs and understanding of dementia: A phenomenological study across three continents

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Nursing students' cultural beliefs and understanding of dementia: A phenomenological study across three continents

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Abstract

Background: Migrant nurses have reported difficulties adapting to their new culture and providing culturally sensitive care for people with dementia. However, to date no studies have explored the impact of student nurse's cultural heritage on their beliefs and understanding of dementia.

Objectives: To explore the cultural beliefs of dementia of student nurses studying in England, Slovenia, Philippines and New Zealand.

Design: An explorative hermeneutic phenomenology design.

Settings: Higher Education Institutes delivering undergraduate nursing education in England (University of Greenwich and University of Essex), Slovenia (Angela Boškin Faculty of Health Care), New Zealand (University of Auckland), and the Philippines (University of Silliman).

Participants: Student nurses studying nursing in England (n=81), Slovenia (n=41), Philippines (n=53) and New Zealand (n=6). Participants from England and New Zealand were from diverse cultural backgrounds. Student nurses at the beginning of their studies (n=100) and towards the end of their studies (n=81) participated.

Methods: Completion of focus groups (n=23), in England (n=10), Slovenia (n=6), Philippines (n=6), and New Zealand (n=1). All focus groups were audio recorded and transcribed verbatim. Data was analysed by applying an inductive theoretical approach of the Framework Method, which supports the generation of themes through open unhindered coding, pinpointing, examining, and recording patterns within the data.

Results: Two major themes were identified in the data: familial piety and dementia discourse. Familial piety emerged from the importance of family and caring for family members with dementia, subthemes included: 'my granddad': familial experience, and 'better to be with her': familial home. Dementia discourse emerged from the terminology student nurses applied, such as: 'preconceptions and misconceptions' of aggression, and 'considered crazy' stigma of dementia due to a lack of awareness.

Conclusions: The cultural heritage of student nurses impacted on their beliefs of dementia; however their understanding of the needs, care and support of a person with dementia changed and developed through clinical experience and education.

Keywords

INTRODUCTION

Globally 50 million people are estimated to be living with dementia, which is predicted to increase to 75.6 million in 2030 and 135.5 million in 2050 (World Health Organisation [WHO], 2015; 2017). Dementia is a syndrome which disrupts normal brain functioning, altering thinking, behaviour and the ability to perform activities of daily living (WHO, 2017). People with dementia have complex needs and require support from health and social care professionals, and family members.

The impact of dementia on a person is unique and a person-centred approach to their health and social care needs is essential (Vernooij-Dassen and Moniz-Cook, 2016). Person-centred care respects an individual's personhood, which is bestowed on them by others within the context of social relationships (Kitwood, 1997). Personhood defines the elements that make a person an individual and this does not diminish with a diagnosis of dementia (Kitwood, 1997). An element of personhood is culture, as culture influences an individual's norms, values, beliefs and customs (Dilworth-Anderson and Gibson, 2002).

Culture may also influence beliefs regarding dementia, which may range from dementia as a normal part of aging, to the belief that dementia is retribution for previous sins (Flaskerud, 2009). Therefore, the provision of person-centred care requires health and social care professionals to understand the cultural beliefs and values of the person with dementia and their family members. This is particularly important due to world migration and an aging population (Moyce et al. 2015; Beard and Bloom, 2015).

Health and social care professionals, especially registered nurses are also a culturally diverse workforce. The nursing profession has become globally mobile due to nurse shortages and recruitment strategies (Lloyd and Ferguson, 2017; Aluttis et al.2014). Migrant nurses have identified challenges of adapting to a new culture, which included: difficulties working with colleagues, people with dementia and their family members who held significantly different cultural beliefs (Emilsson, 2011; Moyce et al. 2015). However, culture is not a static entity and the process of acculturation may impact on migrant nurses' cultural beliefs to prevent further cognitive dissonance (Yong and Manthorpe, 2016).

A recent systematic review has identified four elements of acculturation of nurses and healthcare professionals working in aged and dementia care (Brooke et al. 2018). The four elements include: the influence of their cultural perceptions of dementia illness and older people, secondly their cultural perceptions on the appropriateness of service use for people with dementia, thirdly acculturation into the workforce and lastly support with cross- cultural

communication. Brooke et al. (2018) concluded the need to support migrant nurses and healthcare professionals to adapt to the host country, workforce and language with a focus on local dialects to enable them to provide person-centred care for people with dementia.

The exploration of acculturation has focused on registered nurses and unqualified care providers (Buscemi, 2011). Currently there has been no exploration of acculturation of students completing an undergraduate nursing degree. Student nurses are recruited from culturally diverse populations (Walsh and Shutes, 2013; Nichols et al. 2015) although educational initiatives have focused on student nurses' knowledge and attitudes of dementia rather than understanding their cultural beliefs and values (Kimzey et al. 2016). Undergraduate nursing education may be an optimal time to support acculturation or enable student nurses to understand the impact of their own cultural beliefs regarding dementia. This process would support student nurses to provide culturally sensitive person-centred care for people with dementia and their families.

The aim of this study is to explore the cultural beliefs and values of undergraduate student nurses regarding dementia at the beginning and towards the end of their programme from England, Slovenia, Philippines and New Zealand.

METHOD

The consolidated criteria for reporting qualitative research (CORECQ) studies (Tong et al. 2007) was adhered to in reporting the methods of this study.

An explorative hermeneutic phenomenology design, which allowed for descriptive data of student nurses cultural beliefs and values to be collected via focus groups and analysed through interpretation (Smith et al. 2009). The process of interpretation is dynamic and iterative, necessitating some interplay between the parts and the whole (Smith et al. 2009). Focus groups provided a natural environment for participants with a shared culture (Kitzinger 1994); similar to the clinical or classroom setting student nurses influenced and were influenced by their peers (Krueger and Casey, 2009).

Reflexivity

All the authors of this paper are experienced healthcare professionals from fields of nursing and paramedic science who have varied research, education and clinical backgrounds; and experience in caring and supporting people with dementia across primary, secondary and tertiary care sectors.

Participants

Student nurses were purposively recruited from two Higher Education Institutions (HEI) in England (n=81), one in Slovenia (n=41), Philippines (n=53) and New Zealand (n=6). Student nurses at the beginning or towards the end of their studies were invited to participate. 181 student nurses participated in 23 focus groups. Student nurses were asked to self-define their own cultural heritage at the beginning of each focus group (refer to Table 1). Focus groups completed in England and New Zealand were culturally diverse compared to those completed in Slovenia and the Philippines.

Insert Table 1 here

Procedure

Ethical approval was gained from each participating HEI Research Ethics Committee. All student nurses were informed of the voluntary nature of participation in the study and provided a participant information sheet at the end of a lecture, and then provided opportunity to ask questions prior to providing written informed consent. Confidentiality of student's identity and information was assured, unless any information disclosed raised concern for the safety of patients or students.

A schedule with questions and prompts was designed to ensure rigour and transparency of data collection (Noble & Smith 2015). The schedule commenced with the opening question of "what is dementia?" which was followed more specific questions of: "What are your beliefs regarding dementia?" "Where do your beliefs about dementia come from?"

All focus groups were completed in classrooms within each HEI. The majority of focus groups were completed by the first author, with support from XX, and in Slovenia XX. Focus groups in Slovenia were conducted and analysed in Slovenian, prior to translating the data into English. This process was completed to ensure the meaning of student nurses beliefs and experiences were not lost in translation. Data saturation was operationalized as complete when no new additional information was emerging (Guest et al., 2006). Field notes were completed during each focus group. Data were collected from November 2016 to August 2017, audio recorded and transcribed verbatim. Focus groups lasted between 30-90 minutes (mean length 45 minutes).

Data analysis

Data were analysed by applying the Framework Method as described by Ritchie and Spencer (1994). The Framework Method is an inductive approach that supports the

generation of themes from the data through open unhindered coding, pinpointing, examining, and recording patterns within the data (Gale et al., 2013).

Four authors (XX, XX, XX, XX) worked independently on data from the University of Essex to identify codes and themes, following this process a series of meetings were held and a tentative framework developed (refer to Table 2). The framework was applied and re-examined and re-defined to incorporate data from the remaining HEI's until the essence of the data was achieved, leading to the construction of meaning across and within the identified themes. Multiple meetings occurred to discuss the development of the themes and any discrepancies, an audit trail completed, and the process continued until agreement was achieved. This formed a transparent, iterative and rigorous process (Noble and Smith, 2015).

RESULTS

Two major themes were identified in the data: familial piety and dementia discourse (refer to Table 2 for an overview of subthemes). All student nurses discussed beliefs of dementia as a normal part of aging prior to family experiences or commencing their studies, and the importance of patience when communicating and caring for a person with dementia.

Table 2: Themes and subthemes identified in each focus group
Insert Table 2 here

Familial Piety

The importance of family and caring for family members with dementia was discussed throughout all of the focus groups. A number of subthemes were identified: 'my granddad': familial experience, and 'better to be with her': familial home.

'My granddad': familial experience

Familial experiences were prominent and important for student nurses, as they discussed both the care their family members with dementia received at home and within institutions. Familial rather than clinical experiences helped student nurses to understand dementia from a different perspective, which included how a person can live with dementia and the trajectory of the disease.

> *"My granddad had dementia and that made the difference because I was able to understand what is like living with dementia."* UGE, FG1, P1 (Black British, Caribbean)

However, familial experiences also supported student nurses to understand some of the challenges of caring for a family member with dementia and the emotional stress this can place on a family.

> *"For me it was my aunt's husband, he had a stroke and he got dementia, the most severe kind, and actually only then did I realize that emotions take over reason."* ABFHC, FG1, PA (Slovenian)

Only student nurses from the Philippines did not discuss familial or clinical experiences of dementia, as many students had not come into contact with a person with dementia.

> *"I have only heard about dementia like through our nursing research or through books, so also I haven't actually met one."* USP, P2 (Filipino)

'Better to be with her': familial home

Student nurses studying in the Philippines were proud their culture was family orientated and included respect for their elders. These student nurses deeply believed in reciprocal care and a family devoted to each other. This approach reinforced the view that placing a family member in a nursing home was not appropriate.

> *"For us given our culture and family orientation we have high respect for our grandparents, especially our grandparents, we sometimes call our grandparents mama. We prefer to have them at home and just accept the fact that, well he or she might not get better."* USP, FG2, P2 (Filipino)

> *"So, growing up I see my mother taking care of relatives, so I would never send my parents to a nursing home. For me it is because they have devoted their lives to me to take care of me, so I would also do the same for them."* USP, FG1, P2 (Filipino)

The difference between cultural beliefs of providing care at home was expressed by a student nurse from England who found the English members of her family 'stepped away' from providing care and support, unlike her Guyanese family members.

> *"My Mum's family are Guyanese; they are more able to provide a lot more support (to a family member with dementia) because they live in a big house together."* UEE, FG3, P5 (Guyanese and English)

Whilst student nurses studying in England, Slovenia and New Zealand who explored familial burden of caring for a family member with dementia. These views underlined the belief that caring for a family member prevented a person from 'living their life'.

> *"I think that is one of the reasons, people prefer to move them into nursing homes to relieve the burden, so that life can go on."* ABFHC, FG4, PK (Slovenian)

> *"I think from more like the New Zealand if someone has a dementia that would definitely be like a reason to put them into a home."* UANZ, FG1, P1 (White New Zealand)

Dementia Discourse

Student nurses discussed dementia using terminology such as: 'preconceptions and misconceptions' of aggression, and 'considered crazy' stigma due to a lack of awareness.

'Preconceptions and misconceptions' of aggression

Cultural preconceptions of dementia were identified by student nurses prior to commencing there studies, especially relating to aggressive behaviour. However, during their studies and clinical experience they realised these preconceptions were in fact misconceptions.

> *"I did some volunteering for a few months for the Alzheimer's society and through that experience I really got to know these people and how they are at home… I didn't witness any aggression."* UANZ, FG1, P5 (White New Zealand)

> *"I used to have the misconception, that people with dementia were aggressive, agitated all the time, and this is not the case. The majority of the time, if you can speak with them to look after their needs, they are very rarely agitated."* UEE, FG3, P1 (White British)

Student nurses from the Philippines who had no experience of people with dementia continued to hold the belief that they would be aggressive.

> *"Some people would go to the extent of locking the dementia patient in their house because they can't control them because they are aggressive, he or she is aggressive." USP, FG5, P1 (Filipino)*

'Considered crazy': Stigma due to a lack of awareness

Student nurses from the Philippines and those from Africa studying in England emphasised the stigma and shame of having a family member with dementia, which impacted on family members seeking a diagnosis and outside support.

> *"My Grandfather, back home, it was the stigma, they were ashamed, they kept him inside, they kept him away, he came to my Father's house so people would not know that something is wrong with him."* UEE, FG5, P6 (Black African)

> *"The culture of the Filipino people is that sometimes they are ashamed that they have a family member with this (dementia), so they would not dare to consult with professionals."* USP, FG5, P1 (Filipino)

Student nurses from the Philippines and Slovenia believed stigma and shame was connected to a lack of awareness of dementia, and improvement in awareness would reduce the stigma and shame.

> *"I'd say there's a lack of awareness… Everyone has heard of it, but they don't know what actually happens to people, it's only during clinical training that you see what's actually going on."* ABFHC, FG6, PN (Slovenian)

> *"For me dementia is not well known here in the Philippines and Filipinos take care of their older family members at home, but they don't understand what dementia is, so for me there is a lack of awareness of dementia that causes stigma in the Philippines."* USP, FG5, P6 (Filipino)

However, student nurses studying in England and New Zealand believed national campaigns to raise dementia awareness had been effective, but this had not necessarily led to improved understanding of dementia or support for family members caring for someone with dementia.

> *"There is a lot of awareness now, a lot of families don't understand dementia and I think that maybe if they had somewhere to go to actually talk about it and find out, it would help them cope with the patient's illness."* UGE, FG2, P7 (White British)

> *"In New Zealand the Alzheimer's association are looking to raise awareness about Alzheimer's and the stereotypical views that people may have and upon that and build on peoples understands."* UANZ, FG1, P4 (South Korean)

DISCUSSION

This study provides an insight into the similarities and differences of cultural beliefs of student nurses' regarding dementia. Student nurses from England, Slovenia and New Zealand were influenced by their familial and clinical experience, which provided them with insight and knowledge into dementia. Student nurses from the Philippines did not have either of these experiences but expressed the need to care for their family at home. All student nurses believed dementia was a natural part of the aging process prior to commencing their studies. Aggression by a person with dementia was discussed, but student nurses believed this to be an act of frustration due to communication difficulties or poor care provided by family members. Student nurses in the Philippines and Slovenia believed the stigma and shame of having a family member with dementia was due to a lack of dementia awareness in their countries. However, student nurses studying in England and New Zealand believed dementia awareness alone was not sufficient as this did not support people with dementia and their families.

Familial Piety

Familial experiences of dementia were described by many student nurses, and the importance of these experiences in supporting them to understand dementia, and the impact on the person with dementia and their family. However, there remains a need to support student nurses who do not have familial experiences of dementia. A number of educational initiatives have commenced, such as the Buddy Programme (Morhardt et al. 2013) and the Time for Dementia Programme (Banerjee et al. 2017). Both programmes engage people with dementia and their families to mentor and share their experiences with students. These structured longitudinal approaches alongside education in undergraduate programmes aim to improve student's attitudes and knowledge of dementia. These programmes appear to address the familial experiences described by student nurses in this study that enabled them to care for people with dementia and their family members. There remains the need for similar programmes to be provided in all undergraduate nursing programmes.

Student nurses studying in the Philippines did not discuss familial experiences of dementia, but the importance of caring for their older family members at home. The student nurse's cultural beliefs remained during their undergraduate education, which may have been influenced by a lack of residential aged care in the Philippines, as this is a relatively new concept with very few facilities available (Department of Health, 2012). Another explanation for the student nurse's continuing cultural beliefs may have been their poor knowledge of

dementia; this has been recognised in a recent study which included nurses and other healthcare professions working in the Philippines (Dela Vega et al. 2018). Therefore, there remains the need to address dementia in undergraduate nursing education in the Philippines from both a theoretical and practical perspective to empower future nurses to support families to care for relatives with dementia.

On the other hand student nurses from England and New Zealand were more likely to discuss a diagnosis of dementia as a reason for admission to an aged care residential facility, due to the burden of caring for a person with dementia, which is comparative with research exploring family members experience of caring for a person with dementia (Cronfalk et al. 2017). In Western societies the relocation of a person with dementia to a residential aged care is more common (Toot et al. 2017). However this is not without consequences as family members have discussed the need to keep monitoring and supporting the needs of their loved ones and maintained a level of responsibility for their care and support (Cronfalk et al. 2017). Family members may feel an element of relief however feelings of loss, guilt and shame are also common, prior to family members adapting to the new situation and re-establishing relationships with their loved one without being their carer (Graneheim et al. 2014). The implications of relocating a family member into an aged care residential facility need to be understood by nurses to enable them to support families through this transition period.

Dementia Discourse

Many of the student nurses discussed that a person with dementia may become aggressive. Physical and verbal aggression of residents with dementia in aged care facilities has been identified as one element which causes stress for nursing staff (Hazelhof et al. 2016). However, physical and verbal aggression by people with dementia can be significantly reduced by the implementation of nonpharmacological interventions (Brodaty and Arasaratnam, 2012; Fisher and Buchanan, 2018). A number of nonpharmacological interventions have been identified, all of which need to be developed by nurses to support person-centred care, and include: psychosocial and educational, physical activity, and sensorial therapies (Cabrera et al. 2015). An introduction of nonpharmacological interventions will enable student nurses to understand how behaviours that might appear to challenge can be addressed through appropriate communication and interventions.

Student nurses studying in the Philippines and Slovenia identified the impact of stigma regarding dementia, and recognised a link between stigma and dementia awareness. However, student nurses from England and New Zealand believed dementia awareness was

not enough to chagne stigma. In Western countries stigma has been identified in the general public, with a view that people with dementia would have less social support and interactions and face institutional discrimination, and those who believed dementia was a mental illness held stronger beliefs (Nielsen and Waldemar, 2016; Stites et al. 2018). There remains a need to develop public health messages that address these beliefs, in the meantime student nurses need to understand these beliefs by the general public, which may impact negatively on the care and support of the person with dementia.

Limitations

A limitation of this study is the specific cultures represented by the participants, and therefore the results cannot be generalised beyond these cultures. Another limitation was the invitation process, as all students in identified cohorts were invited, which may have resulted in participants with an interest in dementia volunteering providing some bias in their experience and knowledge.

RECOMMENDATIONS

A number of recommendations for undergraduate nursing education have emerged: the need for programmes that engage people with dementia and their family members to mentor and share their experiences with student nurses; the inclusion of theoretical and practical perspectives of dementia for student nurses studying in the Philippines; the need to understand the ongoing responsibility of family members following the relocating a relative with dementia to an aged care facility; an introduction of nonpharmacological interventions for people with dementia, and the impact on stigma on the care and support of people with dementia and their family members.

CONCLUSION

A phenomenological framework provided detailed and in-depth accounts of student nurses' cultural beliefs and understanding of dementia. The two themes of familial piety and dementia discourse have clear implications for the development of undergraduate nursing education to ensure all student nurses are supported to develop an in-depth knowledge and understanding of dementia to empower them to care for and support people with dementia and their families.

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Table 1: Overview of focus groups with student nurses

Institution Country	Focus group	Year of study	Number of participants	Self-defined cultural herita
University of Greenwich England	1	3	11	Black British African (n=9), Black British Caribbean (n=1), Eas
	2	1	10	White English (n=7), Black African (n=1), Black British (n=1),
	3	1	7	White British (n=2), Muslim British (n=1), Asian (n=1), Indian S Caribbean (n=1)
	4	1	7	Black African (n=3), Black African and Scottish (n=1), White B Indian British (n=1), White British (n=1)
	5	1	8	Afghanistan (n=1), Pakistan (n=1), Irish (n=1), White British (n= (n=1), Ghanaian (n=1), Pakistan (n=1)
University of Essex England	1	3	9	White British (n=7), Asian (n=1), Filipino (n=1)
	2	3	7	White British (n=6), White British and Italian (n=1)
	3	1	8	White British (n=6), Guyanese and White British (n=1), Polish (
	4	1	7	White British (n=4), White British and Bosnian (n=1), American
	5	1	7	Black African (n=4), White British (n=2), Nigerian (n=1)
University of Silliman Philippines	1	2	8	Filipino (n=8)
	2	2	9	Filipino (n=9)
	3	2	9	Filipino (n=9)
	4	4	10	Filipino (n=9), Rwanda, in East Africa (n=1)
	5	4	9	Filipino (n=9)
	6	4	8	Filipino (n=7), Asian, born in India (n=1)
Angela Boškin Faculty of Health Care Slovenia	1	1	6	Slovenian (n=6)
	2	1	9	Slovenian (n=9)
	3	1	7	Slovenian (n=7)
	4	3	7	Slovenian (n=7)
	5	3	6	Slovenian (n=6)
	6	3	6	Slovenian (n=6)
University of Auckland New Zealand	1	3	6	New Zealand Europeans (n=2), Maori (n=1), South Korean (n=1 Kong (n=1)

Total number of focus groups: 23
Total number of participants: 181

Table 2: Overview of the themes by focus group

		Familial Piety		Dementia Discourse	
Higher Education Institution	Focus Groups	Experience	Familial homes	Aggression	Stigma due to a lack of awareness
University of Greenwich England	1	X	X	X	X
	2	X	X		X
	3	X	X	X	X
	4	X	X	X	X
	5	X		X	X
University of Essex England	1	X	X	X	X
	2	X	X	X	X
	3	X		X	
	4	X	X		X
	5	X	X		
University of Silliman Philippines	1	X	X		X
	2	X	X		X
	3	X	X		X
	4	X	X		X
	5	X	X	X	X
	6	X	X	X	X
Angela Boškin Faculty of Health Care Slovenia	1	X	X	X	
	2	X	X	X	X
	3	X			X
	4	X	X		X
	5	X	X	X	X
	6	X		X	X
University of Auckland New Zealand	1	X	X	X	X