A qualitative study exploring nurses' experiences of supporting South Asian people with dementia and their family carers

Abstract

Aims: To explore nurses' experiences of providing support to South Asian people with dementia and their family carers and to identify barriers and enablers of good transcultural care.

Design: A qualitative, phenomenological design was used.

Methods: Fifteen registered community and in-patient nurses were recruited via one NHS Mental Health Foundation Trust. Nurses were from diverse backgrounds, (Black, Ghanaian, Irish, Mauritian and White), 13 female and two male, and had been qualified from between two and 49 years. One-to-one semi-structured interviews were conducted between July-October 2019.

Results: A thematic analysis identified three themes. '*Communication challenges'* highlighted the impact of language barriers and consequences of misunderstandings due to a dissonance in cultural values between nurses and interpreters. *'The bi-directional impact of culture*' identified the two-way dynamics of transcultural work, the process of countering mutual stigma, and revealed an original perspective on how 'cultural desire' grows through practice experiences rather than being a prior motivation for learning. *'Learning experiences'* showed that most learning was informal, experiential and prolonged, with nurses feeling they had unmet learning needs.

Conclusion: Nurses have minimal training opportunities and are under-supported in their transcultural work, potentially perpetuating the disadvantages that South Asian people with dementia and their families face in relation to healthcare. Enhanced cultural understanding of self and others and application of specific communication strategies could support nurses, together with interpreters, to build rapport and effective working relationships with each other and service-users.

Impact: Transcultural nursing is a key competency, but nurses experience difficulties with providing care which is recognised as effective by South Asian family carers. The development of more acceptable and effective services requires improved mutual cultural understanding between nurses, interpreters and families, underpinned by joint brief training interventions, leading to more effective professional communication, better care outcomes and improved satisfaction with services.

Key words: Qualitative, thematic analysis, nurses, experiences, transcultural, carer support, interpreters, communication, training

MAIN TEXT

1. INTRODUCTION

Caring for a relative living with dementia is stressful (Alzheimer's Disease International, (ADI) 2022). Family carers may not feel prepared and require support and guidance from nurses and the multi-disciplinary team as they learn how to find and interact with services and develop the skills and understanding that enable them to continue in the role (Hovland & Mallett, 2021). Nurses working in diverse communities globally require transcultural nursing skills, as ageing migrants are at higher risk of health problems, including dementia (van den Heuvel et al., 2020). Challenges for nurses include language barriers and mutual misunderstandings of health-related norms and behaviours (Ilgaz, 2022). Nurses do not always have access to effective learning opportunities that would support their professional development in relation to transcultural care, meaning they may struggle with this aspect of their role (Fadaeinia et al., 2022). Understanding their experiences could enable organisations to design improved processes, education and support for nurses working transculturally.

2. Background

There are more than 55 million people living with dementia globally (ADI 2022), many of whom are older people who moved to a new homeland for economic, social, political, and environmental reasons. The South Asian (SA) diaspora extends globally with large SA populations in Canada, the USA, the Gulf states, Africa, Australia, and elsewhere (Clini & Valančiūnas, 2021). Most SA (Indian, Pakistani and Bangladeshi) migrants in the United Kingdom (UK) arrived in the second half of the last century, when labour shortages led to demand for workers from former colonies (Sharma, 2012). The first generations of migrants are now ageing and prone to age-related conditions, including dementia (Giebel et al., 2017). In the UK, 3% of people living with dementia are from minority ethnic groups (Alzheimer's Society 2022), a proportion that is expected to grow (Ogliari et al., 2020).

Despite the positive outcomes anticipated and often achieved through migration, the process itself is immensely stressful, as is adapting to a new environment and way of life; many migrants experience poverty, discrimination, and difficulty in meeting basic needs, including those related to health (Mak et al., 2021). The precise mix of genetic, cultural, and socioeconomic factors behind ethnic inequalities in health is contested but SA people have increased susceptibility to diabetes and cardiovascular disease (Sidhu et al., 2016) which in turn are associated with higher risk of dementia (van den Heuvel et al., 2020). SA people in Western countries are less likely to receive a diagnosis (Ogliari et al., 2020), come to services later (van den Heuvel et al., 2020) and use services less than other groups (Parveen et al., 2016). Giebel et al., (2017) identified barriers to services at the levels of individual patient, carers and community, health professionals and service structures and type.

Explanatory models guide pathways to care (Helman, 1995). Giebel et al (2014) found SA elders who did not consult their GP about memory problems took an approach of accepting fate, or God's will, while Blakemore et al (2020) found it was common for SA people to believe dementia was part of normal ageing and that care is best done by family. These beliefs are incongruent with seeking help. Difficulties with a second language may lead to poor health literacy when up-to-date information is not accessible (Ilgaz, 2022), so culturally embedded beliefs, including that dementia is a form of madness (and therefore stigmatised) may persist. However, identification of barriers as 'cultural' or linguistic may sometimes misleadingly locate causative factors within communities rather than systems. Parveen et al (2017) found a broad range of minority ethnic service users reported their family doctors were reluctant to explore health problems with older people or refer them on to specialised services. Brijnath et al (2021) concluded that the 'family crisis' narrative is inaccurate, and instead families experienced a difficult process of making sense of the situation and navigating complex routes to services.

Once accessed, service responses have been experienced as inadequate. Blakemore et al (2018) identified that assessment tools are ineffective and community engagement has been minimal. Some services have been experienced as excluding, undermining and harmful, leading to 'profound distrust' and families avoiding or postponing asking for help (van den Heuvel et al., 2020). People with dementia and family members also reported fears of being 'diminished' by services that they experienced as lacking empathy and understanding (Baghirathan et al., 2020). Therefore, SA people tend to arrive later at services (van den Heuvel et al., 2020).

Delayed access to care limits timely support. For example, it may be too late for advance decision making, limiting the autonomy of the person with dementia, and leaving families unsure of their relatives wishes as dementia progresses. Early access to support could promote improved communication and understanding of behaviour, reducing isolation and stigma, and improve carers' experiences too (Woods et al., 2018). Anti-dementia medication could be prescribed at a point it would be most effective (Jenkins et al., 2016). Safety with medication management strategies and other responses to potential problems, such as getting lost, sleep pattern disruption, communication problems, managing personal care, behaviour changes and environmental adjustments, together with carer support, would all become available with earlier recognition and specialised nursing interventions (Jenkins et al., 2016).

It seems that a combination of factors perpetuate reduced access and lower quality care for minority groups in the UK. Similar dynamics have been identified in USA (Quinones et al., 2020), Australia (Brijnath et al., 2021), across Europe (Alzheimer Europe, 2017), Nordic countries (Nielsen et al., 2015), and Iran (Amiri & Heydari, 2017). Acceptable, responsive culturally congruent services are required to address this gap in provision. There is considerable research exploring the experiences of family carers from SSA backgrounds, but little research exploring the experiences and perspectives of dementia care nurses working transculturally in this role. Insight into their experiences could increase understanding of barriers and enablers of effective interventions and help to identify training needs to support nurses caring for people with dementia from South Asian backgrounds.

3. THE STUDY

Aims

The aims of this study were to understand nurses' experiences of providing support to SA people with dementia and their families, and to identify barriers and enablers of good transcultural care in in-patient and community settings.

4. Methods/Methodology

2.2 Design

A qualitative phenomenological design was used. Semi-structured interviews were conducted.

Theoretical framework

A qualitative paradigm was used to guide the design and analysis of this study. The use of qualitative research was not to generate new theory, rather it was to understand lived experiences using a phenomenological approach (Husserl, 1997). Phenomenology is concerned with the study of experience from the perspective of the individual. It provides a mechanism for understanding subjective experiences, gaining insights into motivations and actions, and avoiding assumptions. The authors did not use a specific theoretical framework to guide the analysis (beyond a qualitative phenomenological approach); instead we took an inductive approach to data analysis, and used a range of cultural, health and behavioural theories to understand our findings.

Study setting and recruitment

The study was conducted in four clinical centres (one inpatient, three community) in a large multi-cultural city in the UK. The different settings enabled access to a range of different nurses' experiences. Purposive sampling was used. Participants were recruited through an invitation sent via all matrons managing teams of specialist nurses caring for older people with dementia in a large mental health Trust. The nurses provided mental health care, carer support and advice on physical health issues.

Inclusion and exclusion criteria

The inclusion criteria were registered nurses whose roles involved the care and support of people with dementia from a SA background and their families. Other professional groups and those not working with people with dementia from SA backgrounds were excluded.

Data collection

It was necessary to use a method of data collection that permitted nurses to express themselves in ways that were not constrained or limited to a range of numerical responses. Interviews enable researchers to gain deeper understanding of the phenomenon being explored and are widely used methods of eliciting the viewpoint of participants for qualitative analysis. They have the potential to provide unexpected insights into factors which may not have been considered relevant and enable insight into valuable details of the context.

A semi-structured interview schedule (Table 1.) guided the interviews. This approach enables nurses to share details of their experiences and express their thoughts about their work. The in-person interviews lasted between 11-55 minutes and were conducted during the nurses' working hours. Data were collected between July and October 2019 by both authors, who are female and both educated to PhD level and employed as healthcare educators, one in nursing and one in health psychology. No other people were present during the interviews, apart from one interview when the participant requested that a student nurse be allowed to observe. The nurse researcher was known to some participants, who were aware of her interest in transcultural care. Data saturation was achieved when no new issues were being raised and there was repetition.

Interviews were recorded following local NHS Trust guidelines for research, which involves using encrypted Dictaphones. Each interview was transcribed verbatim and anonymised.

Data analysis

The data were analysed using thematic analysis (Braun & Clarke, 2006). This involves gaining familiarity with the data by reading and re-reading transcripts and making initial notes, drafting initial codes for elements of meaning in the data, developing initial themes from these codes, reviewing, and refining themes, defining, and naming the themes, and writing up findings. The authors conducted the first four steps of this process independently before liaising to discuss, refine, agree, and name the themes and sub-themes. Both authors met regularly and completed a reflective log to ensure our perspectives were ‘bracketed’ and data were collected and analysed following a phenomenological framework.

Ethical considerations

The study received ethical approval from the Health Research Authority and Health and Care Research Wales; IRAS project ID 257256.

Rigor and reflexivity

The researchers followed a research protocol to standardise the approach to data analysis. They kept individual reflective notes concurrently through data collection and analysis, to reduce risk of personal experiences and preconceptions influencing the process. Separate analysis (the first four steps of thematic analysis) was conducted. Initial themes were reviewed by each author, any differences were discussed and agreement was reached after the initial independent analysis. These steps increased dependability, confirmability and credibility.

Participants

Fifteen registered nurses were recruited as participants for the study, no participants dropped out during the study. All but two participants were female (reflecting the nursing workforce), and from white, Mauritian or Black African and Caribbean ethnic backgrounds. The age range was 23 to 71 years, with an average age of 45 years. Nurses had been registered for between two and 49 years and were working in a range of in-patient and community roles.

Table 2. Participants’ demographic details.

5. FINDINGS

Most participants had many years’ experience in nursing and transcultural work although some nurses had less experience as they were at an earlier stage of their career. Years since registration appeared more salient to nurses’ experiences than their age, gender or place of work. All were socially and professionally familiar with people from different ethnic groups to their own. Gender-neutral pseudonyms were used to promote participants’ anonymity.

Three main themes were identified: Communication challenges (sub-themes: ‘The impact of language barriers’ and ‘Interpreting issues’), Bi-directional impact of culture (sub-themes ‘Cultural norms and family-orientated care’ and ‘Countering stigma’) and Learning experiences (sub-themes ‘Limited relevant learning’, ‘Learning by experience’ and ‘Learning from colleagues’).

Communication Challenges

This theme reflects participants’ concerns about the difficulties arising from not sharing a common language with service-users. Problems included inaccurate assessment processes, delays with diagnosis, problems with building rapport and then isolation for service-users, with subsequent feelings of guilt. However, with time and experience, the nurses adapted their communication approach to include non-verbal and observation skills to understand their patients’ needs.

The impact of language barriers

The research participants were monolingual English speakers. All expressed concerns about the impact of being unable to converse directly with service-users. Despite this, they were able to use nursing skills to enable some rapport and comfort for their patients:

'we'd sit with her and she responded quite well to just holding hands, a bit of touch, so just getting a smile from her when she was really unwell was really nice' Indie

However, mostly the nurses focused on problems arising from not sharing a language. These difficulties began with building the basics that underpin a therapeutic relationship and continued into concerns about appropriate assessments. These were reported as relying on ethnocentric knowledge, such as asking who the UK prime minister is or which American president was assassinated in 1960s, knowledge that is potentially inaccessible to someone who does not speak English or engage with English-language media. In this example the problem seemed to lie in the vagaries of English spellings:

'can you read these words? so 'pint, dough, height', well of course they can't read them'. Lee

Poor communication led to poor understanding, for example about the nature of dementia,

'she has got dementia and that was explained when I'd done the visit a few months back, they were aware of that, but they didn't really understand that this is what's going to happen as she deteriorates' Alex

There were concerns that lack of shared language could have other consequences for service-users, for example delays to referrals. In one person's case, the communication difficulties appeared to result in lack of a diagnosis, possibly inappropriate conclusions about her needs and subsequent social isolation:

'She's actually in a care home but she never got a diagnosis.... and when I went to visit her ...she only spoke, I think it was Urdu and there wasn't any staff there that spoke her language' Bobbie

These concerns often led staff to feel guilty about the lower standard of care offered to South Asian service-users.

'*the reason why I felt so bad is not necessarily for the language difficulty but, there's a lot of evidence about dementia patients being ignored and just talking to carers and I almost did that because I thought there was a language barrier'*. Lee

However, one nurse did express a process of adjustment to feeling linguistically and culturally separate from her service-users, indicating that with time and experience her confidence increased and she was able to work effectively despite the initial communication barrier:

'you feel a bit anxious going somewhere where you know they're not going to really speak English. I think with experience you become a bit more confident and comfortable going into different areas and…because we work in this area, such a wide variety of different people that we meet, different nationalities, you get used to it. Yeah, after a bit, it's…I quite enjoy it…' Frankie

Lack of a shared language meant SA service-users were missing out on prompt, appropriate person-centred care. The issues appeared to affect all stages of patients' journeys through services.

Interpreting Issues

The nurses recognised the need for interpreters' assistance and valued their input. However, managing the processes of arranging suitable interpreters and directing conversations via an interpreter was often difficult, time consuming and frustrating. Working through an interpreter of any type was '*definitely a challenge'* although all the nurses were committed to providing a good service and saw interpretation as key to achieving this.

Community nurses were not always aware they would need an interpreter until they arrived at the person's home, in which case the options would be to use a family member if available or postpone. As everything needs to be repeated in both languages, appointments can last longer, or issues may not be explored in sufficient depth:

'you're just time limited and sometimes carers what they just want is time to talk… When I did the assessment all he did was talk, he just wanted to talk, he didn't want medication. He said, could you just listen to me, just listen' Charlie

Reliance on family members to interpret was perceived as problematic at times. Language barriers sometimes exist between younger and older family members which means nurses cannot get the information required. Two of the nurses reported that families claimed the service-user did not speak English, so that the relatives' perspectives were prioritised:

'*Sometimes you don't get the full picture of what's going on, because they say what they want to say and what you want to hear and not what you're meant to be hearing'* Alex

Family members and official interpreters would sometimes avoid 'culturally difficult' or sensitive issues (including intimate bodily functions and stigmatised behaviour) which nevertheless need to be explored as part of the nurses' assessment. Not all professional interpreters were effectively trained. They sometimes failed to appreciate the need to explore issues in more depth and sometimes took control, trying to hurry a conversation or move it on to problem-solving. Brief summaries rather than word for word feedback were noted by several participants. This nurse challenged the professional interpreter:

' "what did she say, is she saying that she's got tenderness down here or has she had any bleeding?" and the interpreter's like, "I just can't ask that". And I'm like, "well why can't you ask that?" I would be asking that and at the peril of offending them but we have to ask these questions.' Morgan

The nurses gave examples of when they remained true to their nursing objectives which required managing interpreters to ensure important questions were asked:

'he wasn't giving me a chance to ask the questions that I needed to ask, the salient ones and more interested in what can be done and not looking at what's currently happening. Missing the point altogether. I said, "hold on you're here specifically for this, let's just pull it back together" '. Alex

The above examples highlight some of the challenges of working with bilingual family members and trained interpreters. These included finding an interpreter, being confident that the interpreter was reporting back accurately and lack of shared understanding between nurses and interpreters about the purpose of conversations and what could or should be asked.

Participants identified that some of these challenges could be addressed by further training, both for the interpreters and for themselves. For interpreters, this included the importance of verbatim translation, respecting confidentiality, and avoiding prompting or 'leading' the patient's replies. Nurses recognised that working through an interpreter was a skill that they could develop which enables them to support and manage interpreters to obtain essential patient information.

In the absence of an interpreter, bilingual colleagues were sometimes co-opted to help with interpretation. The nurses reported this as an ideal response, being more convenient, more accurate and more in-tune with their own understanding of mental health issues. The additional responsibilities were considered to be *'favours to us'*. Interpreting colleagues included student nurses, support workers, doctors, and managers. Bilingual colleagues were portrayed as agreeable to stepping forward to support monolingual colleagues and minority ethnic service-users. However, the nurse could then feel uneasy about being side-lined:

'The clinical person then is the person doing the interpreting. They're the more responsible person in a way. They're not, because I'm the nurse, but I really feel like I'm a bit of a spare peg sometimes…' Noel

While this help was appreciated, it depends on colleagues' goodwill and availability, and raises questions about appropriate use of highly qualified staff members' time and expertise. Interpretation is essential to support monolingual nurses but poor interpretation, whether by professionals or family members, led to concerns about whether patients' voices were truly heard, limited options and lower standards of care.

Bi-directional impact of culture

This theme represents how actual and anticipated cultural differences between the nurses and their service-users influenced the process of delivering and receiving care. The nurses focused more on the 'different' characteristics of SA cultures rather than their own assumptions for the most part. However, this dynamic usually appeared to lessen with experience, especially when the nurses took a reflective approach to their practice.

Cultural norms and family-orientated care

The nurses noted how cultural norms influenced service-users' behaviours in ways which could sometimes make delivering care easier, because families would provide care, but also sometimes more difficult. In the following example, the nurse can see the benefit for the service-user, family members and nurses:

'…it's nice to see that they've all got a big family and it creates a positive impact on them I suppose, seeing familiar faces and making sure that their family are there every day and making sure their needs are met. Sometimes when they're here we don't really need to do anything for them…so, say when families do come they've actually said, oh no they like to bath then, they like to feed them, they like to take them to the toilet and they like to be involved in their care …' Hayden

Nurses reported the role of some women within extended families resulted in high levels of carer stress, particularly when support was limited or the wider family was reluctant to facilitate use of formal support services:

'I have come across daughters-in-law that find it…become quite resentful I think, sometimes because they might be a bit more…they'd be happy to have carers and the fact that isn't what the family want, so they're put in that position as they've got to be the carer, even though they probably don't want to do it or they're finding it really stressful'. Frankie

However, when care is shared, both family members and nurses appreciate the difference:

'We built a relationship with, not just with the service-user, but with nearly the entire family …And I got to know all of them, just because I was caring for their family, and it went really well'. Jamie

Nevertheless, there was potential for conflict when the care was not conducted according to nursing standards, for example through unsafe lifting practices, meaning that the nurses had concerns for family members welfare in addition to concerns around being able to fulfil their own roles:

‘it could be mobility issues, and they want to do all these things for their family and it’s hard to say no to them, because it is our role, and we have to make sure that they’re okay at the end of the day. It’s a good thing and a bad thing, I suppose’. Hayden

The nurses experienced positive and negative emotions in response to their perceptions of the advantages and disadvantages of a family-orientated approach to care.

Countering Stigma

There were differences between nurses’ understanding of dementia and that of some SA families. These differences were based on stigmatisation of the condition resulting in reluctance to accept the diagnosis and fear of the healthcare system:

‘they find it very embarrassing, they don't want to be tagged with that. So, it's the difficulty to get the family acceptancy that it’s normal, as much as it's not normal, it's normal. … So, you are heavily dealing with the family as well’. Jamie

‘ with the Asian [patients]… we have a long waiting time per treatment. A number of things, a fear of the system…I don’t know, a bit of apprehension, I think. Glenn

The nurses were therefore faced with the additional tasks related to building trust in services, alongside explanation of the nature of dementia, supporting families to accept diagnoses and responding sensitively to stigma associated with mental illness.

A strong relationship enabled the nurses and family carers to work in partnership as they developed a supportive care plan that aligned with the family’s preferences and the nurse’s assessment of need:

‘We did talk about care packages to try and relieve the stress, but she wasn’t keen on that. But we just worked with her and supported her in looking after her Dad at home. Trying to get additional help and services that would suit them and they would accept. And she would ring and run things past me and so I always felt that we did have quite a good relationship and it worked well’ Frankie

Effective listening skills within responsive relationships appeared key in avoiding culturally unacceptable interventions, thus building acceptability of previously stigmatised services.

While initially some of the nurses believed cultural stereotypes, most described how, with experience, they gradually put their assumptions aside and listened more responsively to the needs of their service-users. This was not the case for all participants with one anomalous participant using negative attributes and broad generalisations to describe barriers to engaging with patients and families:

‘I don’t think they believe in medication… they have obedience to the priest who tells them, take this herb’ Glenn

Conversely and in contrast to the anomalous participant, other nurses from minority backgrounds described how their ethnicity may have lessened cultural barriers and promoted greater trust. For one nurse, her racial identity appeared to enable greater approachability, but the subsequent closeness had a cost:

‘you're a black woman, just like us, so you should understand. And you should know that this is embarrassing for us, you are growing away from your roots and these were their words. You are growing away from your roots. … sometimes when I'm on shift, when I see them coming, I just have to leave the office’ Jamie

The white nurses sometimes came from a position of unawareness:

'I used to just think that, oh, I'll treat everybody all the same, but everybody's different. And so, me thinking treating everybody the same was the right thing well …was not always the right thing to do' Dylan

Over time, most nurses seemed to move from problematizing cultural groups, towards a more collaborative approach to care. The families of South Asian people living with dementia also required practical support. Culturally sensitive services were often unavailable, or may have suited one group, but not all. Some adjustments were considered easy, for example in ensuring a female carer with the same religious beliefs and language as a service-user was available. Meeting dietary needs was also recognised as being key to timely acceptance of a service.

The nurses highlighted the importance of understanding the wider context, meaning they became involved in signposting and helping families navigate the system. This flexibility could take the pressure off where other support might not:

'..like pointing them to the welfare benefits. So we do more. It's not just going in there and saying that that person's got dementia and that's the only work that I can do. Because …it's a package, and it makes it easier for the carers to care for somebody if they've got that additional support behind them'. Frankie

This sub-theme highlights the complex inter-relationships between mutual perceptions, stigma, identity, expectations, and behaviours of nurses and service-users. The examples reflect how most nurses addressed stigmas associated with dementia and service-use, and how they achieved deeper understanding of the nature of supportive interventions.

Learning Experiences

This theme reveals the extent to which the participants found prior transcultural nursing education useful and how they felt about meeting their ongoing learning needs. They engaged in different types of learning including formal training, learning from peers and learning from experience.

Limited formal learning

Most nurses described only having access to mandatory training, most of which was online. It had become difficult for most nurses to access training opportunities due to time and cost-related constraints. However, one nurse expressed feeling lucky because her specialist role enabled her to access masterclasses and gain deeper levels of understanding:

'*if you're judgemental, even your approach to them, they feel, 'I don't feel confident to confide in this person'. That's actually a downfall of us. It's not that person's fault for not wanting to engage so it helps you see things, the masterclasses, from completely different perspectives'*. Owenn

The training available to the specialist nurse was not routinely available to other nurses. Most nurses could not remember if they had learnt about transcultural nursing in their pre-registration programmes, some had had limited training over ten years ago, and most explained that staffing levels limited their access to any learning that was not mandatory.

The nurses who had completed their initial nursing programmes many years previously found it difficult to remember what they had learnt, but most reported receiving little initial education about either dementia or transcultural working. In considering the extent to which she was prepared for transcultural care, the following nurse argued that despite no specific transcultural learning, by being person-centred and taking a holistic view of her patients, she would include their cultural identity too:

'*even when I trained the focus was on the individual and trying to move away from labels and trying to make care more personal. So, for each new person that stands in front of me, I need to think about their experience, and where they are in the world and, how their…what's happening to them is affecting them and those that love them…'* Bobbie

The nurses were aware of ethnocentric misunderstandings and appeared to recognise that their lack of insight might mean they were making inadvertent mistakes. Some suggested language training would be helpful with one nurse enrolling onto a language course privately to help support South Asian service-users:

'*I have been learning Urdu to try and at least be able to show that I'm...I don't know what the word is, that I'm not just an ignorant white person, basically, who expects everyone to follow what their advice is'*. Lee

The nurses noted aspects of good practice within the Trust or region that could be expanded. These included having leaflets or pre-recorded audio resources in different languages, access to an advocacy service, a 24-hour multi-lingual helpline and more community-based day centres for service-users. A directory with information about religions, cultural beliefs and local culturally congruent services would be useful. When considering face to face training, there was a consensus that learning from experts by experience would be powerful and memorable.

Gaps in resources, information, and support roles such as a link person or diversity champion that could help nurses in their role were reported:

'I think the Trust just expect you to know where to signpost to, it's just expected that you know it really'. Morgan

'*I think we need somebody in each team who would be, like, an equality and diversity lead. That doesn't exist anymore, it used to but now we don't have that'*. Lee

Overall, the nurses shared that despite little formal learning, they were able to glean useful information from colleagues, patients, and everyday practice. However, this could be piecemeal, and there was agreement that more formal, structured learning would be beneficial, particularly if supported by online resources and specific transcultural nursing champions.

Learning from colleagues

Despite the lack of formal training opportunities, nurses were motivated to learn, and created opportunities to learn from each other and from colleagues in partnership-working organisations. These peer conversations involved informally sharing information and support which facilitated deeper learning and reflections around assumptions and improving transcultural understanding. In the following example, the nurse indicates how growing self-awareness and listening to others more carefully helped her see things from a different perspective:

'*I'm not too religious so that's where I used to struggle before. I'm working with South Asian nurses and we have a chat about these things, and they are giving me reasons and they are really highlighting me on it. So, before I wasn't too attentive in that side, but now I am'*. Jamie

Clinical supervision was another opportunity for learning from colleagues:

'*She [clinical supervisor] was the one who got us to have these conversations about assumptions, to try and make sure that we're going in with an open mind, without deciding what we're going to do before we even get there'*. Lee

The nurses helped each other's learning through formal and informal working relationships. This was mainly supportive and responsive, rather than in-depth and challenging. The examples of deeper learning above indicate that this could result in more sensitive practice.

Learning from experience

Many of the nurses described changing their attitudes with time and experience. Initially the nurses believed cultural stereotypes but over time, with experience, they realised that becoming accepting of families' priorities and supporting their model of care had more positive outcomes:

'… So you make an opinion, but once you start to go in there, you see how things are different and how they do try and work together. I think in the past I might have judged and thought, well, this is what you need, but once you get to know people, that isn't what they want. They're looking for your support and they're not looking for the person to be moved or for carers to come in. They want the support so that they can do it themselves' Frankie

The nurses described learning as they went along, through '*years of experience and sometimes trial and error*' picking up useful snippets of information and understanding, which built over time to support their current and future practice. The nurses used a range of different examples to illustrate transcultural knowledge and behaviour. Simple insight into cultural traditions, such as the importance of removing shoes indoors, helped express courtesy while also building the relationship:

'When you have an awareness of that sort of thing, you can talk about it before anybody even has to ask you and then that helps you to build up a rapport, but I only know that through experience. If a new, qualified nurse came in with no experience they wouldn't know that, there's no training on that, you just learn as you're going' Lee

Once communication was established and trust built, the nurses were better able to work in a positive, person-centred way, finding sensitive solutions, thus leading to better outcomes for families and more job satisfaction for the nurses.

6. DISCUSSION

This study has revealed new insights to the ways that nurses perceive their ability to provide care to SA people with dementia and their families. Crucially, findings indicate that a lack of opportunities for support and training often leads to nurses not feeling confident working with SA families. Many rely on their clinical experience to build culturally sensitive strategies. Culturally driven mutual expectations changed with experience and can develop into positive attitudes which underpin effective transcultural care for SA elders with dementia. The identified inter-related factors were primarily focused on linguistic and cultural differences, reflecting existing beliefs and evidence around transcultural nursing, while both reinforcing and challenging stereotypes. In addition, unexpected complexity in the process of learning more about self as a cultural being through relationships with service-users, and revelation of the impact of underlying unseen cultural values through exploring the dynamics of working with interpreters, offer new perspectives on issues for personal and professional reflection, and for taught content in nurse education.

Counter-intuitive factors related to nurses' cultural identities and their assumptions, feelings and experiences, point to possible gaps in learning for some and shifts in cultural norms for others, and, drawn from the implications of the nurses' experiences, perhaps for service-users too. For example, service-users who were initially wary were willing to accept help once nurses adopted a more culturally sensitive approach. These insights could underpin the design of brief training interventions to promote high-quality transcultural practice.

This study indicates that mental health services may have a 'stigma by association', with consequent lack of trust resulting in delays to engaging with health services. Furthermore, care that is not culturally competent has significant negative consequences for service-users and their families (Ali & Johnson, 2017) and contributes to health inequalities (Ali & Watson, 2018) providing a strong rationale for achieving transcultural competence.

Linguistic issues, cultural norms and learning experiences explain nurses' perceptions of the challenges that future educational interventions have the potential to address.

Linguistic challenges

Language concordant care contributes to patient satisfaction and is key to a person-centred approach (Ali and Johnson 2017). Not sharing a language with patients and families has negative consequences for care provision (Ali & Watson 2018, Zhang et al., 2021), and specifically, this study has identified delayed or minimal rapport building, ethnocentric and inaccurate assessments, limited therapeutic interventions and delayed access to resources. This results in a sub-standard experience of care for patients and families, together with frustration and guilt on the part of the nurses.

Use of interpreting services is an obvious solution to lack of shared language, but this was fraught with challenges. Our findings extend those of previous studies in identifying that nurses felt under-prepared to communicate through an interpreter and found some interpreters' practices frustrating and undermining (Gerchow et al., 2021). These difficulties seemed to reflect poor communication between the nurse and interpreter, in that expectations were not always clear (for example, the requirement for a verbatim translation, rather than a summary) and culturally driven assumptions about acceptable lines of questioning, approach to therapeutic rapport and professional behaviour were not shared. At times this meant crucial questions were not asked, resulting in gaps to the assessment process which may contribute to substandard care.

Cultural issues in the interpreting relationship

Our findings indicated that most nurse participants appeared to value equality within relationships and feel that any perceived hierarchical differences should be minimised. This is congruent with Hofstede's work on cultural values and beliefs (Hofstede et al., 2017). This 'low power-distance' value is demonstrated in the nurses' focus on listening carefully to patients and valuing their perspectives. However, many interpreters, raised in SA cultures where high power-distance and hierarchical relationships are the norm, may expect patients to do as health professionals tell them and may even feel uncomfortable if they are not clear who in the relationship is in control. This might then explain their apparent need to become directive within the interpreting relationship. In 'avoiding uncertainty' (Hofstede et al., 2017), the interpreters would also have a strong need to 'fix' problems rather than to explore them. Nurses socialised or trained in the UK, on the other hand, may feel more comfortable exploring uncertainty. Hsieh (2010) who previously worked as an interpreter herself, identified a dynamic in which service providers and interpreters experienced conflict as they negotiated who managed the conversation and controlled the resulting narrative, a dynamic which, according to Kilian et al (2020), means the patient's voice is lost. In this study, when nurses wanted to explore issues, interpreters sometimes acted as a barrier, which could potentially contribute to health inequalities.

Colleagues as interpreters

In what would appear to be an ideal solution, SA staff members were frequently co-opted into interpreting roles. Having mental health training, being easily accessible, part of the team and so involved in mutual obligations and being comfortably bi- (or multi) lingual, meant the monolingual nurses saw their colleagues as an invaluable resource. They appeared to believe their colleagues were happy to help. There is some support for this assumption in the literature; Patrikkson et al (2022) identified that bi-lingual neonatal healthcare practitioners perceived their interpreting experiences 'as a gift' and gained satisfaction from helping others. However, in common with Ali & Johnson's (2016) participants, they also recognised the cost to themselves as they were expected to be available, which added to their workloads. Unofficial interpreting on top of a professional's normal role is disadvantageous to the individual because it adds to their workload, directs them away from their own priorities and risks pigeon-holing them into roles where this skill is useful for others, thus limiting their own progression (Gerchow et al., 2021). Additionally, an unanticipated outcome of using a colleague to interpret is that the nurse's own role in the interaction becomes limited, they may lose a sense of responsibility with some anxiety about continued accountability within the now peripheral nature of their role.

Transcultural practice and cultural dimensions

The nurses frequently noted the collectivist approach to care within SA families, reflected in the stereotype of 'looking after their own' to describe care within the family. Hofstede's work explains how people from different cultural backgrounds relate to each other through cultural dimensions (Hofstede et al., 2017). According to this analysis, SA cultures are 'collectivist', meaning that the person orientates themselves towards a group identity, while Western countries tend be more individualist in outlook. While they had some concerns about the family carers' understanding of the nature of dementia, generally the nurses appeared to respect family approaches and came to appreciate how effective the system of family-orientated care was, despite their occasional misgivings about the stresses involved. Some nurses from Black backgrounds appeared to experience some conflict between the demands of their professional culture, which reflects the UK majority in orientation towards the individual and promoting egalitarian relationships, and their personal alignment with a more collectivist understanding of relationships. For one nurse, this became emotionally challenging when a family appeared to put pressure on her to align with them, causing conflict around her perceived identity and undermining her sense of self. Some of Patriksson et al's (2022) participants felt similar emotional distress when challenges to professional boundaries resulted in disappointment then disagreement. The nursing profession needs to be aware of this issue and to provide support to nurses when this happens (e.g. clinical supervision). One participant appeared to perceive ethnicity as a hierarchical construct, rather than approaching transcultural care as a collaborative partnership between the nurse and service-users. This indicates that experiential learning and reflection is an ongoing process, with nurses in this study at different stages of this journey. There is a need to train all nurses in cultural competency so that that patients are more likely to build good relationships with all nurses regardless of whether they share the same cultural background.

The nurses conveyed interest in cultural factors. The less experienced nurses (and more experienced nurses reflecting back) tended to focus on visible practices (such as knowing to take shoes off in a patient's home), revealing a sense of 'othering' the service-user group by highlighting social norms different from their own. They also noted families' determination to care for their relatives at home and high levels of stigma around mental illness in SA communities. However, many of the nurses had observed their own development in becoming more accepting and less judgemental, acknowledging their own cultural identity and role in the relationship dynamics. This change seemed to be achieved through strong relationships with service-users, enabling learning from each other, together with time and experience. Leininger (2002) describes this process as cultural adjustment. This more accepting, positive approach proved inspiring to the nurses themselves who gained greater job satisfaction and came to feel that the relationships that followed then facilitated collaborative problem-solving with the families. While Campinha-Bacote (2002) suggests 'cultural desire' is a pre-requisite for cultural competence, our participants' accounts appeared to indicate the opposite; that cultural desire grew from positive practice experiences.

Implications for learning

Our findings indicate that a shared educational intervention aimed at groups comprised of both nurses and interpreters, with learning outcomes focused on mutual cultural understanding and specialist communication skills, could enhance care outcomes. Most nurses indicated that their current learning tended to be experiential, through interactions with colleagues or service-users, with no formal professional development opportunities related to transcultural care. This is congruent with research outcomes in other specialities: for example, Rayment Jones et al (2021), exploring the experiences of pregnant women, found high-quality interpretation is key to both accessing healthcare and communicating concerns. They concluded that current interpreting arrangements in the UK are not fit for purpose. Their participants reported inaccurate interpretation, lack of confidentiality and sometimes disrespectful interpreters, whose behaviour meant the women felt unable to disclose their concerns.

Building on existing knowledge this study highlighted nurses' own need for training in how to work with interpreters, and their accounts plus the literature indicates that interpreters may benefit from a similar intervention. The nurses highlighted that when working with colleagues with understanding of mental health and services, or well-trained interpreters, the outcomes for all parties (patients, relatives nurses and interpreters) appeared to be more positive. Some reported that when interpreters were team members, employed by the Trust, higher quality communication could be achieved, resulting in improved relationships and outcomes. Cultural competence learning opportunities are required for all nurses, including those who may previously have assumed themselves, and been assumed by others, to have greater understanding because of their own cultural backgrounds. The costs of training may be offset by the benefits for service-users, their families and the professionals and save too through more efficient and accurate care planning and delivery.

Teaching should include content designed to improve understanding of the cultural values that underpin health related behaviours, and how to work effectively with interpreters. Ideally, interpreters would be employed and trained 'in-house' together with clinical colleagues. While training and reflective practice are important for nurses, their ability to support patients also requires adequate resourcing, including information to address knowledge gaps and appropriate community provision to which they can refer patients. This could create an opportunity for nurses to increase their capacity to provide a comparable level of care and reduce anxiety or feelings of guilt. These implications for learning are likely to extend beyond this clinical group and setting and support nurses caring for patients from wider locales either through continuing education or initial nursing education.

Strengths and Limitations of the work

This study provides unique insights into experiences of practice which can inform the challenges and opportunities for transcultural training. Nurses were working in a range of roles and had different levels of experience. Interviewing nurses in different roles and from different sites meant the findings were not restricted to one specific set of processes and reflected a broader range of experiences and insights.

The cultural identities of the researchers (one SA British, one white British) and different professional backgrounds contributed different perspectives and enriched the process of conducting and analysing the study, while use of reflective journals ensured any bias was managed.

A limitation of the study is that no participants were from SA backgrounds. These perspectives could have added a useful additional dimension, particularly as there are many SA cultural groups.

The researchers did not recruit SA people living with dementia for service-user representation on the study team, as gaining informed capacitous consent would have been problematic. However, the researchers were advised and supported by an experienced transcultural dementia care nurse. Repeat interviews were not conducted nor were participants invited to provide feedback on transcripts or findings due to resource constraints.

Recommendations for Further Research

This study identified gaps in training and care. Further research is required to explore the factors, within and beyond practice experiences, that underpin change in attitudes, values, and behaviours in transcultural care. A joint training programme for nurses and interpreters should be co-developed, implemented and evaluated. Future research should explore how transcultural support, resources and training can be implemented in an accessible way that provides knowledge, skills, opportunities, and motivation to reflect and improve transcultural care.

Implications for Policy and Practice

Policies clarifying the requirement for professional interpreters, rather than family or colleagues, are needed. These policies should include guidelines on interpreting standards for interpreters and healthcare professionals. In-person learning opportunities should include joint sessions for interpreters together with nurses. Staff providing interpreting support should have this work recognised in their workload allocation to avoid over-working staff to avoid risk of burnout, fatigue and being unable to complete their main job. Transcultural training opportunities should be routinely available to nurses as part of their Continuing Professional Development package, Provision of resources to support nurses in their role and opportunities to reflect and identify mechanisms for building relationships with SA patients will improve quality of care and reduce stigma towards mental health services thus removing an important barrier to access.

CONCLUSION

This study explored the experiences of dementia care nurses working with SA service-users with dementia, and their families. Our findings extend those of previous researchers in identifying specific communication challenges, particularly in relation to the difficulties of providing mental health care through an interpreter. The findings also showed nurses' commitment to providing high quality transcultural care. The nurses conveyed respect for and interest in the cultural beliefs, health behaviours and well-being of their service-users. The nurses were often inspired by service-users to learn more about cultural issues. They were aware of the implications of low-quality care for SA people with dementia and their families, and as individuals appeared to feel responsible despite the lack of resources and lack of training. The nurses had clear ideas about how improved care could be achieved. In the absence of training opportunities, they learnt from service-users, their families, and their colleagues. There is scope for brief, focused training opportunities that include learning about underlying cultural values and how to apply this understanding in practice, to address nurses' learning needs and contribute to faster, better and safer care.

ANONYMISED CONFLICT OF INTEREST STATEMENT

No conflict of interest has been declared by the authors

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