Dementia Care, Nurse Education and Nurse Well-being: An Auto-ethnographic Critical Analysis and Review

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Abstract

This auto-ethnographic critical analysis and review provides an account of my development as a researcher in the field of dementia care nursing and nurse education. The included peer reviewed publications have been chosen to illustrate my research skills and unique contributions to nursing knowledge and education. My clinical nursing experience was in transcultural dementia care and included studies reflect my ongoing commitment to this field. Some of the included papers were written for practice journals to promote application of theory to practice for nurses in clinical practice.

I chose an auto-ethnographic approach to writing this review with the intention of producing an engaging and meaningful account which would enable me to convey the significance and impact of my professional development as a researcher to best effect. This reflective, subjective approach to writing aligns with the qualitative nature of my research.

My research has addressed four key themes: i) Identifying nurses' or service users' experiences and needs, ii) Extending and sharing knowledge of dementia care, for nurse education, iii) Exploring what works in educational interventions for nurses and allied health professionals and investigating factors that sustain practice change and iv) Evaluating interventions designed to support nurse well-being. Early studies explore nurses' learning needs, then building on this to how nurses can best learn about dementia care and from there to acknowledge that nurses' own well-being is key to the provision of high standards of care, and exploring how this might be achieved in education and practice.

Contributing to the evidence and values that empower nurses within the hierarchical culture of healthcare has become a thread that runs through my practice, teaching and research.

My contributions to knowledge lie in new understandings of how cultural factors influence application of theory to practice in dementia care nursing and in identifying the profession's related ethical responsibility for members' well-being. Current understandings of Kitwood's (1997) personhood theory (Kitwood and Brooker 2019) continue to prioritise the well-being of people with dementia while ignoring the costs to their professional care providers. My distinctive contribution here is to identify how the personhood of nurses working in dementia care is systematically denied, a cost which is detrimental to their well-being and therefore important for its own sake, but which has significant relevance too for the subsequent impact on quality of care, staff turnover, burnout and nurse retention. Barriers to application of theory to practice in dementia care may lie in insufficient application of theory, in that the theoretical constructs should be applied with nurses as we expect for patients. Adjusting future training programmes accordingly could impact on nurses' professional self-esteem, job satisfaction, retention and their ability to apply learning in practice.

Key words:

Dementia care, nurse education, transcultural nursing, qualitative research, ethics in healthcare, nursing culture, autoethnography

Contents

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Introduction

This analysis and review summarises and synthesises the process of my development as a researcher and writer and illuminates my contribution to the field of dementia care and research. Using an autoethnographic approach I have threaded together more personal considerations around my life before, during and after nursing, my clinical experience, the wider background of dementia care and education, relevant literature and where my studies fit in relation to this context. My papers and this review tell the story of my career and professional journey so far, with emphasis on my research, experiences, findings and significance for practice. The underpinning ontology and epistemology are explicated. New understandings of how the care of people living with dementia can be taught more effectively, and how the well-being of nurses in the field is key to both learning and professional commitment are drawn from this body of work and are my key contributions to knowledge.

Context and Background

The context of my work is the field of dementia care and education in the UK, with a focus on the experiences of people living with dementia and their family carers, and those of registered nurses and unregistered staff employed to care for and support them. The term 'dementia' refers to a range of progressive conditions in which cognitive impairment leads to significant difficulties with memory, language, managing everyday activities and relating to others (Jenkins, Ginesi and Keenan 2016). There are around 885,000 people living with dementia in the UK, a number anticipated to grow to 1.6 million by 2040 (Wittenberg et al 2019). Dementia is associated with low mood, agitation and behavioural issues (Mendes 2018) and affects around 80% of people in care homes and around 25% of acute hospital in-patients (National Collaborating Centre for Mental Health 2018). Dementia is an age-related condition and doubly stigmatised, through ageism and discrimination on the basis of cognitive impairment (Nguyen and Li 2020). Service users and service providers experience stigma and stigma-by-association that results in structurally embedded neglect of their (practical, emotional social and financial) needs (Werner et al 2012).

Government policy focuses on implementation of iterations of the Prime Minister's Challenge on Dementia. The current version (Department of Health (DH) 2016) reiterates the themes of risk reduction, reducing inequalities, improving quality of care (by 2020), fostering supportive local communities and social inclusion for people with dementia and promoting rights by ensuring better implementation of the Mental Capacity Act (2005). The requirement for better training and education is noted and will be re-emphasised in a planned update of 'Making a Difference in Dementia: Nursing Vision and Strategy' (DH 2013). However, chronic underfunding of services has meant that policy intentions remain unfulfilled (Alzheimer's Society 2021a) despite government stated ambitions to make the UK the best country in the world to live with dementia and for conducting dementia-related research (DH 2016).

Dementia care is a highly skilled specialism because of the complex needs of people with dementia and extensive support needs of family care-givers who may experience high rates of anxiety and depression (Abreu et al 2019). But high-quality care is time-consuming, and without suitable staff numbers and consistent leadership both exhausting and potentially thankless; workplace stress often leads to burnout and intention to leave the profession (Zwijsen et al 2015). External criticism adds to the pressures on staff; those on the frontline of care may be held responsible for poor practice (Care Quality Commission 2014).

Despite the challenging nature of the field (National Institute for Health and Care Excellence 2018) and its difficult context, training has been identified as a possible solution to low standards of care

(Department of Health 2016, Glasper 2019). Nevertheless, access to suitable educational interventions tends to be limited (Surr et al 2017).

The UK government spends around £85 million per year in dementia research but only 14% of this research explores care issues, with the vast majority aimed at prevention (Alzheimer's Society 2021b). Meanwhile, questions around how to provide consistently effective care remain unanswered (Surr et al 2017). People with dementia and their family members bear the brunt of financial and social costs when people are cared for at home (Care Policy and Evaluation Centre 2019). When they are in hospital or care homes, nurses and their colleagues experience physical and emotional exhaustion, often working unpaid overtime in an attempt to cover the gap in staffing levels and compensate for under-resourced services (Islam et al 2017). This reflects my own practice experience of struggling to meet the extensive needs of patients and their families in stretched services and provides the rationale for my body of research; the gap in the literature reflected neglect of familiar practice problems. As a nurse educator, I am motivated to deliver learning experiences which meet practitioners' requirements for underpinning values and evidence-based understandings, but appreciate that evaluating alternative approaches to providing education which can sustain practice change is central to ensuring future cohorts of nurses can move beyond having knowledge, to feeling empowered to use it for the benefit of patients, families and their own well-being.

Autoethnography is an approach in which the researcher weaves their own experiences and learning into a story which conveys the significance of each study from a personal and cultural (in my case, nursing) perspective. My research is a response to questions arising from my clinical practice, it derives from the challenges, questions and reflections of my career in nursing and nurse education. In a sense this has become a 'career long PhD'. The account will provide a narrative analysis relating how 'the data' of my history, values, motivations and experiences within nursing influence each element of my work. Riessman (2008) suggests narrative analysis is an interpretative process of deriving meaning from such events and experiences. It is more than story-telling: it is 'strategic, functional and purposeful' (2008:8) and often reflects issues of power within specific time-frames and cultural contexts.

A personal, evocative approach, situated in the challenging context of dementia care nursing in the UK and grounded in relevant evidence and theory, will support me and the reader in gaining deeper understanding of the implications of each choice of research question, each method of gathering data, and each strategy of analysis. In addition it will enable me to share with the reader how research findings have changed me, in my practice as a nurse, nurse educator and researcher, and the impact my work has had on other nurses, people with dementia and mental health nursing education.

My area of expertise from practice and teaching is older peoples' mental health, with a focus on dementia care and transcultural nursing. My publications reflect these interests and my increasing awareness of the importance of the nurse in the care relationship and how the experience of nursing has an impact on the nurse's own well-being and consequent commitment. The thread running through the included papers, my previous nursing practice and current teaching, is the importance of recognising the experiences of all parties, respecting them and responding to them through person-centred attention, and this is where my contribution to knowledge lies.

Using an autoethnographic narrative approach is congruent with these values, as the researcher brings their own history and beliefs into the process of researching (Adams, Holman Jones and Ellis 2015). Autoethnography offers the opportunity to synthesise my personal and professional selves.

Like many health service researchers I am firmly rooted as a nurse in clinical practice and in the need to conduct and share findings of rigorous, clinically relevant research to inform and improve care.

Autoethnography facilitates understandings of connections between the personal and the cultural, and enables critique of taken-for-granted discourse and new insights into cultural issues (Stahlke Wall 2016). Perhaps particularly within nursing, the nurse is not independent of the culture of their profession, but must acknowledge its impact both on the self and consequent professional assumptions and endeavours, and their interpretation. Autoethnography is a method suited to a situation when the researcher identifies with the researched, particularly as a member of a marginalised group (Priddis 2015). Denzin (2014) suggests this is because it has the potential to unsettle taken for granted assumptions and allow a voice to those who may be previously unheard. Delamont (2007) challenges this assertion in saying that proponents of the method tend to be privileged middle-class people rather than those whose disadvantage a researcher should be aiming to challenge. I am both a nurse and so in some respects unheard, and an educated person in a privileged role, whose voice has already been amplified through opportunities such as publication and conference presentations. But my research does address the needs of those I identify with – nurses caring for people with dementia, and so is designed to benefit those in less powerful positions; both service providers and users.

This autoethnographic account is not research, but it is certainly a lot of hard work for something Delamont (2007:1) describes as 'essentially lazy'. I will address Delamont's critique by taking an analytical, ethical approach, and explaining how in my research I have fixed my 'gaze' on those 'whose side we are on'. In taking an autoethnographic approach to this critical analysis and review, I am using the strengths of the method to be open, reflective and subjective in connecting with the reader, to share how my self and my research are situated within a specific nursing field and its culture, driving change for marginalised groups within this field.

The approach requires the researcher to acknowledge their own vulnerability as they share their feelings and story with honesty, alongside the stories of their participants. In doing this I will harness an outsider's skill to reflect on an insider narrative (Adams, Holman Jones and Ellis 2015), enabling the best of both worlds and shedding light on the less obvious underlying dynamics of my nursing research journey. As this narrative progresses I will modify the voice of the account, being reflexive, 'observing myself observing' (Holman Jones, Adams, and Ellis 2016) sometimes analytically and sometimes emotionally, according to my own, my anticipated readers' and my story's priorities.

In retrospect I can see how my personal history prepared me for mental health nursing. I had had a peripatetic childhood and the frequent changes of schools had made me acutely aware of the nature of insiders and outsiders, how communication and empathy have the power to exclude and include and had found that others identified as outsiders were the most open to newcomers. So before coming into nursing I was already very interested in language, migration, how relationships mitigate emotional stress, transcultural issues and the impact of stigma and discrimination, partly due to my own experiences but significantly also due to friendships with Jewish and Irish peers. The insights gained from being welcomed into homes very different from my own were key in teaching me about the benefits of a positive approach to difference and the strengths of diversity (Homan et al 2020). I had also been made aware of the trauma that follows direct discrimination as expressed by first and second generations (friends' grandparents and parents) and the generally (but not always) casual and unintentional discrimination experienced by my peers (Gerrard et al 2018). So I was primed to hear patients' stories (psychiatric diagnoses are similarly stigmatising and excluding (Switaj et al 2016)) and with experience grew in commitment to influencing the nature of mental health nursing.

An autoethnographer can choose to take either an evocative or an analytical approach to their work, each using different forms of language to explore their subject (Bochner and Ellis 2016). However, as Priddis (2015) does, I will meld evocative and analytical approaches to writing, according to the nature of the story as it unfolds and the emphasis at that point. At some stages the story will focus more on the values, emotional aspects, motivations and ethics of my work, while at others the emphasis will lie in more technical aspects, evaluating and exploring research methods and findings. While the two may meld as the account progresses, for example when I discuss the implications of findings, I will be code switching (Cooper 2013). Code switching is a habit that historically (Crystal 1987) has related to linguistic borrowing between languages by people who are bilingual, but more recently it has been repurposed to relate to those who share a common language but who express themselves differently according to their cultural (minority or majority social group) milieu (Bush 2020). It is a skill that most of us share, but it is associated more with people who move to a second homeland, membership of a minority group or people who move between different social settings. It is a practice I have used since childhood, adjusting accent and vocabulary according to where I am and who I am with. It becomes hard not to, even though I sometimes feel embarrassed as my accent flexes during a conversation, or inauthentic as if posing as a member of a group where I do not belong. Code-switching is a skill of mental health nurses; we adjust to the language of our clients while also negotiating complex professional jargon and persuasiveness with a range of other professionals and patients' family members.

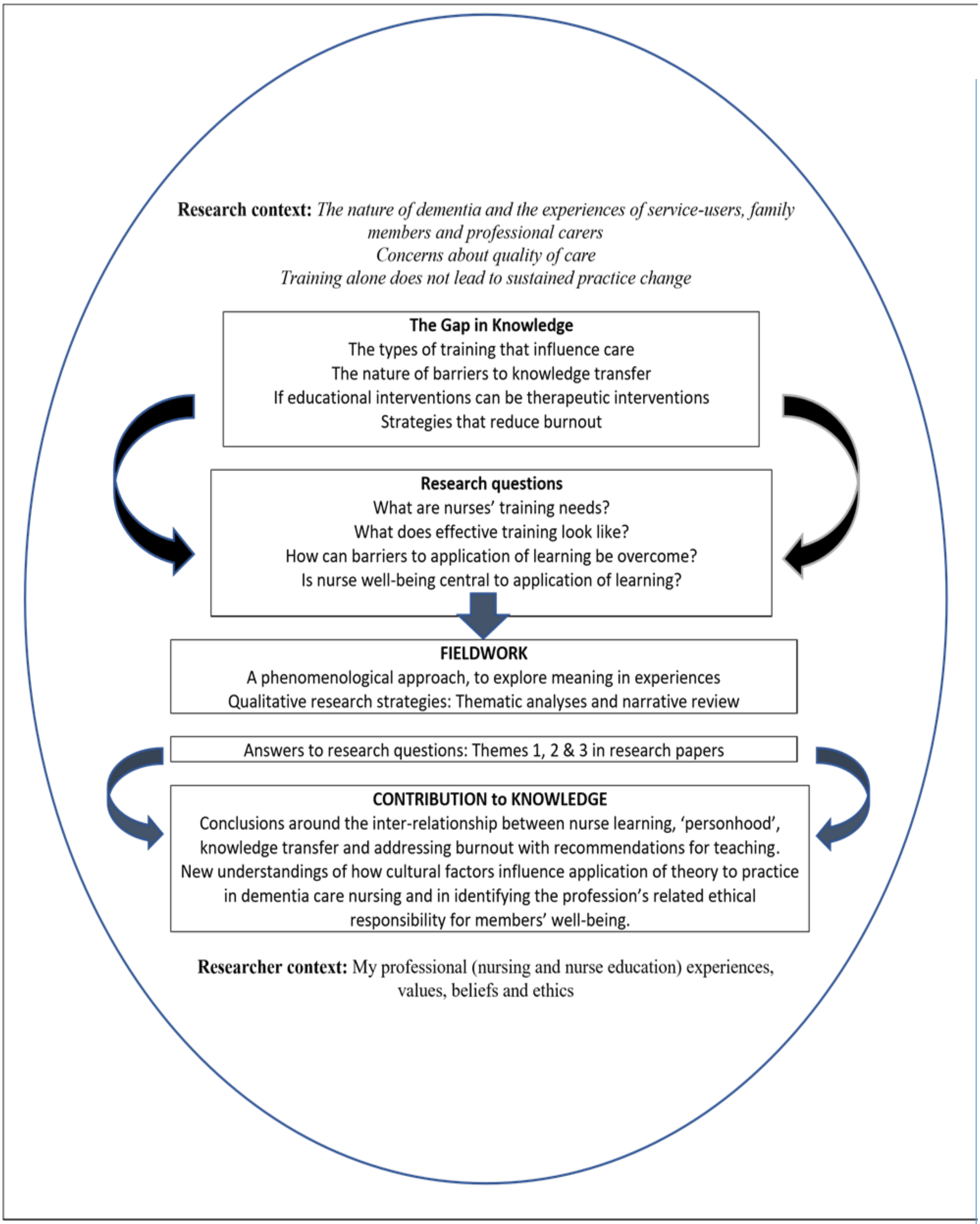
This narrative will clarify my research journey, decision-making, the research strategies and skills developed, the inter-relationships between papers and my original contribution to the field of dementia care nursing in the UK. The papers are appendicised below and will be referred to throughout this account. Peer reviewed research papers are complemented by articles written for the nursing press. In writing to promote practice change, with a view to the well-being of patients and nurses, I am committed to improving practice and feel it is important to facilitate access to research and to enable theory-practice application for practitioners, who mostly do not read research journals. A textbook and these articles are part of this submission and will similarly be synthesised into the analysis.

The route to PhD by published works suits a person like me who gradually built a portfolio of publications. I came late into an academic career and did not originally envisage becoming involved with research or intend to complete a doctorate. However, as each study built on the gains of the previous, and in common with the consequences of doctoral work, each complemented or reflected my practice and teaching purposes, taught and embedded a range of research methodology and co-ordination skills and the ability to communicate findings to different audiences and has had impact on the field through original insights and impact on practice or policy.

My research focuses on addressing gaps in knowledge around how learning influences dementia care, the nature of barriers to knowledge transfer, responding to burnout in nurses, exploring whether educational interventions can be therapeutic interventions and creating and evaluating strategies designed to reduce burnout. Most of my research has followed the pattern of awareness, via practice and evidence, of an issue related to nurses and their care of people with dementia, and conducting studies to explore these issues further. (Please see Figure 1.)

The questions I have been aiming to answer are 'What are nurses' training needs?', 'What does effective training look like?', 'How can barriers to application of learning be overcome?' and 'Is nurse well-being central to application of learning?' In working towards answering these questions, four themes thread through my work and papers (Table 1).

Figure 1. An overview of my research process



My research involves exploring the perspectives and experiences of participants, so uses qualitative approaches in primary research and literature reviews.

In common with most health researchers, I have worked in in small research teams with colleagues with a range of interests and specialities. Within projects my roles included leading and collaborating on design, data collection, analysis and dissemination. My original contributions will be evidenced below (and in Table 2), but in summary, focus on specific aspects of the experience of living with dementia, the nature of relationships between education and application of learning for dementia care and factors that may facilitate or inhibit application of theory to practice, particularly highlighting ethical issues around the importance of the profession's responsibility towards members' own well-being.

Table 1: Themes, papers

Theme number	Theme	Papers
1	Identifying nurses' or service users' experiences and needs	1, 3, 4, 5, 7, 8, 9, 10,15
2	Extending and sharing knowledge of dementia care, for nurse education	1, 2, 3, 6, 8, 9, 11, 12, 13, 14
3	Exploring what works in educational interventions for nurses and allied health professionals and investigating factors that sustain practice change	2, 3, 4, 5, 8, 9, 11, 15
4	Evaluating interventions designed to support nurse well-being	7, 8, 10, 15

My analysis and review will clarify the relationship between the themes and papers, while showing how my work relates to the context of dementia care in the UK and how it has developed over time to form a coherent body of publications, contributing to original knowledge and perspectives and influencing practice. This body of work and the critical analysis and review that follows is presented in this document as evidence for recognition at doctorate level.

My History: From Nurse to Researcher

I came into nursing in the 1980s having completed a degree in Social Geography and recognised the implications of unemployment figures on my prospects for paid employment. I had worked as a care assistant and been told that I had the skills of a mental health nurse ('not a nurse'[1] – these were the days of task-orientated care) so applied for training and within two weeks was accepted and getting on with it. To my surprise I found myself engaging with and revelling in the role which resonated with my personal strengths (and perhaps personal and professional needs).

I specialised in community mental health care for older people and by chance ended up working in an inner-city multi-ethnic catchment area. My caseload did not reflect the local populations, in particular south Asian elders were under-represented, and within that group Pakistani people were even less visible. This was despite extensive evidence of higher levels of need in minority communities (Wallace Nazroo and Becares 2016). I addressed this from three directions, firstly I took

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[1] The skills of mental health nurses have not always been recognised as equal to those of adult /general nurses

evening classes in Urdu, to build trust family by family, secondly I developed relationships with the GP surgeries, to promote referrals and thirdly I built on existing relationships with community organisations to build trust more broadly in the communities. This was a stressful process, no-one else seemed to have done anything similar and there was no guidance in the nursing literature about transcultural working with older people in mental health services. I attended training and tried to read around the subjects, but found my learning from experience was preparing me more than I was learning there. I also became aware of extensive racism within services and the different ways potential service users experienced barriers to getting the care they needed, not least because service providers believed stereotypes and felt overwhelmed by linguistic and cultural differences. Potential patients believed stereotypes about services too, so that by unspoken mutual agreement, staff and communities avoided contact. (This dynamic was later identified as 'the circle of fear' by The Sainsbury Centre for Mental Health, (2002) and remains entrenched despite extensive research since (Codjoe, Barber and Thornicroft 2019)). I decided to write up my experience and sent an article to the Journal of Dementia Care (Jenkins 1998). The intention was to encourage mutual engagement by sharing simple skills and approaches. I wanted to feel heard but also hoped to recruit collaborators.

The people that heard me were nurses of African-Caribbean backgrounds, motivated by similar factors in relation to patients and colleagues from their own backgrounds (Codjoe, Barber and Thornicroft 2019). I have to thank them for guiding me towards becoming an effective ally in transcultural work. Gradually a team formed, we worked together in overlapping geographical areas and collaborated on a range of cultural competence and anti-racism training for staff. I led a more formalised outreach team whose work involved developing and delivering accessible, acceptable mental health services for minority ethnic elders. The various strands of our work came together and we were recognised through a Beacon award[2] , which led to opportunities for sharing our approach in local and national conferences. At the same time I began delivering sessions for pre-registration nurses at the University. I enjoyed the opportunity to influence others' practice, so halfway through my working life and after 20 years in nursing, began to consider an academic career. I joined BCU as a lecturer in 2004. My commitment to research grew as I realised opportunities to address some of the challenges raised in practice. This research echoes my practice values and concerns in giving equal value and attention to the needs of nurses as of patients and in revealing connections between nurses' well-being, their learning and their commitment to high quality care.

A range of evidence investigating training and educational interventions has aimed at improving dementia care in acute hospitals (Surr et al 2016) care homes (Surr et al 2019) and the community (Clemson et al 2018). However, ongoing debate over the past decade has increasingly focused on ensuring immediate post-training positive feedback can translate into recognisable practice change (e.g. Surr et al 2017, Morris et al 2018). I have been part of this debate (for example Jenkins, Smythe, and Galant-Miecznikowska 2014, Smythe et al 2016, Smythe et al 2020), contributing through a range of studies with original outputs that built and extended understanding in the field.

In summary, my research has focused on exploring factors that promote high quality care and interventions, nurses' perspectives on training needs and then on exploring the factors within and beyond teaching that may facilitate students' capacity to embed high quality care after the immediate post-learning time frame. In the sections that follow I will use an autoethnographic lens

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[2] *Beacon awards were a government initiative (around the year 2000) designed to recognise good practice and promote it. Grants of £25,000 financed training and conferences hosted by award winners

to analyse a range of my publications, highlighting important aspects of my professional development as a researcher and my publications' originality, rigour and significance.

The journey through my publications

This is an auto-ethnographic critical analysis and review which documents my journey across boundaries as a practitioner-teacher-researcher in the field of dementia care. The research methods, analytical approaches and all aspects of structuring and conducting rigorous and relevant research are reported in my publications. I have communicated findings and implications for practice to my academic, educational and practice worlds via peer reviewed journals, national and international conferences and the classroom. But this document you are reading now is a personal one. It ties together who I am as an individual, my personal and professional values and experiences, the conduct of my research, the studies' implications for my own learning and for others, and how the sum adds up to a picture of a researcher demonstrating their contribution to their field.

I will explain how I have addressed ethical dilemmas, outline my research skills and findings, highlight the relevance of my learning from befriending, analyse the threats associated with nursing culture and consider the nature of positive transcultural working in relation to my current research. I will explain how my findings around nurse education for person-centred dementia care indicate how adjustments can be made to promote sustained impact in practice. Lastly I will identify my own contribution to knowledge, in an analysis of the limitations of the person-centred approach in nursing and for nurse education, given the barriers within our culture and context.

I will now explore my research experience in the context of the cultures of dementia care practice and nursing education, relating how my studies grew alongside my voluntary befriending and training work with BUDS (Better Understanding of Dementia in Sandwell), how each influenced the other and how the research came to respond to my concerns about the experiences of people with dementia, their family members and increasingly, to the nurses and care workers involved in their care and support whom I teach at BCU. As the account proceeds I will consider my own experiences within these cultural contexts, reflecting on the process of learning about research by doing it, exploring the implications of researching the experiences of people like me, (who self-identify primarily as a nurse, while working in nurse education and research) and as Holman Jones, Adams and Ellis (2013:22) advise, 'embracing vulnerability with a purpose', aiming to engage the reader in the story of how I came to make original contributions that change dementia care nursing, through the lens of viewing nursing from insider and an outsider perspectives.

The social context of my work, gaining local understanding through befriending

I am not an insider where I live in the Black Country. I also cannot explain the experience of dementia from an insider perspective. My voluntary work with befriending services has helped me understand how positive a genuine person-centred approach can be, for the people with dementia, their family carer and for me. In my role as befriender I have supported five families, for an average of a couple of years each. Spending two to three hours a week with a person in their own home, getting to know them intimately, their histories and geographical connections, understanding their family and its dynamics, the person's anxieties and frustrations, what makes them happy and being there reliably as a listener, advisor and supporter, makes becoming person-centred natural. I am able to anticipate and prevent distress before it happens, model communication skills for family carers and support the people with dementia in continuing with activities that maintain their identity. The time I am there allows a break for the family carer, although often they use the time to talk themselves. The carer is never alone, but never has a meaningful conversation. Sometimes I feel regretful that I was not able to provide this standard of care when I was a nurse in practice, in some respects I am a better nurse now. I have the time to reflect on the meaning of theory (e.g. Kitwood 1997) and to be with people in a way I never could before. The role has many benefits for me, I get to practice nursing skills, understand the experience of living with dementia in more depth, realise the limitations of evangelical pronouncements about nursing possibilities and can use anonymised experiences for examples for teaching and for reflections for professional revalidation. I can use brief stories to illustrate points, as in this one for 'perseveration': 'by the time the carer and I had finished talking, the scarf she'd (person with dementia) knitted was long enough to reach the front door and back'. This story reflects the deep need for connection and time on behalf of the carer, our shared prioritising of her need for attention over that of her mother, our relationship, which by this stage was confiding and trusting, and the nature of her Mom, who at times was completely undemanding, living in an endless present moment. Afterwards we felt guilty, as if the abandonment could be measured in the rows of knitting, but also amused. The scarf really was incredibly long. Later the daughter told me she often unravelled her mother's efforts when she was asleep, so that the wool and activity could be regenerated again the next day, metaphorically reflecting how she often perceived the pointlessness of their existence together. But one day, when the old lady was knitting, she showed me some of her previous creations, little scarves of varying lengths. I laid them out on the coffee table to admire them. We could see that they could join together to make a blanket. We then spent many evenings together designing the blanket arrangements which I then sewed together, sitting on the floor at her knees (this was partly to stop her throwing things in the gas fire) while she clicked along above. These little blankets became sought after items for the next generation, who wanted something made by Nan for their own children. Her daughter found this very moving, as the mother had always provided for everyone and as a family they re- glimpsed her in her rightful matriarchal role.

Sandwell is in the Black Country, so I also get insight into a different dialect and how older people use expressions which seem to come from a bygone age. There is also a difference in education level and social class – often we begin by finding each other alienating. Gradually in each relationship we built rapport and mutual understanding through me listening to stories of their lives and finding meaningful activities to share. To the lady I visit now, I am 'our wench' which neatly covers not remembering my name and something about our relationship. I enjoy being in another cultural group, which I have observed to be tightly woven, very connected with the locality, valuing of traditions, both supportive and controlling of its members. When BUDS ask me to cover their training I can use the opportunity to encourage people who might not otherwise consider it, to think about applying for nurse education. If I need to recruit family carers for research, I can ask my BUDS contacts. So the work integrates with my role and research at BCU.

The professional context of my work

My work in teaching derives from practice-related values. Before I became involved in research in earnest, I had developed a range of brief teaching or training interventions for care homes and local authority care workers that ran alongside my pre and post-registration teaching responsibilities. I designed these with the dynamics I experienced in the world of dementia care nursing in mind. As practitioners, we were accustomed to putting patients' needs first, while neglecting our own and each other's and ignoring the emotional consequences associated with our roles. We disassociated from our own and others' emotions, risking failure of empathy and burnout (Edberg et al 2015). We spent all day listening to other people, but remained unheard ourselves. My research is about hearing people like us, nurses who are committed, hard-working, but often overwhelmed and invisible, then acting on lessons learnt.

I am a member of a small research team in which I work closely with a research nurse and a psychologist and then with research assistants and others according to the needs of the project. The team originated in my links with the local mental health trust and local authority, who asked me to collaborate in providing and evaluating brief training interventions and then in a study identifying the competencies required for effective dementia care within their services **(Paper 1).** Early team projects focused on the impact of learning on practice and how learning can be embedded post-practice. My role within this team is to lead on design of educational interventions and the qualitative elements of studies. I lead or am an equal partner in other studies focusing on aspects of promoting the well-being of people with dementia and professional and family carers and exploring online peer support for nurses (Table 2).

My research sits where a conflux of disempowered people meet in potentially further disempowering situations, in practice or in education. Nurses and care staff are under-valued (Royal College of Nursing 2020) although recently their contributions have been recognised, if not rewarded (Palmer 2020). Their expertise is often invisible, has low status and may be negatively affected through stigma by association (Scales et al 2017, Ebsworth and Foster 2016). They may struggle to articulate their techniques and competence and attribute positive outcomes with patients to ‘a magical touch’ rather than skills honed in years of patient-nurse interactions (**Paper 4**), reflecting conflicting indications of self-esteem, as they perceive themselves to be both more skilled than other professionals, as did Scales et al’s (2017) participants, yet simultaneously devaluing of their own professional expertise.

This undermining dynamic initially extends in projection of lack of expertise onto teaching staff in a similarly stigmatised specialism; as a tutor I am conscious of the priority of establishing my platform of expertise in dementia care practice experience while showing I have something extra to offer which will support students’ professional development, making their working lives easier and more satisfying. I have found I need to respond to these dynamics before we can relate to each other in a way that facilitates learning, and this continues through a session, module or programme as a background to the planned learning. I invite students in to a world of reciprocal recognition, where we feel confident and proud of our expertise, we can articulate it, challenge it and use it, not only for patients but also for mutual support and for re-establishing individual professional self-esteem (Maher et al 2017, Dey et al 2018, **Paper 15**).

In researching experiences of nurses and care staff before and after training or support interventions, I must acknowledge the dynamics inherent to their positions within health and social care (H&SC) services to challenge any ‘blame-culture’, including internalised negative perceptions from care providers themselves. ‘Person-centred care’, based on the work of Kitwood (1997) and others since, is argued to be essential for promotion of well-being among people with dementia (Brooker and Latham 2016). Person-centred care requires knowledge of individuals’ life-histories and consideration of how behavioural indications of distress may reflect unmet psychological needs, which should then be attended to sensitively and with appropriate communication skills (Morris et al 2018). While Kitwood (1997) and more recent authors who have taken his ideas forward (e.g. Brooker and Latham 2016) acknowledge the disadvantaging experiences of care workers, including registered and non-registered staff, this has not yet translated into the impetus for changes in conditions for these staff members; I feel that concern for their well-being is motivated by the impact of their poor quality working lives on those they care for, rather than for their own sakes. Policy rhetoric around quality of care is not supported by funding (The King’s Fund 2018); a long-standing problem which is particularly significant in dementia care (Alzheimer's Society 2018). In acknowledging that insufficient time is a barrier to person-centred care and that extra funding 'is not economically feasible' (Oppert O'Keefe and Duong 2018) it seems that the human and financial costs are to be borne by the least powerful actors in the care environment, care workers, generally women (Erol, Brooker and Peel (2016).

Throughout the process of learning from H&SC colleague research participants, I ensure that their well-being is not second to anyone else's. This is achieved through study design, ethical approval processes and by including stakeholders, including people with the same backgrounds as study participants in bid development and subsequently the research steering groups (Boaz et al 2018), for example representatives of patient groups (**Paper 4**) a nursing home manager (**Paper 8**) and a newly qualified nurse (**Paper 10**). Studies require ethical approval, but designing educational interventions does not, even though stakeholders' (eg commissioners, the Nursing and Midwifery Council, care home owners, health and social care managers, family members of people with dementia) intentions in ordering education interventions is to ensure quality of care, often leveraging power to hold individual staff members responsible for post-training actions, ignoring cultural and structural barriers to change in care environments and their own related responsibilities. As such nurse education and brief training interventions may be used as a method to control H&SC staff rather than for their empowerment.

My research papers (Table 2) are complemented by a range of articles, designed to counteract this dynamic, written for practitioners and student nurses (Table 3). Published in practice journals, they include **papers 11, 12, 14 and 15**. I am also lead author of a book (**Paper 13**). These sources are more accessible in both style and availability, and so more likely to influence and support nurses. The content reflects my teaching (**12, 13**), support and mentoring of colleagues (**14, 15**), and learning from and applying research (**11, 14**).

Table 2: Research papers

Paper number	**Paper title**	**My research activities** (CRediT – Contributor Roles Taxonomy (Consortia Advancing Standards in Research Administration Information (CASRAI) https://casrai.org/credit/)	**% contribution**	**Funded research**	**Theme**
Current study	Evaluation of an online peer support group for newly qualified nurses (research ongoing)	Conceptualisation, analysis, funding acquisition, investigation, methodology, supervision, writing (original draft), writing (review and editing)	40	*	4
Current study	A qualitative study exploring nurses' experiences of supporting South Asian people with dementia and their family carers (research ongoing)	Conceptualisation, analysis, funding acquisition, investigation, methodology, project administration, supervision, writing (original draft), writing (review and editing)	50	*	1, 2, 3
10	**Jenkins, C,** Oyebode, J, Bicknell, S, Webster, N, Bentham, P, Smythe, A (2021) Exploring newly qualified nurses' experiences of support and perceptions of peer support online: A qualitative study *Journal of Clinical Nursing* *https://doi.org/10.1111/jocn.15798*	Conceptualisation, analysis, funding acquisition, investigation, methodology, supervision, writing (original draft), writing (review and editing)	40	*	4
9	**Jenkins, C**, Webster, N, Smythe, A and Cowdell, F (2020) How do registered health and social care practitioners change their practice post Mental Capacity Act training? A narrative review *Journal of Clinical Nursing* https://doi-org.ezproxy.bcu.ac.uk/10.1111/jocn.15256	Conceptualisation, analysis, investigation, methodology, project administration, supervision, writing (original draft), writing (review and editing)	80		1,2,3
8	Smythe, A, **Jenkins, C,** Oyebode, Bentham, P, Dyer, J, Downs, M. Galant-Miecznikowska, M (2020) A Qualitative Study exploring nursing home nurses' experiences of training in person-centred dementia care on burnout *Nurse Education in Practice* *https://doi.org/10.1016/j.nepr.2020.102745*	Conceptualisation, analysis, funding acquisition, investigation, methodology, supervision, writing (original draft), writing (review and editing)	40	*	1,3, 4

7	Webster N., Bentham P., Smythe A., **Jenkins C.**, & Oyebode J. (2019). Experiences of peer support for newly qualified nurses in a dedicated online group: Study protocol. *Journal of Advanced Nursing*. 75, 1585-1591. https://doi-org.ezproxy.bcu.ac.uk/10.1111/jan.14001	Conceptualisation, analysis, funding acquisition, investigation, methodology, supervision, writing (original draft), writing (review and editing)	40	*	3
6	**Jenkins, C.** and Feldman, G. (2018), Recognition of pre-clinical signs of dementia: A qualitative study exploring the experiences of family carers and professional care assistants. *Journal of Clinical Nursing.* 27 9-10 1931-1940 https://doi.org/10.1111/jocn.14333	Conceptualisation, analysis, funding acquisition, investigation, methodology, supervision, writing (original draft), writing (review and editing)	80		2
5	Smythe A., **Jenkins C.**, Galant-Miecznikowska M., Bentham P., & Oyebode J. (2017). A qualitative study investigating training requirements of nurses working with people with dementia in nursing homes. *Nurse Education Today*. 50, 119-123. https://doi.org/10.1016/j.nedt.2016.12.015	Conceptualisation, analysis, funding acquisition, investigation, methodology, supervision, writing (original draft), writing (review and editing)	40	*	1, 3
4	Smythe, A, **Jenkins, C.,** Bentham P. & Oyebode JR (2015). The experiences of staff working within a specialist mental health service in relation to development of the skills for the provision of person-centred care for people with dementia. *Dementia* Vol. 14(2) 184–198 https://doi-org.ezproxy.bcu.ac.uk/10.1177/1471301213494517	Conceptualisation, analysis, funding acquisition, investigation, methodology, supervision, writing (original draft), writing (review and editing)	40	*	1, 2, 3

3	**Jenkins, C**, Smythe, A and Galant-Miecznikowska, M (2014) How can training interventions for nurses promote person-centred dementia care in nursing homes? *Mental Health Nursing* 34(5) 16-19	Conceptualisation, analysis, funding acquisition, investigation, methodology, supervision, writing (original draft), writing (review and editing)	60	*	1, 2, 3
2	Smythe A, Oyebode, **Jenkins, C**. Bentham P. (2014) An evaluation of an innovative approach to training for staff working with people with dementia in acute hospital settings. *Nursing Older People*, 26, 2 18-24. Doi 10.7748/nop2014.02.26.2.18.e527	Conceptualisation, analysis, investigation, methodology, supervision, writing (original draft), writing (review and editing)	40	*	2, 3
1	Smythe, A, **Jenkins, C**, Bentham, P and Oyebode, J. (2014) Development of a competency framework for a specialist dementia service, *The Journal of Mental Health Training, Education and Practice*, Vol. 9 (1), pp.59 – 68 doi: 10.1108/JMHTEP-08-2012-0024	Conceptualisation, analysis, investigation, methodology, supervision, writing (original draft), writing (review and editing)	40	*	1

Table 3: Practice papers

	Paper title	**% contribution**	**Theme**
15	**Jenkins, C** and Germaine, C (2018b) Solution-orientated learning to build resilience in mental health nursing students and recently qualified nurses *Mental Health Practice* 21 (7) 24-27	80	1, 3, 4
14	Bale, L and **Jenkins, C** (2018) Nursing students' experiences of delivering dementia friends sessions to peers *Nursing Older People* 30, 6 doi: https://doi.org/10.7748/nop.2018.e1046	50	2, 3
13	**Jenkins,** C, Ginesi, L and Keenan, B (2016) *Dementia Care at a Glance* Chichester. Wiley	50	2
12	Bunting, M and **Jenkins, C** (2016) Transcultural nursing strategies for carers of people with dementia *Nursing Older People* 28 (3) 21-25 DOI: 10.7748/nop.28.3.21.s23	50	2
11	**Jenkins, C,** Smythe, A, Galant-Miesznikowska, M, Bentham, P and Oyebode, J (2016) Overcoming the challenges of conducting research in Nursing homes *Nursing Older People* 28 (5) 16-23	60	2, 3

Applying values when planning learning and research

Insight drawn from interviews and focus groups (**Paper 3, Paper 5**) (and my own experiences in health care), led me to plan and manage the learning opportunities with person-centred values in mind, but counting the 'persons' in the room - the learners - as equally important members of the care triangle. I see it as my responsibility to listen as well as talk, learn who they are as individuals as well as a group, what their emotional as well as learning needs are, how they prefer to learn, and to structure learning to meet peoples' needs, empower them and promote their professional autonomy, if they want this. I take a person-centred approach to teaching, using Rogerian values (Rogers 2004), believing in the learner's capacity for growth and supporting them using empathy, congruence and unconditional positive regard and providing a social environment conducive to learning.

I have used these values to underpin a range of modules for pre and post registration nurses, allied health professionals, and for the local authority and local trusts in a range of brief training interventions. My research informs my teaching – the dialogue between them is based on application of values and evidence to empower nurses and their service-users.

This research sits at a juncture of ethical values; where rights of the cognitively impaired are highlighted and nurses' responsibilities emphasised, but where moral responsibility towards nurse and care worker colleagues is often unacknowledged. I barely recognised it myself at first, despite my similar professional experiences of taking responsibility for consequences of unreasonable workloads, then feelings of guilt and inadequacy as a result of inevitable gaps in care. Like other nurses, I internalised values which became so taken-for-granted that they were imperceptible. 'Blaming the victim' is a handy political tactic, but more effective when the victims can also blame themselves and then in some cases position themselves in education to acculturate the next generation. It is disempowering to accept that part of one's identity can be perceived as victimised. Perhaps driven by denial, I had not really appreciated the extent to which these values were systematised and structured into nursing practice, nor that I was colluding, nor that many other nurses' experiences were far worse than my own.

Responding ethically to difficult dynamics: stories from practice link with stories in research

Nursing research ethics protect participants, researchers and the research process (Doody and Noonan 2016). As a researcher my responsibilities include being alert to potential harm to all parties, and to incorporate sensitivity to issues that may lead to harm or distress. For example, in **Paper 6**, early identification of dementia could lead to suicidality (Hodge 2018), while misuse of data would undermine the autonomy of participants, break the law (Mental Capacity Act 2005) and potentially disadvantage future generations. The field of dementia care and dementia research is full of ethical dilemmas, even leaving aside physiological research around prevention and treatment. Questions such as 'whose interests should prevail?' (E.g. patients' or carers'? **Paper 8**) 'What degree of adjustment is it reasonable to expect from family or paid carers?' 'How should this work be recognised and remunerated?' 'How can the rights of people with dementia be upheld?' (**Paper 9**) all lead to ethical quandaries where the researcher must balance respect for participants' autonomy, their duty to do no harm, and openness to challenging perspectives, all of which have the potential to undermine current services and people whose livelihoods depend on the current model. When research uncovers poor practice (**as in Paper 8**), the researcher must address the consequences, moving beyond finishing with 'more research is required', the conclusion must sometimes be '*this situation must stop* '.

As a researcher I must manage and support the emotional well-being of participants, while often encouraging them to share their difficult stories about practice and their roles in services (**Paper 5**). As a nurse I am aware of many similar stories to those I have heard from participants, often their reports trigger my own memories of significant professional challenges, requiring me to 'remain with' the participant and be a witness to their story, rather than reflecting on my own. My ethical responsibilities in research extend to managing my own emotional well-being, often in the context of having chosen to explore areas which I know could become problematic (**Papers 1, 3, 4, 5, 7, 8, 9**).

The stories I heard from research participants were often difficult to listen to, especially when their recollections elicited my own. Many highlighted the discrepancy between managers' understanding of the nature of nursing and their expectations for priority in response to adjust around their priorities rather than around those of service users. For example, nursing home nurses reported being asked to save on essential continence care resources, despite the consequences for pressure area care and service-users' dignity (**Paper 5**). In another case I was asked at very short notice to attend a meeting about the Beacon award , at the time I was on my way to help a carer whose husband who had dementia had become stuck inside a small wardrobe and was not able to extricate himself. The manager felt I should leave him there and prioritise the meeting and took a negative view of my conflicting priority and decision. In my current study, a participant described how an interpreter had a private conversation with a patient, making her feel as if she was a spare part in the interview, disengaged, disempowered and superfluous. It reminded me of the time when I challenged the interpreter about an aside she was having with a patient's family, and she said with no hint of concern that they were selling her a carpet. Participants described times when interpreters had refused to ask sensitive questions about alcohol use or suicidal thoughts, which reminded me of when an interpreter refused to tell me what the patient had said, she believed the patient's account of bad spirits in the house and had become afraid to say anything in front of them. I felt homesick for practice and the geography of multi-ethnic Birmingham where sudden reveals of opposing cultural assumptions required a rethink of priorities and sensitive re-navigation to ensure we worked together again in the same conversation, acknowledging and often enjoying discovering our different perspectives (explored in **Paper 12**). Once, after a long and trying assessment via an interpreter, I thanked the old lady for answering my questions, saying 'do you have any questions for me?' 'Yes' she said, 'do you keep sheep or goats?'

Keeping sheep or goats can be both a real assessment, if we were in Pakistan, or a useful metaphor for how rich or poor a person is, something I did not realise for a long time. In the moment I was more taken aback by her grown-up grandson, who did actually roll about on the floor in uncontrollable laughter. Goats can cope with the challenging terrain of poor peoples' pastures, while 'sheep' as a metaphor in English relates to people who follow the crowd. Dementia care is definitely goat territory, a difficult and relatively unsupported domain where both patients, families and staff have to keep on going, using their initiative, calling in favours, without always knowing if they will cope or how, taking calculated risks, balancing rights and constraints, all without falling off a precipice into disaster when care fails. Participants often spoke of situations, familiar to me, where they were called to an emergency by a patient's family, only to be reprimanded by senior management when some administrative detail had been overlooked as a result.

Personhood and person-centredness: Values driving approaches to teaching and research

In retrospect, I can see how practice experiences shaped me as a researcher, in that (in common with Bochner and Ellis 2016) my motivation is about justice, for nurses as well as their patients. But the immediate impact of hearing the stories was to intensify my determination that people would feel seen in my teaching and perceive empathy and person-centred attention. So, initially more about care than restitution. I felt that without this therapeutic element, any attempt to develop understanding designed to change practice would be futile (**Papers 2, 3, 4, 8, and 15**). I wanted a feeling of emotional safety in the classroom, so that students would feel able to take risks in considering new perspectives and unthreatened as they reflected on previous practice norms and allowed themselves then to build new practices. This attention to personhood reflects the practical and ethical guidance Kitwood (1997) finds essential in the care of people with dementia, as well as the person-centred approach to counselling (Rogers 2004). I was also influenced by ideas behind constructive alignment (Biggs 1996) and adult learning (Mortiboys 2012, Race 2014), which I interpreted as an educator's responsibility to create learning opportunities which were engaging, active, relevant to practice and which involved mutually supportive social relationships between students. The taught content reflected the gaps identified in the literature (Surr et al 2017), my own practice experiences and BUDS relationships which helped me understand how person-centredness could have a deeper impact, and the issues that research participants highlighted as required for positive effective dementia care in their settings. The content also reflected the National Dementia Curriculum (Waugh et al 2013) (for which work from **Paper 1** informed my contribution). It covered not only basics about the nature of dementia, but putting theory into practice around communication skills, responding to distress, environmental adjustments, carer support and other issues directly relevant to everyday dementia care, based on the work of Kitwood and others (Downs and Bowers 2014, Brooker and Latham 2016).

Qualitative research skills: Exploring nurses' learning needs, finding out about emotional needs too

This account and my research are subjective. The need to understand my own (through this account) and other nurses' lived experiences (through the research studies) reflects my belief that knowledge of how people make sense of their reality (an interpretivist epistemology (Holloway 2005)) is valuable for identifying, gaining insight into and subsequently addressing the issues nurses face in applying learning in practice and more generally in our working lives. I believe that reality is 'an ongoing social act' (Coule 2013:152) constructed by and reflected in the perceptions of the people involved, and that understandings can be reached through exploring them.

Most of my studies have been situated in the constructivist paradigm, using shared language and insider knowledge as a means to gain access to participants' views, but in **Paper 10** I took an interpretative phenomenological approach. Whilst aware phenomenological research and constructivist approaches can sometimes be in conflict, use of a different method allowed me to understand participants' lived experiences afresh, putting preconceptions aside (Finlay 2009) and aiming for more nuanced, deeper insights which go beyond accepted subjective and objective dualism, revealing a shared universal perspective of phenomena.

As a researcher with a shared nursing background I value being attuned to the everyday existence of others in professional situations that matter to me (Holloway 2005) and acknowledge that I become part of the research through the process of designing studies, asking questions and interpreting data.

When I began the research studies my ontological position was taken-for-granted or 'unexamined' (Coule 2013) rather than considered, carefully chosen, explicitly identified and embedded, as recommended (Crotty 1998). I gradually came, in a back-to-front process, to realise the importance of identifying my own theoretical perspective, with aligned epistemology, through the iterative process of conducting the studies and learning from each, and in writing this critical analysis and review. So my identity as a researcher has grown over time, in becoming more competent in conducting and reporting qualitative research and in understanding my position in relation to the principles that underpin it.

This constructivist ontological position and interpretative epistemology are aligned with exploratory, qualitative methodologies. Research design decisions accordingly resulted in methods in which participants' experiences of their working lives could be heard and valued. Focus groups and individual interviews offered a means to collect rich accounts which became my data. Thematic analysis (e.g. Braun and Clarke 2014) allowed me to interpret and gain insight into my areas of interest.

In the first stages of the early studies, I explored learning needs with a view to designing learning to fit the particular needs of nursing home nurses, mental health specialist nurses, acute nurses, and currently, nurses supporting South Asian families caring for a person with dementia (Papers 1-5, Themes 1, 2 and 3). My focus was on identifying gaps in understanding and skills, priorities for learning and the needs of service users in different care environments.

I drew on my expertise as a mental health nurse to conduct focus groups, which were valuable for gaining insight into participants' experiences, feelings and opinions. As a nurse and nurse researcher, I was both one of them, but not one of them. Sometimes I found myself asking the questions I wished someone had asked me, perhaps to validate my own prejudices and experiences. I was once a research participant and enjoyed the sense that my opinion and feelings (about ethical decision-making for and with people with dementia) might change future practice (Brannelly 2006). Now when I do interviews and focus groups I find myself emphasising respect for the time and attention participants share with me, in return trying to convey that I will interpret their words with integrity. The skills of a mental health nurse are transferable to managing a focus group or interview. The researcher needs to put aside their own assumptions, listen acutely and encourage the person to tell their story without leading them, nevertheless conveying encouragement and empathy. It is also important to bear the research focus in mind, manage and structure the questions and timings. (Subsequently the researcher must ensure verbatim transcription and protection of anonymity through rigorous data storage and later, deletion). After the interview, participants should feel validated, hopeful and that they have contributed to something worthwhile. I worked with a co-researcher, also a mental health nurse; in a shared series of projects we have alternated and shared roles through leading and conducting them, sometimes one being to the fore and sometimes the other. Having a peer with whom to share thoughts honestly, and to consider different perspectives on the way to framing our questions and deliberate around how to listen to people and to conduct interviews and focus groups with empathy, seemed to help participants feel safe and so expand on their thoughts with us.

I came into the early stages of the research journey with some insights into the practical difficulty of applying learning in practice drawn from my own experiences, but it was only after the initial exploratory studies (**Papers 1, 2, 4, and 5**) that I came to realise the extent of these issues. As a nurse I am acculturated to the desirability of expressing only concern for patients and their relatives, not my own needs or those of my colleagues, so I focused initially on improving care. However, with each preliminary study I found that nurses' emotional needs were at the forefront of their experiences of nursing, when asked about gaps in skills and knowledge, regardless of qualification status or setting, people often replied about feelings.

Ethical quandaries in dementia care research

My research also seeks to answer the question 'what works in teaching and learning in dementia care?', but this too resulted in ethical dilemmas. Some aspects of learning can be measured, although I have taken a qualitative approach to answering this question, believing that the answers lie in the outcomes as experienced by learner participants. It could be argued that service-users could report more meaningfully on differences to their care post-learning. Dementia is a long-term condition, but by the time it has progressed to the extent that nursing care is required, the person would find it much more difficult to articulate their thoughts about how care has changed. People with dementia have very poor short term memory, so would not remember who had cared for them or how. As memory is lost on a generally 'last in first out' basis, a person may go back in time to feel they are young again (Robertshaw and Babicova 2020). Expecting them to account for recent experiences and information would be unrealistic, force them to confront their inabilities and conflict with principles of person-centred care. An observational process 'Dementia Care Mapping' (DCM) (Griffiths et al 2019) can be used to assess nurses and carers interactions and approaches, it is framed to gauge this from the perspective of the person with dementia. This is a very different approach to gaining a person's perceptions through their own words, as in interviews or focus groups.

As part of the nursing home nurses' training requirements study (**Paper 5**), I trained as a DCM mapper, (a role which involves systematic observation and recording of the actions experiences and emotions of a people with dementia throughout a day) and as part of a small team 'mapped' several care home environments before and after brief training, for comparison. The DCM training was comprehensive, but ethical issues around capacity and consent, together with practical issues in the care homes, meant we felt uncomfortable about using this data. In compliance with the Mental Capacity Act (2005), care home managers or family members gave proxy consent on behalf of non-capacitous residents, who were unable to consent to the intrusion into their living space (mapping only takes place in shared spaces, not bedrooms or bathrooms). It became clear that residents without dementia resented this intrusion, as did some staff members, who coped either by avoiding rooms where mappers were, or by going the extra mile for the residents they thought were being mapped at the expense of other residents. It also became clear that the care home workers had little idea about the diagnoses of their residents, we were often directed to observe people who remembered us between sessions and who did not have dementia. Another ethical issue was the difficulty of not stepping in to address neglect. As a researcher I could not become a nurse, yet the need for nursing care felt far more pressing. Basics such as taking residents to the toilet and giving them food while still hot were often left undone. One resident who was Punjabi speaking told me she had not spoken to anyone for months, no one spoke her language. She constantly tried to engage me in conversation and begged me to phone her family in India throughout each visit when I was supposed to be observing other people. In common with Rosenhan's (1973) patients, the residents had more idea about each other's mental health than the staff did.

These difficulties, and other serious issues – fire exits being triple locked, abusive interactions, residents with capacity clearly asking the research team to arrange their transfers out of the care homes we visited, research participants challenging practice as a result of training and then being fired, others reporting being charged for certificates provided for free through the research funding - meant that conducting research in care homes felt like a barrage of ethical challenges. The question was not so much about what to do (report to the Care Quality Commission [3]* (CQC)) as when to do it. As individuals we each had to choose whether we were a nurse first and researcher second, or the other way round. We discussed ethics practically, pragmatically and frankly. Ethics were no longer abstract concepts or a stepping stone to the next stage of a project. We divided into utilitarian pragmatists who, having weighed up alternative consequences, prioritised getting the job done, versus me, arguing that regardless of the consequences we had to do what we knew was the right thing for the patients, at the time that was best for them (right away). Bochner and Ellis suggest that ethical conundrums are usually unanticipated before a study begins, so researchers should do as we did, respond in real time, 'negotiate and try to resolve misunderstandings and disagreements' (2016:154) re-examining ethical questions, ensuring they take care of the participants but not forgetting the duty of self-care either.

I am a nurse first, but I did not get research ethics permission to be a nurse. My role was to observe, listen, learn, apply learning and report. As a team we had ethical duties to the funders too; reporting to CQC too early would put the whole project in jeopardy, undermine relationships which had taken months to build, possibly undermine future research for other researchers in nursing homes, and neglect the aims of our own projects, which were to improve care through empowering educational interventions for staff. We held off.

We completed the project then called CQC. Of course we could not hope to change practice more broadly if we stopped the project early, so it could be argued (and was) that for the greater good, we should continue. But now when I pass a care home I wonder how many people there would beg any stranger to help them escape, how many do not have basic needs met, how many are desperately lonely. But the initial exploratory research did not only highlight residents' distress, the nurses and care workers were similarly emotionally and practically neglected. Many told stories of working unpaid hours and missing their children, missing breaks and meals, managing residents' diabetes but not having time to manage their own, dealing with abusive relatives and exploitative care home owners, feeling deskilled and that no other employment options were open to them. One remembered fondly how an agency nurse once thanked her. Many spoke through tears.

Conducting research in care homes was challenging. The practicalities made each step time-consuming and frustrating. For example the staff turnover meant that often appointments were made with a person who was no longer the home manager the following week. In an evaluation for Birmingham Care Development Agency, when initial iterations of training for carers had positive feedback, for the next run the care home managers sent themselves, to see what was going on, undermining implementation fidelity and necessitating another week's sessions.

In the study evaluating training for nursing home nurses (**Papers 3 and 5**) we faced multiple barriers, mainly driven by costs, as even when training was free, the backfill of staff was difficult due to staffing levels. At the time there was no guidance for conducting research in care homes. Our experiences revealed a gap in the evidence base around nursing home care, we found many challenges there for residents and staff, and for ourselves as researchers. I wrote a practice paper about these challenges with thoughts on how to overcome them, to aid future researchers by

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[3] *Footnote: The Care Quality Commission is the independent regulator of health and social care in England*

alerting them to potential barriers and with suggestions for how these barriers could be overcome (**Paper 11**). The initial feedback from reviewers was that the article was too pessimistic, directing for it to be toned down. This indicates another form of pressure on nurses to focus optimistically on what we can do rather than challenging the systemic barriers that may obstruct us.

Nursing culture revealed through research: disempowered, but still brave

When asking nurses questions about how they practice, or what their learning needs are, the subtext implies to the respondent that they are the 'fixable' factor; by learning new skills and understandings it is you who will be able to put these things right. The care home nurses answered these questions in this spirit. They wanted to improve care, take a more person-centred approach and to take responsibility for this. The same has applied to other groups of nurses, acute, mental health and those involved in transcultural dementia care, whose views I have explored in theme 1 studies. The first study (**Paper 1**) was conducted before I began investigating learning needs specifically. I led the qualitative component of a mixed-methods study to underpin development of a competency framework for the local mental health trust, reported on in more depth in **Paper 4**. By informing the National Dementia Curriculum (see above) this work has influenced nurse education at BCU and training for local trusts and social care workers in Birmingham and beyond.

Our participants were remarkably honest about their stressors, emotions and abilities, even though their employer had commissioned the study and they were aware of how the findings could be used. Ethical approval was in place and participants were made aware, via the usual participant information and consent forms, of their rights and our responsibilities to them in relation to anonymity and confidentiality. Nevertheless, the conversations often felt risky. As a previous NHS employee, I knew how power could be abused and oppressive management practices be leveraged from seemingly innocent encounters. When asked to be frank, many NHS workers would know to become more guarded. Once when I responded with honesty to a senior manager's request, he grabbed the phone so he could make an emergency call, saying my words were about to cause a coronary arrest, effectively both silencing and distracting from my argument. Hiding or minimising honest responses in self-protection could be viewed as legitimate and protective, given our history. Many oppressed minority groups make the same arguments (Tekeste et al 2019), sharing truth with oppressive powerful groups is unnecessarily exposing and may reveal weaknesses which could later be exploited. 'Speaking Truth to Power' is considered brave and empowering (Berry-McCrae 2018), but sometimes risky and limiting (Lilach 2020). Many of my Caribbean patients, having told me their stories, would advise against doing the same, saying, 'don't tell nobody your business', revealing ambivalence about the benefits of openness. Mental health nurses can remove peoples' liberty and combine with others to force medication and other treatments against peoples' will, but my studies' narrative and a theme which runs through many papers (**1, 4, 5, 9 and 10)** indicates they do not generally consider themselves to be powerful. In my research I am effectively asking a vulnerable group to 'tell me their business'. Therefore I and my research colleagues have a duty of care, to protect participants from any further disadvantaging and even abusive consequences of sharing their stories, then to present their perspectives clearly, justifying their trust by disseminating findings effectively to enable practice change.

In **Papers 1 and 4**, and others (**Papers 3, 8, 9 and 10**) the nurses talked about disempowering elements of their roles, including feeling side-lined and of lesser status than other professionals. They spoke with respect and admiration of their Health Care Assistant (HCA) colleagues, feelings which were not often reciprocated. Neither group valued formal learning; all agreed that nursing is a vocation, that person-centred care cannot be learnt (although it's possible to model yourself on a colleague) and that you are born with 'it', or not. These feelings were echoed by family carer participants' opinions, they noticed a 'knack' and felt good care came from the heart. Even a nurse manager agreed that empathy cannot be taught.

These beliefs contradict well-known evidence about the impact of nurse education on recovery and mortality (Aiken et al 2012, Chau et al 2018) and reveal conflict within the profession about the relevance of evidence based-practice, values and critical thinking abilities we aim to promote (Lasater, Atherton and Kyle 2020). Not only that, the cumulative impact of this belief system (projected onto, but also internalised by the nurses) seems to undermine nurses' confidence, self-respect and ability to respond assertively to under-estimations of their competence and their potential to drive practice change. In this dynamic nurses are held within a 'double-bind' (Hornung Lampert and Glaser 2016), in which contradictory assumptions disable their subjects. Nurses simultaneously feel angry and undermined by beliefs about their competence, which is 'magical' rather than learnt and earnt, so cannot then dispute others' evaluations of their abilities, thus reinforcing their 'one-down' position, and further undermining self-belief. The absence of professional confidence has significant ramifications for the profession and our patients. This is powerfully illustrated in **Paper 9** in which nurses, the very people who are likely to know patients best, report deferring to doctors and other professionals when involved in best interests decision making.

Burnout and the threat to nurses and nursing

Many of my studies (**Papers 1, 3, 4, 8, 9 and 10**), point towards nurses' weak sense of 'self-efficacy', a characteristic associated with burnout in response to stress (Yao et al 2018). Burnout refers to a state in which a professional feels emotionally exhausted, with a sense of depersonalisation and low personal accomplishment (Mudallal, Othman and Al Hassan 2017). It can be measured using the Maslach Burnout Inventory (Maslach, Jackson and Leiter 1996), as used in **Paper 2**. Burnout is associated with high work demands, long hours, lack of autonomy and role conflict (Manzano-Garcia and Ayala (2017) and results in nurses intending to (or actually) leaving the profession (Webster et al 2019). Hornung Lampert and Glaser (2016) identify that professionals coping with contradictory demands but who have autonomy in their roles manage more effectively; this is confirmed in the findings of **paper 14**. However, findings more commonly highlighted the contrast between nurses' wish to provide excellent care for patients while neglecting to ensure care for themselves and their colleagues (**Papers 4, 5, and 8**). Weak 'self-efficacy' implies little autonomy. Despite guidance and analysis around the autonomous nature of the professional nurse (Appleby and Roberts 2019), this was absent from the experiences described by research participants, with negative consequences for patients (**Paper 9**) and nurses (**Papers 4, 5, and 8**).

The studies combine to indicate that a person-centred approach is required for both patients and nurses

Conversations with the nursing home nurses in focus groups (**Papers 3, 5 and 8**) were startling in highlighting the extent to which the nurses felt that despite their own difficult working conditions, lack of control within their roles and consequent feelings of burnout they remained committed to providing a high quality of life for their residents. The 'double-bind' around little control but excessive responsibility and blame that is implicit within nursing culture is rarely challenged. Nurses frequently take responsibility for the consequences of structural problems, even though no amount of individual change could impact on more than the immediate care provided by a team, and sometimes not even that. As a nurse researcher and educator, it is difficult to disentangle myself from this dynamic, while aware of the impediments associated with under-funding and undermining hierarchical relationships I too have taken responsibility for unreasonable unrealistic practice objectives, taught nurses that you ‘can change your corner of the world’ and conducted research that promotes and then evaluates ‘person-centredness’ even though this is dependent upon resources which may not be available (**papers 2**, **4, 5 and 8**). Nurses are taught throughout pre-registration curricula to be person-centred (van Leeuwen and Jukema 2018) and continue to aspire to this principle (van Bogaert et al 2017). The exploratory study (**Paper 5**) indicated nursing home nurses valued a person-centred approach but the challenges of staffing levels often inhibited their ability to act accordingly (in **Paper 2** barriers were time and the physical environment). Nurses recognised that active engaging relevant learning opportunities would help them learn new knowledge and skills and commit to a person-centred approach, but when it came to embedding learning in practice long-term, even after working with a practice coach, results were mixed (**Paper 3**).

This dynamic became even clearer in **Papers 4 and 5**. Exploring acute mental health nurses’, mental health nurses’ and nursing home nurses’ experiences revealed similar experiences and emotions in different settings. These findings reinforced the requirement for a person-centred approach in nurse education, but also led the team to consider whether further supportive interventions could embed learning (and subsequent self-efficacy) more effectively, but also support the nurses’ mental health. The educational interventions I and the team developed thus incorporated supportive guidance in practice (**Paper 2**) leadership skills (**Paper 5**) and supportive clinical supervision (**Paper 8**). While the nurses reported these interventions were helpful in improving the quality of their interactions with people with dementia, and that they felt more optimistic about their ability to do so, the findings related to individuals rather than the cultural and environmental contexts that would be required to sustain practice change. Nurses face the difficulties of coping with both their patients and the dynamics of the workplace and culture. In considering whether emotion-focused support or ‘problem-based control coping’ was most effective, Hornung Lampert and Glaser (2016) found that an emotional style was associated with ‘prolonged involvement in psychologically dysfunctional work situations’ while taking control of problem-solving (ie being solution-focused) helped workers maintain mental health and deal with contradictory demands. In my teaching practice I often combine being person-centred and empathetic with a solution-focused approach (Franklin 2015) to problem solving. Supporting nursing students to learn this thinking style can empower them to manage their own stressors and be focused in managing their own development, with a view to building resilience and lessening risk of burnout. I wrote two practice papers promoting this style of interaction with student nurses (**Paper 15**) and Jenkins and Germaine 2018a) and presented this at an international nursing conference in Japan.

I apply study findings too in my teaching of nurses and in mentoring junior colleagues. There are three strands to this: While I found I was increasingly drawn to the idea that the emotional experience in the classroom, and in learning relationships, was equally as important as the taught content, I also wanted to contribute to teaching self-efficacy through a solution-focused approach, while developing the mental health nursing evidence base, to build nurses’ confidence (Jenkins and Germaine 2018a, **Paper 15**). The student nurses in **Paper 14** felt confident in their platform of expertise, and within a less demanding context this was reflected in high levels of motivation and feelings of satisfaction within their role.

In more recent papers (**Paper 9, Paper 10**) I note the structural limitations which interact with cultural factors to disempower nurses and at times even make us complicit in our exploitation. Acceptance of the constraints of our professional world seems endemic in health care, leading to recommendations for personal responses, including resilience building, in response to cultural and structural problems such as hierarchical relationships and chronic under-staffing. This trend is reflected in Erol et al's (2016) review as well as much of my own work. Thompson (2016) argues that although structural change is essential for preventing oppression, having awareness of the impacts of marginalisation while contributing through personal interventions (such as a solution orientated approach to managing workplace stressors **Paper 15**) means a worker can become part of the solution.

My most recent study explores recently registered nurses' beliefs about online peer support (**Paper 10**). Subsequently an intervention was created and evaluated; early findings indicated nurses' experiences of being newly qualified were equally if not more difficult to my own 30 years previously. Unfortunately an online chat resource was not perceived as safe and so did not enable the newly qualified nurses to alleviate each other's worries (paper in review).

Building the platform of expertise for professional confidence: The example of new knowledge of early indicators of dementia

Nurses from all professional backgrounds (and more widely in my teaching for allied health professionals) have been interested in dementia as a condition affecting their own family members, as well as many of their patients. Many described fearing dementia and the sense that its development was something out of anybody's control. In countering this message, the argument that something can be done to postpone, if not prevent it, depends on very early identification of clinical signs (Mitchell et al 2013). I worked (**Paper 6**) with a colleague from another faculty, our intention was to develop machine learning algorithms based on my literature search and research findings. (However, unfortunately it emerged that the collaborating partners' objectives were to monetise insights from the research in unethical strategies which could harm potential participants and the public, by using data without permission and selling it to insurance companies). Challenging their assumptions that this behaviour was acceptable was extremely difficult.

I conducted focus groups of family and professional carers, asking about the time before they realised their relative/patient developed dementia. We confirmed known factors (eg. subjective complaints about memory, low mood) and identified a previously unknown characteristic, 'low threshold of frustration'. Our recommendations have implications for practitioners, who can use a simple question to identify the need for a more in-depth assessment, so that the person affected can follow health promotion advice and take anti-dementia medication at a time when it is more likely to be effective. This paper has been cited in relation to stigma reduction (Young et al 2019).

The process of conducting this research was very affecting. I had previously run carer support groups and recognised the dynamic in the focus groups. It was difficult to balance the need to explore experiences with the feeling of wishing to provide emotional support, guidance and to promote mutual support in the dynamics of the groups. With the professional carers, this was less pronounced, but here I felt the need to validate their professional self-esteem. The Rogerian approach to facilitating focus groups was sometimes too effective, as unconditional positive regard may have led some carers to feel free to express racist opinions. The factor that brought people together was a relative's diagnosis, which is common across social groups (Russ et al 2013). I was able to draw offenders away from their topics, but did not directly confront them as I would normally have done. I was aware of the need to make people feel safe in the discussion, being judgemental would have had an inhibiting effect on other participants. In retrospect I wish I had been more assertive. Especially since the Black Lives Matter movement I am more aware of the impact of silence as a form of collusion.

This project (**Paper 6**) was a useful learning experience. Not only was I leading it, but the staff in the wider team in the other faculty had very different ideas about ethical approval and I had to be assertive (successfully so) in protecting data and in ensuring the dissemination process was fair and followed nursing journal and HELS faculty standards. Staff in the other faculty had technological solutions in search of a problem to solve, it was interesting to see how some senior academics (not my co-author) felt that people with dementia did not have agency or rights. It was anxiety-provoking to resist this pressure, an experience that was reminiscent of standing up to consultant psychiatrists as a junior nurse. The study resulted in practical, applicable knowledge for dementia care nurses, but also reminded me of the core need to feel confident in a well-argued point of view, especially when advocating for people with little ability to be heard.

People with dementia and other service users may need nurses to advocate on their behalf. Facilitation of a strong knowledge-base in relation to professional confidence has become a thread that runs through my practice, teaching and research. Nurses need professional confidence, with a solid platform of knowledge upon which to base their position. A narrative review (**Paper 9**) ('What is the nature of Mental Capacity Act training and how do health and social care practitioners change their practice post-training?') began as an exercise in developing research skills, but aligned well with my teaching and practice. For this review I appraised 16 relevant papers and reported findings using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). I often teach nurses and allied health professionals how to apply the Mental Capacity Act (2005). The review revealed how active teaching approaches with scenarios for applying knowledge, make learning more effective. But significantly the review identified contextual barriers, mainly related to a hierarchical culture in health care, to effective implementation of the legislation. Again the findings reflect the sometimes harmful nature of healthcare culture and need for nurses to be inoculated against it while working from within to change it.

Transcultural relationships and transcultural research

My interest in cultural perspectives began very young; I identify one moment as a child when sledging with a recently-made friend who was Jewish. My mother had given me two 'penguin' biscuits, one each. When I offered one to her, she hesitated. I was surprised as they were considered a treat in our family. She explained that she did not know if they were kosher. I had never come across this, and had a feeling that what I was learning was the edge of a whole new world, something that wasn't directed by adults, it was what I myself wanted to know. I recognise this now as intrinsic motivation and that feeling of wanting to understand other peoples' perspectives on life is the same. More recently (but still 25 years ago) I made a friend who had recently come to the UK to be a family carer. She was learning English and I was learning Urdu. We took it in turns to guide and practice on each other and gained insight into each other's family lives. It is striking to be asked, 'so which side will you marry your daughters into?' and she was surprised that I would bother borrowing from the bank when there was a community arrangement to manage financial issues. She supported me in joining this and understanding a little about Islamic banking. We shared mutual astonishment at our opposing approaches to strawberries (which are surprisingly tasty with salt and pepper). Throughout the years of our families' relationships we have helped each other extensively; I feel my career would not have gone in the same direction without everything I learnt from her and her extended family.

My practice experience, when I was teaching myself about transcultural care, then my MSc in transcultural nursing, plus friendships that grew from mutual language learning support, teaching transcultural nursing and co-writing a practice paper with a student (**Paper 12**) combined to position me as a co-researcher on this study with a psychology colleague from the Faculty of Business, Law and Social Sciences. This study explores nurses' experiences of supporting South Asian family carers who look after relatives with dementia. The study reflects the most interesting aspects of my clinical practice, exploring questions I would have loved to answer when I was a community mental health nurse. Together with a student nurse I wrote about this in an article for nurses in practice (**Paper 12**), aiming to provide a critique of the current situation and to offer pointers, drawn from literature and practice, that would support nurses in providing culturally congruent care. It is easy to be diverted by stereotypes and assumptions. This principle has been illustrated again in the current study which will lead into development of a brief teaching or workshop intervention with the goal of enhancing transcultural working skills.

Again having a colleague with whom to be honest and reflexive helps in validating our approach and minimising bias. Though of course I am biased. As in the past, this service user group (older people, specifically those from black and Asian backgrounds) are under-served, still stigmatised and since my time in nursing, there are fewer community resources and nurses have less time to spend with patients. The nurses feel the frustrations of not being able to provide care that is suitable and feel deskilled when referring on to third sector agencies. It is saddening to see people in the job I used to love blaming themselves for system-wide inadequacies. In the interviews many said to me 'well you know how it is' but this is not completely true, how it was and how it is are different, and this difference is related to under-funding rather than lack of commitment from the nurses involved. Investment in staff numbers and staff training had the potential to build on the pioneering work for which we gained the Beacon award, but instead service provision is based on expediency rather than evidence.

Challenging expectations of individual change within embedded cultural norms

While the combined study findings imply that nurses' well-being can be enhanced through a stronger evidence base, improved professional confidence and mutual support, it would be harmful to suggest this is possible without broader changes to health and social care policy, funding and management. In aiming to empower individuals within this context, much of my work has involved designing teaching interventions that incorporate or promote skills for self-management as well as for positive changes in care. The teaching interventions for acute hospital nurses (**Paper 2**) and care home nurses (**Papers 3 and 8**) consider how insight into the needs of people with dementia, when combined with a person-centred approach to teaching and staff support, enables practice changes to be more securely embedded. The literature review reinforced awareness of this necessity as unsupported staff did not incorporate learning about the Mental Capacity Act (2005) into their practice (**Paper 9**). In synthesising themes from study findings, I identify that emotional well-being is essential in enabling nurses to invest their energy and commit to promoting well-being for others. Lack of emotional well-being in the workplace or classroom can result in a form of vocational dissonance – a feeling of alienation from one's real values to the extent of becoming uncaring about self, colleagues and patients.

Sharing findings and influencing practice

However, a person-centred approach to research, learning and practice can contribute to creation of a nursing culture in which nurses develop professional self-esteem and as individuals become part of a solution-orientated approach to changing nursing culture. My role allows me to contribute to building a more positive dynamic, as I can continue contact with practice, influence learner nurses, mentor junior colleagues and conduct research. The conflux is mutually advantageous and has had benefits for me and my career. It comes with responsibility to share my work, which I have disseminated at local national and international conferences in addition to the publications discussed here. I believe in acknowledging and sharing the benefits from opportunities that have come from my work. For example after visiting the village in Holland for people with dementia, I wrote a practice article sharing their philosophy and how it is put into action (Jenkins and Smythe 2013), and did the same after visiting the old age centre in Japan, after a conference (Jenkins and Germaine 2019). I have worked in partnership with colleagues and students in getting projects published (**Papers 14 and 17**, Maher et al 2017, Dey et al 2018, **Paper 15**). Other means of dissemination include through the BUDS network, Researchgate and ongoing relationships with the local mental health trust and practice teams.

My research in nursing homes allowed insight into this different world. As noted in **Papers 3, 5, 8 and 11,** nursing home nurses face extensive and unique demands, often working in isolation to support people with the most difficult experiences of dementia. Nursing in these environments can be harmful to nurses' physical, social, financial and emotional well-being. Despite this, the research participants I encountered there and in the classroom retained commitment to the well-being of those in their care. Conducting research in nursing homes enables participants to become visible and can drive social change (Toms et al 2020). Research is key to improving the quality of life of all parties, but is challenging because of the various barriers identified in these papers, summarised in **Paper 11** and confirmed since (Toms et al 2020**)**. The key learning outcomes are to ensure nursing home nurses' experiences are validated, that demands on them acknowledge the constraints facing the sector, that learning opportunities are designed to reflect the realities of residents and nurses' lives and that structural barriers to change are identified so that they can be challenged.

The research and publications explored in this account show how I have used the skills of a researcher, educator, volunteer befriender and nurse to influence practice in an under-researched area. The contribution to knowledge lies within this mix; in building understanding of how nurses learn about dementia care, what the barriers are that prevent them fully applying new understandings, how nursing culture is a contributing factor within this and how teaching can meet emotional needs, be empowering within the cultural context, and aid application of learning in practice. Evaluation of teaching interventions demonstrates that building professional self-esteem through a strong knowledge base is complemented by a person-centred approach to teaching, in which teaching interventions incorporate respect for nurses' personhood too.

Critique and review, conclusions

In this auto-ethnography I have explored my learning and contribution arising from a range of publications considering how person-centred dementia care can be taught and learning evaluated. It sits within the theoretical frameworks of Kitwood's (1997) 'personhood' theory, Rogers (2004) person-centred theory and in relation to nurse education, a constructively aligned (Biggs 1996) and solution-focused (Franklin 2015) understanding of the learning process. Taking an autoethnographic approach (Adams et al 2015), and threading my personal and professional self through the narrative, I have analysed barriers to application of learning in practice, then building on findings, considered how educational interventions could become therapeutic interventions in response to the painful emotions associated with burnout, which so many nurses experience. Throughout this process I have realised both the value and limitations of person-centred attention in the classroom. While experiencing person-centredness in the classroom has proved effective in enabling practitioners to understand and commit to person-centredness in care, the practical cultural and structural barriers faced in clinical environments have limited the extent to which practice change can be achieved through education. Through my research I aimed to address the questions: ‘What are nurses’ training needs?’, ‘What does effective training look like?’, ‘How can barriers to application of learning be overcome?’ and ‘Is nurse well-being central to application of learning?’ New understandings from my studies has the potential to transform future dementia care education. In considering nurses’ educational needs and what effective training would look like, I have highlighted that training interventions based around a person-centred approach to care need to reflect the principles of the theory (Kitwood 1997) both in identifying and engaging relevant active learning opportunities but also in keeping nurses’ emotional (personhood-related) needs to the forefront both in the classroom and in practice, a feature which has been largely neglected to date. The ‘new culture’ that Kitwood (1997) envisaged and that Brooker and others (including Baldwin and Capstick 2007, Downs and Bowers 2014, Brooker and Kitwood 2019) have championed since, would become more sustainable when nurses’ needs are acknowledged within care environments and relationships. These conclusions indicate that barriers to application of theory to practice in dementia care lie in insufficient application of theory, in that the theoretical constructs should be applied with nurses as we expect for patients. The process of re-interpretation of Kitwood’s ideas is incomplete and needs further exploration.

Current understandings of Kitwood’s (1997) personhood theory (Kitwood and Brooker 2019) continue to prioritise the well-being of people with dementia while ignoring the costs to their professional care providers. My distinctive contribution here is to identify how the personhood of nurses working in dementia care is systematically denied, a cost which is detrimental to their well-being and therefore important for its own sake, but which has significant relevance too for the subsequent impact on quality of care, staff turnover, burnout and nurse retention.

Strategies to meet personhood related needs include listening to nurses in the classroom and in practice to validate their experiences, identify unmet emotional and practical needs and reveal gaps in their knowledge base and ability to apply theory to practice. In educational environments and while learning in practice, interventions can include building a platform of expertise to promote professional confidence, modelling and role playing to develop skills (e.g. communication, responses to distress, therapeutic interventions) and assertiveness, while mutual support within learning groups enables learners to identify that structural and cultural factors are the context within which they as individuals work.

In this review and in recent publications I have built the argument that personhood theory and the person-centred approach are inadequate models for providing a robust challenge to practice norms, that rhetoric exploiting shared nursing values to emphasise individual change can be harmful and unrealistic, and that cultural changes are needed to empower nurses for our own professional well-being and so that we can use our expertise to improve practice. The findings and analysis that contribute to these conclusions are my original contribution to knowledge.

My emphasis has changed over time, as I have learnt not only how to plan, structure and conduct research, but also reflect on the significance of findings, embed them into my teaching, disseminate them to different audiences and then re-engage with emerging challenges in subsequent studies. In taking an autoethnographic approach I have made the account both personal and cultural in focus, which I feel is congruent with telling the story of this process and my development as a nurse, educator and researcher who is situated in a certain context and time, reflecting the professional culture as an insider member, but also as an outsider and observer.

Autoethnography is still an unusual approach to scholarship, going against many accepted standards and principles of how research excellence is recognised (Farrell et al 2015). However, reflexivity, or the researcher's self-awareness and insight into their own biases and decision-making, is a characteristic associated with rigour in qualitative research (Johnson et al 2020), where interpretative methods are used to enable improved understanding (Denzin and Lincoln 2011). This account has foregrounded reflexivity in exploring my research, which itself has used been guided by conventional means of demonstrating methodological rigour. Rigour and significance are addressed within each peer-reviewed publication, while originality and impact are reflected in my contribution to the Research Excellence Framework (REF), also underpinned by peer review. While research is highly structured, systematic and transparent (Johnson et al 2020), guided by accepted frameworks (I have followed PROSPERO, PRISMA and COREQ guidelines, as well as reporting requirements of a range of peer-reviewed journals) research is also an adventure. It is somewhere we have permission to explore the spaces where we are unsure what lies there, where we respond to setbacks, challenges and unexpected barriers, and where we connect with others in both practice and the research world, aiming to weave our steps together, building knowledge and understanding, for our patients, colleagues and profession.

In common with most researchers (and nurses), most of my work has been collaborative. As a member of research teams, my individual contribution is difficult to assess. In teamwork, we do not keep a tally of who does what and how much of it each person does. In most studies I have led on designing and delivering educational interventions, on interviewing in focus groups and one to one interviews and in analysing data, then interpreting findings and writing conclusions (**Table 2**). I have led and contributed to bid-writing and the administration work associated with the projects.

In reviewing the collection of studies reviewed, I can identify that facilitation of a strong knowledge-base in relation to professional confidence has become a thread that runs through my practice, teaching and research. My contribution to knowledge lies in identifying the need for a person-centred and solution orientated approach to nurses' learning, not only to counter burnout, but also for nurses' empowerment. The call to social justice associated with autoethnography (Adams et al 2015) in this case involves acknowledging the priority of working to dismantle harmful hierarchical professional norms in healthcare.

While my research itself is not auto-ethnographic, in synthesising the review through this lens I have attempted to show how the approach is congruent with demonstrating scholarship at PhD level. According to Adams et al (2015:102) the goals of auto-ethnography are to make 'contributions to knowledge, valuing the personal and experiential, demonstrating the power, craft and responsibilities of stories and storytelling, and taking a relationally responsible approach to research practice and representation'. In this critical analysis and review I am narrating the story of the process that led to my contribution. I am showing that I have completed a succession of projects of scholarly research, have engaged with and evaluated my topic critically and interpreted and created knowledge. Deeper understanding of the barriers to application of person-centred learning for person-centred dementia care have extended the boundaries of my field.

A PhD by publication offers the researcher-practitioner an opportunity, through critical engagement with their work, to contribute responsibly and ethically to the development of their professional self while concurrently influencing the evolution of that profession. The impact of these publications includes changes to local nursing and midwifery education, and impact more widely on the practice of qualified health and social care professionals through the National Dementia Curriculum (Waugh et al 2013) and by dissemination of findings through publications and conference presentations. My work has been cited (162 times) and read extensively (ResearchGate https://www.researchgate.net/profile/Catharine_Jenkins). It has impact for colleagues in mentoring them in research and in publishing work, and for the broader research and nursing community in contributing to the range of evidence that supports further enquiry into dementia care practice and nurse education.

This account did not only share research experiences and outcomes. In sharing values and emotions, at times in theoretical mode and at others becoming more evocative, I have imagined you the reader engaging with empathy (as Bochner and Ellis 2016 suggest would happen) with this story. However, autoethnography is not therapy (Bochner and Ellis 2016). In describing autoethnography as 'cultural understanding via autobiography' Farrell (2017) counsels against over self-absorption and alerts the reader to the hazards of sharing vulnerability. There is a risk that auto-ethnographical accounts become over-personal and under-interpreted and for these reasons I have hesitated sometimes to give details about personal experiences. I hope they are balanced by engagement with theory and integration of analysis and findings with clinical applicability. These potential problems and ethical issues around the protection of self and others require attention: Chang (2016) suggests that auto-ethnographic work requires authentic, trustworthy data, reliable, transparent research processes, attention to ethics, analysis and interpretation of the author's experiences and an attempt to make a scholarly contribution through engagement with existing literature and in its conclusions.

While I agree that autoethnography is not therapy, the process has been therapeutic. I have learnt to acknowledge and recognise the significance of my body of work, have identified the journey of learning from each early project, building towards more recent and ongoing studies and can reflect now on how the work echoes values that grew from transcultural relationships as a young person, and which have held strong in my professional life in nursing, education and research.

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Development of a competency framework for a specialist dementia service

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Abstract

Purpose – *The purpose of this paper is to discuss the development of a competency framework for staff working in a specialist service for people with dementia.*

Design/methodology/approach – *A qualitative and purposive methodology was used and included focus groups, questionnaires and interviews. Content analysis together with synthesis of literature was used to generate the competency framework.*

Findings – *A competency framework was developed with eight main clusters. These were: skills for working effectively with people with dementia and their families; advanced assessment skills; enhancing psychological well-being; understanding behaviours; enhancing physical well-being; clinical leadership; understanding ethical and legal issues; and demonstrating skills in personal and professional development.*

Research limitations/implications – *Further research is needed to include service user perspectives.*

Practical implications – *The framework could be implemented in practice by managers, health care professionals and training providers as a tool to identify strengths and limitations in knowledge skills and attitudes and to identify areas for competency development through specific training.*

Originality/value – *The competency framework contributes to the development of a training curriculum for staff working within a specialist service.*

Keywords *Training, Competency, Dementia*

Paper type *Research paper*

Introduction

This research was conducted within an NHS Trust serving a large urban multi-cultural population, in collaboration with a local university. The Trust was seeking to identify the training needs and competencies required to ensure that staff are equipped with the necessary knowledge and skills to ensure people with dementia receive high quality care. In response to this agenda, this paper describes the development of a competency framework for staff working within a specialist mental health service for people with dementia. This service provides expert advice and the care and treatment of complex cases. It includes memory assessment provision, community mental health teams, in-patient units, respite and day hospital services. The current skill mix of staff comprises 40 per cent nursing staff, 27 per cent health care assistants (HCAs), 6 per cent medics, 6 per cent allied health professionals, 3 per cent psychology, 12 per cent other. This appears to be consistent with similar Mental Health Trusts.

The National Dementia Strategy (Department of Health, 2009) identifies the need for raising competency across health, social and third sector provision for care of people living with dementia. As part of the implementation of the strategy, dementia services are currently undergoing transformation, with the development of new roles such as "Dementia Pathway Co-ordinator" and "Primary Care Liaison Worker", and the division of holistic services into functional teams including Assertive Outreach, Memory Assessment and Primary Care Liaison.

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Competencies are acquired personal skills which reflect potential ability to provide a consistently adequate or high level of performance in a specific job function (Mace, 2005). In a study conducted in the same Trust, staff frequently found it difficult to identify their specialist skills, although a wide range of skills and in-depth knowledge regarding working with people with dementia exploring the experiences of skill development (Smythe *et al.*, 2009). The conscious competence model posited by Maslow (1940) explains progression from unconscious incompetence to unconscious competence whereby the person is skilled and it now comes naturally, so it is difficult to describe.

Two NHS-focused competency frameworks identify generic competencies required across the whole of the health care workforce (Department of Health, 2004) and the mental health workforce (NIMHE, 2004), respectively. The former captures generic competencies across six core areas: communication, personal and people development, health, safety and security service improvement, quality, and equality and diversity.

The latter includes: working in partnership, respecting diversity, practising ethically, challenging inequality, promoting recovery, identifying people's needs and strengths, providing service user centred care, making a difference, promoting positive risk taking and personal development and learning. Whilst these skills provide a foundation for care of people with dementia, additional specialist competencies are also necessary to enable staff to deliver skilled assessment, diagnosis and treatment, to those with dementia who have the most severe and complex difficulties.

Literature review

A literature search was carried out in order to identify existing competency frameworks for dementia care. This was undertaken through major electronic databases (PsychInfo, CINAHL, BNI, EMBASE, ELITE and MEDLINE) for the years 2004-2010 using key search terms related to knowledge and skill frameworks (e.g. "competencies", "framework"); terms around dementia and terms connected with the workforce. Nine dementia care competency frameworks were identified (see Table I). They had been developed using a range of methods, including drawing

Table I Competency frameworks relevant to consideration of dementia care

Author	*Framework*	*Scope*
Royal College of Psychiatrists (2009)	A competency-based framework curriculum for specialist training in old age psychiatry	Profession specific framework for psychiatrists working in old age
Skills for Health (Department of Health, 2004)	Competency for older people	Generic framework for all staff working with older people
Iliffe *et al.* (2004)	A toolbox of skills to share across dementia settings	Competencies for the dementia care pathway
Skills for Care and Development (2005)	Knowledge set for dementia	Generic framework for all staff working with people with dementia
Health Care for London (2009)	Dementia integrated care pathway-workforce competencies	Generic framework for all staff working with people with dementia
Tsaroucha *et al.* (2010)	West Midlands Competencies Framework for Dementia Workers	Generic framework for all staff working with people with dementia
Adams (2008)	Competencies framework for dementia care nursing based	Framework developed for nursing staff working with people with dementia
McCarron *et al.* (2008)	Supporting persons with intellectual disability and advanced dementia	Framework developed for staff working with people with dementia at end of life
Traynor and Dewing (2002)	Admiral nurse competency framework	Framework for admiral nurse role
de Vries *et al.* (2010)	Workforce Development for Dementia: Development of Role, Competencies and Proposed Training for; "Primary Care Liaison Worker" to Support Pathway to Diagnosis of Dementia	Frameworks for specific dementia roles
Tsaroucha *et al.* (2010)	Competency framework for dementia pathway co-ordinator	

from national frameworks, job specifications and literature reviews, as well as interviews, questionnaires, expert panel discussion and Delphi panels.

A number of frameworks have been developed for particular professions or roles. These include that of the Royal College of Psychiatrists (2009), who developed a competency-based curriculum for psychiatrists who specialise in old age work. Competencies are arranged under seven sub-headings: medical expert, communicator, collaborator, manager, health advocate, scholar and professional.

Adams (2008) developed a competencies framework for dementia care nursing which included seven competencies including promoting a culture of values and respect for the diversity of people with dementia and their families, improving outcomes for service users, multidisciplinary and multi-agency working. The skills and theory associated with each competency are identified within the framework.

Traynor and Dewing (2002) developed a competency framework for Admiral Nurses whose work focuses primarily on the needs of carers and supporters of people with a dementia. The Admiral Nurses actively participated in the project and the development of the competency framework structure. This framework is structured around eight core competencies including therapeutic work, sharing information about dementia and carer issues, advanced assessment skills, prioritising work, preventative work and health promotion, ethical and person-centred care (PCC), balancing the needs of the carer and the person with dementia and finally promoting best practice.

de Vries *et al.* (2010) developed competencies and models for role development and training for a "Primary Care Liaison Worker" who would support the diagnosis and pre-diagnosis of dementia. Competencies include knowledge/awareness of dementia and dementia-related issues, which includes having up-to-date research and clinical knowledge, a comprehensive understanding of the behaviours of individuals with early cognitive impairment, including an advanced awareness of the impact of the fear and stigma associated with a diagnosis of dementia and of potential losses associated with a diagnosis of dementia; skills in interacting with people with a wide range of illnesses including mild cognitive impairment; competencies in providing education/facilitation and giving information to families and caregivers; skills in pre-diagnostic screening and personal qualities such as empathy, warmth and genuineness.

Most profession specific frameworks seem to draw on expert opinion from each profession rather than going back to the basics of analysing job content.

By contrast, some generic competency frameworks, developed for professionals who work with patients with dementia in a wide range of settings have been based on analysis of job specifications. These include "Department of Health, Skills for Care and Skills for Health" (2010) and "Skills for Care and Development" (2005). Health Care for London (2009) has also developed a workforce competency framework based on the frameworks developed by Skills for Health and Skills for Care, as well as those of other relevant professional bodies.

Tsaroucha *et al.* (2010), used interviews with patients, carers, staff and other key stakeholders develop the "West Midlands Competencies Framework for Dementia Workers" as part of a project to develop a core competency framework and to conduct a mapping exercise in order to plot the developed competencies and skills against the dementia care pathway. The framework includes core competencies around knowledge and awareness of dementia-related issues, PCC, interaction with patients, interaction with families, understanding challenging behaviour and promoting best practice.

Within the competency frameworks identified, an example of implementation is found in the study conducted by McCarron *et al.* (2008) who subsequently developed and evaluated an educational programme.

Summary

Universal themes are evident in the existing frameworks, including the need for competence in PCC, knowledge and awareness of dementia and managing perceived challenging behaviour.

The rationale for this study is that there is no competency framework which has been developed for staff across a range of different disciplines working in a specialist dementia care setting. It was therefore appropriate to fill this gap, in line with Trust aims, to try and establish the areas and levels of competence required of the specialist dementia workforce.

Method

In order to develop the competency framework it was necessary to develop an in-depth understanding of the roles within the service. Several different data collection methods were used in order to achieve this. These included semi-structured interviews with key clinical leads, followed by a questionnaire and focus groups ($n = 16$), conducted with a wider sample ($n = 86$) of staff and family caregivers. Unfortunately due to time constraints it was not possible to extend ethical approvals to include service users' perspectives.

In total, 30 one-to-one interviews were conducted with key clinical leads in the Trust, including psychology, occupational therapy and physiotherapy leads, modern matrons, ward managers and community MH team managers. Interim findings from these interviews were then used to develop questionnaires. Participants were asked to identify three specialist competencies (related to their role), three generic competencies (that they would expect everyone to have) and lastly describe how their practice is different from that of other professionals not working with people with dementia. Questionnaires were sent electronically to the clinical leads ($n = 7$), including those who had been interviewed and others in the service, and managers ($n = 17$) who were asked to circulate the questionnaire to staff in their teams. In total, 26 were returned (a response rate of 17 per cent). The focus group explored areas of interest highlighted by the interviews and questionnaires.

Content analysis (Donovan and Sanders, 2005) of the responses was then used to produce the framework, integrating the findings with those of previous frameworks.

This process, which can be described as "inductive", initially aims for data reduction by taking a large volume of material and attempting to identify case consistencies and meanings (Patton, 2002). According to Weber (1990) content analysis is misunderstood and a common preconception is that words and phrases mentioned are simply counted. Slight differences in words were collapsed into single categories. These categories were then compared and matched to arrive at a single merged list consisting of eight themed clusters. The team used existing literature, expert opinion and reflection to confirm the categories. We then returned to the focus group participants to undertake respondent validation.

Findings

The findings from the semi-structured interviews, focus groups and questionnaire are incorporated in the resulting competency framework (Table II).

Nurses' emphasis on generic skills

During the focus groups nurses often focused on generic rather than profession specific skills. These were the skills that participants felt that all staff should have regardless of role or setting. These included:

- communication;
- counselling skills, e.g. empathy/understanding;
- developing flexible approaches to PCC;
- managing perceived challenging behaviour;
- providing activities and engagement; and
- recognising symptoms of ill-being, maintaining independence and levels of functioning, and supporting carers and their families.

Table II Competency framework for clinical staff working in specialist dementia services

Competencies	*Source*	*Level*
Cluster 1. Skills for working effectively with people with dementia and their families		
Demonstrate an understanding of dementia	FG, LR, SS, INT[a]	1-5
Understand the principles and values of person-centred care and demonstrate a person-centred approach and an understanding of how to work with people with moderate to severe dementia, e.g. patience, respect, understanding, compassion, empathy (knowing the person, seeing the person)	SS, FG, INT, LR[a]	1-5
Demonstrate an awareness of approaches aimed at improving quality of care, e.g. dementia care mapping	INT, LR	5
Understand the impact of dementia on individuals in terms of emotions, needs, relationships and practical issues	FG, SS, LR, INT[a]	1-5
Knowledge on how to involve individuals and families in their own care planning	LR, FG, INT	4
Knowledge of the health and social policy and planning issues related to dementia and an understanding of care pathways	LR	4-5
Understand relevant dementia models of dementia care, e.g. Brooker's (2007) VIPs model and Sheard's (2008) BEING approach and identify strengths and weakness	LR	4-5
Demonstrate sensitivity to diversity relating to age spirituality, religion and disability promoting an all-inclusive culture	INT, FG, LR	1-5
Demonstrate effective communication skills (non-verbal/verbal) and the ability to identify strategies which can be used to overcome cognitive and sensory impairments	SS, INT, FG, LR[a]	1-5
To be able to undertake an advisory role, liaising effectively with individual's carers, families and other professionals, have knowledge of local service provision and signposting skills	SS, FG, INT, LR[a]	4-5
Understand and demonstrate an awareness of the factors associated with safeguarding vulnerable adults	SS, INT, LR	1-5
Cluster 2. Advanced assessment skills		
Demonstrate advanced assessment and diagnostic skills	SS, INT	5
To understand the psychological consequences of cerebral and physical disease	INT	5
Demonstrate an understanding of the psychological and emotional impact of diagnosis on the individual and their family	SS, LR	4-5
Demonstrate an awareness of the common types of dementia and how the illness presents	SS, FG, INT, LR	1-5
Demonstrate an in depth knowledge of the causes of dementia and pathophysiology underpinning the most common types of dementia and an understanding of disease progression	SS, INT, FG, LR[a]	4-5
Demonstrate advanced observational skills to gather information in order to interpret behaviour	SS, INT, FG	1-5
To be able to successfully communicate results of diagnosis and its impact to individuals and their families	SS, LR	5
To have knowledge of MCI and dementia and to distinguish between dementia, age-related changes, delirium and other mental health problems including depression and to understand the relationship between depression and dementia	SS, INT	4-5
Demonstrate an understanding of dual diagnosis, e.g. dementia and depression, dementia and learning disabilities	FG, INT, LR, INT[a]	4-5
Specialist evidenced-based knowledge of a range pharmacological treatments for a range of dementia conditions relating to prevailing NHS guidelines	INT	5
Demonstrate advanced counselling skills when supporting an individual and their families during or following diagnosis	FG, LR	4-5
Ability to assess factors associated with self-harm, self-neglect, suicide and risk of harm from others	LR	4-5
Cluster 3. Understanding of the behaviours of people with dementia		
Ability to recognise the needs of people with dementia, maximising strengths and minimising weakness	FG, LR	1-5
Develop and implement skills in problem solving, and recognition of behaviour changes	FG, LR	1-5
Recognition of triggers for behavioural and psychological symptoms of dementia (BPSD), e.g. unmet need	SS, FG, LR, INT[a]	1-5
Undertake appropriate behavioural analysis and assessment of need using methods such as ABC	FG	4-5
Knowledge of anger management and de-escalation techniques	LR, INT	1-5
Ability to manage expressions of distress	LR	1-5
Develop strategies to ensure the person's life history and individual preferences are taken into account	FG	1-5
Knowledge of the bio-psychosocial influences on behaviour and use of corresponding evidenced-based management strategies	SS	4-5
Have evidenced-based knowledge of pharmacological treatments of behavioural disturbance	INT	5
Promote safety of individuals and staff members and contribute to the safe and effective management and reduction of risk, e.g. through medication, counselling, etc	FG, LR	1-5
Cluster 4. Enhance the psychological well-being of people with dementia		
Demonstrate the ability to develop establish and maintain an effective therapeutic relationship and rapport with people living with dementia and their families	SS, FG, LR, INT[a]	1-5
To be able to offer effective support and use of basic counselling to people with dementia and their families	SS	1-5
To be able to determine psychological formulations	INT	5
To be able to deliver evidenced dementia focused interventions, e.g. validation therapy, reminiscence, life review, cognitive stimulation (CST), cognitive-behaviour therapy (CBT), reading for well-being	SS, INT	4-5

(continued)

Table II

Competencies	*Source*	*Level*
Promote positive views of people living with dementia by valuing experiences and life stories	FG	1-5
Be able to engage individuals in meaningful occupational activity, facilitate groups and 1:1 activity which take into account the person's preferences and choice	SS	1-5
Undertake activity analysis and, graded activity and adaptation	SS	4-5
Understanding occupation and activity as a method of assessment	SS	4-5
Think creatively and innovatively about the provision of activities, promoting positive meaningful social interactions and see activity in the widest possible sense	SS, INT	4-5
Demonstrate ability to connect with people who are cognitively impaired with reduced attention spans and maximise brief positive interactions	FG, LR	1-5
Cluster 5. Demonstrate skills in clinical leadership		
Demonstrate a high-level knowledge of research evidence in relation to dementia and dementia care	LR	5
Demonstrate ability to transfer and adapt own skills to a variety of settings	FG	4-5
The ability to recognise negative ward cultures and to undertake effective change management when necessary	INT	1-5
Demonstrate advanced skills in research and evaluation	LR	5
Be able to identify evidenced-based practice (EBP) and promote EBP, keeping knowledge and skills up to date	LR	4-5
Demonstrate effective leadership skills working effectively and assertively in a team, contributing to the decision-making process	INT	1-5
Support the education, teaching and learning for other staff members	FG	1-5
Demonstrate a multi-disciplinary perspective and promote multi-disciplinary working, working effectively across professional boundaries, understanding and respecting each professional group	INT	4-5
To deliver group presentations/seminars	LR	4-5
Cluster 6. Demonstrate skills in personal and professional development		
Be able to clarify and confirm own professional role, demonstrate professional confidence and manage personal and professional development	FG	4-5
Be able to demonstrate effective skills in clinical supervision and mentorship	FG, LR	4-5
Undertake reflective practice and recognition of emotional labour and its impact on care practices	FG, LR	1-5
To recognise the need for appropriate or additional support in the work place and be able to identify means of accessing this	LR, FG	1-5
To be able to manage grief and loss appropriately	LR	1-5
Be able to practice autonomously and exercise own judgement	FG, LR	1-5
Demonstrate effective coping skills/stress management, resilience and emotional competence	INT, FG, LR	4-5
Identify gaps in knowledge and seek appropriate education/learning	FG, LR	1-5
Cluster 7. Enhance physical-well-being of people living with dementia		
Demonstrate an understanding of all aspects of physical well-being	LR	1-5
To be able to undertake assessments of physical well-being	SS, FG	4-5
Ability to adapt the physical environment to maximise the individuals level of functioning	FG, LR	4-5
Demonstrate an in depth understanding of pharmacology and pharmacovigilance (medication management)	SS, INT, FG	4-5
Be able to deliver effective end of life/palliative care and support individuals and their families through the end of life process	SS, FG, LR	1-5
Demonstrate an understanding of co-morbidity of physical and psychological problems	LR	4-5
To deliver interventions to improve physical well-being, e.g. music/environmental approaches	SS, FG	1-4
Be able to assess the risk of falls and deliver falls prevention	SS, FG	1-4
Undertake effective health promotion	LR	1-5
Manage continence/incontinence effectively	FG	1-4
Ensure individuals receive an adequate nutritional/fluid intake and undertake effective monitoring	INT, LR	1-4
Demonstrate awareness of pain management strategies	FG	1-5
Recognise delirium and undertake an appropriate course of action	LR	1-5
Deliver effective sleep hygiene advice	LR	1-5
Cluster 8. Demonstrate an understanding of the ethical and legal issues in relation to people living with dementia		
Understand the appropriate legal and ethical frameworks and how they can be used to support practice	LR	4-5
Undertake the assessment of capacity and obtain valid informed consent	SS, INT	1-5
To have knowledge of Knowledge of Mental Capacity Act, Living wills, Advanced Directives	INT, FG	4-5
To be able to undertake discussions with individuals and carers agreeing advanced care decisions planning and review processes	LR	4-5
Support ethical decision making in relation care practices and act as an advocate for people with dementia and their families	LR	1-5

Notes: FG, focus group; LR, literature review; SS, staff survey; INT, interview. [a]All four sources

In some interviews the participants also referred to tasks rather than technical skills or knowledge. Examples of these tasks included: "depot injections, administering medication, organising the unit and supervising doctors' reviews […]".

Profession specific skills

Other professions clearly articulated profession specific skills. These included advanced assessment and diagnostic skills, delivering psychological therapies and clinical leadership, for example, grading tasks, activity analysis, using tactile prompts, manual handling and developing psychological formulations.

The HCAs also perceived their work as being skilled. In particular they saw themselves as specialists in managing behaviour perceived as challenging. Assisting with personal care was also seen as central to the HCA role. This was recognised by the trained staff:

> The fact that they spend so much time on the floor and you know, they are involved in a lot of personal care with them and they are observing them throughout the day. I think they are very, very good at picking up changes in people. You know, it's not necessarily people saying that they feel unwell, but just a general change in demeanour or you know, they are very good (Nurse, FG 4).

When discussing specialist skills the focus group participants described being able to draw on reasoning, problem solving and observational skills. Depth of knowledge and the ability to apply this in a meaningful way to a range of situations was also seen as important. Assessment and monitoring, teaching, consultancy and sharing knowledge with other colleagues, carers and families were all perceived to be important for specialist roles:

> I think we are very good at sharing information with the carers and explaining basic things with them in a way that they understand. Where, perhaps other people might think that they already know about it, or they have heard it before when actually nobody has took the time to sit down and explain (Physiotherapist, FG 14).

> So it's monitoring, supporting […]. identifying risk because things change.

> Yeah, liaison as well, obviously reviewing frequently […] (Community Nurse, FG 5).

> Yes and also the ability to observe and interpret what you have observed and maybe to ask relevant questions because what you see could be due to the dementing process or anxiety, or whatever it is […] (Occupational Therapists, FG 9).

> I think that is what **** was saying that the depth of knowledge about dementia itself and how you apply what you know, sometimes it's looking at things in a different way […] (Community Nurse, FG 5).

Struggling to make competence explicit

However, findings from the focus groups also identified areas where participants struggled to define competencies:

> Sometimes when you work with a specific group, you take your skills for granted don't you? It's kind of natural, it's like second nature and then when someone says what do you do, it's seems so natural, it's hard to exactly explain what you do (Occupational Therapist, FG 9).

Qualities and attributes for PCC

Participants identified a wide range of qualities or attributes which they felt were essential in the delivery of PCC. These included attributing value to people with dementia, respect for subjective experiences, a non-judgemental approach, patience, an emphasis on seeing the person as a whole, enabling and empowering the individual with dementia and a person-centred approach. The participants commonly used terms such as "communication" … "respectfulness, calmness and dignity" in relation to PCC.

Personal qualities

Carers focused on personal qualities such as kindness and patience, rather than skills. They valued soft skills, for example, the ability to listen and understand, create a warm atmosphere, and demonstrate respect and empathy:

> The kindness that they show the patients […] how you would like to be treated yourself (Carer FG 11).
>
> It would be great if nurses nursed from the heart, when we mention about all these qualities people have and that is said to me so often […][…][…] (Carer FG 11).
>
> It's a vocational job. You have either got a vocation to do this. I think a lot of people just do it to earn money and some people do it because they love it (Carer FG 11).

Development of an integrated framework. The competencies generated were divided into a total of eight clusters which can be seen in Table II. Each item was classified as generic, specialist or advanced. Generic competencies were defined as the competencies which all staff require who are working with people with dementia, including those staff who are working in a wide range of settings including residential and nursing homes. Specialist competencies were described as those competencies necessary for staff of all disciplines working within a specialist mental health service. Some of these may be acquired through professional training. Advanced denotes competencies which seem to be complex enough to require further higher professional training (Hamric, 2005).

Each competency was critically appraised by the research team and separated into levels. Steinaker and Bell's (1979) Experiential Taxonomy (the five levels, of exposure, participation, identification, internalisation and dissemination indicate increased depth of learning), was adopted in order to carry out this process. Where there was disagreement, the allocation was debated until consensus was achieved. Several fundamental or generic competencies were shared across all five of these levels as it was recognised that everyone working with older people with dementia requires these skills, e.g. an understanding of dementia, knowledge of person-centred approach. Specialist competencies were identified as level 4 of the taxonomy and advanced as level 5.

Discussion

The development of this framework has a number of strengths including the triangulation of methods used to generate the competencies (interviews, questionnaires, literature and focus groups). The competency framework builds on pre-existing frameworks which have been predominantly developed using systematic literature reviews and analysis of job specifications, and the work was also shaped using the findings from the focus groups which were conducted with staff and carers to explore their experiences of working with people with dementia.

The competencies can be viewed in terms of focus on skills vs knowledge and their function in supporting change in practice (Michie *et al.*, 2011). A rationale for dividing competencies in this way was that skills and knowledge typically require different modes of assessment and training. For example, it may be possible to teach competencies identified as knowledge based using techniques such as e-learning whereas attitudinal and skills-based competencies may require more experiential methods (Michie *et al.*, 2011).

Noticeably, within the framework there are competencies that are only generated from the literature review, these include theoretical constructs that might not easily come to mind for staff when interviewed, e.g. use of models (Brooker, 2007; Sheard, 2008). However, disturbingly, suicide risk assessment was not identified by staff as a competency, despite evidence to suggest older people with dementia are at increased risk of suicide (the risk of suicide in people with newly diagnosed Alzheimer's disease is highest among people who receive the diagnosis early in the course of their illness; Leong, 2010). This may identify a gap in basic professional training.

The framework includes specific competencies in clusters 2, 3 and 4 that were not apparent in the more generic frameworks, reflecting the needs of a specialist workforce for knowledge and skills to provide a good service. These include advanced assessment, diagnostic skills, therapeutic skills and problem solving for managing perceived challenging behaviour.

In this study it is argued that a number of steps were taken to minimise limitations and enhance quality, including triangulation of methods. Limitations include the small number of questionnaires returned by staff, while the focus groups did not include staff from medicine or psychology. However, these professions did participate in the interviews with key clinical leads and the staff questionnaire. In addition, as the project was considered a service evaluation, it was not possible to include service users. Further research is therefore required to consider their perspectives.

Carers identified approach and the ability to demonstrate warmth and empathy as essentials of quality care. Benbow *et al.* (2011) found that both people with dementia and family members could recognise "those who gave of themselves in caring" (p. 199) echoing our findings that these qualities should be recognised as competencies.

The competency framework (Table II) reflects a continuum of professional expertise and responsibilities reflecting the range and responsibilities of staff within a specialist service. The competencies which were identified as specialist provide evidence regarding the distinct strengths and roles of a specialist mental health service. A training programme will be developed based on the competency framework, using a similar approach to that adopted by McCarron *et al.* (2008). The aim of this training programme will be to enhance the knowledge approach and confidence of staff thus improving care experiences.

Conclusion

The competency framework developed within this research drew on a series of interviews with staff, focus groups and questionnaires to outline generic, specialist and advanced skills necessary for roles within specialist dementia services. The research approach proved a useful and effective model for the development of a competency framework. This competency framework thus provides a new and innovative contribution to the field of dementia care education, linking theory and practice for all grades and disciplines while offering a continuum of competencies that can be used to develop a training curriculum for a specialist service. The framework could be implemented in practice by managers, health care professionals and training providers as a tool to identify strengths and limitations in knowledge, skills and attitudes and to identify areas for competency development through specific training. Further research is required to gain the perspectives of service users regarding essential competencies and to undertake an evaluation of the framework.

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EVALUATION OF DEMENTIA TRAINING FOR STAFF IN ACUTE HOSPITAL SETTINGS

Analisa Smythe and colleagues investigated the effectiveness of a brief psychosocial intervention delivered in the workplace compared with a standard teaching approach

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Abstract

The development, pilot and evaluation of a brief psychosocial training intervention (BPTI) for staff working with people with dementia in an acute hospital setting are described.

The project had two phases. Phase one involved adapting an existing competency framework and developing the BPTI using focus groups. For the pilot and evaluation, in phase two, a mixed methods approach was adopted using self-administered standardised questionnaires and qualitative interviews.

Qualitative analysis suggested that delivering skills-based training can develop communication, problem-solving and self-directed learning skills; benefit staff in terms of increased knowledge, skills and confidence; and be problematic in the clinical area in terms of time, organisation and the physical environment. These factors must be taken into consideration when delivering training. These changes were not reflected in the quantitative results and measures were not always sensitive to changes in this setting.

Definitive conclusions cannot be drawn about the efficacy of the intervention, due to the contradictory outcomes between the quantitative and qualitative data. Further developments and research are required to explore how staff and organisations can be supported to deliver the best possible care.

Keywords
Acute hospital, cognitive impairment, dementia, service evaluation, skills, training, ward based

THE TERM ‘dementia’ is used to describe a syndrome involving progressive decline in memory, reasoning, communication skills and the ability to carry out daily activities (Department of Health (DH) 2009). One quarter of people in acute hospital beds have dementia (Alzheimer’s Society 2012), yet acute hospitals remain challenging environments for people with memory problems, who have worse outcomes than those without dementia in terms of increased length of stay, mortality and institutionalisation (DH 2006). The National Dementia Strategy (DH 2009) and the revised Quality Outcomes for People with Dementia (DH 2010) have identified improving outcomes and quality of care in acute hospitals as priorities.

The Alzheimer’s Society (2009) found ‘unacceptable variation in the quality of dementia care provided on general wards in hospitals across England, Wales and Northern Ireland’. Carers were dissatisfied with the following aspects: nurses not recognising or understanding dementia; lack of person-centred care; those with dementia not being helped to eat and drink; lack of focus for social activities; and limited involvement of family members. Staff concerns included managing challenging behaviour, communication and not

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having enough time to spend on one-to-one care. The report highlighted that acute hospital staff should have the right knowledge and skills to better meet the needs of patients with dementia.

A number of randomised controlled trials (Fossey *et al* 2006, Visser *et al* 2008, Ballard and Aarsland 2009, Chenoweth *et al* 2009, Kuske *et al* 2009) have sought to evaluate the effect of training for mental health or acute hospital staff on the quality of dementia care, as have two systematic reviews (Livingston *et al* 2005, McCabe *et al* 2007).

The results demonstrate substantial variability in the content, length and type of training interventions that have been evaluated. Interventions have been based on different theoretical frameworks (Mustafa *et al* 2013) with a mixed content (McCabe *et al* 2007). Person-centred care and behaviour management are common areas of focus.

When assessing the effect of training, McCabe *et al* (2007) found that most studies considered impact on staff knowledge or attitudes, while some explored staff behaviour or outcomes for people with dementia.

Gandesha *et al* (2012) and the Royal College of Psychiatrists (2011) examined the adequacy of dementia care training for acute hospital staff and found deficiencies in areas such as coping with signs of distress.

Conventional didactic classroom approaches to training have not improved knowledge sufficiently to support practice change (Ballard and Aarsland 2009, Smythe *et al* 2013). Staff have little opportunity to leave the clinical environment for training, or to meet as a team to reflect and learn together (Smythe *et al* 2013). Therefore training delivered in the clinical setting may be more feasible and have greater potential to enhance practice. It is difficult to isolate the main ingredients for success, but ensuring training is embedded in a whole-systems approach could prove necessary to deliver sustained application of new knowledge (Kuske *et al* 2009, Perry *et al* 2011).

Aim

The aim of the project was to develop, pilot and evaluate a brief psychosocial training intervention (BPTI) for staff working with people with dementia in an acute hospital setting.

Method

The first phase involved adapting an existing competency framework (Smythe *et al* 2013) to meet the needs of staff in acute hospital settings. Focus groups were conducted with acute hospital staff and the findings used to design the BPTI.

The second phase was to pilot and evaluate the BPTI using self-administered standardised questionnaires and qualitative interviews.

Phase 1 Potential focus group participants were consulted about the BPTI's parameters and content to promote a sense of ownership (McCarron *et al* 2008) and identify their needs. Six focus groups were conducted with 32 participants, drawn from a range of disciplines, including nursing, and service settings.

These discussions were recorded, transcribed verbatim and analysed using thematic analysis. Participants self-selected by attending at advertised times. Verbal consent was deemed acceptable in the context of a service evaluation.

Five themes were drawn from the thematic analysis:

- Everybody should be trained.
- Understanding the disease and the person.
- Dealing with challenges.
- Hands-on training.
- Making it practical.

Everybody should be trained Unqualified staff reported not having enough knowledge to provide effective care for people with dementia:

- ‘I mean as much as I love my job... I could never say I know what I am doing’ (P1, FG1).

Staff recognised that ‘everybody should be trained’ (P2, FG3) in dementia care and how to best care for people with the condition, ‘because everyone interacts with them’ (P1, FG2).

Understanding the disease and the person Training also needed to include an understanding of the perspectives of people with dementia:

- ‘Thinking how that would feel... just being frightened all the time and not understanding’ (P5, FG3).

Staff reported a need to know how the dementia process affected the person:

- ‘... the difference between dementia, delirium, and depression, you know, could be identified, the progression of the disease process itself... I mean a lot of people don’t know that dementia is a terminal illness’ (P3, FG6).

Dealing with challenges Staff also thought they needed skills in managing perceived challenging behaviour:

- ‘How to deal with aggression, and I think it is important, as sometimes it is really hard. You have patients sometimes where it takes four or five nurses to hoist the patient back to bed, kicking and scratching us’ (P4, FG1).

Communication training was also identified as a need:

- ‘Alternatives to repeating yourself... I was finding it frustrating that I was saying the same thing over and over and I wasn’t getting anywhere. As far as I was concerned, I was hitting a brick wall’ (P3, FG4).

Hands-on training Qualified staff thought the best way to teach staff about dementia care was through observation:

- ‘How do you teach for dementia? The range is so huge... You can’t teach for that, but if you observe someone doing it... you show people’ (P1, FG6).

Making it practical Participants thought training should be relevant and realistic for the ward setting:

- ‘It’s like you have a training session, and it’s not practical on the ward. We can’t do it that way ‘cause it’s just not practical – we haven’t got the time, we haven’t got the equipment, or whatever... It’s all good and well when you’re sitting in a classroom but when you are actually putting it into practice, you don’t have a lot of time, you know, or the staff’ (P7, FG6).

Staff were aware of the effect of their lack of knowledge and skills on people with dementia and their own work. They expressed enthusiasm for learning and training. As a result of insufficient training opportunities they appeared to see learning from each other as an option, if a suitable role model was available. They emphasised that training must be practical, realistic and relevant.

Previous work exploring training needs in a specialist mental health setting (Smythe *et al* 2013) found similar themes around skills, attitudes, barriers and enablers. Staff in both settings perceived practical or ‘hands-on’ training to be more valuable than didactic teaching, particularly when working with positive role models. Gaps in knowledge about the aetiology of the disease process, managing behaviour, lack of time and inadequate staffing were all identified as barriers to person-centred care.

Phase two The project aimed to examine the feasibility and staff’s experiences of implementing the BPTI on the wards compared with a standard teaching approach or no training. The standard teaching approach consisted of a six-week, classroom-based rolling programme. Content included delirium, managing behaviour perceived as challenging, nutrition and hydration, the importance of activities, falls management and end of life care. Delivery was didactic and focused on physical health needs.

Participants appeared to see learning from each other as an option, if a suitable role model was available

We hypothesised that, in contrast to the standard teaching, the BPTI would facilitate development of professional confidence and self-efficacy, self-esteem and acknowledgement of emotional labour. The BPTI aimed to provide opportunities for staff to address attitudes, and therefore develop emotional competence, empathy and a non-judgemental approach. Training aimed to address the barriers identified and to enable staff to make connections with people with dementia by exploring ways to provide meaningful occupation and enhance wellbeing.

The BPTI was designed to be delivered for one hour a week over five weeks. The trainers were a mental health nurse/researcher with teaching experience and two general nurses. A manual was written and used to ensure implementation fidelity. Each session began with a conversation outlining training objectives and delivering important messages, followed by working alongside the staff member and subsequent feedback and reflection. This was expected to be cost effective as staff were not required to leave the clinical area to attend the training.

Thirty participants, from three different wards, received the BPTI. This group was diverse in terms of age, gender, length of experience and qualifications.

Most staff did not attend the standard training; attendance was sporadic and 86 staff in total attended one or more sessions in 2012.

We hypothesised that poor attendance rates related to difficulties releasing staff, prioritisation of statutory training and staff preferences for a hands-on approach.

Descriptive data about staff demographics were collected and a range of self-administered standardised questionnaires were completed by both groups at baseline and pre- and post-training:

- The Inventory of Geriatric Nurse Self-Efficacy, which measures confidence (Mackenzie and Peragine 2003).
- The Approaches to Dementia Questionnaire (ADQ), which measures attitudes (Lintern *et al* 2000). Two sub-dimensions were measured: ‘hope’ and ‘recognition of personhood’, along with a combined total score (‘total approaches to dementia’).
- The Maslach Burnout Inventory (MBI), which measures personal accomplishment (PA),

depersonalisation (DP) and emotional exhaustion (EE) (Maslach *et al* 1996).

- The Alzheimer's Disease Knowledge Scale (ADKS), which measures knowledge (Carpenter *et al* 2009).

These measures have been used together in similar UK studies and all showed high interrater reliability and validity (Rose *et al* 2010, Moyle *et al* 2011). The questionnaires were returned to an independent researcher rather than one of the trainers.

Scores were compared between the two groups at baseline and post-training. Initially, descriptive statistics were computed to explore the distribution of the obtained data, for example, measures of central tendency, assessments of normality, internal reliability, and frequency distributions.

A series of statistical tests for differences, predominantly the t-test, was carried out using the Statistical Package for Social Sciences to explore any possible relationships across the key variables measured pre- and post-training. Further analysis was carried out using all the data sets together to identify any significant changes.

Ethical considerations The project was considered by the organisation's research and development department to be a service evaluation and was subject to trust research governance procedures. All the staff volunteered to take part in the project having received an information sheet. Data were anonymised and stored securely.

Results

Quantitative A total of 81 staff from the three wards completed questionnaires and received either training as usual or the BPTI. Of these, 15 (19%) participants did not complete the follow-up questionnaires, due to various reasons, such as staff moves, night shifts and sickness. Complete data were obtained for the remaining 66 (81%).

No significant differences were found between the group of participants who did not receive the BPTI (training as usual/standard approach) and the group who received the BPTI. On the third ward positive trends were identified, but again these were not statistically significant.

For 'self-efficacy', the mean values measured in the groups ranged from 46-56. The possible range of scores is 9 to 63, which suggests that although the instrument does pick up a spread of scores, these mean values particularly at baseline were close to the ceiling of possible scores and therefore it is questionable that a change could have been detected.

For the ADQ ('hope', 'recognition of personhood' and 'total approaches to dementia'), only values for 'hope' lay close to the ceiling of possible values (19). However, being close to the floor of possible values does not prevent sensitivity to possible change, that is, increase, with this instrument.

For the MBI PA the mean measures across the groups were between 33 and 38, with the possible range of scores 0 to 48. For the MBI DP the mean measures across the groups were between 1 and 6, with the possible range of scores 0 to 30. For the MBI EE, the mean measures across the groups were between 9 and 18, with the possible range of scores 0 to 54. Only in the case of the MBI DP was there a question of the sensitivity of detecting change as in all cases the mean scores were close to the floor of possible values.

Finally, for the ADKS, the mean values of the groups were between 20 and 23, with the possible range of scores 0 to 30, which gives confidence that the instrument has the potential to map changes in either direction.

Wards were busy, staffing was an issue and it was a struggle to cope with training demands alongside clinical duties

Qualitative findings Interviews were conducted with staff from both groups (n=15) to explore their experiences of training. Interviews were audio-recorded and transcribed verbatim. These transcripts were analysed using thematic analysis.

Wards were busy, staffing was an issue and it was a struggle to cope with training demands alongside clinical duties. Some staff would have preferred to receive the training while off duty.

Staff reported feeling self-conscious because they perceived they were being watched or assessed. Others preferred the practical approach of the BPTI compared with theory-based learning:

- 'Rather than sitting people in classrooms, listening which can be frustrating and it was just long enough… it was more easier to talk to everyone, I liked it because you were doing something practical, I learnt a lot more than if it's a big group in a classroom, mainly because I don't stand up and talk myself' (P5, FG2).

Staff thought that the training increased their awareness of the needs of people with dementia and that they were more knowledgeable and more skilful as a result. They described better understanding the emotions and behaviour of people with dementia, which increased their tolerance, understanding and confidence:

- 'I think it gave me more patience…more confidence in how to talk to them, and more understanding that they don't mean to do things that they do. Cos it's not their fault' (P5, FG2).
- 'It was interesting because you were learning more about that person. However many years you have been in nursing, it makes you think. Because they [the training] are all things you do every day, but you can always find room for improvement. I mean different ways of going about and trying to make that little bit more of an approach to them and satisfy them' (P5, FG2).

Trainers' reflections on delivering BPTI Staff were often not available to work in groups due to the nature of the environment. There were no communal areas and 40% of patients were in single rooms. It could not be ensured that staff allocated for training would be delivering care for someone with dementia as the wards were mixed specialty. There was evidence of some resistance, because sometimes the trainers were asked to reschedule with no notice. It was often necessary for one of the trainers to backfill so as to free the member of staff receiving training to work with someone with dementia.

Discussion

The aim of the project was to investigate the feasibility and staff's experiences of implementing the BPTI on the wards compared with a standard teaching approach. Mixed methods were used to gain a comprehensive understanding of its effect.

It was hypothesised that quantitative results would demonstrate significant improvement for the BPTI group post-training compared with pre-training. However, in contrast to qualitative findings this did not happen. While they did not contradict the qualitative findings, the quantitative results were inconclusive and, when positive trends were identified, they were not statistically significant.

This is probably due to the relatively small sample size in which statistical significance was unlikely to be achieved. Sample size was not in the researchers' control due to lack of resources. The measures were validated in UK studies conducted in nursing and residential homes. Floor and ceiling effects may have undermined their validity (Wang *et al* 2009), because the meanings of high or low scores could not be scrutinised and understood.

Therefore, if the project was repeated it would be appropriate to replace the self-efficacy and MBI DP measures.

Staff described better understanding the emotions and behaviour of people with dementia, which increased their tolerance

The project design had limitations as there were insufficient resources to ensure staff attended standard training or to provide a dummy intervention for the classroom-based group. Therefore, it was not possible to measure the impact of the extra time and attention that the staff who were allocated to the BPTI arm may have received. Participants may not have had enough time to complete the questionnaires in the practice environment and questionnaire fatigue may have arisen.

It was not possible to explore the variation between the trainers because they did not work independently with participants. Therefore a participant may have received training from one or more trainers.

It is accepted that this is a limitation. Due to limited resources and from a practical point of view, it was not possible to ensure the rater was blind to treatment allocation. We considered this, but concluded that as soon as the researcher started talking to the staff, it would be obvious to them whether they had received the BPTI.

Initially, it was anticipated that staff would be trained in small groups of five to enable peer support, however, time pressures and restrictions with staff rotas made this impossible. Therefore, staff had to be seen individually and this increased the time needed to deliver the training substantially while limiting chances for role modelling and group teaching, thus diluting its impact. In addition the physical environment prohibited opportunities for patient group activity and engagement.

The approach had been identified as cost effective; being ward-based there was no requirement for expensive backfill provision. However, in practice, one of the trainers was required to backfill for staff. It was difficult to ensure implementation fidelity as trainers were similarly constrained by competing organisational demands.

In summary, skills-based training delivered in the clinical area can be restricted by time, organisational and environmental factors that should be taken into consideration when delivering this approach.

Conclusion

Definitive conclusions cannot be drawn about the efficacy of the intervention, due to the contradictory outcomes between the quantitative and qualitative data. The intervention was based on sound learning and psychological theories, a systematic literature review and was congruent with the outcomes of the focus groups. However, due to the barriers discussed, it was not possible to implement the BPTI as envisaged and this may have contributed to the discrepancy between the findings.

While an acute care setting is not ideal for people with dementia, inevitably many will require this type of admission, therefore effective training for staff is essential. This project explored the use of a practical ward-based approach that may be considered as a stage in progress towards training that will support acute staff in delivering the care they would like to offer people with dementia. The perspectives of people with dementia and their families should be sought. This was not possible in this project due to the nature of the ethics permission. Further developments and research are required to explore how staff and organisations can be supported to deliver the best possible care for people with dementia in acute hospitals.

Online archive

For related information, visit our online archive and search using the keywords

Conflict of interest
None declared

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How can training interventions for nurses promote person-centred dementia care in nursing homes?

Catharine Jenkins and colleagues describe how education can improve nursing care

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Abstract
This paper discusses the context of dementia care in nursing homes and the importance of culture change for embedding a person-centred approach. It addresses drivers for change (competency frameworks, government policies) and a range of training interventions that have been provided to enable staff to achieve these competencies. It also outlines the teaching approaches that are most likely to enable individuals to change their practice and influence their colleagues.

Key words
Dementia, person-centred care, nursing homes, training, education

Reference
Jenkins C, Smythe A, Galant-Miecznikowska M. (2014) How can training interventions for nurses promote person-centred dementia care in nursing homes? Mental Health Nursing 34(5): 16-19.

Introduction

There are currently approximately 800,000 people living with dementia in the UK (Alzheimer's Society, 2013). The population is ageing and the expected rise in numbers in future generations is now well-known and widely quoted (Glasper, 2014; Grout,2014).

Approximately one-third of people with dementia in the UK are cared for in a nursing home environment (Alzheimer's Society, 2014). Concerns are frequently raised in the media about the quality of care in these environments (e.g. BBC Panorama 2014) and while for many care is of high quality and person-centred, this is not always the case (Department of Health, 2013).

The National Dementia Strategy (DH, 2009) requires the dementia care workforce to have 'the necessary skills to provide the best quality of care'. Dementia care education has historically been limited in pre-registration nursing courses (Blakemore, 2014), despite the high numbers of people with dementia in general hospitals (DH, 2013), leading nurses to feel under-prepared (Gandesha et al, 2012).

It has been suggested that education of both pre-and post-qualification nurses should include a stronger focus on dementia (Blakemore, 2014), and this is particularly relevant for those working in nursing homes.

However, these nurses may have less access to training post-qualification in comparison to peers working in the NHS (Wilson Brown et al, 2013).

Living with dementia in care homes

The term 'dementia' refers to a range of progressive syndromes including Alzheimer's disease, vascular dementia, Lewy Body disease and alcohol-related dementia, all of which have a gradual impact on a person's ability to remember, orientate themselves, communicate, sequence activities and keep themselves safe (Nazarko, 2013).

People in later stages of dementia usually need assistance with managing personal hygiene and eating a healthy diet. They also tend to have difficulties in both understanding others and expressing themselves.

A person with severe dementia may be orientated to a time in the past and believe that they are a young child or have parental or work responsibilities.

These issues often lead to frustration and behaviours collectively known as 'behavioural and psychological symptoms of dementia' or 'indications of distress', which include repetitive speech, resistance to care, disinhibition, aggression and crying (Parker et al, 2012). As a result caring roles can be very stressful for both family and professional carers (Adams, 2008).

People with dementia who live in care homes may also experience difficulties because of the unfamiliar environment and because the person-centred ideal may not be a reality (May et al, 2009).

Cultures of care

People in later stages of dementia need practical assistance with the functions outlined above. Some need emotional support for the emotional distress that can follow from feeling disorientated, separated from loved-ones and being recipients of personal care from people who may be perceived as strangers (Hammar et al, 2011).

At the time when people most need to communicate their needs they are least able to do it, so staff need to develop insight into the person's experience, preferences and communication styles in order to respond sensitively (May et al, 2009).

Kitwood (1997) emphasised the benefits of a person-centred culture of care that aimed to change the approach from the previous 'old culture' organisationally-orientated care, where lives were managed around the timetable that was convenient for staff and institutions.

'New culture' or person-centred care is individually designed recognising personal preferences for practical assistance, the importance of life history and engagement in meaningful conversation and activity with the aim of providing a social environment that supports identity or 'personhood' (Kitwood, 1997).

Since then others have built on Kitwood's ideas to acknowledge that caring has an impact on carers and their needs should also be recognised in recommendations for care delivery (Nolan et al, 2006; Adams, 2008). Despite the work of Kitwood and others, people with dementia living in care homes may still be cared for within institutional regimes that fail to recognise individual preferences and offer minimal meaningful activities (Harmer and Orrell, 2008).

Drivers for change

Concerns about the quality of care provided in nursing homes have been raised within the media (BBC, 2009; Brindle, 2014) and by the Alzheimer's Society (2013) and the Care Quality Commission (2013). Evidence showing high-quality care is possible similarly drives change.

Hanson (2014) describes a person-centred homely approach where staff value their work and both residents and family members are highly appreciative. This and other accounts (van Zadelhoff et al, 2011; Sheard, 2008) confirm that we should confront the 'low expectations' of care identified by the Alzheimer's Society (2013).

Government priorities include provision of high quality dementia care for people living in care homes (DH, 2009; DH, 2013) while the Social Care Institute for Excellence (SCIE, 2013) states that research into high-quality care is as important as that into prevention.

Jeon et al (2013) explored how research around person-centred care could influence practice through an educational care planning intervention. Brown Wilson et al (2013) recommended a biographical approach to care planning, while Krumm et al (2014) emphasised the importance of palliative care principles such as excellent pain management and spiritual care.

Although staff training in dementia care is widely promoted as being inherently 'good', with the ultimate goal of improving the quality of life and care for residents (Nolan et al, 2008), literature reporting outcomes of such training programmes suggests that findings are equivocal and benefits inconsistent (Bourbonniere and Strumpf, 2008).

There is substantial variability in the length and type of training interventions that have been evaluated. Indeed there appears to be lack of consistency in the educational/training programmes with research teams implementing various programmes of differing intensity and length, based on different theoretical frameworks, and including many with a mixed content (McCabe et al, 2007).

Spector et al (2013) divided dementia care training evaluation studies into five categories according to approach: behavioural orientated; communication; person-centred; emotion-orientated and 'others'.

This latter category included skills-based approaches, practice-based approaches, a goal planning intervention and a systematic consultation approach (including behavioural management techniques; positive care planning, communication skills and reminiscence).

A variety of outcomes were measured, with most studies considering impact on staff's knowledge or attitudes and some considering staff behaviour or outcomes for those with dementia such as antipsychotic prescribing or use of restraints (Spector et al, 2013).

The lack of comparability makes it difficult to draw conclusions about topics or areas of competence that need to be covered in training for staff working with people with dementia.

In addition, it is hard to isolate the key ingredients in success, but the literature implies training should be supported by and embedded in the organisational structures and that ongoing support, supervision and organisational change may prove necessary to demonstrate a sustained implementation of the new knowledge (Spector et al, 2013; Kuske et al, 2007).

Competency frameworks for health care professionals (Tsaroucha et al, 2011; Smythe et al, 2014; Higher Education Dementia Network, 2014) are designed to provide thorough guides on outcomes for educational and training programmes while also having relevance for job descriptions.

Competency frameworks outline the achievable and measurable qualities, skills values and capabilities required of care deliverers, from the generic (communication skills, care planning, information sharing) to role-related specifics (assistance with personal care, prescription of appropriate medication, diagnosis sharing, staff guidance and support).

Competency frameworks are based on literature reviews and compiled with input from a variety of stakeholders, including people with dementia and family carers. Therefore it could be argued that if the competencies are achieved this is what good care should look like. However, the proof of the care is in the recipient's experience.

In order to express how good care might feel from the perspective of people with dementia, the government (DH, 2013), in partnership with the Dementia Action Alliance, has phrased how the outcomes should feel for care recipients, in a series of 'I statements' such as:

- I get the treatment and support, best for my dementia, and for my life.
- I feel included as part of society.
- I understand so I am able to make decisions.
- I am treated with dignity and respect.
- Those around me and looking after me are well supported.
- I am confident my end-of-life wishes will be respected. I can expect a good death.

While these statements express a positive experience of care that most would support, it seems unlikely that a person with severe dementia would be able to articulate them so clearly. Proxy measurements of quality of life may also be used, for example the opinions of family members, (Mesman et al, 2011) dementia care mapping (Brooker, 2007) and analysis of behavioural indications of distress (Beerens et al, 2012).

Understanding what good and poor care look like and how they may be experienced, plus having lists of competencies to aim for, are clearly steps on the way to achieving good outcomes. However, the analysis, moral arguments, recommendations and rhetoric developed from Kitwood's (1997) time onward have achieved only partial impact in delivery of consistent person-centred practice within new cultures of care.

Barriers

Roles involving nursing people with dementia in any environment are challenging, demand physical and emotional energy and require a range of skills that when carried out well are often invisible to others (Holman, 2014).

However, the care assistants who carry out most of this work are among the lowest paid in the UK and are at high risk of job strain and burnout (Koehler, 2014; Edvardsson et al, 2009). As with trained nurses, they receive mixed messages in the media about their worth (Donelan et al, 2008) while being trained by people who may be perceived to be high on rhetoric and low on recent experience of the stark intimacy of personal care (Adams, 2008).

The nurses who lead and manage teams of care assistants may be in different, but likewise difficult, positions. Some, in first jobs post-qualification, may be charged with promoting high standards of care and 'culture change'. Others may have chosen nursing home work to fit around family responsibilities or as a 'step down' from the demands of acute care toward the end of their careers.

Nursing in a nursing home is challenging. Residents have increasingly complex needs; professional decisions have to be made independently, care needs to balance with costs and outcomes, and different pressures from owners, relatives, residents, colleagues and CQC inspections (and associated bureaucracy) to be managed, resulting in low levels of morale throughout the sector.

Opportunities to 'model' good care may be limited by the need to spend time on medication administration and managerial aspects of the role (Smythe et al, 2014a).

Nurses find they are usually the only qualified staff member on duty and are responsible for a range of clinical, ethical and managerial decisions (Bedin et al, 2012). They may not receive sick pay and some nurses report being expected to access learning in their own time (RCN, 2012).

While care philosophies may speak of a person-centred approach, unspoken messages underscore financial imperatives and homes are often under-staffed (RCN, 2012). There is a perception that working with older people is of a low status (Fussell et al, 2009) and undervalued (RCN, 2012).

Training is costly, and even when it is free, the backfill costs for qualified staff make it unaffordable for some organisations (Alzheimer's Society, 2013) and it could be argued that the homes which need it most are least likely to access it.

The nursing home context can thus raise barriers to the education of its nurses. Even when nurses are able to access training it can still be difficult for them then to lead changes within the culture of the organisation.

Education that changes practice

Education and training are seen as central activities that deliver changes in practice but many training packages are found to have little or no impact after a short period of time (Mace, 2005).

Training interventions can vary in length, some awareness-raising being as brief as an hour, while academic courses at higher levels may take years to complete. There is also a wide range of free online learning packages that offer excellent resources that explain the nature of dementia, offer insight into the experiences of people living with dementia and promote a positive person-centred problem-solving approach to care (e.g SCIE Open Dementia Programme 2009).

While knowledge and understanding are an essential foundation, alone they do not necessarily lead on to doing things differently and superficial learning tends to have little or no impact (Sheard, 2009).

There is a big step between knowing what you are aiming for and achieving it, in relation to both competencies and cultures of care. While culture is sometimes defined as 'the way we do things round here' (Martin, 2006) and this is observable, culture has also been likened to an iceberg, an analogy which reflects the 'under-the-surface' nature of values, beliefs and assumptions.

Educational interventions need to be creative, stimulating, challenging, emotionally engaging and relevant in order to address these core aspects (Rogers, 2007). They need to have outcomes that aid qualified nurses to apply and share principles of good practice, to lead confidently and support colleagues so that their needs are met as well.

In addition nurses need to be able to cope with their own stress and responses in emotionally intelligent ways, often with minimal immediate support. Nurses need to truly understand and value a person-centred approach, where life histories and compassion underpin everything from assistance with practical daily care to provision of personally relevant activities and emotional and spiritual support.

Insight and empathy motivate, while clinical and leadership skills are required to enable nurses to make the vision real for residents, staff and visitors.

Adult learners thrive in environments that respect their experience, focus on relevant activities and welcome discussion and challenge (Rogers, 2007). Adults see learning as a social experience and learn best by 'doing' (Race, 2006).

Active experiential approaches to learning are more likely to 'stick' (Beard and Wilson, 2006) while reflection and discussion in small groups enables participants to build personal meanings from learning (Biggs and Tang, 2011). Educational interventions that change practice tend to be emotional, personal and interactive experiences that are felt as inspirational and transformational, affecting 'hearts and minds' (Sheard, 2008).

In addition the ongoing impact of educational programmes depends partly on the support available from leaders within the organisation (Cleary et al, 2010) and mutually between colleagues who attend the same training programme (Mace, 2005).

Therefore training programmes need to take into account the organisational contexts within which outcomes are expected to be applied and take steps to anticipate and address barriers within these contexts, then develop strategies that will increase the likelihood of training making a long-term difference to practice.

Our previous research into training needs and preferences

Our previous research, which explored the dementia care training needs of specialist staff and nurses working in acute hospitals confirmed that adult learners prefer active, experiential approaches to learning and that these were successful in changing practice long-term (Smythe et al, 2013; Smythe et al, 2014b).

We also found that while care assistants in specialist mental health services preferred to learn separately, they later revealed that some learning was difficult to implement as qualified staff were not always in tune with the person-centred approach.

Some nurses and qualified social workers 'sent themselves' on courses that were designed for care assistants, which alerted us to the gap in provision for this group.

The acute hospital nurses benefitted from in-practice reinforcement of classroom learning through a 'working alongside' approach to address particular practice problems, although this was difficult to implement in the acute setting.

Our current study

The current study is funded by a grant from the Burdett Trust for Nurses and builds on our previous findings.

We have designed a dual element training intervention and study that will explore which combination of interventions (classroom-based training, work-based learning and clinical supervision) have the most impact in changing practice in nursing home settings.

The programme will focus not only on knowledge, attitudes and skills, but also address leadership issues, burn-out and changing cultures of care.

We plan to evaluate the impact of the training interventions on the nursing participants, care staff, the people they care for and their relatives, by using a range of measures including evaluation tools, dementia care mapping and interviews. **MHN**

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The experiences of staff in a specialist mental health service in relation to development of skills for the provision of person centred care for people with dementia

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Abstract

It is estimated that 820,000 people in the UK have dementia. Dementia costs the UK 17 billion a year and in the next 30 years this will treble to over £50 billion a year. There is a need to raise competence of staff delivering care to people living with dementia across health, social and voluntary sector provision. Effective education and training will build capacity and improve staff knowledge. However, at present not enough is known about the experiences of staff involved in gaining the skills, knowledge and attitudes required to support provision of high quality care for people with dementia.

This study was conducted within a large National Health Service Trust in the UK serving an urban, ethnically mixed population, in collaboration with a local university. The trust responded to government policy by seeking to identify staff training needs.

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The aim was to explore the experiences of staff working within a specialist mental health service in relation to development of skills for the provision of person-centred care for people with dementia. To achieve this, staff roles, experiences of dementia training and the ways in which staff feel they learn were explored through focus group interviews. Relatives' views of staff competencies necessary for effective care provision were also explored to supplement the data from staff. A total of 70 staff and 16 family carers participated and data were subjected to inductive thematic analysis.

Five themes emerged: competency-based skills, beliefs, enablers and barriers and ways of learning. Findings suggested participants felt that skills for person-centred care were innate and could not be taught, while effective ways of learning were identified as learning by doing, learning from each other and learning from experience.

Keywords

dementia, training, education, mental health personnel

Context

In the last 15–20 years, psychosocial understandings of dementia have emerged to supplement biomedical understandings. These approaches, such as that of Kitwood (1997), are situated within a bio-psychosocial framework and emphasise individual identity, personal history and social relationships in addition to neurological and health factors. Therefore, in offering interventions for people living with dementia there is a need for a holistic person-centred focus.

Three systematic reviews have recently considered evidence for the effects of educational interventions on delivery of dementia care. Perry et al. (2010) concluded that to improve outcomes, educational interventions need to be combined with wider organisational support including social network strategies, adequate financial reward for both training participation and quality of care, and be supported by protocols for structured care and management.

Livingston, Johnston, Katona, Paton, and Lyketsos (2005) found that there is consistent well supported evidence for the use of staff education in the management of neuropsychiatric symptoms. However, improvements in knowledge and skills were not always sustained over time. McCabe, Davison, and George (2007) concluded that the variety of education programme, including the content and training modalities, with research teams implementing various programme of differing intensity and length, based on different theoretical frameworks, and with a mixed content make it hard to draw conclusions about how to best ensure competence.

There are a small number of randomised controlled trials (RCTs) that examine the effectiveness of staff training (Chenoweth et al., 2009; Kuske et al., 2009; Visser et al., 2008). Chenoweth et al. (2009) compared person-centred care (PCC; CADRES), dementia care mapping and usual care in dementia in 289 patients. There was a reduction in agitation in sites providing mapping and person-centred care, compared with usual care. Fewer falls were recorded in sites that used mapping but there were more falls with person-centred care. Kuske et al. (2009) attempted to measure staff's sensitisation to the experience of the residents with dementia and their communication competencies. Their findings suggested significant positive effects of their training programme on caregivers' overall competence in managing patients with dementia and a reduction in the use of neuroleptic medication. However, again this effect was not sustained at the 6 months follow-up.

Echoing the conclusions of Perry et al.'s (2010) review, studies suggest that staff organisational and environmental factors are important determinants of whether newly learned skills are implemented in the workplace. On-going support, changes in working conditions and more time for residents beyond basic physical care, as well as other organisational or environmental changes, have been found to facilitate the implementation of newly learned skills (Burt & Alyward, 2000; Cohen-Mansfield, 2001; Kuske et al., 2009).

Visser et al. (2008) found staff training did not impact on residents' behaviour, quality of life or on staff levels of burnout; despite a positive change in staffs' attitudes to working with people with dementia. According to Visser et al. (2008) staff training offered in isolation from the socio-cultural context may not be an effective way of managing behavioural symptoms in dementia.

The above studies demonstrate substantial variability in the length, intensity, content and type of training interventions that have been evaluated, with research teams implementing various programme based on different theoretical frameworks, and including many with a mixed content (McCabe, Davison, & George, 2007). Common areas of focus are PCC (though details of how this was operationalised were not always given) and behaviour management but the differing modes of delivery mean that it is hard to draw conclusions about whether they impact on quality of care. Almost half of the studies reviewed found no positive changes as a result of the training that had been delivered.

In a related area, McCarron, Fahey-McCarthy, Connaire, and McCallion (2008) carried out a large qualitative study in order to understand the experiences of staff in supporting persons with intellectual disability and advanced dementia. The accounts were interpreted to gain an understanding of their education and training needs. A core theme which emerged from the focus groups was staff perceptions of the fundamentals of good care at end-of-life for persons with dementia. These perceptions included the belief that person-centred care, comfort and spiritual support are paramount.

The lack of comparability and varied training programme make it hard to draw evidence-based conclusions about topics or areas of competence that need to be covered when training for staff working with people with dementia (Tsaroucha, Benbow, Kingston, & LeMesurier, 2013). In addition, it is hard to isolate the key ingredients in successful training (National Collaborating Centre for Mental Health, 2007), but some of the findings imply that ensuring training is supported by and embedded in the organisational structures is important. Ongoing support and organisational change may prove necessary to demonstrate sustained implementation of new knowledge (Kuske et al., 2009).

It is evident that there is a lack of research that evaluates well-designed in-service training programme for healthcare professionals who are caring for people with dementia. In addition, the majority of studies have been carried out within residential and nursing homes and there is little research which focuses on the training needs of staff within specialist mental health services. There is, therefore, a need for further studies which establish the training needs of staff, particularly within specialist mental health services. Such research could inform the development of effective training.

In this study, we aimed to explore staff experiences of working with people with dementia within a specialist mental health service with a view to developing a better understanding of the skills, attitudes and knowledge they feel they require to provide high quality care.

We also hoped to develop an understanding of how staff feel they best learn and develop their ability to provide good quality care. Furthermore, we aimed to supplement staff perspectives by gaining relatives' views of staff competencies necessary for effective care provision. Our method was somewhat similar to that of McCarron et al. (2008) reviewed above.

Method

Design

The investigative approach was based on a qualitative/naturalistic method, since we wished to explore the subjective experiences of staff. In particular, a phenomenological approach seemed suitable. Phenomenology investigates subjective phenomena in the belief that critical truths about reality are grounded in people's lived experiences (Darroch & Silvers, 1982). The goal of a phenomenological study is to fully and accurately describe the lived experience and the perceptions to which it gives rise, not to generate theories or models or to develop an explanation (Morse & Field, 1996). In tune with the foundations of one major phenomenological approach, interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009), we aimed to attempt, as far as possible, to gain an insider perspective of the phenomenon being studied, while acknowledging that the researcher is the primary investigative instrument (Fade, 2004).

Data were collected through focus groups. Willig (2001) describes focus groups as group interviews that use interaction among participants as a source of data; the researcher takes on the role of a mediator gently guiding the discussion. It was considered that this medium would provide a containing and stimulating setting in which staff would feel empowered to express their views. The participants shared experience of working in the same environment (e.g. of caring for people with dementia on a particular ward). In order to ensure a further degree of homogeneity, and thereby both safety and focus, wherever possible focus groups were conducted separately with qualified and unqualified staff and different disciplines.

Participants

A total of 14 focus groups were conducted with staff, with 70 participants in total. Two further focus groups were conducted with caregivers with a total of 16 participants. Purposive sampling was used as staff were selected on the basis of being from a particular setting and discipline. The participants were from a range of professional disciplines, including nurses, occupational therapists and physiotherapists, and included qualified and unqualified staff from two continuing care wards, two community mental health teams and two assessment wards. Family carers were recruited from a carers' group whose relatives had been admitted to a continuing healthcare setting.

Procedure

Ethical issues and recruitment

Although ethical approval was not sought, as the project was considered a service evaluation, we obtained approval from the Trust research and development department and ethical principles were followed. Staff were invited to take part and those expressing an interest were given information sheets and were made aware that they could withdraw from the study at any time. Written informed consent was gained. Staff were reassured that steps had been taken to ensure their anonymity, that the data would remain confidential and identity would be protected.

Focus groups

The groups were conducted in a quiet room in participants' clinical areas and were facilitated by two members of the research team. Each focus group lasted approximately 45 min. Key areas of discussion included current roles and skills, gaps in skills and knowledge, experiences of previous training and suggestions for improving training outcomes. The focus groups were audio-recorded, anonymised and transcribed verbatim.

Analysis

The aim of the analysis was to identify key themes arising across the 14 focus groups to gain understanding of staff experiences and perspectives around necessary competencies, learning and skill development. We achieved this by carrying out an inductive and interpretive analysis of the scripts, combining the methods of thematic analysis (Braun & Clark, 2006) and those of IPA (Smith et al., 2009). The initial steps of analysis were reading and re-reading the text to gain familiarity with the material; assigning codes which captured the meaning of sections of the text; integrating these to draw out themes; and identifying clusters of themes and giving them descriptive labels which were often drawn from the participants' own words (e.g. 'ways of learning' or 'feeling misunderstood'). These steps are common to both inductive thematic analysis (Braun & Clark, 2006) and IPA (Willig, 2001). In the process of analysis, we paid attention to underlying meanings implied in participants' language as well as superficial content. In order to identify major themes that were common across the large number of focus groups, as well as to develop some idea of the differences between professions, we drew from IPA's idiographic emphasis. Thus we constructed a summary table of themes, together with illustrations of each theme, for each focus group. Comparing these across the 14 groups, emergent themes that appeared more commonly in the accounts of particular grades of staff or professions were exposed. This comparison allowed us also to generate a list of master themes to reflect common experiences across the whole sample (Palmer, Larkin, De Visser, & Fadden, 2010; Smith et al., 2009). Data from the two focus groups with carers were separately analyzed using the same approach.

Findings

The aim of the research process was to explore the participants' lived experiences, making sense of these to gain an understanding of skills development for the provision of PCC for people with dementia. Five themes emerged from the analysis of staff focus groups: competency-based skills, beliefs, enablers and barriers and ways of learning. Each of these will be discussed in turn.

Competency-based skills

At times the participants struggled to define the core skills they use when working with people with dementia. Although they felt confident in providing care, they seemed to find it difficult to define the process, perhaps because it had become automatic and engrained. This is demonstrated in the following extract:

> “Sometimes when you work with a specific group, you take your skills for granted don’t you? It’s kind of natural, it’s like second nature and then when someone says what do you do, it seems so natural, it’s hard to exactly explain what you do” (Occupational Therapist, FG 9).

When discussing specialist skills, the focus group participants described being able to draw on reasoning, problem solving and observational skills (e.g. understanding behaviour as a form of communication of unmet need). Depth of knowledge and the ability to apply this in a meaningful way to a range of situations were also seen as important. Teaching, consultancy and sharing knowledge with other colleagues, carers and families also emerged as an important part of the specialist role:

> “I think we are very good at sharing information with the carers and explaining basic things with them in a way that they understand. Where, perhaps other people might think that they already know about it, or they have heard it before when actually nobody has took the time to sit down and explain” (Physiotherapist, FG 14).

Differences between professional groups emerged from the analysis. In contrast to other disciplines, nurses tended to talk about their competence in generic core skills, such as communication, basic counselling skills and flexible approaches to PCC rather than profession specific skills. In some focus groups, the nursing staff referred to their competence in terms of practical tasks. Examples of these tasks included: ‘Depot injections, administering medication, organising the unit and supervising doctor’s reviews, etc.’ It is important to acknowledge that some of these tasks may be profession specific. Nurses work in more specialist or advanced roles such as community psychiatric nurses (CPNs) identified assessment, liaison and risk assessment as key skills.

The healthcare assistants (HCAs) perceived themselves as specialists in managing perceived challenging behaviour and carrying out interventions around personal care. This was recognised by the trained staff:

> “The fact that they spend so much time on the floor and you know, they are involved in a lot of personal care with them and they are observing them throughout the day. I think they are very, very good at picking up changes in people. You know, it’s not necessarily people saying that they feel unwell, but just a general change in demeanour or you know, they are very good.” (Nurse, FG 4).

Allied health professionals were much more confident in articulating the specialist elements of their role. Occupational therapists, for example, were clearly able to define discipline specific skills such as knowing how to work with activity and occupation, the retention of functional abilities, enhancement of capabilities and social integration. In contrast, nurses reported feeling unclear regarding the remit of their role. They described it ‘as a bit of this and a bit of that’ or even ‘General dogsbody....taking charge of the ward’. This seemed to be associated with a lack of professional confidence, the word ‘dogsbody’, for example, giving an impression of being in a lowly position. This is also reflected in the quote below:

> “I think that our sort of accountabilities has gone up and up and yet our ability to make anything happen has gone down and down. Our status, in any group, I think we are

> probably… you know, well I think we don't have any status in any conversation compared to O.T, and psychology. I often feel that, I don't know if you feel very side-lined and as though your input isn't particularly… Do you ever get that feeling?" (Community Nurse, FG 5).

In addition to talking about skills or areas of knowledge, participants identified a wide range of qualities or attributes which they felt were essential in the delivery of PCC. These included attributing value to people with dementia, respect for subjective experiences, a non-judgemental approach, patience, an emphasis on seeing the person as a whole, enabling and empowering the individual with dementia and taking a person-centred approach.. The participants commonly used terms such as 'communication'…'respectfulness, calmness and dignity'.

Beliefs. The belief that skills for PCC are 'built in' or 'implanted' was a theme in 10 of the 16 focus groups. This belief, shared by all levels of staff, potentially challenges the idea that PCC can be taught. Although the participants here tended to identify themselves as having 'natural' abilities, the belief could be undermining to others perceived as needing to learn how to be person-centred. Many of the participants found it difficult to articulate, place or conceptualise their skills thus the idea of an indefinable something and 'magical touch' emerged.

> "I think it's fair to say that the majority of staff have got it built in already otherwise they wouldn't be here. The caring bit is built in or you could say already implanted" (HCA, FG 3).
> "I question how much you can teach somebody…. They can all sit here around this table saying exactly how they should behave, and they go out there and behave exactly the same way they were. And there are people who never do a patient centred care course that are fabulous with the patients. So I do wonder how much you can actually teach somebody" (Unit Manager, FG 3).
> "We tend to meet the needs and the patients are so different in our environment than when they were at the other place. So we probably have some kind of magical touch…..."(HCA, FG 3).

Nurse managers and HCAs shared the belief that caring abilities are 'natural', but this belief was not shared by allied health professionals who focused more on their skills and the competencies required to carry out their roles.

Barriers and enablers. Participants spoke of a number of barriers to the provision of PCC. Some participants felt that they had adequate knowledge and understanding of PCC approaches but were unable to provide PCC due to lack of time or inadequate staffing. In their view, it was not a lack of knowledge which meant they could not deliver PCC but other factors over which they had limited control. Participants seemed to feel that providing PCC would take up too much time. This is demonstrated in the following extract taken from a focus group conducted within a continuing care unit: "It's difficult to implement it, you know you want to spend time with each client but you know time doesn't… allow you…" (Nursing Assistant FG 3).

Some described the very pressured environment in which they felt they worked:

> "Because they need to be fed and everything. It's very difficult when you've got 18 dementia patients up, down, round and about, and you are trying to gather them altogether and you know, probably just 3 of us. One's shouting, one's trying to sit down, one's wandering... maybe…and you have to go and get him and you feel just whoa!!" (Nursing Assistant, FG 3).

The participants felt that if they set aside time for PCC this would mean they would not have enough time to complete essential tasks. PCC was, therefore, seen as a separate task or activity rather than as part of a holistic approach which could co-exist with other activities. This is demonstrated in the following extract, in which the participant is explaining her view that true PCC would involve letting some residents stay in bed until they chose to get up; however, the set dinner time means that this is not possible, as if she left the residents in bed they would miss their meal:

> "We just haven't got the time to do that [PCC]. I'm afraid you know we do go in and if they are asleep we might go back and leave them till last but they need to get up all in one swoop. There would be nobody up for dinner." (Nursing Assistant, FG2).

The HCAs and nurses in particular felt at times that they lacked control, had a low status within the organisation and that their role was undervalued by more senior staff.

> "You care about the clients on a one-to-one, but about the work environment and that...you're like...oh, I don't care, I'm just coming to work. You've got no passion for it and that's what happens. You start losing your passion when people don't listen to you and that really gets you down" (Nursing Assistant, FG 4).

Participants perceived the environment as stressful and challenging. This was attributed to a number of factors, such as not feeling valued, time restraints, working with signs of distress and the emotional labour of 'counselling', 'advising, negotiating between individuals and other patients/family/the outside' and generally 'comforting people through illness, fear and upset.'

A number of factors that might enable PCC were also described including mutual support from colleagues, job satisfaction and connections with individuals with dementia. The participants frequently spoke about the strong emotional ties which they developed and 'we care' was a major theme throughout the focus groups. Mutual support from colleagues was viewed as an important source of job satisfaction. The participants also perceived mutual support as an important means of managing stress. Participants who reported high levels of job satisfaction appeared to find 'joy' in their work, looking for rewards in caring. This was accompanied by feelings of self-esteem and vicarious happiness: "To see them happy, it kind of gives you know. It, you've done something you have given something back, sort of thing. That thing you need." (Nurse, FG 3).

Ways of learning

Participants valued learning from experience and learning by doing. Staff described how they had learnt their skills 'on the job' usually through working with more experienced staff. Participants looked for positive role models, staff who they could look up to, who they identified as 'trainers'. On occasions negative role models were identified who 'get the job done quicker'. Positive role models or 'trainers' appeared to be people who were very experienced ('they had done it for years') and who expected a lot from themselves and others ('expect high standards'). They were also perceived to 'have got it' in terms of being person centred. This is demonstrated in the following extract:

> "It's a god send to be fair. They know what they're doing, and you can watch 'em. There's no point just watching them once or twice, you've gotta really watch them.

> You gotta think oh I'll do that next time, or I'll do that next time you know..." (Nursing Assistant, FG 2).

Some nursing assistants seemed to have little regard for qualifications or training. Formal training was viewed as unnecessary and resistance to it was strong. The nursing assistants felt that they had been trained already by the 'trainers'. Some also felt they knew more than external trainers as they worked with individuals with dementia everyday. They claimed that the way practices were taught in the classroom did not 'fit' with their daily work and felt that the external trainers were out of touch with the 'real world' describing them as 'outsiders'. This can be seen in the following extract:

> "Like I said it's not effective on the actual unit, it's ok from the classroom on the board where they've got all their information from the Internet. But they need to come and do it for real, because you don't ... You do role play on a course, it's totally different in the ward ... Because when you role-play getting them up, they don't start biting, or punching, or kicking" (HCA, FG 4).

Findings from focus group with family carers

Three themes emerged from the focus groups conducted with family carers including 'a caring nature', approach and kindness and patience.

The carers' views echoed many of the themes identified in the focus groups held with staff. They valued those staff who they perceived to 'have got it' in terms of being person-centred. Carers described nursing as a 'vocation' and felt staff needed to have a 'good heart' and a 'caring' nature; "It's a vocational job. You have either got a vocation to do this. I think a lot of people just do it to earn money and some people do it because they love it" (Carer, FG 16).

They also identified approach as key; one carer described the staff as having 'winning ways'. When asked to elaborate she explained how staff 'can read the patients..., understand that they are all individuals'. Another carer described staff as having a 'knack' in using their experience and skills to de-escalate situations. Carers perceived that a person-centred approach involved the ability to listen and understand, create a warm atmosphere, and demonstrate respect and empathy. 'Kindness' and 'patience' were also identified as important qualities. Family carers' beliefs reflected those of nurses, in feeling that a caring nature comes from the heart rather than from training.

Discussion

The focus group conversations seemed to reveal that staff believed that the skills for PCC were built in and could not be taught. This was also a belief held by family caregivers, who felt that nursing is a vocation. In addition, some groups of staff found it difficult to identify their skills and thus the idea of 'magical touch' emerged.

Unconscious competence

The findings illustrated that participants, particularly nursing staff, frequently found it difficult to identify their specialist skills, although a wide range of skills and in-depth knowledge regarding working with people with dementia was evident during data collection. This combination of evident knowledge and lack of awareness of it seems to illustrate 'unconscious competence'. The conscious competence model posited by Maslow (1940) includes stages of learning, progressing from (1) unconscious incompetence (you don't know that you don't know something) to (2) conscious incompetence (you are now aware that you are incompetent at something) to (3) conscious competence (you develop a skill in that area but have to think about it), to the final stage (4) unconscious competence (you are good at it and it now comes naturally). Compared to the other professional groups interviewed, nursing staff found it harder to articulate the nature of their professional role. Similarly, Hurley (2009) found nurses lacked a distinctive professional identity, sharing overlapping skills with other professionals, but identifying pride in their unique ability to carry out a wide range of skilled functions. Thorsteinsson (2002) deconstructed the idea of the 'magical touch' of nurses, identifying instead that this embodies attributes such as kindness, and a good attitude and manner, as well as clinical competence.

Professional confidence

Lack of professional confidence was an issue for some individuals particularly those from nursing backgrounds. Professional confidence is associated with having the confidence, belief and ability to do your job effectively (Adams, 2008) and is related to being able to make decisions independently and being open to new ideas or evidence (Cowen & Moorhead, 2006). This appears to be related to the concept of self-efficacy which describes a person's belief in their own competence (Bandura, 1977). This may be an important variable because it affects students' motivation and learning (Dinther, Dochy, & Eggers, 2011). There is a lack of research evidence exploring issues of professional confidence and models for its development, although Watson, Hockley, and Dewar (2006) demonstrated that nursing staff, who acquired additional knowledge of interventions developed new confidence in their role. Nolan (2000) conducted focus groups with 50 nurses, from which they concluded that nurses feel 'disempowered'. Elderly care nurses may delegate personal care to lesser status workers particularly in settings such as continuing care, thus making contact care work a marginal part of their role. This in turn may underlie the HCAs' attitude that they know how to work with people with dementia better than those who are assigned to teach them. Chesser-Smyth and Long (2013) identified a correlation between professional confidence and competence, indicating that nurses who were self-confident also carried out care more effectively and achieved better patient outcomes..

Barriers and enablers

Staff identified barriers and enablers to good practice. Perceived barriers included staff shortages and time pressures and the culture of the organisation, this being consonant with the conclusions of Perry et al. (2010) and Visser et al. (2008). Lack of role clarity and professional confidence, as well as stress, burnout and emotional labour were also identified as barriers. In addition, some of the comments made by staff revealed that they thought of PCC as being an additional, time-consuming demand on their time. Enablers included making connections with people with dementia, mutual support and job satisfaction. The findings suggest staff value learning from experience, learning by doing and learning from each other.

Ways of learning

The participants spoke of finding it difficult to translate and apply class room learning to their practice. This is a central issue for teaching and curriculum design. The value they placed on learning by experience support the use of approaches based on active and experiential learning and also the use of problem-based approaches to learning delivered in the clinical area.

The findings suggested staff valued pragmatic learning or ‘learning by doing’ as a means of gaining knowledge from observation and experience. Experiential learning is learning through ‘reflection on doing’ and focuses on the learning process for the individual and complex information processing (Palmer & Kimchi, 1985). Kolb (1984) developed a theory of experiential learning known as the Kolb cycle, learning cycle or experiential learning cycle. This characterises how experience followed by reflection, can lead on to understanding, which results in changes in action that improve competence.

Androgogical theory suggests participants who are offered an opportunity for experiential learning have life experience to draw on, take a problem solving approach, perceive themselves as self-directed and are orientated to fulfilling social roles (Knowles, 1984). This pragmatic approach appears to facilitate deep learning as opposed to superficial learning. Deep learning is characterised by the learners’ active engagement with the subject matter which leads to the internalisation of new knowledge (Gibbs, 1992) as the information is actively processed (Lehrl & Fischer, 1990). Deep learning is promoted by being able to transfer knowledge from the specific to the general, relate new information to old, generate high quality inferences and exhibit integrated problem solving plans. This is different from a superficial approach which is characterised by memorisation of information and procedures. Examples of this appeared when staff used terms associated with Kitwood’s (1997) observations of poor practice such as ‘objectification’ or ‘malignant social psychology’ without understanding the underlying concept of the social construction of the experience of dementia.. The language used in the focus groups indicated that some staff objectified the patients, so even though they were clearly familiar with the language of PCC it would appear that they did not understand their fundamental meaning, in order to apply this to their everyday practice. Indeed Fook and Gardner (2007) note that being exposed to, or knowing, a theory does not necessarily mean that it is integrated into functioning and action.

Staff identified mutual support and learning from each other as enablers in terms of delivering PCC and as an important means of managing stress and emotional labour. The staff identified their own ‘trainers’ within the clinical area. Those perceived as trainers were experienced, expected high standards, and were perceived by others to ‘have got it’ in terms of being person centred. Vygotsky’s (1978) theories stress the fundamental role of social interaction in the development of cognition, and view interaction with peers as an effective way of developing skills and strategies. Vygotsky’s work suggests that learning occurs during situated activity or in authentic settings and that learning, thinking and knowing arise through collaboration with others (Samaras & Gismondi, 1998). The prominence of teamwork in the findings of the focus groups implies that there would be advantages from providing training in the clinical area as this ensures goals and learning are shared by all members. The principles of social learning theory include that people can learn by observing the behaviour of others (Ormrod, 1999). Thorsteinsson (2002) found that modelling caring behaviour can possibly perpetuate caring behaviour in others.

Strengths and limitations

Respondent validation (Appleton, 1995) enhanced the credibility of the study as the lead researcher returned to participants to summarise and confirm the themes. The staff reactions were very positive and the group frequently used terms such as 'You've got it' and 'That's right', thus confirming plausibility and transparency (Reid, Flowers, & Larkin, 2005). In addition two colleagues (JO, PB) reviewed the transcripts from the focus groups and suggested their opinion of emerging themes. There was no opportunity to carry out a validity check with carers due to time constraints related to the needs of the funding body.

Participants appeared to be open and honest about their experiences and to feel comfortable discussing difficult and sensitive topics such as serious incidents of violence and aggression. Therefore, disclosure seemed to be enhanced rather than inhibited through the presence of other participants. As the researchers had worked within the organisation in a number of roles, they already had predetermined ideas about what staff might consider useful in terms of training. Therefore, the process of 'epoche' (Giorgi, 1985) was adopted in which the researchers consciously put aside preconceptions and reflected on their ability to do this. The research could not be undertaken elsewhere as the focus was established by the funding body who agreed to pay the trust to undertake the project. Although a wide range of professionals were included, it was not possible to recruit medical staff to take part in the focus groups.

Conclusions

The findings suggest that staff believe they learn through experience, doing and modelling themselves on peers who they perceive as having high standards, extensive experience and natural ability. This focus on the importance of experience and natural ability means that staff tend not to value classroom learning. They also feel that trainers do not value their experience or appreciate the skills that they have developed through their practice. Indeed, they expressed the view that they often felt they knew more than trainers who were not seen as credible. As previously stated staff also found it difficult to relate theory to practice.

To offer training which is congruent with the findings of the study, we recommend that training will be more likely to be successful if it includes strong elements of experiential learning; if it gives opportunities for learning through modelling alongside credible trainers using a problem based approach, and 'learning through doing'. The accounts above suggest that training would be more likely to result in changes in practice if it is situating learning within the working environment and is undertaken with teams, facilitating collaborative learning.

Within a problem-based learning approach (PBL), the teachers/trainers take on the role of 'facilitators'. PBL recognises the expertise of staff, creating an adult learning environment. The problem-based approach has an extensive evidence base and is widely used in medical education and has been since the 1960s (Koch et al., 2008). This approach is congruent with the belief system of the participants and the principles of adult learning, harnessing learners' strengths and addressing opportunities for changes in practice.

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A qualitative study investigating training requirements of nurses working with people with dementia in nursing homes☆

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ABSTRACT

Background: The care home workforce (over half a million people in the UK) has a pivotal role in the quality of care provided to the residents. Much care in this setting is inadequate, lacks a person-centred focus and neglects the dignity of residents. A combination of factors leads to burnout in nurses working in nursing homes, contributing to poor quality care. Recent reports have indicated that cultures of care need to be addressed through training, improved workforce support and supervision and that improving the quality of care for people with dementia can be achieved by the development of leadership in nursing and clarifying professional values. Addressing burnout through an educational intervention should improve quality of care and nurses' experiences.
Objectives: The study aimed to explore the training needs of nurses working with people with dementia in nursing homes with a view to developing an educational intervention to reduce nurses' burnout and improve person-centred care.
Design: Four focus groups were conducted with 11 qualified nurses working in nursing homes; data was analysed using thematic analysis.
Results: Four themes emerged through the analysis of the transcripts. Participants reported that their work responsibilities revolved mainly around directing others, day to day care, paper work and supporting family carers. Nurses identified the importance of person-centred ways of being, communication and clinical skills when working in nursing home setting. They expressed their frustrations associated with managing staff levels, responding to behaviour that challenges and lack of time.
Conclusions: The barriers to learning, experience of previous training and gaps in knowledge identified could inform the design of future training and support programmes.

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1. Introduction

"Dementia" is a term used to describe a progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities (DOH, 2009). It has been estimated that globally thirty six million people are living with dementia (Thomas, 2013). Alzheimers Disease International (2013) reported that in high income countries 34% of people with dementia lived in care homes while in low or middle income countries the figure was much lower at 6%. In the UK changes in patterns of health care provision in the 1990s have resulted in fewer hospital beds, reduced length of stay and increased reliance on community health and social services for older people (Department of Health, 2000). As a result over 18,000 care homes provide places for approximately 440,000 people (Wild et al., 2010).

Pot et al. (2013) suggested that a national strategy is essential for structuring care for people with dementia, reporting that 11 countries had strategies in place. The UK National Dementia Strategy (NDS, DOH, 2009) stated improved care for people with dementia can be delivered through an informed and effective dementia workforce. Tolson et al. (2011) confirmed the international nature of this emphasis and suggested there is a need for greater career opportunities and better working conditions for nurses working in nursing homes worldwide.

Cultures of care need to be addressed through training, improved workforce support and supervision (NHS Confederation, 2012, Francis, 2013). Quality of care for people with dementia could be improved by enhancing nurses' leadership skills and clarifying professional values (Edberg et al., 2015). The authors aimed to improve cultures of care by designing a training and support intervention.

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2. Background

The care home workforce (over half a million people in the UK) has a pivotal role in the quality of care provided to vulnerable people (Royal College of Nurses (RCN), 2012). Care home staff carry out work seen as unattractive, at pay rates that are seen as under-valuing, in a sector marked by constant change and resulting in high levels of emotional exhaustion and negative attitudes to people with dementia (Tadd et al., 2012). Staff often receive inadequate training, little respect and few opportunities for career growth (Alzheimer's Society, 2013). Nurses in this sector may experience lack of specific education for clinical leadership and poor professional support (Dwyer, 2011), and hence risk job strain. Edvardsson et al. (2009) argued that the combination of these factors leads to annual turnover rates of up to 96%. Care in this setting is often inadequate; it lacks a person-centred focus and neglects the dignity of residents (NHS Confederation, 2012). Tadd et al. (2012) found that there were often difficulties in recruiting and retaining staff, who often worked long hours. The combination of the factors outlined above is associated with burnout, which in turn is linked to poor quality of care (Edberg et al., 2015). Therefore, if burnout could be addressed through an educational intervention, quality of care and nurses' experiences should improve.

The focus of the research reported in this paper was to collect data to inform the design of this intervention.

3. Methods

This study was designed to explore the training needs of nurses working with people with dementia in nursing homes with a view to designing a training package. In addition, we sought to understand nurses' roles within the care homes, experience of previous training and gaps in knowledge. Focus group interviews were identified as the most suitable methodology as they enable insight into collective views and a range of viewpoints (Lawrence, 2014) and facilitate reflective discussion (Gray and Brown, 2016). Focus groups interviews have been successfully used to develop educational programmes (Barnack-Tavlaris et al., 2013). Data was analysed using Braun and Clarke's (2006) six–step approach.

4. Recruitment and Participants

Nursing homes were identified through the Care UK website and a flyer describing the nature of the study was circulated to them via email inviting participation from qualified nurses. The sampling was purposive to ensure that we included a range of nursing homes, including small and large homes which were both independently owned and part of larger organisations. 11 qualified nurses (1 male, 10 female) from four nursing homes took part; with focus groups conducted at the participants' workplaces. Between two and four participants were present in each group.

5. Data Collection

The focus groups were conducted by two members of the research team (AS and CJ). Each of the four focus groups lasted approximately 1 h and consisted of open-ended questions, in a semi-structured format. A semi-structured interview guide, based on a literature review, was developed to inform the training intervention. We aimed to explore the competencies and skills necessary for working in nursing homes with people with dementia, nurses' roles within the care homes and their experiences of past training.

5.1. Interview Guide

1. *Would you be able to explain your role? What do you spend your time doing?*
2. *What sort of skills do you need to do your job?*
3. *Can you tell us about your previous training*
4. *Training is not always effective in changing practice; do you have any ideas or theories to explain this?*
5. *What would you like to see in future training?*

The focus groups were audio-recorded, transcribed verbatim and anonymised.

6. Analysis

The data was subjected to thematic analysis, a well-recognised method for identifying, analysing, and reporting themes within qualitative data (Braun and Clarke, 2006). Transcripts were read independently by the research team members in order to minimise researcher bias. The lead researcher kept a reflexive diary to record and explore the interpretation process (Noble and Smith, 2015).

7. Ethical Considerations

Ethical approval for the study was received from NRES Committee East of England on the 6th June 2014. Reference 14/EE/0168 IRAS ID 15922. All participants were fully informed and consented to their involvement in the study. Participants were aware that they could withdraw from the study at any time.

8. Findings

Four main themes were derived from the analysis of the transcripts: Responsibilities and frustrations, It's not like the NHS, Barriers to learning, and Future training. The first theme evolved as participants described their roles and responsibilities. This led to discussion about working in nursing homes, nurses' perceptions of how this differs from working in hospital environments and the perceived relative value of work in each environment. In responding to prompts about learning needs, the nurses reflected on their previous experiences, noting the difficulties of applying traditional and online learning to practice and their need for active, experiential, relevant training interventions in which they felt supported by both peers and experienced educators and mentors.

8.1. Responsibilities and Frustrations

When asked about their role the participants from all 4 focus groups agreed that directing and supporting staff was their main responsibility. However, the overall impression from the data was of the overwhelming nature of the different responsibilities, complexity of the roles within a context of little support, considerable isolation and perceived low status of their work.

Many participants reflected on their regret at having to leave behind the caring, person-centred aspects of nursing as they had little time to sustain relationships with residents due to the need to prioritise tasks (e.g. medication rounds, catheterisation, and dressings) 'paperwork' and management issues:

"*The nurses are pretty much in the supervisory role and it is hard. I think it is hard coming off away from the hands on role*"

The focus on tasks and management left many nurses feeling deskilled and regretful, it was also evident that the nurses felt that the unqualified carers had more opportunities for contact and therefore were able to develop the skills which they themselves feared that they were losing, as demonstrated in the extract below:

"*I mean sadly, with the role of nurses and amounts of paper work and legal stuff that we have to do, nursing, you don't do as much nursing sadly. The carers are who are the front role*"

Lack of opportunity to take part in hands on care seems to lead to weaker relationships with residents. This lack of connection is a reflection of the dominance of medical discourse, in which behaviours were seen as symptoms of dementia rather than understood as expressions of emotions or the communication of needs of the person with dementia:

"*I mean, she started, she came here she was chucking things across the room. She was bum shuffling across the floor. It is really quite difficult (…) how to react to that?*"

In the extract below the nurse implies the residents are '*un-fresh*'. This language reflected a non-person-centred approach, including objectification and lack of hope:

"*That what is the problem with a nursing home, with dementia. It is not like working in a psychiatric hospital where people are fresh, and when they get better they are going back home*"

This theme demonstrated the extent of nurses' responsibilities and their frustrations resulting from feelings of disempowerment. Lack of a person-centred perspective and understanding or residents' experiences may have undermined connection and job-satisfaction.

8.2. It's Not Like the NHS

Participants were asked general questions about their feelings about working in a nursing home setting. Nurses reported feeling isolated and different from their counterparts working in the National Health Service. They felt that other health care professionals perceived them to be unskilled, but they appeared ambivalent about their own abilities, describing conflicting feelings about the huge responsibilities and their ability to work independently:

"*You know, what hospital are you working at? I am working in a nursing home…they think you have a half a brain here*"

"*We don't have things on hand like dressings. We haven't got a big drug pot, you know, big drug trolley that we can just fish things out of so I mean, yes it is different*"

The findings indicated that many nurses working in nursing homes had stressors outside their working lives as well as in them. They were often single parents and needed to work close to home and schools, factors which meant they would be less likely to leave their job. These stressors meant that the nurses themselves often reported poor physical and mental health. The nurses reported being unsupported at work and undervalued by their organisations. They felt this lack of support was illustrated by poor training opportunities, career development, low pay and lack of support. The staff appeared to recognise their own worth, but were angered by organisational factors that undermined this:

"*I think traditionally, in comparison to the NHS settings, you know care homes particularly private care homes don't pay the rates you could expect from the NHS. I would think that is the barrier to improvement. And I think equally retention is the problem, because when people come on a fairly low rate of pay and realise what it entails…they find that there is a lot expected of you*"

"*It is not like the NHS, you are very often just one nurse on the shift, on the unit. You haven't got a colleague that you are working alongside very often so if you are not up there then there is no one to do your job*"

The theme illustrates the extent of nurses' ambivalence about roles which were experienced as stressful, isolated and unrecognised.

8.3. Barriers to Learning

We explored barriers to learning and participants' experience of previous training in order to identify gaps in knowledge and inform design of the planned training. Poor quality and basic levels of training were frequently reported as barriers to learning. Previous training was perceived as inadequate, reflected in participants' inability to recall what they had learnt, even recently:

"*sometimes you just go through the e-learning training and blab bla bla dusted and you tend to forget*"

"*You have asked us before what was booklet one about and we already forgot what was it about*"

Many experiences of the training described were based on the 'cheaper options' such as workbooks, DVDs and free computer-based learning, which were perceived as '*very poor*', '*pointless*' and '*repetitive*':

"*I mean, it didn't go down particularly well and I tried to implement it with, you know, it tended to be DVDs and sessions which the DVDs are very long…and it is about taking, depleting your staff off the floor*"

These methods did not acknowledge the skills level and experience of the nurses or reflect the principles of adult learning in which learners build on previous knowledge. In addition adult learners respond best to active, experiential, social learning opportunities in which they construct understanding together. If nurses took on learning independently, the support from their organisation was not guaranteed, meaning they attended training after a night shift or in their free time. This added extra pressures:

"*What it is in a nursing home, it's not like that you have a sunny day and you are off…. So sometimes I had to go, finish here, go to uni, come back and I have to come to work. So I was really tired, I couldn't just cope with everything … so I had to stop at that time*"

The quotes in this theme show how poor opportunities for professional development are denied to many nurses working in nursing homes, despite their aspirations to develop knowledge and understanding.

8.4. Future Training

Nurses were clear about the content which they required in future training. Most focused on the knowledge and practical skills relevant to their roles. Gaps identified included lack of knowledge about dementia and progression of the illness:

"*I think I would like more knowledge of details…the process of the diseases associated with dementia, not only Alzheimer's. There are various diseases and just to be more in depth into dementia and progression of the illness*"

More than half of participants mentioned communication with people with dementia and their relatives as something which they found "*challenging*", therefore it was evident training was required in this area. The skills required to communicate with relatives were identified as another gap. Relatives seemed to expect the nurses to provide them with emotional support, and while family carers were no longer responsible for day-to-day care, they appeared to see 'checking up on' the nurses as part of a new role, acquired in the transition to full time care:

"*Patients with dementia cannot say the words anymore…. How to communicate with them? We need more skills on how to really communicate so we know, you know, what they need*"

Similarly, further skills were required to support relatives:

"*because some nurses find it so difficult to speak to relatives. Because it is a very sensitive issue and relatives ask. I think that's another skill that would help and support nurses, to deal with that difficult conversation, issues…because some nurses find it very difficult*"

Participants were asked to make suggestions for future training. Applicable 'real-world' relevance to practice was seen as central. Participants highlighted the need for interactive training and valued opportunities to listen to each other's views and learn from each other's experiences:

"*And we are talking about being practical; we are providing care for people with dementia and you have to be practical*"

"*When you are in a group, you see other nurses who are from different backgrounds and when you are discussing in a group, you know from what others are saying.*"

During the focus groups more than half of the participants mentioned the importance of training being available for all staff regardless of the role they are appointed to within a nursing home:

"*I think when the carers do the same thing, then we are speaking the same language really. Which helps*"

There appeared to be a lack of understanding around responding to indications of distress. Outdated language used in the focus groups demonstrated attitudinal issues congruent with “old culture” thinking, perhaps reflecting lack of training and the impact of workplace cultures:

“*So I think more on how to handle challenging behaviours like that, with aggression, you know, put nurses and the carers to have training. Some of us here are RGNs and we haven't had access to the patients so don't really know how to handle that*”

Generally the nurses showed insight into the areas of knowledge and understanding they required to improve the quality of care, although the language they used reflected lack of exposure to current thinking.

9. Discussion

The well-being of the nurses working in nursing homes has been addressed in the literature (RCN, 2012) and similar issues arose in this study. Dwyer (2011) found that nurses in nursing homes felt valued by residents but under-recognised both at work and at home. Poor support for staff at work included widespread lack of sick pay, minimal breaks, lack of training, bullying management and high levels of unpaid overtime (RCN, 2012). The lack of training opportunities identified by our participants is yet another indicator that these nurses' roles are undervalued, despite their responsibilities and ability to work in isolation. The isolation of staff working in nursing homes has been known for some time (Chambers and Tyrer, 2002; Davies, 2001).

In our sample, the majority of participants focused on their responsibility for direction of staff when asked to describe the main aspects of their role. According to Wild et al. (2010) the practice interface is narrowing between nurses and care staff, with basic nursing skills being delegated and care staff undertaking what may have previously been considered nursing activities. Therefore it is unsurprising that our findings indicate that, although the input of knowledge and skills from registered nurses (RNs) is recognised as essential in supporting carers' learning and practice, nurses are frequently undertaking management and supervisory roles rather than direct care.

There is a shortage of nurses in all sectors the nursing workforce is ageing (Imison and Bohmer, 2013, Centre of Workforce Intelligence, 2013). Therefore it is easier now for nurses to find jobs elsewhere, adding to the problem of ‘churn’ and increased stress on remaining colleagues. According to Wild et al. (2010) organisations will employ greater numbers of care staff, a less expensive option, rather than RNs. Within a business model, investment in nurses' education may be seen as counterproductive due to the high turnover of staff. In addition face-to-face training has extra costs related to backfill. These factors exacerbate an already challenging situation for underprepared and overworked staff.

Technical procedures such as dressings and dispensing medication are, however, still regarded as constituting nursing care (Tadd et al., 2012). This is illustrated in the study findings as the participants indicated that these tasks are fundamental parts of their responsibilities. Participants therefore placed a great emphasis on their clinical skills; the technological aspects of care giving have increased significantly due to the greater complexity of residents' needs (RCN, 2012). However, the person-centred aspects of care tend to be neglected in favour of these visible technical responsibilities and the necessity of managing staff. In small organisations nurses do not have the opportunity to compare different strategies for problem-solving nor to share the emotional labour of nursing home work.

The nurses recognised the need for active, experiential learning opportunities to address gaps in their skills-base, for example to guide them in communicating effectively with residents and family members, and responding sensitively to behaviours which indicate underlying unmet needs. Relative isolation meant our participants were not exposed to alternative practices and new thinking, which may have led to some lack of awareness about the gaps in their own knowledge-base.

The RCN (2012) found that nurses' experience of being treated fairly and valued equally in terms of career opportunities, pay and grading, and working hours is not consistent. This may also be tied in to social attitudes towards older people, negative media coverage and the low value society places on caring for older people (Jenkins and Macken, 2014). Limited access to training may also be related to assumptions about caring being ‘natural’ rather than skills based (Brooker and Latham, 2016). Limited resources mean that managers tend to focus on legislative requirements and practical issues at the expense of non-mandatory training and promoting person-centred approaches that would enhance the quality of care. Paucity of training opportunities may reinforce the perception of low-value accorded to nursing home nurses.

10. Limitations

Our findings were based on a small sample from four nursing homes from the same geographical area. The focus groups were also small, this may have impacted on the dynamics of the group and quality of the group discussion. More research with larger samples, from other countries with different cultural and organisational contexts is needed to validate our findings.

11. Conclusions

Nurses working in nursing homes highlighted high levels of responsibility, low levels of support and remuneration and frustrations related to the complexities and demands of their role. They recognised some training needs but were not always aware of their limitations due to the isolated nature of their work. However, they highlighted the barriers to accessing training that may actually change practice. In order for training to be effective it should incorporate interactive, practical sessions with relevant content related to the needs of people with dementia and their relatives. Training could be viewed as an opportunity to demonstrate the value of staff and should include all members of the staff team. Training should also include consideration of how barriers to high quality care can be overcome and so promote person-centred approaches for residents, staff and relatives.

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ORIGINAL ARTICLE

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Recognition of preclinical signs of dementia: A qualitative study exploring the experiences of family carers and professional care assistants

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Aims and objectives: To identify preclinical signs of dementia by exploring the experiences of family caregivers and professional care assistants.

Background: Dementia results in disability, emotional strain and financial loss for people with dementia, family members and nations. Informal identification of social and behavioural risk signifiers could facilitate timely interventions with potential to delay onset of serious disability.

Design: A retrospective qualitative approach using a naturalistic interpretive design was used. Focus groups enabled in-depth understanding of the participants' experiences of life or work with people who subsequently developed dementia.

Methods: Purposive sampling was used to recruit family carers and professional carers who had cared for people who later developed dementia. The data from focus groups were fully transcribed and anonymised, and transcripts were analysed by two researchers. These researchers coded and analysed the transcripts independently; subsequently, overlapping and similar themes were identified and consensus reached on final themes. A third researcher was invited to review the analysis and ensure trustworthiness of the study findings.

Results: Findings revealed that preclinical signs of dementia were identifiable in retrospect Participants' accounts resulted in four themes, "Lowered Threshold of Frustration", "Insight and Coping Strategies," "Early signs of poor memory" and "Alarming Events."

Conclusions: Earlier recognition of preclinical signs of dementia would allow affected individuals to follow health promotion advice and plan for the future. Identification of social exclusion prior to diagnosis has implications for antistigma campaigns and development of "dementia-friendly communities."

Relevance to clinical practice: Healthcare professionals could work with those at risk, facilitating lifestyle changes to postpone symptoms and advance planning for improved autonomy. Predementia should be viewed as a disability for which reasonable adjustments can be made at a community level, to enhance and extend emotional well-being and social inclusion.

KEYWORDS
dementia, health promotion, preclinical, risk, social inclusion

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1 | INTRODUCTION

Dementia is an umbrella term that refers to a group of conditions in which memory and other functions gradually become impaired due to changes affecting the brain (Jenkins, Ginesi, & Keenan, 2016). Dementia is not caused by old age but is an age-related condition (Prince, 2015). As the global population is ageing, higher numbers are predicted: by 2050, 135 million people may be affected (Robinson, Tang, & Taylor, 2015). Seven per cent of people aged over 65 have dementia (Alzheimer's Society, 2014). Dementia results in high levels of disability, emotional strain and financial loss for people with dementia and their family members (Jenkins et al., 2016). In addition, dementia is costly for local and national services. Internationally, dementia is estimated to cost $604 billion per year (Prince, 2015).

While screening for dementia has been discouraged due to the perception that unnecessary anxiety results from "an outcome that is both uncertain and unalterable" (Harvard Women's Health Watch, 2014), there is an alternative perspective which suggests population-based insights into risk reduction factors could be applied by individuals who have early awareness of risk. For example, by facilitating timely lifestyle changes (Opie, Ralston, & Walker, 2013) and forward planning (Trueland, 2013). If dementia could be delayed by an average of 5 years, individuals would have a better quality of life for a longer time period (Sabia et al., 2012), the number of people living with the condition would be halved (Prince, Albanese, Guerchet, & Prina, 2014) and £21 billion globally per annum be saved (Alzheimer's Research UK, 2014).

Imaging techniques show amyloid B deposits in the brains of those who later develop dementia decades before symptoms develop (Masdeu & Pascual, 2016). In this preclinical or "prodromal" period, very early symptoms of dementia are subtle and may be mistaken for normal signs of ageing (Boyd, 2013). However, earlier recognition of the significance of preclinical social and behavioural signs would be beneficial. Alternative, informal means of identifying social and behavioural signifiers of risk could enable a window of opportunity for implementation of health-promoting and treatment interventions with the potential to delay onset of serious disability.

The aim of this study was to use focus groups to identify preclinical signs of dementia. We explored the experiences of family and professional caregivers who had lived and worked with people who later went on to develop the condition.

2 | BACKGROUND

The exact causes of most types of dementia are not completely understood, but it is thought that, in the most common form of dementia, Alzheimer's disease, a "toxic cascade" of damage to brain cells, is triggered by genetic, lifestyle and environmental factors (Prince et al., 2014). While types of dementia have specific histopathological findings (plaques, tangles and Lewy bodies), the pathology of dementias is often mixed, so that people with Alzheimer's, vascular dementia, Lewy body disease and other types often have overlapping patterns of neuronal atrophy, and as time goes on, similar histories of memory and functional decline (Jenkins et al., 2016). The subtlety of early symptoms of dementia, General Practitioners' ambivalence about early diagnosis, therapeutic nihilism and the stigma still associated with dementia combine to result in late diagnosis, despite evidence of benefit and government guidelines (National Institute for Health and Care Excellence, 2006). Treatments currently licensed for dementia do not "cure" dementia, but for some people, they slow the progress of the condition while improving mood and functioning (Buckley & Salpeter, 2015). Research studies investigating efficacy of new treatments and repurposed existing medications are ongoing (Jenkins et al., 2016), despite recent setbacks including Pfizer's withdrawal from neuroscience research (De Strooper, 2018).

The sooner the treatment is begun, the better the outcome (partly due to a better starting point), so medication should be given much earlier in the disease process to have any real impact (Alzheimer's Association, 2017). Even though identification of a preclinical condition may have negative consequences, such as low mood due to anticipated loss of autonomy, social status and aspects of self (Mitchell, McCollum, & Monaghan, 2013), people with dementia prefer an explanation for the difficulties they encounter (van den Dungen et al., 2014). Other benefits of early diagnosis include empowerment of the individual to make choices about the future, follow health promotion advice, get their affairs in order and be open with family and friends to maximise understanding and support (Mitchell et al., 2013). Implementation of these strategies would result in significant financial savings from delayed admissions to care homes (Banerjee & Wittenberg, 2009). In addition, government plans (in Europe and globally) that emphasise the importance of early diagnosis and initiatives to combat stigma may result in greater social inclusion of people living with dementia, enhancing their ability to "live well" (Department of Health, 2015; Pot & Petrea, 2013). This is essential because of the potential negative impact of social isolation and exclusion. Kitwood's (1997) work highlights a socially constructed process in which age and frailty combine to attract

What does this paper contribute to the wider global clinical community?

- "Lowered Threshold of Frustration" is a useful concept for raising healthcare professionals' awareness of possible elevated risk of later dementia in their service users.
- Earlier recognition of identified preclinical signs of dementia could allow potentially at-risk individuals to work with healthcare professionals in following health promotion advice and planning for the future.
- Social isolation occurs prior to development of dementia. Social inclusion programmes should respond to the needs of people experiencing preclinical signs of dementia through environmental and interpersonal adjustments.

"malignant social psychology" or stigmatising interactions that both contribute towards and highlight cognitive impairment. He suggests that this undermines older people, leading to low mood and internalised stigmatisation that combines with societal processes to further marginalise those who may be cognitively impaired. Beard and Neary (2013) critique the trend for early diagnosis in the face of limited treatment and support, echoing Kitwood's concerns around medicalisation of ageing and stigmatising diagnoses.

Differentiation between "normal ageing," depression and "mild cognitive impairment" can be challenging (Kaschel, Logie, Kazén, & Della Sala, 2009), and there is a risk of both under- and overdiagnosis of dementia (Skinner, Scott, & Martin, 2016). However, medical treatment is not the only potential positive outcome of identification of risk, as the long "prodromal" period allows those potentially at higher risk to adjust their behaviour in order to both reduce risk and postpone cognitive decline (Lafortune et al., 2016).

Strategies to identify biomarkers for dementia already exist but involve intrusive tests, for example of plasma, cerebrospinal fluids or using scans (positron emission tomography or magnetic resonance imaging), and tend to be expensive and not reliably indicative (Ritchie, Flicker, Smailagic, Noel-Storr, & McShane, 2012; Smailagic et al., 2015). "Everyday life" potential indicators of dementia overlap with those of other conditions including depression, delirium, infection, constipation and diabetes (Jenkins et al., 2016), so prompt assessment of actual symptoms is required to ensure any treatable conditions are identified and appropriately managed. In advance of identifiable and treatable symptoms, small signs may flag up and allow individuals and health professionals to intervene at an earlier stage of "predementia."

The "everyday life" preclinical signs have been identified anecdotally and have been explored in more depth using a range of quantitative research methodologies. Signs include subjective complaints of memory problems, reduced "cognitively complex activities of daily living" (Peres et al., 2011), history of low mood (Stella et al., 2014) and feelings of loneliness (Donovan et al., 2017), all of which are associated with subsequent cognitive decline. Personality changes (Delrieu et al., 2015), perseveration (Stella et al., 2014), intellectual, humour and language changes have also been identified (Benke, 2011; Clark et al., 2016; Lust et al., 2015; Mura et al., 2014). Evidence also highlights physical changes, for example with sleep pattern, gait and appetite (Benke, 2011; Stella et al., 2014; Verghese, Wang, Lipton, & Holtzer, 2013).

Qualitative studies exploring the experiences of people at high risk of developing dementia have not yet been carried out, as this group of people is difficult to identify. Similarly, there are few qualitative studies exploring the experiences of people with mild cognitive impairment, a state argued to be on a continuum between the prodromal predementia stage and diagnosable dementia. Beard and Neary (2013) triangulated qualitative approaches (focus groups and interviews) to explore the experiences of 18 people diagnosed with MCI, which is associated with higher risk of later dementia. Their respondents recognised they had memory problems, which they generally normalised by ascribing them to the ageing process. These accounts confirmed awareness of the stigma surrounding dementia itself and the authors' analysis highlighted how stigma associated with Alzheimer's type dementia was perceived as similarly damaging for people who are potentially living through very early stages. Beard and Neary (2013) recognise the importance of "living with dementia" as opposed to accepting an inevitable decline as usually emphasised in biomedical research. While identification of prodromal stages of living with memory problems may attract stigma, this timeframe also offers a window of opportunity for living well and making positive adjustments.

3 | METHODS

3.1 | Study aim

It is possible that further prodromal indicators could be identified. Research into the experiences of people in early stages of dementia and others is needed to develop further insights (Alzheimer's Research UK, 2015). This study explored the experiences and perceptions of family and professional carers who have known people who subsequently went on to develop dementia. Thus, the study aimed to explore the views, experiences and perceptions of family caregivers and professional care assistants to identify preclinical signs of dementia.

3.2 | Design

The study was guided by a retrospective qualitative approach, to encourage participants to recall and share experiences of individuals' they care for before they were diagnosed with dementia (Holloway & Galvin, 2016). A focus group study was conducted in the Midlands (West and East), England. Focus group interviews promote active discussions among the participants, and the group interaction aids spontaneous disclosure that allowed the researchers to explore participants' experiences, beliefs and opinions (Then, Rankin, & Ali, 2014). This approach facilitated an in-depth understanding of the participants' experiences of life or work with people who subsequently went on to develop dementia.

3.3 | Group composition

Family caregivers have a different relationship with the people for whom they were caring as compared to the professional caregivers; therefore, it was assumed they might have different experiences and perceptions. Two separate sets of focus groups were conducted allowing participants to be more comfortable among people with similar circumstances (Jayasekara, 2012), which not only encourages sharing perceptions and experiences but also more interaction.

3.4 | Participants

Purposive sampling was used to recruit family carers of people with dementia and professional carers who had cared for people who developed dementia. This was to ensure that both groups could recall a time before individuals' dementia became obvious and shared. Information about the study was circulated to a charitable organisation that supports people with dementia and their families and to a home care agency. Interested carers, who had experience caring for people before they were diagnosed with dementia, were invited to attend the focus groups. The carers reflected a diverse society in relation to ethnicity, sexuality, age and gender.

3.5 | Data Collection

Focus groups were conducted between March–May 2016. Four focus groups were conducted, in total 10 family carers and ten professional carers took part in the study. Focus groups for family carers were conducted at a carers' group in a day hospital and in a library local to the carers' homes. The focus groups for professional care assistants were conducted in a study room at their workplace. A moderator and two observers conducted the focus groups. Each focus group lasted approximately an hour and consisted of open-ended questions, based on a guide (Table 1), to ensure consistent questioning between all four focus groups. Questions were asked in any order, to enhance the flow and respond to the thread of conversation. The interviewer followed the discussions closely, without influencing the discussion, and the observers were silently taking notes. While the semistructured interview guide was not piloted tested, the questions focused on carers' experiences of the time before the person they care for developed dementia. Additionally, the guide was reviewed by three researchers to ensure the questions would encourage participation among the participants. The focus groups interactions and discussions were audio-recorded, transcribed verbatim and anonymised.

TABLE 1 Focus group guide informed by literature, experience and personal insights

The central question explored the experiences or behaviour that might be forerunners of dementia which develops many years later.
How long has the person you care for had dementia?
Is there anything in their health history that might have contributed? (prompt: e.g., high BP, diabetes and concussion)
Did you/the person you care for have any concerns about memory? Did you/they worry?
What were the first indications of any problems?
Were there any unusual events that, looking back, might be part of a pattern? (prompt: out of character behaviour, indication of altered judgement and "funny ways")
Did you notice any physical changes (weight change, speed of walking, eating and drinking habits)
Any changes in attitude or behaviour?
How were you/they feeling before the diagnosis and the years before that?
Is there anything else that you would like to tell us about that might be relevant to understanding peoples' experiences before they develop dementia?

3.6 | Data analysis

The analysis adopted a naturalistic interpretive design and followed the guidelines proposed in Braun and Clarke's (2006) thematic framework. Thus, the focus groups recording were transcribed verbatim by a team of people who were not part of the study, to ensure the transcription was not influenced by ideas from the research. Next, all the notes and anonymised transcripts were analysed independently by two researchers, with the intention of reducing opportunities for bias. This involved reading the data several times and noting initial ideas, leading to the generation of initial codes using an open coding procedure. This allowed each researcher to derive a thematic map, which was later followed up by several discussions between the two researchers, whereby overlapping and similar themes were identified, and consensus on final themes was achieved. The data analysis was performed manually to encourage a deeper understanding of the data. It was agreed that four focus groups (two from each group) were sufficient, as similar points arose from the latter groups and no new information or further themes were forthcoming (Fusch & Ness, 2015).

3.7 | Trustworthiness

One of the primary concerns in a qualitative study design is rigour and trustworthiness of the findings; according to Guba and Lincoln (1994), this can be improved by ensuring dependability, credibility and transferability of the findings. Hence, several measures were incorporated in the analysis to ensure this. A third researcher, who was not part of the study team nor data collection stage, was invited to review all the interpretation and derived themes ensuring that final themes were derived from the data and reflected the study aim. In cases of discrepancies, modifications were made through discussion between all three researchers to ensure credibility and understandability, along with corroborating that the themes reflected the study aim. Data were analysed 7 months after collection, due to concerns about recall bias and "churn" in both participant groups respondent validation was not conducted.

3.8 | Ethical considerations

Ethical approval was obtained from Birmingham City University Research Ethics Committee. Participants read an information sheet and gave informed consent, and confidentiality issues were discussed at the beginning of each focus group. During this project, research materials have included consent forms, interview recordings, interview notes and transcripts of interviews with research participants. These data were anonymised and then stored only on a secure University Network drive.

The family carers also described their current stressors during the focus groups. They were supported and, if necessary, signposted to further advice. They also shared ongoing anxieties about the reasons for their relatives' dementia and concerns about the "starting point." These issues were not the primary focus of this project but could indicate the need for further research.

4 | FINDINGS

Two focus groups of family carers, with six participants in one and four in the other, then two focus groups with professional carers (five in each group) were conducted. The group dynamics of all groups were positive, with almost all participants contributing. Thematic analysis, using the six stages outlined by Braun and Clarke (2006), resulted in four themes: "Lowered Threshold of Frustration (LTF)," "Insight and Coping Strategies," "Early signs of poor memory" and "Alarming Events." Family carers were better placed to comment on the timeframe of interest, due to their long-standing, close relationships with the people who went on to develop dementia. Hence, there are more quotes from family carers than from the professional carers.

4.1 | Lowered Threshold of Frustration

This theme arose in all four focus groups. Participants could relate stories in which the people they now care for had become uncharacteristically intolerant, more inclined to show their frustration and less able to manage difficult emotions. Professional carers identified frustration as a common difficulty:

> *Frustrated, more frustrated.*
> *Yes*
> *I've noticed more frustration with the gentleman, very frustrated because he was like he didn't… he felt that nobody was understanding him* (Professional carers)

Family carers did not specifically use the term "frustration," but gave examples where this seemed relevant:

> *I think Mum got a bit more bolshie actually… although before that she was not a quiet person, she'd always said what she thought but she did seem to get a bit more outspoken and didn't care who she was saying it to. I think she possibly upset one or two of her friends by being a bit too outspoken* (Family carer)

In this second example, the wife was empathetic despite not understanding her husband's response:

> *He swore at me in Iceland (shop) and it wasn't him. And I said, 'Okay, I'll leave the shopping. I'm sorry about it, I'll leave the shopping.' And I took him out… and I thought, 'this isn't him' but when he realised what he'd done, he said 'I'm sorry about that* (Family carer)

When looking back to the years prior to the person's diagnosis well before the symptoms became obvious, family carers could recognise times when they had adjusted their own behaviour to try to make life go more smoothly. They did not seem to be aware of this pattern or the reasons for it at the time, but on looking back could identify these adjustments, described by one participant as "thinking for two." Professional carers were more able to use their experience to identify and name frustration, then anticipate and manage potential problems. Family carers initially were not aware of the significance of the pattern that was emerging, but noted that other people outside the family had changed in their attitude towards the person, being aware that they needed to keep an eye out for them, but sometimes avoiding them or allowing friendships to wane. In this theme, participants spoke not only about people they cared for, but others they knew who they felt may have early signs or who they later knew to have dementia:

> *You just have to be very aware of what you say as well, it's just a continual battle inside you to make sure you say the right words, you say it in the right context, and it can get very, very, stressful* (Family carer)

It seems that experiences of being with those who went on to develop dementia were already stressful at times for friends and relatives, perhaps leading to avoidance. The family carers could identify that the social network was shrinking well before the dementia was diagnosed:

> *Basically everyone that she used to know… they used to be round every weekend, it wasn't just us as a family, it would be near enough everyone, so all of a sudden she's got no-one going in, and there's no friends who are able to come across as often …. this is before she even got diagnosed with dementia as well, so it's still kind of the loneliness that gets to you then* (Family carer)

These quotes illustrate the dynamics of changing relationships, in which anxieties, communication problems and subtly alienating behaviours combine in a process where family members recognise problems, but are not able to name them. Other people may begin to distance themselves, leaving the person who may be developing dementia and their close family members isolated when they are beginning to need support.

4.2 | Insight and coping strategies

Awareness of poor memory was confirmed by our participants who reported how changes to behaviour emerged due to awareness of memory issues:

> *I think he's going to get, he's got a bit of dementia coming. And he's always wanting to do something, he's always wanting his brain to, 'I want to do something, I need to keep my brain going' … This is what he's always like, 'I need to keep my brain working'* (Professional carer)

> *she works at a bank but she's taking redundancy because she won't admit… at the moment she writes everything down* (Family carer)

A family carer described how his wife used her insight to respond for the well-being of others:

> *she was a lay reader at church for over 30 years and she would still prepare sermons and deliver them. About four years ago, she decided that she'd done enough and because she was afraid she'd dry up part way through, and she used to take funerals but she was also afraid there that she would dry up partway through you see* (Family carer)

Similarly, a carer's husband perhaps began to lack confidence:

> *he used to love going to the meetings at Wolverhampton and he used to make an excuse to say, "oh it's busy going out" or "I don't want to drive the car in the dark" and I never thought about that* (Family carer)

These examples show that people with some insight into incipient dementia can make adjustments to their activities, aiming for the best outcomes for themselves and other people. In recognising their own potential memory problems, the people who went on to develop dementia employed strategies to maintain their mental functioning and adjusted to protect themselves from marginalisation. They could reduce their responsibilities and seemed to be withdrawing from activities that might reveal their difficulties, both to minimise others' inconvenience and to protect their own identity. However, they did not explicitly share concerns about the implications of the deficits, perhaps due to a belief about "normal ageing," or because the changes were insidious, allowing gradual adjustments, or perhaps due to concerns about potential social exclusion.

4.3 | Early signs of poor memory

In retrospect, many of the examples and incidents described by the participants were clearly caused by early memory problems. While we asked about predementia changes, it is possible that late diagnosis meant that some of the reported signs actually reflected early, undiagnosed dementia rather than predementia. However, at the time, observers did not "put two and two together." Geographical disorientation (getting lost) seemed to be common:

> *he kept getting lost when he was out. And I would say, 'Oh you've been here before' 'Have I? I don't remember this'* (Family carer)

> *she was driving in her car and driving off the village where we live and she said she had no idea where she was driving to* (Family carer)

> *she'd be forgetting things, she'd always forget. "Oh I forgot to do this, I forgot to do that" and we just thought it was old age, it's just the way it is* (Family carer)

It is possible that geographical disorientation is more obvious to an observer than other forms of disorientation because of the discrepancy between expectations of confident wayfinding and the person's actual behaviour. While memory problems are understood by lay people to be a symptom of dementia, perhaps lay beliefs about forgetfulness and normal ageing are more deeply embedded.

4.4 | Alarming events

Later stages of dementia are associated with increased risks due to symptoms such as poor memory, difficulties with reasoning, lack of awareness of dangers and problems with sequencing. Repetitive questioning and absent-mindedness are stereotypically considered by lay people to be caused by age-related changes or "senior moments". However, our participants mentioned examples of difficulties with managing risk and memory-related crises well before they realised that the cause might be dementia:

> *I mean there was one incident where mum set fire to the kitchen, which at the time we put down to a one-off, she'd left the chip pan on and she sat down to eat her tea; she was in a little bungalow, and suddenly noticed fire out of the corner of her eye and went in, picked the bowl of water up, threw it at the chip pan and it went … I mean she looked like she'd been down the mine when I got there. And then proceeds to mop the floor before she pulls the red cord to call the Fire Brigade in case the fireman came and slipped on the floor, and Social Services did come out to her and ask her things and we all sort of put it down to, well, okay it's something anybody can do, but now when you think about it, possibly that could have been part of it. We're never going to know are we?* (Family carer)

In this example, the mother's behaviour revealed possible cognitive changes which together may have contributed to this risky situation. She not only forgot the pan, but also forgot how to manage a "grease fire". Her judgement (or possibly sequencing ability) was impaired, in that she prioritised responding to the wet floor over extinguishing the fire. The description highlights her considerate nature, and it is clear that she could perceive and address risk to other people.

Through their close relationships with people who went on to develop dementia, participants could highlight subtle signs that stood out in the context of the norms of their relationships.

Family member participants' accounts indicated that they learnt to regulate their own behaviour to level out the "emotional temperature" for their own sakes as well as that of the affected person. At first, they were unaware of their own adjustments and described examples of unconscious adaptation. Later, they adapted consciously and occasionally found others had done the same, for example siblings and contemporaries of the affected person dropped hints about the need to "keep an eye on" them, indicating that the older generation had noticed problems but were perhaps protecting the person's dignity using coded messages and entreaties.

Family member participants described patience and forbearance, but also their own stress. Although at this early stage not "a carer," their relationships had shifted subtly so that they were alert to anticipate and pre-empt difficulties, leading to inequality in carrying out the emotional work of the relationships. All the participants reported a sense of isolation, which was compounded by the trend for friends (perhaps alienated by the affected person's expression of LTF or perceived rudeness) to keep a distance.

5 | DISCUSSION

Our first theme and indicator of incipient dementia was "Lowered Threshold of Frustration." This indication seems to be a response to the difficulties of managing stress when usual coping strategies become less effective. Often broadly described as "personality changes" (Boyd, 2013), more specific difficulties in responding equably to stress showed how our participants' relations and clients were less able to manage frustration many years before diagnosis, possibly due to early dementia-related brain changes.

Extreme responses to difficulties in later dementia have in the past been labelled as "catastrophic reactions" (Vroomen, Bosmans, van Hout, & de Rooij, 2013), and it is likely that LTF is a less severe form of this problem. Nowadays, these reactions are reframed as distress in the context of disabling environments or relationships (Brooker & Latham, 2015). In the context of predementia LTC, both the disability and disabling context are unseen. This means that it is very difficult for others to explain the person's behaviour and to adjust to it.

Kitwood's (1997) "malignant social psychology" theory suggests process in which the social value of an individual is diminished, and they become progressively more excluded and denigrated when dementia is identified. Our findings indicate that this process begins before diagnosis, perhaps due to current emphasis on the "medical surveillance" of older people in relation to memory (Beard & Neary, 2013). Donovan et al. (2017) found that people with high amyloid levels reported feelings of loneliness before any clinical signs of dementia became apparent, which appears to confirm this hypothesis. Brannelly (2011) explored the phenomenon of "social death," suggesting that identification of dementia is associated with a dehumanising dynamic involving distancing and exclusion within family groups with marginalisation and discrimination being the norm in wider society. There is an ethical risk to early identification, as labelling a potentially vulnerable person could further highlight difference and an unwanted identity (Beard & Neary, 2013). The professional carer participants noted a change to the apparent social status of the people with early signs of memory problems. Family members spoke to and about their loved ones in a different way, highlighting difference and implying distance.

However, the conversational tone was different when the difficulties were perceived as isolated crises. Our participants could describe examples which in retrospect seem dementia-related, but at the time were explained as an aberration or sign of eccentricity. Family members described these events with warmth and humour, often emphasising their relative's positive qualities, contrasting with the less inclusive language used to describe behaviour which was more obviously part of a dementia syndrome. As members of a dementia-stigmatising society (Williamson, 2015), it is not surprising that participants had internalised devaluing perceptions of people living with dementia themselves. However, they also expressed anger about others' social neglect of the person who now has dementia and resentment about the low level of support from their wider social networks. "Courtesy stigma" or stigma by association (Goffman, 1963) may also isolate family members, particularly spouses, of people who go on to develop dementia and the family carers in our study identified their own feelings of loneliness, corresponding to the marginalisation of the person they now look after. The role of carer for a person with dementia is associated with risk of low mood and isolation (Jenkins et al., 2016); it may be that an exclusionary social process is already progressing in parallel for both parties during the prodromal period.

By the time dementia is identified, an individual is already becoming marginalised because their LTF means other people can find them difficult. Antistigma campaigns are perhaps therefore too late for many in maintaining social inclusion. In addition, campaigns that promote inclusion depend on knowing who is being targeted, so paradoxically the people who most need inclusion may risk being excluded by default from the campaigns designed to assist them. The person's disability at this stage is invisible, even though it is subtly attracting "malignant social psychology" (Kitwood, 1997), later to be compounded by more explicit dementia-related stigmatisation (Beard & Neary, 2013).

The professional carers' ability to recognise dementia-related signs prediagnosis may result from familiarity with later symptoms enabling recognition of the early counterparts. Late problems include disinhibition, anxiety and need for reassurance and practical issues such as difficulties with washing and dressing (Jenkins et al., 2016). Beard and Neary (2013) respondents, who had MCI, were keen to define their own problems as different to those of people with dementia itself. Similarly, the professional carers in our study found their clients confided concerns about memory changes to them, sometimes while taking steps aimed at protecting their memory and functioning abilities. Both groups could relate examples when the affected person adjusted their own behaviour to pre-empt problems, indicating insight, with intention to avoid dementia-related difficulties and maintain a positive nonstigmatised identity.

6 | RELEVANCE TO CLINICAL PRACTICE

This was a small study with interesting findings. Further research is needed to establish the extent to which our conclusions can be extrapolated to other contexts. The aim was to explore very early indicators of dementia to reveal a window of opportunity to enable a person identified as at risk to make lifestyle changes to improve their long-term cognitive functioning. In identifying LTF, the associated adjustments made by the person with memory problems themselves and others in their social network, we tentatively highlight opportunities for earlier identification and subsequent health adjustments, while also raising questions about the implications of social exclusion of people who later go on to develop dementia.

6.1 | Identification and health promotion

"Lowered Threshold of Frustration" could be used as a simple inexpensive means of identifying a person at increased risk of dementia. A simple question such as "Do you find you become angry or frustrated much more quickly than before?" that identifies reduced tolerance of frustration could be included in routine health checks that include depression identification. This could flag up the possibility of early dementia-related changes and offer the option to explore the risk further and discuss lifestyle changes. Depression is a risk factor for dementia, it can be difficult to differentiate the two (they share some symptoms, e.g., disturbed sleep, apathy and low mood), and it is possible that the two conditions have a shared causal pathway (Prince et al., 2014). Health promotion advice for the two conditions also overlaps, so, for example, patients could be advised to spend more time walking outside, to connect to their social network more and to get involved in activities that are enjoyable and stimulating. General health advice such as reducing alcohol intake, stopping smoking, eating a healthy diet and exercising more is important (Lafortune et al., 2016).

The purpose of the lifestyle changes is not to prevent dementia, but to postpone it. A predementia support strategy could promote lifestyle changes, include advice and options for building cognitive reserve (e.g., brain training clubs) and include memory clinic referral and early prescription of Aricept or other antidementia medication. Stress and time management strategies could be taught, to reduce stress and the immune system responses that are thought to contribute to inflammatory processes (Ginesi, Jenkins, & Keenan, 2016). Medical practices alerted to potential future dementia-related problems could signpost to local resources, such as the Alzheimer's Society, if required. This strategy changes perception of appropriate dementia responses from medicalisation towards inclusion of a more social model of understanding (Williamson, 2015). This should reduce therapeutic nihilism, normalise dementia as a disability, empower individuals and harness community engagement.

6.2 | Social inclusion

Our findings indicate that social exclusion may begin before a person develops dementia and well before diagnosis. This has implications for antistigma campaigns and the developing nature of "dementia-friendly communities," which we suggest should also become "pre-dementia-friendly."

Physical and social environments could be adjusted to become minimally frustrating, so as not to trigger a sign of LTF. In common with other disabilities, those living with them have the right to expect that others will make enabling adjustments (Williamson, 2015). As people in preclinical stages of dementia are generally unaware of their specific needs, we should aim to make these dementia-friendly adjustments in all public spaces, in a move of solidarity, but also for the common good.

Dementia-friendly adjustments could include easily navigable towns, easy-to-read architecture (e.g., entrances are clear), brighter lighting, wayfinding aids, clear signposting and use of design to convey purpose (Duffin, 2014). Public-facing employees should be trained in dementia awareness and in warm, clear communication skills (Duffin, 2014). In common with adjustments for other disabilities, these adjustments should be beneficial for all. Technological developments can empower citizens by designing in ease of use and anticipatory responsiveness (Asghar, Cang, & Yu, 2018).

In addition to environmental changes, we need to consider how we talk about dementia. Media guidelines on normalising dementia postponement strategies, admitting to concerns about dementia, avoiding stigmatising terms and being dementia inclusive should help to challenge marginalisation (Williamson, 2015). We should promote a message of hope rather than fear while putting measures in place to promote cognitive health for individuals and support social inclusion by facilitating dementia-friendly strategies for communities.

7 | STRENGTHS AND LIMITATIONS

The four themes presented in this study reflect participants' retrospective accounts enabling insight into experiences of people in the prodromal stages of dementia. We recognise that the "early signs of dementia" theme overlap with known symptomatology, the remaining themes add to knowledge about the experiences and behaviour of people living with early cognitive changes. The strategies adopted in the study design can be considered a strength for ensuring rigour and trustworthiness of qualitative findings.

A potential limitation is our sample was limited to two geographical (East and West Midlands) locations, whereby a broader sample might have added further insights. As we were asking for participants to look back to a time before the person they cared for had dementia (between 5–20 years), it is possible that some of the participants could not recall all the examples. Also, questions may have triggered some of the family carers to confuse the past with current stressors. Hence, precautions were taken when analysing the data to ensure the themes identified explored further preclinical signs of dementia. Our findings confirmed awareness of difficulties on the part of people who later developed dementia, so asking recently diagnosed people with early dementia about their perceptions and experiences would add valuable perspectives.

8 | CONCLUSIONS

Our findings indicate that people in prodromal stages of dementia undergo subtle dementia-related behavioural changes that affect their relationships with other people. This leads to social exclusion, which occurs prior to stigma-related social exclusion associated with more obvious symptoms and actual diagnosis. The social exclusion of people in prodromal stages of dementia has implications for inclusion strategies, which should be based on a social model understanding of dementia. The concept of "Lowered Threshold of Frustration" is useful, having applicability for identification of future dementia risk and health promotion. The benefits of the window of opportunity for health-promoting behavioural changes that may postpone cognitive impairment should be complemented by initiatives that facilitate societal changes to ensure the social inclusion of people who may be at higher risk of developing dementia.

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CONFLICT OF INTEREST

None.

CONTRIBUTIONS

Study design: CJ, GF; data collection and analysis; CF, GF and manuscript preparation: CF, GF.

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PROTOCOL

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Experiences of peer support for newly qualified nurses in a dedicated online group: Study protocol

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Abstract

Aim: To explore experiences of online peer support for newly qualified nurses.

Design: Qualitative study using semi-structured interviews and thematic analysis.

Method: Phase one involves conducting focus groups with newly qualified nurses in the West Midlands area to refine the online peer support environment. Phase two involves 30–40 new nurses joining an online peer group for 3 months; participants will be able to access a general chat community alongside a more structured discussion board. Phase 3 will collect written interview data from all participants about their experiences of online peer support. Face-to-face interviews with 10–12 participants will also be undertaken. The study will run from May 2018–October 2019.

Findings: Data from focus groups, written and verbal interviews will be analysed using thematic analysis with the aid of NVivo software. Findings will be disseminated to participants and key stakeholders involved in the study and also via publication and networking events.

Conclusion: If online peer support is found to be beneficial to new nurses, it may be adopted by local NHS trusts as part of an innovation scheme.

Impact: It is important that the psychological well-being of nurses is addressed as more nurses are now leaving than joining the profession; this is an international concern. Online peer support may offer a sustainable and accessible means of promoting psychological well-being in the nursing workforce. In such a way, contributory factors to low retention rates such as burnout, stress and job dissatisfaction may also be reduced.

KEYWORDS

newly qualified, nurses, nursing, online, peer group, qualitative, smartphone, social and emotional well-being, social media, support

1 | INTRODUCTION

This protocol sets out how we intend to explore experiences of peer support for newly qualified nurses (NQN) during a transitional stage in their careers. Post-qualification is a particularly vulnerable time for nurses, a time when individuals may feel socially isolated and easily overwhelmed by workplace pressures (Edwards, Hawker, Carrier, & Rees, 2015). This can lead increased stress and intention to leave

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the profession (Gardiner & Sheen, 2016; Rudman & Gustavsson, 2011; Walker, Costa, Foster, & de Bruin, 2017). More nurses are now exiting than joining the workforce, with 2,112 nurses under the age of 25 leaving during 2016-2017 (NHS digital, 2018). Although such an exodus may have been influenced by the Brexit decision in the UK, figures for previous years also highlight a significant proportion of young leavers; 1,975 for 2015–2016 and 2,051 for 2014–2015. Nursing retention is a global concern (Kinghorn, Halcomb, Froggatt, & Thomas, 2017) and turnover is expensive from personal, organizational, and financial perspectives, with staff shortages contributing to poor continuity of care due to reliance on agency workers (Fallatah, Laschingler, & Read, 2017). Nurses are exposed to numerous daily stressors due to the demands of the profession (Lee, Yen, Fetzer, & Chien, 2015; Steege, Pinekenstein, Arsenault, & Rainbow, 2017) and without adequate social and emotional support staff may develop symptoms of burnout, with younger nurses being particular susceptible to this occupational risk (Maslach & Leiter, 2016; NHS Health Education England, 2014). Burnout can manifest in symptoms of fatigue, impaired cognitive function, depression, and anxiety and has also been linked to intention to leave the workplace (Cooper-Thomas, Anderson, & Cash, 2011; Heinen et al., 2013). It is therefore imperative that strategies to improve the working lives of newly qualified staff become a priority.

1.1 | Background

There is evidence that peer support and mentorship in nursing have many benefits, resulting in improved staff retention and a higher quality of care (van der Heijden et al., 2010). Smartphone technology is an accessible medium of communication, and online support has been used extensively by patients with beneficial effects (Doswell, Braxter, DeVito Dabbs, Nilsen, & Klem, 2013; Ganasegeran, Renganathan, Rashid, & Al-Dubai, 2017; Marin et al., 2016; O' Connor & Andrews, 2016). To assist in the development of an online peer support intervention, a literature review was conducted to investigate the previously published literature on peer support for nurses. Eight electronic databases were searched, comprised of AMED, British Nursing Index, CINAHL, EMBASE, Medline, Science Full Text, PsychINFO, and PubMed. The search was restricted to English language peer reviewed papers published between 2000–2018 using search terms and synonyms relating to newly qualified nurses and peer support. Findings of the literature review demonstrated that smartphone messaging was found to improve the well-being of nursing staff in the Philippines by meeting needs for socializing and providing an opportunity for catharsis (Bautista & Lin, 2017). Similarly, social media applications like Facebook® and WhatsApp® have been used successfully as support tools in rural midwifery practice in South Africa where staff reported that it was difficult to meet in person (Chipps et al., 2015). However, a scarcity of research into online peer support for nurses was noted, with most studies offering such provision from an educational perspective as opposed to a social and emotional one (Doswell et al., 2013). Additional studies were retrieved on face-to-face peer support and mentoring in nursing, with both being recommended as a means to preventing nurses from quitting the profession (Nkwantabisah, Hackstaff, Paluch, & Zerwekh, 2016). One interesting finding of a study regarding the use of mentoring for student nurses was that they reported a preference for online mentoring as opposed to face-to-face delivery – an important consideration for improving current practice with younger graduate clinicians (Mollica & Mitchell, 2013). However, mentoring is qualitatively different from the collegial support that is provided by a peer group. Whilst mentoring operates on an inherently hierarchical structure provided conveying how new nurses are supported by those with more experience, peer support is by nature more egalitarian. Such egalitarian support was also identified as helpful for nurses during first year student placements (Morley, 2014) and additional papers were retrieved which detailed nurses' informal use of text messaging as social support (Bautista & Lin, 2017) and the development of a smartphone application aimed at improving social support for both students and mentors on nursing training programs in the UK (Colton & Hunt, 2016).

With the evidence base being so limited, a search of grey literature was undertaken to review online support provided in the

Why is this research needed?

- More nurses are now exiting than joining the workforce, with 2,112 nurses under the age of 25 leaving during 2016-2017 (NHS digital, 2018). Retention of nursing staff is of global concern.
- Lack of social and emotional support for nurses has been highlighted as a contributory factor to work related stress and burnout. If left unaddressed, these stressors can result in intention to leave the workforce.
- Research into using technology to support the emotional and social wellbeing of nurses is relatively limited. This study aims to contribute to the evidence base.

Whar are the key findings?

- This protocol outlines out how a qualitative study involving online peer support groups will be conducted with newly qualified nurses across the West Midlands region. Findings will be disseminated to participants and key stakeholders on completion of the study.

How should key findings be used to influence policy/practice/research/education?

- If online peer support is found to be beneficial, it may be adopted by local NHS trusts by means of regional innovation schemes. The study will contribute to the limited evidence base on the use of technology to support the emotional and social wellbeing of newly qualified nurses and provide recommendations for future research, practice and policy.

disciplines of teaching, midwifery, counselling, and social work. This involved searching additional sources including Google Scholar, unpublished reports, and dissertation abstracts. In doing so, a recent 5-year peer support strategy into improving the retention of social workers was discovered (Betts, 2016), although no research has been published on this project as of yet. Additionally, a paper on a stress management support group for social workers was found (Meier, 2000), but this was an older study which used an outmoded Listserv mailing list format. Participants in this study reported benefits to online group support with most individuals commenting that it helped them cope with workplace stressors. The findings of the literature review identified that peer support is beneficial to the emotional and social well-being of nurses but that more research needs to be undertaken in this area, particularly into online support. The present study aims to contribute further to the evidence base by exploring experiences of online peer groups for newly qualified nurses.

1.2 | Theoretical framework

The findings of the literature review were supported by Chipps et al. (2015) who similarly acknowledged a lack of research into the use of technology to support nursing staff and that which does exist has limited theoretical foundation. For the present study, the theory of organizational socialization (Van Maanen & Schein, 1979) will be used as a framework for the model of peer support. This theory has been used previously in nursing research, with two studies highlighting the role of effective socialization of newcomer staff in reducing intention to quit, staff turnover, stress, and burnout (Cooper-Thomas et al., 2011; Taormina & Law, 2000). Other outcomes related to positive organizational socialization include more efficient role learning, job involvement, workgroup commitment, task mastery, and increased job satisfaction (Cohen & Veled-Hecht, 2010; Cooper-Thomas et al., 2011).

The theory of organizational socialization assumes that employees undergoing a workforce transition are in an anxiety provoking situation which may result in loneliness, isolation, and work-related stress. This process is observable in the transition from student to newly qualified nurse. Organizational socialization is the means by which new members of a group can effectively adjust to their new environments. Collective socialization explains some of the group processes that occur when new staff members are socialized into a workforce or college group. This is a positive process which involves newcomers engaging with each other in shared experience, such as that provided by a peer support group. The theory further elucidates that although organizational systems can perpetuate problematic ways of working, these may be transformed slowly as new employees bring with them the potential for workplace change. The study will also use a formal socialization process in that it will be externally initiated, introduced, and mediated in the context of a professional NHS workforce. As the peer support study is time bound and constrained to a 3-month period, the socialization process will be a fixed one; this will be communicated to the participants via information sheets during the consent process.

1.2.1 | Person-centred theory

The peer support groups will be delivered from an integrative model combining person-centred and solution-focused theory. It has been argued that the construct of 'person-centred' is poorly conceptualized and suffers from a lack of standard definition (Morgan & Yoder, 2012). For the purposes of this study, we use the definition provided by Sharma, Bamford, and Dodman (2015) who undertook an overview of 46 reviews of person-centred care. They highlight six core concepts associated with being person-centred; communication, getting to know the person, empowering the person, establishing a therapeutic relationship, shared power and responsibility, and trust and respect. The intention of the peer support group is to provide a space where nurses can collaborate with one another to reflect on their work, gain psychological support, share power and responsibility, and feel empowered. It is anticipated that promoting communication between nurses in a peer group founded on values of trust and respect may foster mutually supportive, therapeutic interpersonal relationships.

1.2.2 | Solution-focused theory

Solution-focused theory is a goal-oriented model that seeks to concentrate on what works, resources, collaboration, simplicity and progress (De Shazer & Berg, 1997). It emphasises humanistic values, a hopeful perspective on the future, collaboration, and empowerment (Franklin, 2015) and therefore integrates successfully with a person-centred model. Previous research has suggested that problem-solving based peer support groups may be beneficial in reducing stress and burnout in healthcare professionals (Peterson, Bergström, Samuelsson, Åsberg, & Nygren, 2008). Additionally, several studies have highlighted how person-centred and solution-focused theories can be integrated effectively in clinical research (Walsh et al., 2017) and therapy (Cepeda & Davenport, 2006; Fitzgerald & Leudar, 2010). By integrating these two models, it is anticipated that the peer support group will provide a space where nurses will feel psychologically supported, valued, and be encouraged to think about practical ways of negotiating problems in the workplace in collaboration with their peers.

2 | THE STUDY/REVIEW

2.1 | Aims

This study aims to explore experiences of an online peer support group for newly qualified nurses. The objectives were:

- To develop an online peer support intervention for newly qualified nursing staff that can be accessed via smartphone
- To run the online peer group for 30–40 new nurses
- To interview new nurses about their experiences of the online peer support group

2.2 | Methodology

2.2.1 | Study design

A qualitative design will be used to obtain both written and verbal interview data from participants about their experiences of the online peer support group.

Phase one: Focus groups and consultation

The first phase of the study will consist of exploratory focus groups and consultations held with NQN and key stakeholders. Recruitment for the focus groups will take place between May–July 2018 and conducted from June–October 2018. The groups will be facilitated by a research nurse, nurse lecturer, and a research assistant, recorded on an encrypted portable recording device and subsequently transcribed. It is anticipated that there will be four focus groups each comprised of around 6–8 participants, all of whom will be not more than 18 months postgraduation. The purpose of these groups will be to ask new nurses to share their knowledge and experiences to contribute to and further refine the peer support group design.

Phase two: Peer support groups

Peer support groups will run for 3 months in five rolling enrolment groups of 6–8 NQN from November 2018–March 2019. The online peer support will be delivered via the social collaboration application Basecamp. This format was decided after consultation with a university-based smartphone application researcher/lecturer and NHS Trust Chief Clinical Information Officer who identified it as a secure means of communication for healthcare professionals. It will be accessible via smartphone, iPhone, and PC/Mac. Peer groups will be accessed via a secure login, only available to individuals who have been invited to join via NHS email address. On logging in, participants will be presented with links to a group discussion forum, general chat area and direct messaging function to contact the research team. There is an expectation that participants will engage with their peer support group 3–4 times a week. The groups will run in adherence to the ethical code of the Nursing and Midwifery Council (NMC, 2015) and will be moderated by the research team at least twice a week. Moderators may instigate discussions if conversation falls quiet, but it is anticipated the groups will be primarily a space for peer-to-peer communication, with moderators being present only to ensure participant safety.

Phase three: Semi-structured interviews

After 3 months, all participants will be invited to feedback their experiences of using online peer support via written interviews that will be returnable via email. Additionally, semi-structured verbal interviews will be carried out with 10–12 participants; two from each peer support group. These will be recorded on a portable recording device and subsequently transcribed by the research team. Qualitative data from both written and verbal interviews will be analysed with the aid of NVivo software using a thematic analysis approach or related framework approach dependent on the volume of data. This methodology will identify common themes and patterns in participant experiences of online peer support.

2.2.2 | Selection of hospitals

The study will recruit participants from NHS trusts based in the West Midlands area of the UK.

2.2.3 | Selection of participants

Participants will be identified by the research team from NHS trusts. Preceptorship training days will be attended by the research team to disseminate information about the project at both study sites. All newly qualified nurses (not more than 18 months post-qualification) will be invited to participate. Participants will be free to choose whether they would like to take part in the Phase 1 focus groups or the Phase 2 peer groups and qualitative interviews. Printed posters and online advertising will be used to invite participation alongside launch events where participants will have an opportunity to find out more about the study. The events will be held at convenient times and locations for all staff and will be developed in collaboration with key stakeholders and steering group members. Individuals who are interested in taking part will be given the contact details of the research team and emailed a participant information sheet (PIS). A link to a digital consent form will be then forwarded alongside further instructions on how to take part in the selected phase of the study.

Inclusion criteria

Participants will be newly qualified nursing staff from NHS trusts in the West Midlands. They must have completed their clinical training but be not more than 18 months post-qualification.

Exclusion criteria

This is a study confined to the West Midlands area of the United Kingdom and is limited to nursing staff working at the nominated study sites. Nurses from other regions are excluded from the study.

2.2.4 | Data collection

Consent forms will be administered via online survey software and in person. IP addresses of respondents will not be stored to uphold anonymity. Focus groups will be recorded on a portable recording device and transcribed verbatim by two members of the research team. Interviews and focus groups will use semi-structured guides and be recorded on a portable device. Attention will be paid to interview technique and clarifying questions will be used where meaning may be obscure or open to interpretation.

2.2.5 | Data management and analysis

The focus groups conducted during Phase 1 will be analysed and coded by the research team with the aid of NVivo software. Each recording will be transcribed verbatim and analysed using template analysis (Brooks, McCluskey, Turley, & King, 2015). Two different researchers will code the transcripts, with any disagreements being discussed with a third member of the research team to reach consensus. Caution will be exercised in terms of making interpretations. All data will be stored on password-protected computers and only accessible by the research team. Paper data and all identifiable personal information will be destroyed at the end of the study. No one outside the study team will have access to the anonymized data unless they are from a research governance authority. The data will be archived and stored for 10 years.

2.3 | Ethical considerations

2.3.1 | Approvals

Before either site can enrol participants, the Chief Investigator will ensure that appropriate research ethics committee approvals are in place via the Health Research Authority (HRA; IRAS number: 24105) and local NHS R&D approval. For any amendment to the study, the Chief Investigator, in agreement with the NHS trusts, will submit information to the HRA for them to give approval for the amendment. It has been ascertained that this study will not require NHS Research Ethics Committee (REC) approval due to participants being NHS staff members rather than service users/patients.

2.3.2 | Consent

Written informed consent will be obtained from all participants. Informed consent will involve a discussion between the potential participant and a member of the research team. This discussion will explain the nature of the study including aims, objectives, and possible risks associated with participation. During the consent process, there will be opportunity to ask questions about the study. Potential participants will also be given a participation information sheet (PIS) in written or electronic form. This study will not involve patients and will recruit from a staff group practicing as Registered Nurses; therefore it is assumed that there will be no issues around assessment of capacity. All participants must be capable of giving consent for themselves and understand the nature and purpose of the research, including the benefits and potential risks involved. Potential participants will be informed that there is no requirement to take part and that they are free to choose whether they participate or not. Participants will be free to withdraw from the study at any time without giving any reason.

2.3.3 | Risk assessment

Potential risks that have been identified are risk of psychological harm by interacting with others on an online forum. Material may be discussed which could be upsetting and participants may become more aware of their own negative feelings as a result of discussing them. However, this risk is not expected to be any greater than participants would be exposed to in daily life and has been assessed as being at a tolerable level after introducing measures to reduce it. These measures include regular moderation of the online forum; ensuring participants have contact details for the research team and a direct messaging function to contact research staff in the online portal itself. The peer support groups may also make participants more aware of their own positive feelings and enable them to develop resilience at a challenging point in their career.

The NMC code will be adhered to as an ethical framework as for the conduct of participants online. The code presents the professional standards that nurses and midwives must uphold to register to practise in the UK. Onus will be on participants to abide by this code. If information is disclosed about poor practice, safeguarding patients or vulnerable adults and children, steps will be taken to address these concerns following NHS policy and procedures. Safeguarding measures will be put in place if a participant discloses that they are feeling suicidal or at risk of harming themselves or others at any point during the study. This process may involve sharing of information with external agencies to mitigate harm to the participant. Such limitations to confidentiality will be discussed with participants prior to the consent process.

2.4 | Validity and transferability

External validity is assumed to be satisfactory as nurses will not placed in an artificial environment to complete the project and will interact with smartphone technology in a manner similar to that in their everyday lives. Therefore, findings may be expected to be transferable to the rest of the UK. Caution is recommended for transferring findings to areas outside of this as the NHS is specific to the UK and comes with its own particular set of organizational characteristics. It is important to bear in mind that this is a study involving new nurses working in the areas of general nursing and mental health. Findings may not be transferable to more experienced nurses or to those working in different specialisms.

3 | DISCUSSION

3.1 | Strengths

There is a lack of research into the use of technology to emotionally and socially support nurses. It is expected that this study will contribute to furthering knowledge in this area and provide recommendations for future research based on data from the qualitative interviews. As this is a charity funded project involving peer support, it is hoped that NQN will perceive the study as an independent means of supporting one another whilst still abiding by their professional code of conduct. The ability to contact experienced nurses in the research team via the online forum may scaffold learning in addition to ensuring participants feel safe in the online environment. It is anticipated that the online intervention will be an accessible means of gaining practical and emotional support from colleagues where the ability to communicate with peers is often limited.

3.2 | Limitations

There are limitations to the qualitative aspect of the study design. In contrast, a quantitative study could investigate relationships between use of the online peer support group, emotional well-being, and intention to leave the nursing profession. However, due to anticipated difficulties with recruitment and constraints to funding and time, a quantitative design will not be possible for this study.

4 | CONCLUSION

The study aims to explore experience of online peer support for newly qualified nurses in the NHS during a time of professional transition. On evaluation, if it is found to be an accessible and helpful means of providing support, it may be adopted as an innovation scheme in the NHS trusts involved in the study.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE; http://www.icmje.org/recommendations/):

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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Original research

A qualitative study exploring nursing home nurses' experiences of training in person centred dementia care on burnout

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1. Introduction

There is significant concern about nurse burnout in nursing homes. This paper reports on the impact of training in person-centred dementia care (PCDC) in combination with supervision, designed to reduce burnout and impact on other related outcomes.

Approximately a third of the 850,000 people living with dementia in the UK live in nursing homes (Alzheimer's Society, 2014). The proportion of people with dementia who are cared for by professionals increases as countries develop and at present, formal care of people with dementia makes up 40% of dementia related costs in developed countries (Alzheimer's Disease International, 2015). Despite the financial investments in care and care environments, underfunding of care is an ongoing issue due to pressure on budgets and increasing complexity of need (Royal College of Nursing (RCN) 2012). There is a shortage of nurses worldwide (RCN, 2012) and nursing home nursing is often perceived as low status and unrewarding (RCN, 2012). Staff shortages and lack of investment mean that life is often difficult for nursing home residents and stressful for the nurses who care for them (RCN, 2012) with unresolved work stress having the potential to lead to burnout.

Heinemann and Heinemann (2017) commented on the emergence of burnout research and claimed that despite the growing health science literature on this topic and efforts to clarify the concept over the past forty years, there is still much confusion around the term. There is no consensus around the definition of burnout however it is commonly perceived as a form of stress and as a process rather than a significant event. Job-related burnout was described by Maslach et al. (1996) as a syndrome that occurs among people who work in the human services. According to this theory which remains the most prominent in the literature, the key components of burnout are increased feelings of emotional exhaustion (as emotional resources are worn-out staff are no longer able to give of themselves at a psychological level); the development of depersonalisation (disengagement from the residents who staff care for); and reduced personal accomplishment (where staff feel unhappy about themselves and dissatisfied with their accomplishments on the job) (Maslach et al., 1996).

Nurses who work with older people in nursing homes share experiences in common with nurses who work within the acute and primary health-care sectors (Jeon et al., 2010). O'Connor et al. (2018) in a meta-analysis on the determinants of burnout which included individual factors, high workloads and role conflict. Low rates of burnout were associated with a sense of autonomy at work, and a sense of community at work. Burnout is clearly directly linked to the quality of care that a workforce delivers and has negative consequences which include poor health outcomes and poor job performance (DH 2009; Rose et al., 2010).

Cooper et al. (2016) found that burnout presents a threat to workers' own health and to residents' quality of care. In addition, staff turnover, referred to as 'churn', has negative consequences for people with dementia who need PCDC, care provided by staff who know their history and preferences and with whom they have an ongoing relationship (Sjögren et al., 2013). Burnout has been linked with dispassionate care as staff develop negative attitudes to those being cared for (Duffy et al., 2002) as well as diminished patient contact (Maslach and Jackson, 1981; Dellefield et al., 2015) and negative attitudes towards people with dementia (Brodaty et al., 2003). Therefore, it is essential that burnout among nursing home nurses is addressed.

2. Background

This paper reports on the qualitative findings of a mixed-methods study investigating the impact of training in PCDC which included skills-based training and ongoing supervision intended to help embed and sustain learning in practice.

Both the Marmot Review (2010) and National Institute for Health and Clinical Excellence (2006) have recommended strategic and coordinated approach to reducing burnout. In a review on interventions to reduce burnout Public Health England (2016) reported that much of the literature on interventions to reduce burnout have focused on large

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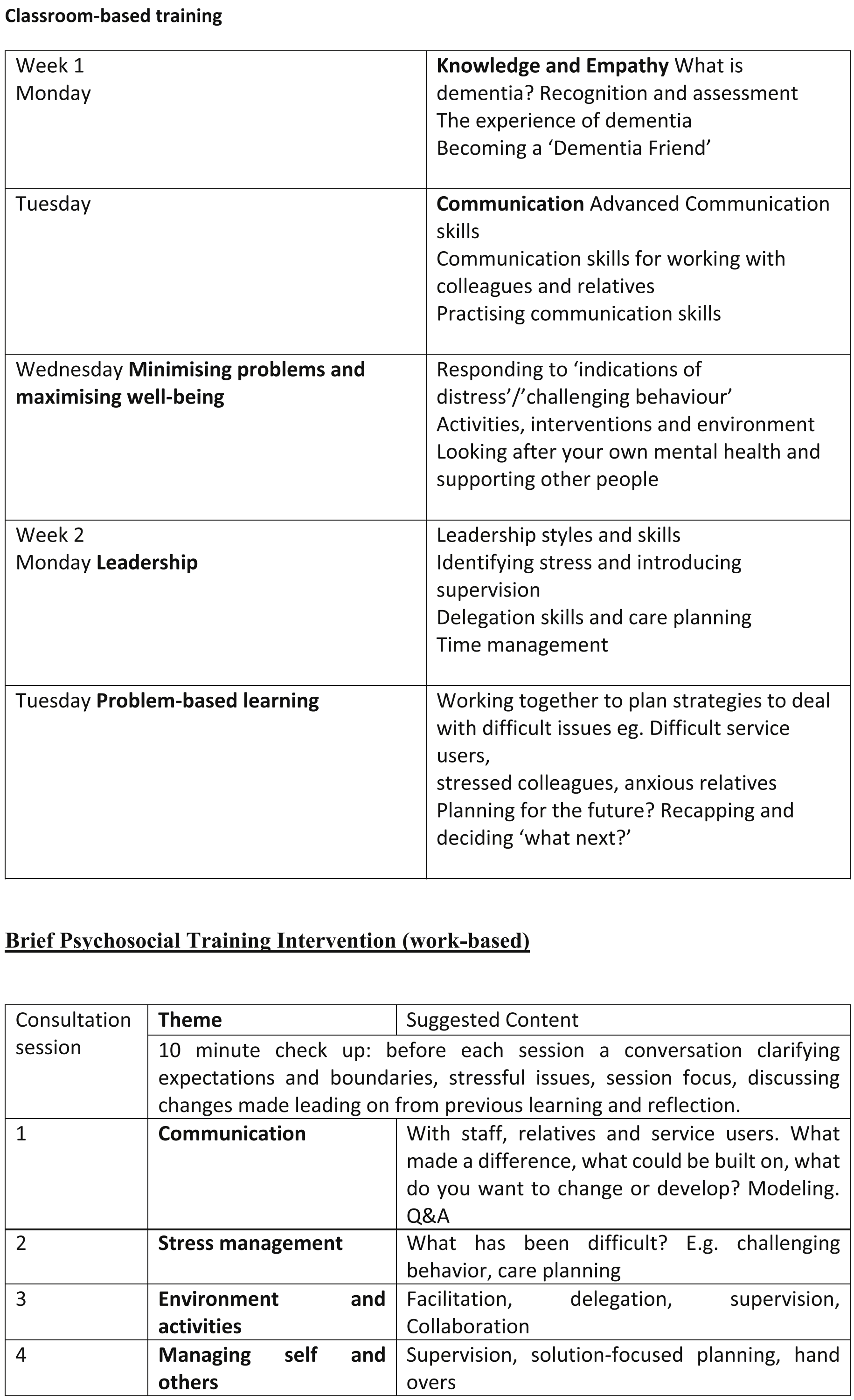

Classroom-based training

Week 1 Monday	**Knowledge and Empathy** What is dementia? Recognition and assessment The experience of dementia Becoming a 'Dementia Friend'
Tuesday	**Communication** Advanced Communication skills Communication skills for working with colleagues and relatives Practising communication skills
Wednesday **Minimising problems and maximising well-being**	Responding to 'indications of distress'/'challenging behaviour' Activities, interventions and environment Looking after your own mental health and supporting other people
Week 2 Monday **Leadership**	Leadership styles and skills Identifying stress and introducing supervision Delegation skills and care planning Time management
Tuesday **Problem-based learning**	Working together to plan strategies to deal with difficult issues eg. Difficult service users, stressed colleagues, anxious relatives Planning for the future? Recapping and deciding 'what next?'

Brief Psychosocial Training Intervention (work-based)

Consultation session	**Theme**	Suggested Content
	10 minute check up: before each session a conversation clarifying expectations and boundaries, stressful issues, session focus, discussing changes made leading on from previous learning and reflection.	
1	**Communication**	With staff, relatives and service users. What made a difference, what could be built on, what do you want to change or develop? Modeling. Q&A
2	**Stress management**	What has been difficult? E.g. challenging behavior, care planning
3	**Environment and activities**	Facilitation, delegation, supervision, Collaboration
4	**Managing self and others**	Supervision, solution-focused planning, hand overs

Fig. 1. Training Intervention in Person-Centred Dementia Care.

scale health care organisations such as the NHS and identified that there was a gap in the evidence for effective interventions for small and medium organisations e.g. nursing homes. Unlike their counterparts in primary and secondary care, nurses working in nursing homes often have limited opportunities for on-going training, may gain little or no respect and recognition for good work, and have very few opportunities for career growth (RCN, 2012).

Many employers choose to provide online or brief training interventions, these approaches may improve knowledge but have minimal impact on practice (Jenkins et al., 2014; Surr et al., 2016). Therefore, more in-depth training is needed (Surr et al., 2016) that addresses the roots of problems such as burn-out that lead to staff turnover and poor care. There are also difficulties in evaluating which approaches to training have sustained impact on practice (Hazelhof et al., 2014; Surr et al., 2016).

2.1. The potential of training in PCDC to reduce burnout

Training in PCDC has the potential to impact on burnout, empower nurses and improve the experiences of residents while also enabling nurses to (re-)gain professional satisfaction and commitment to their roles (Surr et al., 2016). Training that helps nurses to understand behavioural distress, may also have benefits in terms of reducing stress and behaviours which challenge and levels of agitation (Passalacqua and Harwood, 2012; Barbosa et al., 2017). Training in PCDC may also be a means for reducing the risk of abuse and neglect which can be associated with high levels of burnout. This is particularly the case for depersonalisation (Vahey et al., 2004) as it encourages the member of staff to value the person with dementia (Edvardsson et al., 2011). For example, the significance and role of everyday activities may become more meaningful as they are seen as opportunities for connecting with and valuing the person with dementia, rather than tasks (Edvardsson et al., 2013).

Training in PCDC may also lead to a reduction in staff turn-over and improved staff satisfaction (Broughton et al., 2011). Duffy et al. (2009) suggested training programmes aimed to increase self-efficacy and reduce caregivers' frustrations could assist with reducing burnout in care staff. Duffy et al. (2009) also found that knowing how to provide PCDC, as well as being able to achieve positive outcomes at work may lead to an increased sense of personal accomplishment.

3. The study

3.1. Aims of the study

The study was designed evaluate the impact of training and supervision on burnout and related outcomes. Focus groups were used to inform adaptation of the training. Mixed methods including quantitative measures (primarily the Maslach Burnout Inventory), and subjective experience were used to evaluate the impact of training and supervision. This paper focuses on the qualitative evaluation.

Focus groups conducted to guide adaptation of existing training revealed that alongside traditional knowledge-based training delivered in the lecture room, nurses also wanted practical, hands-on training that models person-centred practice (Brooker et al., 2015) delivered by credible trainers (Smythe et al., 2014). There is tentative evidence to support the hypothesis that training combined with supervision or ongoing support is more likely to maintain outcomes and have a positive impact (Surr et al., 2016; Westermann et al., 2014). Therefore, the formal classroom training sessions of our intervention were followed by reflective coaching sessions in the workplace and by clinical supervision.

The intervention combined classroom-based and skills-based training, which involved the trainer working alongside the nurses. We explored how the knowledge and skills that were taught were implemented in practice. One third of the nurses subsequently received clinical supervision based on a restorative approach which was intended to sustain outcomes from the training. Restorative supervision is an evidence-based model offers a reflective space where conflicting ideas can be discussed and restores the clinicians capability to think. It is suggested that the restorative function recognises the emotional effects on individual work and in particular the work of people in distress (Scarfie, 2001).

3.2. Design

3.2.1. The training and supervision intervention

The training intervention involved a five day programme of classroom-based training focusing on PCDC to the care of people with dementia, leadership and self-care. This was followed by a 'working alongside' skills-based intervention over two five-hour shifts per nurse. This involved modelling person-centred approaches to dementia care and advice about applying theory from the training intervention to practice. Please see Fig. 1 for an overview of the training.

3.3. Method

The qualitative evaluation of the training described here involved interviewing a subset of those who had received the training and supervision intervention. Overall, the training and supervision intervention was delivered to 74 registered nurses, from 47 nursing homes within a cluster randomised controlled trial which used quantitative questionnaire-based measures. The quantitative aspects will be reported separately.

We took a naturalistic and constructivist stance to focus on nurses' accounts, experiences and meanings, concentrating on how the nurses' interpreted their own social world (Robson, 2011). Through interviews we aimed to acquire multiple perspectives (Robson, 2011), in tune with the constructivist position (Creswell and Plano Clark, 2007). We aimed to understand whether, why and how the intervention had made a difference (Woods and Russell, 2014) and to explore the most important parts as viewed by its recipients, as this has implications for the refinement of the intervention.

3.4. Sampling approach

We recruited interviewees from thirteen of the 47 homes either post-training or post-training and restorative supervision. We included a proportion (eight) who had received training and supervision (T + S) and five who received training only (TO). Numbers were chosen to allow the collection of a range of experiences with recruitment continuing to a point where nothing new was emerging (Creswell and Plano Clark, 2007). It was not possible to recruit equal numbers from each group due to time constraints.

3.5. Participants

Twelve participants were female and one male; all were qualified to diploma level and had extensive experience of working with people with dementia.

3.6. Setting

Participants were drawn from nursing homes in the Midlands of the United Kingdom. The classroom-based training intervention was conducted in training facilities in a local university. The skills-based element was conducted in the nursing home where the participant worked, as did the restorative supervision.

3.7. Data collection methods

Interviews took place shortly after the completion of the intervention at the nurses' place of work. The interviews were used to understand the nurses' perspectives of the intervention. The interviews lasted approximately one hour and were audio recorded.

3.8. Ethical considerations

Participants was voluntary and informed consent was received. All data was anonymised including the of supervision records.

Ethical approval for the study was received from NRES Committee East of England on the 6th June 2014. Reference 14/EE/0168 IRAS ID 15922.

3.9. Data analysis

The interviews were recorded and transcribed verbatim and analysed using Template Analysis (TA). This is a process for organising and analysing textual data according to themes (King, 1998). Central to the technique is the development of a coding template and the use of a priori codes. To develop these codes the half-way position described by Waring and Wainwright (2008) was adopted, where codes were developed based on the theoretical position of the research as well as after exploration of the data from initial interviews. Our initial template reflected the aims of the research and included Reactions to Training and Experiences of Supervision.

After the first four interviews were analysed the template was modified in to include some tentative inductive sub-themes (e.g. sub themes for nurses' perspectives on and reactions to the training included feeling overloaded, self-blame and enhancing self-efficacy), hierarchically linked to the two main topics (Reactions to training and Experiences of Supervision). Any predefined codes which turned out not to contain any significant data were deleted. Data was sorted and scrutinised to explore possible relationships and trends in themes (King, 1998). The final template served as an organising framework for the interpretation of the findings.

3.10. Reflexivity and trustworthiness criteria

The COREC qualitative checklist was used (Tong et al., 2007), to ensure that rigour was achieved, and that credibility, transferability, dependability and confirmability were promoted. Approaches to ensure credibility included looking across the data to explore deviant cases which contradicted our expectations in relation to major themes (Mays and Pope, 2000). To assist with the process of reflexivity and enhance confirmability, coding was undertaken independently by the researchers and compared to allow for reflection, discussion and reconciliation of different interpretations. Therefore, there was a clear audit trail evidencing how decisions were made throughout the study.

Reflexivity was crucial during the analysis of the qualitative data (Parahoo, 2006), therefore the authors attempted to consider the effects of our experiences and backgrounds throughout this process.

Other methods of assuring credibility included the use of purposive sampling for the qualitative interviews. Murphy et al. (1998) stated that wherever possible purposive sampling should be used to ensure quality. Transferability refers to the degree to which qualitative findings can be transferred to other settings (Bitsch, 2005). This was addressed in our study through providing a thick description of the data, referring to context, setting, and by providing details of the methodology (Korstjens and Moser, 2017). This helps other researchers to replicate the study (Anney et al., 2012) and readers of research to know whether the findings might apply to their own setting. Dependability relates to consistency and repeatability, this was assured through the use of an audit trail where all documents e.g. interview notes, scores and transcripts were kept for checking and auditing.

4. Findings

Findings from the qualitative interviews are presented under the two main aims, Reactions to the training and Impact of supervision. Pseudonyms have been given to the participants. Beneath participant quotes, 'T&S' refers to participants who received training plus supervision, 'TO' refers to those who received training only.

Reactions to the training:This theme set the backdrop for understanding how the training impacted on the nurses, as the findings shed light on how the nurses feel at work, their roles and responsibilities, and the significant pressure that they are under. Sub-themes included experiences of burnout, implementing PCDC, feeling more confident, and opportunities to participate.

4.1. Experiences of burnout

The sub-theme of "experiences of burnout" emerged from a series of introductory questions that were used to explore whether and how the nursing home nurses experienced burnout, and how this was expressed.

Analysis of the data revealed the nurses felt overloaded, isolated and in poor health. These factors combined to result in burnout. Physical and emotional exhaustion arose from feelings of being overloaded and unsupported. Individuals' poor coping strategies and unhealthy habits appeared to combine to exacerbate the impact of unsupportive environments. There was a wealth of data relating to staff feeling unsupported at work and undervalued by their organisations. This is demonstrated in the quotation below:

> "Because it's like … you give someone a drop of blood, but they want two drops, so you give them three drops and it keeps going and going, you know and now I'm always lifeless. Because I can't give any more blood, do you know what I mean?(Sahib T + S)

As the lone qualified member of staff the nurses expressed a sense of isolation, having no colleagues to turn to for clinical guidance, reassurance or peer support.

> "Nobody says to you, you've had enough now, so down to the staff room. Hold on, I can't remember the last time I had supervision and that's down to staffing and not having enough nurses and managers and having to do shifts because there are no nurses". (Jane T + S)

The 24-h, seven day a week nature of needs in the homes combined with staff shortages meant that the nurses were aware that no one else was there to solve any problems that arose in their absence. This led them to feel 'on duty' even.

when at home.

> "It's like if you're off today you're thinking oh no I've got to go to work tomorrow. You just can't relax at home because you're even having calls at home, so you couldn't even have an off day". (Matilda T + O)

Despite the feeling of being under pressure, the nurses appeared to feel a compulsion to 'be there'. They often recognised this was unhealthy but were unable to explain their own behaviour.

> "It makes me think I'm not good at it, and I get angry with myself, well why can't you do it, other people manage … they do. … I need to carry on until I've done it and if it half kills me I'll carry on …" (Vanya TO)

Despite their personal commitment to continue at work, the nurses described the impact on the quality of care of colleagues being off work, as the pressures resulted in increased sickness, absenteeism and staff turnover as demonstrated in the quotation below:

> "They also had a big staff turnover, people came and went all the time and so there was no continuity. The residents didn't get used to faces, they used a lot of agency nurses so there was no continuity…" (Gemma T + S)

It also appeared Senior Managers did not restrict the long working days and continued to foster this unhealthy behaviour:

> "It was easier for them [management] to ignore it because I was then still getting the job done, as long as I was churning out the results I needed, coming to work so they [management] wouldn't need to worry about replacing me, or having another man down or having disruption and chaos coming to the workplace, they allowed me to continuously work these hours." (Matilda TO)

The high demands, including pressure to work long, sometimes unpaid, hours, appeared to be associated with physical and emotional symptoms of stress.

Participants reported adopting unhealthy coping strategies, such as smoking and drinking, and prioritising client well-being over that of their families. Several interviewees highlighted that physical symptoms of stress were having a negative impact on their life and health.

> "It happened twice at work where they had to call for an ambulance for me and that was due to stress at work…it was like a crushing; a severe pain like a heart attack, I was really sweaty and when you're in a medical field, you know what's happening". (Catherine T + S)

The health problems affected the nurses' emotional well-being at home, which led on to an impact on relationships with others. The nurses were aware of the negative consequences of their behaviours, and expressed concern for their own long-term well-being:

> "I wouldn't even smile and when I got home the children would run away … yes it affected my personal life because I would get home after twelve hours, I couldn't walk or talk, let alone eat, it affected my life as a whole" (Sue T + S).

> "I work very long hours … but I need to stop doing that now because it's taken a toll on my health … because if not I'm going to kill myself". (Yvonne TO)

This theme suggests that the nurses may be struggling to meet the competing demands of the home, balancing the heavy workload along with the needs of the residents and the emotional burden of caring. The nurses felt that this had an impact on their physical and emotional health.

4.2. Implementing person-centred approaches: "Thinking about the person"

The classroom training included learning material about the experience of dementia and enhanced communication skills. Subsequently it seemed from the accounts that some of the nursing home nurses were more likely to adopt a person-centred approach to care following the training intervention.

While participants did not explicitly use this term, to know the person's history and understand their identity appeared to be something which they now considered:

> "a woman here … that has Alzheimer's and it was her birthday a few days ago and she kept saying to everybody … 21 ½ nearly. Well we never really … So that if she is in that sort of age, in her early twenties, to get her daughter to try and think of things she can talk about to see if she can have a conversation with her mum about something her mum will remember". (Sheila T + S)

Another participant explained how she was now much more aware of the importance of recognising residents' past lives to treat them with respect in the present:

> "I think knowing about these people's pasts you know. You're talking to them like they're stupid and they're not and you get into that habit where you're like 'come on' because you're disappointed and frustrated" (Catherine T + S).

4.3. Enhanced self-efficacy

A second strong sub-theme under the main theme of reactions to the training, reflected an increase in the sense of self-efficacy reported by some of the nurses following the training intervention. Some of the nurses appreciated their own worth and said that they were more positive about their skills and abilities than they were before the training. Enhanced confidence enabled the nurses to share new knowledge and influence care. This had a subsequent impact on workload management as some realised they could delegate responsibility rather than carry it all:

> "Before the training I used to find pride when people phoned me at home …. And I felt glad that people are phoning me. But when … actually mentioned that when your team can't deal without you, it really made me think, I really need to share the education and when you do, things you just go smoothly so now I can go for a meeting for two hours and they don't look for me because they know what they're doing and why they're doing it". (Sue T + S)

The skills-based training appeared to be a beneficial aspect in terms of enhancing confidence as trainer was able to provide positive feedback on practice in the home, providing opportunities for embedding and reinforcing good within the home.

> " Everybody needs … a pat on the back and when you don't get it you know so when the change comes around and you do, you do feel really valued you know especially because within yourself you feel undervalued you act that way and when you're praised and valued you act that way as well." (Jaz TO)

Positive reinforcement was valued and seemed to boost morale. The training appeared to reduce feelings of isolation. Participants reported that the classroom training had provided valuable opportunities for sharing practice and experiences of working in a nursing home. They seemed to feel reassured that "*everyone was in the same boat*" and "*they were the same as everyone else*". They valued sharing ideas with a view to problem solving for managing difficult situations at work.

> "It was really nice to feel like 'Oh God it's good to know that were not the only ones' because you do tend to get a bit, 'are we being picked on'? So you know it's nice to know that we're not, you know any different from anybody else. We have the same sort of problems with the kitchen staff and with the caring staff and the relatives and all the normal types of things." (Jaz TO)

4.4. Opportunities to participate: "There was something different about it"

The participants reported that the training was very different from the training which they usually received, which was usually in the form of workbooks, DVDs and free computer-based learning, which they described as 'very poor', 'pointless' and 'repetitive'.

Participants reported how they had been able to bring what they had learnt from the training into their work. This included their use of new leadership approaches and strategies for managing stress at work which were both part of the curriculum (See Fig. 1: Outline of Intervention).

Participants favoured active learning such as role play, group exercises and discussion used in the classroom and found these particularly enjoyable.

> "We did loads, the leadership bit was when we did the role play, that was good, and a lot we did on dementia and following through, and picking up on the communications and behaviours, although we still need behaviour training, not for the residents, for the staff!" (Matilda T + O)

4.5. Impact of supervision

There were numerous examples in the interviews where the supervision appeared to support staff in preventing burnout, in implementing ew learning, and in encouraging experimentation and reflection. The supervision process seemed to support participants to work flexibly and creatively, and adopt a solution-focused approach to manage challenging situations:

> "Afterwards bringing into the Home the bits we have learnt but then it's tweaking it for here. For me, for my staff and also tweaking it for nights, because that's different from days. So the supervision brought it more centred for me, for my staff and residents" (Amanda T + S)

The supervision modelled a way for the nurses to direct responsibilities back to their teams, rather than taking on everything as the senior member of staff. Socratic questioning was used, an approach which this participant was able to adopt in her own role supervising others:

> "I found it really helpful especially when you have to supervise the carers or the senior care nurse. So we will ask them a question like: 'Which way do you feel better?' So we are not telling them 'You do it this way' and they will get the feeling that they have told you what the solution is" (Gemma T + S)

The nurses spoke of the way that engaging in the process of supervision enabled them to become effective supervisors themselves, eager to create opportunities for providing effective supervision in their workplace.

5. Discussion

In this study, nurses' accounts appeared to indicate that both classroom-based training and workplace-based training impacted positively. They reported reduced feelings of burnout, adopting a more person-centred approach to working with people with dementia, and enhanced leadership skills. The workplace-based training was described as being particularly helpful in assisting the nurses with applying the training to real world care practice.

A recent review looking at the provision of dementia training for the wider workforce (Surr and Gates, 2017) recognised common features which were similar to the ones here, suggesting that training should be relevant to staff's role in the work place, be facilitated by a credible trainer, and involve group learning. The nurses who experienced supervision were able to articulate a sense of job satisfaction which may have resulted from a more genuine 'deep acting' response to the stresses of managing high levels of emotional labour (Maxwell and Riley, 2017).

Our findings confirmed those of previous studies indicating that working as a nurse in nursing homes is stressful (Engstrom, Skytt and Nilsson 2011; Westermann et al., 2014). The accumulation of devaluing but accepted experiences in nursing homework, such as low pay and few opportunities for progression, have been found to have a negative impact on health over time (Sojo et al., 2015). This, in combination with perceived lack of control, high levels of responsibility and anticipated criticism is recognised as damaging for workers and known to lead to burnout and ill health (Engstrom, Skytt and Nilsson 2011). In this study, the nurses' accounts indicated strong feelings of responsibility, isolation and overload that were impacting on mental and physical health and well-being. Many of the nurses in our study had been diagnosed with serious long-term conditions and this is consonant with research suggesting that long-term stress has an impact on the immune system and results in vulnerability to long-term health problems (Kendall-Tackett, 2015).

Caring for people with dementia, whose distressed behaviour can be challenging, has been found to be associated with poor physical health for nurses, together with high levels of burnout (Cookson and McGovern, 2014). However, the nurses in this study did not complain of stress arising from looking after the residents of the homes, but spoke of holding sole responsibility, professional isolation and staffing levels as the main sources of stress. This echoes work with continuing care nurses and other health professionals which has found that burn-out is more related to team and organisational relationships than to caring for patients (Rose et al., 2010). It seemed that the isolation and overload resulted in perceived barriers to using constructive ways of coping such as taking time for relaxation or using social support, including spending time with family, or having professional support. Instead the nurses' gave accounts of using harmful temporary stress management strategies.

Against this backdrop of stress and burn-out, we sought to discover whether and how the training intervention had impacted. In the nurses' accounts of their experiences of training, it seemed that among the most well-received aspects of training in person-centred dementia care were the trainers' collaborative approach and credibility, as well as the value placed on practical tips and group activities. It appeared that the solution-focused approach (Franklin, 2015) which was used in the classroom, workplace and supervision elements of the intervention to address problem-solving, self-care and leadership led to an enhanced sense of control at work. Having a sense of job control has been found to be associated with person-centred practice, more positive engagement with work responsibilities (Kubicek et al., 2014) and job control (Fearon and Nicol, 2011) and seems to be protective by mitigating the consequences of job demands (Schmidt and Diestel, 2013). It is suggested that good care can be achieved through strengthening the position of nursing home nurses, alternative models of paying for care (Horton, 2017) and better staffing (Dellefield et al., 2015).

In addition the opportunities in the classroom that allowed the nurses to share stories seemed to be a crucial element in reducing their sense of isolation. It increased the feeling of being in a similar situation to others, and this was experienced as mutually supportive and reassuring, perhaps because when similar experiences emerged, responsibility could no longer be attributed to an individual (the nurse themselves) but instead could be perceived as systemic (Sojo et al., 2015), thus enabling the nurses to reject self-blame. Telling stories is congruent with the culture of nurses' professional life, and is an acknowledged informal method for sharing values and developing empathy (Wood, 2014).

The nurses who experienced supervision were able to articulate a sense of job satisfaction which may have resulted from a more genuine 'deep acting' response to the stresses of managing high levels of emotional labour (Maxwell and Riley, 2017).

The nurses noted an increase in confidence and emotional well-being and greater willingness to share their knowledge. The implications of our findings are that there are ethical and business reasons to teach nurses working in nursing homes about high quality dementia care and leadership skills, and to support them and reinforce their personal development with a working-alongside model and clinical supervision. This training approach reinforces the value of nurses, including, importantly, to the nurses themselves.

Reducing staff turnover is essential to the smooth running of the Home and to the well-being of people with dementia, who are better nursed by people who know them well, understand their life history and are committed to a person-centred approach. Delivering care from a person-centred perspective is dependent on staff too meeting their needs for personhood. The physical health of nurses also needs attention and working conditions should be designed to facilitate nurses taking care of their own physical and emotional health.

5.1. Limitations

It was not possible to recruit equal numbers as the nurses to each group were not available for interview as they had left the home where they worked. The sample was purposive with nurses being selected based on their availability and willingness to participate. Studies which evaluate staff's reactions may be at risk of bias due to social desirability bias where the participant may be likely to say what is socially acceptable (Lavrakas, 2008). Selection bias may be difficult to overcome and is difficult to avoid completely (Kukull and Ganguli, 2012). It is possible that more motivated participants, or those who perceived themselves to be experiencing burnout, agreed to be interviewed. Our study participants were all qualified at diploma, rather than degree level, so we were not able to explore the relationship between the level of a nurse's education and their susceptibility to burnout.

6. Conclusions

Working long hours, feeling overloaded, unsupported, isolated, and not feeling valued all combined to create an extremely unfavourable work environment and led to nurses' experiences of burnout. The training and supervision appeared to reverse or break through some of the conditions that led to burnout. The nurses reported the intervention had enhanced their confidence and reduced isolation. It also appeared that the training and supervision created the beginnings of change in individual practices with the nurses seemingly more likely to adopt a person-centred approach to delivering dementia care.

Both the skills-based aspect of the training and the supervision appeared to assist the nurses in applying what they had learnt in the classroom. Therefore it seemed that the training and supervision had the effect of starting to reverse the vicious circle associated with development of burnout, by providing the nurses with strategies to cut through their sense of isolation and powerlessness, and to deal more effectively with the pressures of work. The findings suggest a need for further research to examine the effectiveness of supervision alone and alternative strategies to improve the well-being of nurses working in nursing homes.

CRediT authorship contribution statement

Analisa Smythe: Conceptualization, Funding acquisition, Writing - original draft, Formal analysis. **Catharine Jenkins:** Conceptualization, Funding acquisition, Writing - original draft, Formal analysis. **Magdalena Galant-Miecznikowska:** Conceptualization, Funding acquisition, Writing - original draft, Formal analysis. **Jane Dyer:** Conceptualization, Funding acquisition, Writing - original draft, Formal analysis. **Murna Downs:** Conceptualization, Funding acquisition, Writing - original draft, Formal analysis. **Peter Bentham:** Conceptualization, Funding acquisition, Writing - original draft, Formal analysis. **Jan Oyebode:** Conceptualization, Funding acquisition, Writing - original draft, Formal analysis.

Declaration of competing interest

The are no conflicts of Interest to declare.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.nepr.2020.102745.

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Ethical approval details

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REVIEW

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What is the nature of Mental Capacity Act training and how do health and social care practitioners change their practice post-training? A narrative review

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Abstract

Aim and objective: To identify training strategies and determine how registered health and social care practitioners change their practice after Mental Capacity Act training.

Design: Narrative literature review.

Data sources: Seventeen databases were searched up to December 2019: CINAHL, Social Care Online, PubMed, Social Policy and Practice, Discover, MEDLINE, Science Direct, Ovid, 0of Science, British Nursing Index, DH-Data and King's Fund Library Catalogue.

Review Methods: Empirical studies of any design investigating Mental Capacity Act training were searched and screened. Data were extracted to a bespoke spreadsheet and quality assessed. Reporting followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

Results: Of 162 papers identified, 16 were included comprising qualitative, quantitative and mixed-methods studies. Trainees valued interactive training with close alignment to practice. Training did not lead to demonstrable practice change. Barriers in the context and cultures of care environments were identified.

Conclusion: To facilitate application of Mental Capacity Act legislation, identified barriers should be addressed. Future training should be interactive, scenario-based and relevant to trainees' practice.

Relevance to Clinical Practice: The Mental Capacity Act is widely misunderstood and implemented poor. Training is proposed as a solution, but the nature of training that will positively affect practice remains unknown. This review aims to address this gap in the evidence base. Interactive training, using scenarios that reflect practice complexities, has the most positive impact. Cultural norms in care environments may impede application of this legislation.

The review has international relevance as there is a global imperative to adhere to the United Nations Convention on the Rights of Persons with Disabilities. The review will

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inform training design and delivery to ensure that people with impaired capacity to make decisions are given the best opportunity to act autonomously.

KEYWORDS
health care, impact, Mental Capacity Act, narrative literature review, nurses, social care, training

1 | INTRODUCTION

Globally, capacity legislation is gradually aligning with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), which accords equal recognition in law to people with disabilities, emphasising their rights as citizens. In line with international legislation, the intention of the Mental Capacity Act (Department of Health, 2005) (MCA), which applies in England and Wales, is to promote the autonomy of people who may temporarily or permanently lack capacity to make their own decisions by providing a framework to guide decision-making (Hinsliff-Smith et al., 2017).

The act reflects a social model understanding of disability in which disability is framed as impairment in combination with societal barriers, which together impede rights to equal social inclusion (Croucher, 2016). This viewpoint is increasingly influential; global capacity legislation is gradually aligning with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which drives equal recognition in law to people with disabilities. Therefore, European capacity legislation is going through a process of reformation, away from prioritisation of safeguarding and substitute decision-making on the basis of diagnosis and towards supported decision-making (European Union Agency for Fundamental Rights, 2013). This process is not universal; for example, although the CRPD has been ratified by most states in the African Union, informal practices in many African countries are restrictive of people with disabilities, and current legislation reinforces discriminatory practices (Mental Disability Advocacy Center, 2016). The MCA (2005) for England and Wales, the Adults with Incapacity (Scotland) Act 2000 and The Mental Capacity Act (Northern Ireland) 2016 are harmonised with the values of the CRPD in identifying capacity as “decision-specific” and evaluated on the basis of cognition, rather than “status” or diagnosis, while prioritising empowerment over protection.

Initially, the act was well-received, and it was described as “a sound framework for balancing autonomy and empowerment with safeguards and care” (Ward, 2005:70). However, there are suggestions that the MCA is generally not implemented as intended (House of Lords, 2014).

Two million people in the UK are estimated to have conditions that limit their decision-making capacity (Social Care Institute for Excellence (SCIE), 2016). Consequently, the act is relevant to the practice of any registered or nonregistered worker in health or social care, in addition to voluntary workers and family carers who provide informal support (Daniel & Dewing, 2012). This equates to approximately 6 million individuals in England and Wales (SCIE, 2016). National Institute for Health and Care Excellence (NICE) Guidance (NICE, 2018) states that training is central to effective MCA implementation. This guidance points to existing research into MCA training being of low quality and highlights the need for further research into optimum approaches to training.

What does this paper contribute to the wider global clinical community?

- The review has international relevance as there is a global imperative to adhere to the United Nations Convention on the Rights of Persons with Disabilities. Similar legislation (related to people who potentially have impaired capacity) internationally may lead to similar issues with application of learning from training
- The review will inform commissioners and providers regarding design and delivery of training for health and social care providers and practitioners to ensure that people with impaired capacity to make decision are given the best opportunity to act autonomously.

Mental capacity is defined as the ability to make one's own decisions, based on the ability to understand and reason (Daniel & Dewing, 2012). Capacity is not determined by diagnosis or individual characteristics, but is dependent on the impact of a person's impairment and the nature of a specific decision to be made at a particular time (Taghizadeh Larsson & Österholm, 2014). The MCA applies to all types of decisions, from the humdrum (such as what to wear) to the highly significant (which care home to choose) (Hinsliff-Smith et al., 2017). The first principle of the act requires practitioners to assume service users’ capacity (Department of Health, 2005 (s1(2))); this and subsequent provisions reflect the intent of the legislation primarily to promote autonomy, with the best interests principle (explained below) in place should a person is not able to make a decision for themselves (Mackenzie & Rogers, 2013).

There is provision for those concerned about their future decision-making abilities to plan ahead, using advance decisions (legally binding recorded decisions to refuse treatment in specific circumstances) and statements (concerning a person's preferences), and to clarify who they would have represent their interests should decisions need to be made on their behalf (NICE, 2018). The act provides guidance for researchers who are conducting studies involving people who may lack capacity; for example, the project must have ethical approval, and the focus of the research must be linked to the person's "impairing condition" and have a chance of benefitting the individual or others with the same condition (Department of Constitutional Affairs, 2007). The legislation also provides a structure for professionals that clarifies and directs the process of respecting an individual's decisions. It guides assisting with decision-making, assessing a person's capacity to make a specific decision and, if a person is unable to make a decision, guiding the professional (or family or voluntary carer) substitute decision-makers in determining a person's best interests so that a decision reflects their values and lifestyle, with minimal restrictions to the individual (Department of Health, 2005 (s1(2–6)), Stevens, 2013). Under an amendment to the MCA, Liberty Protection Safeguards are due to replace Deprivation of Liberty Safeguards by autumn 2020. These provisions authorise care in a hospital or care home for a person who does not have capacity to consent, but for whom the arrangements are necessary to avoid harm (Social Care Institute for Excellence, 2019).

Consequences of limited understanding and implementation of the MCA are significant. For example, misinterpretation of the concept of "capacity" (Wilson, Seymour, & Perkins, 2010) and how it should be assessed (Marshall & Sprung, 2016a) leads staff to assume that individuals cannot make their own decisions (Care Quality Commission, 2013). People living with dementia are at particularly high risk of being systematically excluded from decision-making (Taghizadeh Larsson & Österholm, 2014) while people with intellectual disabilities still face barriers due to poor adaptation to their needs (e.g. provision of accessible information which would support decision-making) leading to negative experiences of services and poor outcomes (Sheehan et al., 2016).

MCA training was not and still is not always mandatory. Poor implementation of the MCA cannot continue as the outcome for service users with dementia, intellectual disabilities, mental health problems and other disorders may be to undermine their autonomy and deny their human rights (Marshall & Sprung, 2016a).

In light of the need for more effective implementation of the MCA, and allied legislation in other countries and the centrality of training in this quest, the purpose of this review is to identify, evaluate and synthesise published papers that report on health and social care practitioners' MCA training, to explore the nature of training interventions and establish the ways and means through which practitioners change their practice post-training and make recommendations for future practice and research.

2 | AIMS AND METHODS

To identify training strategies and determine how registered health and social care practitioners change their practice after Mental Capacity Act training.

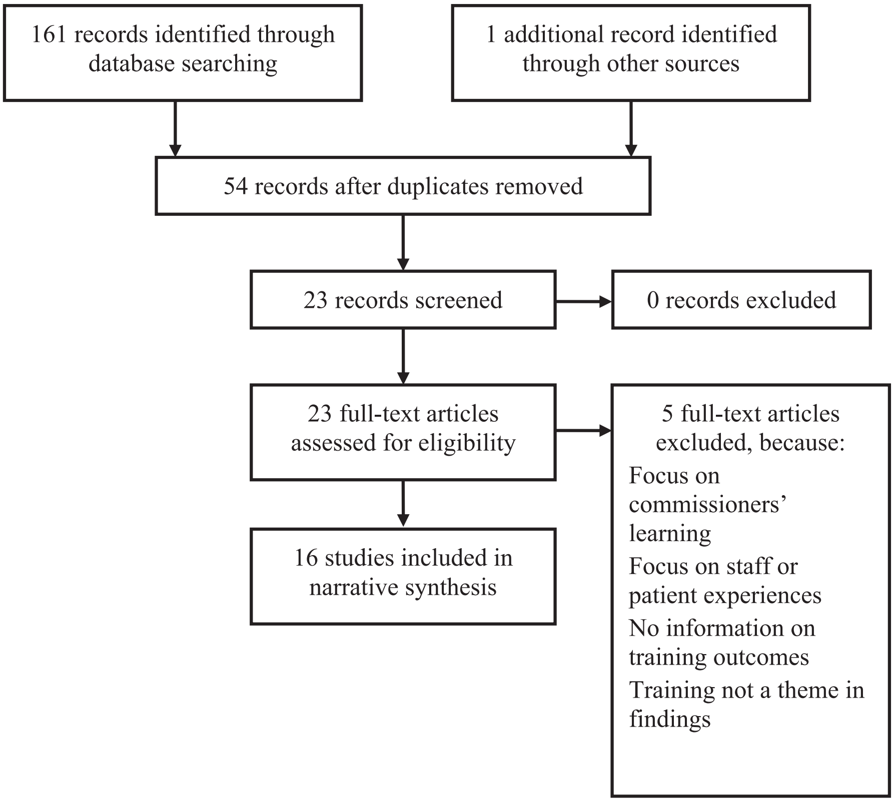

FIGURE 1 Prisma flowchart showing stages of the search process

2.1 | Objectives

In published empirical studies to identify.

- types and durations of MCA training
- training evaluation methods
- participant evaluation
- impact of MCA training in practice

This review is registered with PROSPERO, the international prospective register of systematic reviews (CRD42018094478) (Jenkins, Cowdell, & Smythe, 2018).

2.1.1 | Design

We conducted a systematic search to identify literature. As included studies were methodologically disparate, we broadly adopted the approach of Popay and et al., (2006) to guide and structure our narrative synthesis and thus "tell the story" of MCA training impact. Evidence was synthesised in three main stages: developing initial synthesis of findings from identified relevant studies, exploring relationships within the findings and evaluating the strength of the synthesised outcome (Kastner, Antony, Soobiah, Straus, & Tricco, 2016). Reporting followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) format. Please see Figure 1 and Supplementary File 1.

The review team comprised three nurses, one with expertise in the Mental Capacity Act and nurse education, one with expertise in the care of older people and qualitative research methodologies and one with expertise in research into dementia care education and mixed-methods research, and a research assistant.

2.1.2 | Search methods

We searched the databases CINAHL, Social Care Online, PubMed, Social Policy and Practice, Discover, MEDLINE, Science Direct, Ovid, PsycINFO, ASSIA, Social Services Abstracts, Science Direct, Academic Search Premier, PubMed, Web of Science (all databases), British Nursing Index, DH-Data and King's Fund Library Catalogue using the search terms Mental Capacity Act AND training OR education OR learning up to 6 December 2019. Limiters were articles published in English language and post-2007 as the MCA applies only to England and Wales and was enacted in this year, so training would not predate this. For completeness, we used forward and backward citation searching and hand-searching selected journals.

2.2 | Inclusion criteria

- Empirical studies
- Evaluating MCA training for health and social care staff

2.2.1 | Search outcomes

The initial search yielded 162 papers; with de-duplication, this was reduced to 54. One author (xx) screened title and abstract and excluded clearly irrelevant papers ($n = 31$). The remaining full texts ($n = 23$) were screened by two authors (xx, xx). In the event of disagreement, we had planned to consult with other co-authors. One further paper was identified from reference checking of included papers. A total of 16 papers are included. Stages of the search are documented in a PRISMA flow chart (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009) (Figure 1).

2.2.2 | Quality appraisal

Quality of included papers was assessed using the Hawker checklist which is adaptable and designed specifically for reviewing disparate data systematically (Hawker, Payne, Kerr, Hardey, & Powell, 2002). It comprises nine questions each with a score range of 1–4 with 4 being the highest. Scores ranged from 13–36. Four papers (Bose & McLiggans, 2019; Schofield, Di Mambro, & Schofield, 2012; Willner, Bridle, Dymond, & Lewis, 2011; Willner, Bridle, Price, Dymond, & Lewis, 2013) evaluated specific training programmes, and these scored most highly. However, we included lower scoring papers as these contributed to answering our review question.

2.2.3 | Data abstraction

Data were abstracted to a bespoke spreadsheet in which we recorded standard information (author, publication date and study design/paper type). In relation to our review aim and objectives, we extracted (when available) details of training intervention, trainers and trainee, evaluation approach, participant evaluation and reported impact of training (Table 1).

2.2.4 | Synthesis

Synthesis was achieved by developing grouping tables to explore relationships within and between studies and creating brief textual descriptions of each study. From this, we derived two key themes each underpinned by sub-themes: first, "the nature of MCA training" with sub-themes of "positive reactions but lingering anxieties" and "misunderstandings and misapplications," and second "problems in changing practice post-training," with sub-themes of "institutionalised under-resourcing" and "hierarchy confidence and responsibility."

3 | RESULTS

3.1 | Study characteristics

Of the included studies, seven were quantitative, seven qualitative and two mixed methods. Quantitative studies (McCormick, Bose, &

TABLE 1 Details of training intervention, trainers and trainee, evaluation approach, participant evaluation and reported impact of training

First author, date	Study design/ paper type	Training intervention	Trainers and trainees	Evaluation approach	Participant evaluation	Reported impact of training
Manthorpe et al., 2009	Qualitative (thematic analysis of interviews with safeguarding leads)	Based on DH training materials. Expectation to “cascade”	Trainers: not reported Trainees: social work, safeguarding adults co-ordinators	Interviews	Overall helpful	Remaining anxiety and lack of confidence reported by participants
Sawhney et al., 2009	Quantitative (questionnaires. Results presented as percentages)	Not specified	Trainers: not specified Trainees: Learning disability psychiatrists	Questionnaires	Overall adequate	Trainees remained unaware of crucial aspects of legislation relevant to their profession
Lee-Foster, 2010	Case study (description and evaluation of a specific training programme)	One day face-to-face training. Toolkit and written assessment to embed knowledge	Trainers: not specified Trainees: Independent Mental Capacity Advocates	Telephone interviews and analysis of written assignments	Overall positive	None reported
Shah et al., 2010	Quantitative (pilot questionnaire, results presented as percentages)	Not specified	Trainers: not specified Trainees: old age psychiatrists	Questionnaire with free text	Not reported	Participants could outline their duties in relation to the principles and direction of the act
Pike et al., 2010	Case study	E-learning, plus face to face for key staff	Trainers: not specified Trainees: staff and volunteers in contact with vulnerable people in Cornwall	Description and analysis of local training strategy	Not reported	Trainers aware of need to include knowledge transfer and address workplace culture in future training
Willner et al., 2011	Quantitative (pre- and post-training quiz with statistical analysis)	Ten-minute presentation	Trainers: not specified Trainees: new recruits attending compulsory health organisation induction	True–false quiz	Not reported	Some improvements in knowledge after very brief training, but concerns identified about areas of weakness. Clinicians’ knowledge was not better than nonclinicians. Small increase in knowledge from pretest to post-test
Samsi, 2012	Qualitative (Thematic analysis of interview transcripts)	Conferences and training based on DH resources	Trainers: not specified Trainees: Admiral Nurses	Interviews	Not reported	Trainees could explain aspects of the act but did not feel confident about applying their knowledge
Gough & Kerlin, 2012	Qualitative (semi-structured interview analysed using grounded theory approach)	Classroom-based workshops	Trainers: not specified Trainees: care home workers	Interviews plus focus group with care home managers and deputies, key decision-makers	Delivery style not suited to care home workers needs	Not reported

(Continues)

TABLE 1 (Continued)

First author, date	Study design/ paper type	Training intervention	Trainers and trainees	Evaluation approach	Participant evaluation	Reported impact of training
Schofield et al., 2012	Quantitative (Statistical analysis of pre- and post-training assessments)	E-learning package, using vignettes for knowledge application	Trainers: not specified Trainees: trainee doctors and medical students (n = 49)	Pre- and postintervention tests	Not reported	Small but statistically significant improvement in MCA related knowledge, and improvement in confidence
Phair & Manthorpe, 2012	Case study (incorporating survey data, analysis of interviews and analysis of local policies)	Face-to-face theoretical teaching	Trainers: not specified Trainees: nursing and medical staff	Survey, interviews and focus groups	Not reported	Levels of awareness of the act varied. Many staff members were not confident in applying it.
Willner et al., 2013	Quantitative (pre- and post-training structured interviews with scored true/false questions, results subject to statistical analysis)	Lecture and advanced interactive, scenario-based workshop	Trainers: Two university lecturers Trainees: healthcare staff	Interviews with questions about "vignettes"	Not reported	Participants were sensitised to the need to assess capacity, rather than knowing how to do so. Confidence exceeded their measured knowledge.
Manthorpe and Samsi (2016)	Qualitative (thematic analysis of semi-structured interview transcripts)	In-house work-based training/ none	Trainers: not specified Trainees: care home workers	Interviews	Not reported	Limited recall of learning. Junior staff lacked confidence. Senior staff more knowledgeable and confident.
Marshall and Sprung (2016b)	Mixed methods (sequential exploratory design, Phase 1, an electronic online questionnaire, subject to statistical analysis, Phase 2 interview transcripts were subject to content analysis)	Mandatory two-hour trust training	Trainers: not specified Trainees: community nurses	Questionnaire and focus groups	Training perceived as rushed, "tick-box" and "dry."	None reported
Morriss et al., 2017	Quantitative (online questionnaire, results presented as percentages) focusing on psychiatrists and advance decisions to refuse treatment	Variety of types (e.g. used role play, training in advance decision-making, capacity assessment)	Internal (NHS) and external (Royal College of Psychiatrists, law firms) trainers	Questionnaire	Preference for external trainers, preference for role plays and discussion	Training had minimum impact on psychiatrists' attitudes and behaviour around advance decisions to refuse treatment. Training had minimal impact on MCA documentation
McCormick et al., 2017	Quantitative (online questionnaire, results presented as percentages, free text subject to thematic analysis)	Organisational training, 1–4 hr	Trainers: not specified Trainees: speech and language therapists	Questionnaire plus free text	Preference for profession-specific face-to-face training	None reported

(Continues)

TABLE 1 (Continued)

First author, date	Study design/ paper type	Training intervention	Trainers and trainees	Evaluation approach	Participant evaluation	Reported impact of training
Bose & McLiggans, 2019	Mixed methods (pre- and post-training questionnaires with multiple choice answers, Likert scales and open-ended questions subject to content and thematic analysis)	A 2-hour training session in decision-making and capacity	Trainers: Two 4th-year Speech-Language Therapy (SLT) students Trainees: 39 SLT students	Questionnaire plus free text	Very positive. Preference for interactive profession-specific training.	Improved accuracy in assessing decision-making capacity as evaluated (using video) immediately post-training. Self-rated improvements post-training in awareness, knowledge and confidence.

Marinis, 2017; Morriss, Mudigonda, Bartlett, Chopra, & Jones, 2017; Sawhney, Mukhopadhyay, & Karki, 2009; Schofield et al., 2012; Shah, Banner, Heginbotham, & Fulford, 2010; Willner et al., 2011, 2013) investigated training experiences (Sawhney et al., 2009; and Shah et al., 2010) or post-training knowledge of psychiatrists and medical trainees (other than Willner et al., 2011 and Willner et al., 2013, who surveyed newly appointed clinical and nonclinical staff members). Response rates tended to be low (27%–55%). Bias may also have been introduced due to self-selection (McCormick et al., 2017; Morriss et al., 2017).

Willner et al. (2011), Schofield et al. (2012) and Willner et al. (2013) tested knowledge post-training, which resulted in higher response rates. Using true/false statements and scored responses, all three studies found improved knowledge. However, Willner et al. (2011) noted positive bias towards "true" statements, which may have skewed their results. This bias may have affected the results of Schofield et al. (2012) in a similar way, but this study did not provide a detailed breakdown of the questions and responses. The quantitative studies measured knowledge and sometimes confidence, but did not report on retention of learning, knowledge transfer or practice change. However, the quality of the quantitative studies was fair to good scoring 23–34 on the Hawker et al. (2002) scale.

Qualitative studies (Gough & Kerlin, 2012; Manthorpe, Rapaport, Harris, & Samsi, 2009; Manthorpe & Samsi, 2016; Samsi, Manthorpe, Nagendran, & Heath, 2012) were conducted using structured or semi-structured interviews, with one study (Gough & Kerlin, 2012) also using a focus group. Participants were drawn from a wide range of health and social care backgrounds. Participant numbers ranged from 8–26. Participants expressed views which related to the nature of their own professional responsibilities, training experiences and localities, so findings may not be transferable. These studies scored between 19–36 on the Hawker et al. (2002) indicating generally good quality. We included three case studies: Phair & Manthorpe, 2012; Lee-Foster, 2010; and Pike, Indge, Leverton, Ford, & Gilbert, 2010. Case studies may be less rigorous in their methods because researchers are evaluating their own work or because the focus of the study is necessarily local and small. The Hawker checklist scores for these studies were poor to fair (13–27). Nevertheless, the in-depth detail and reflection on outcomes can mean conclusions are valuable, bearing limitations in mind.

There were two mixed-methods studies. Marshall and Sprung (2016b) used a questionnaire (response rate 17%, despite measures to encourage participation) investigating training outcomes and confidence, followed by interviews. The evaluation of this study using the Hawker checklist was also good (31). Bose and McFiggans (2019) used a questionnaire pre- and post-training, measuring knowledge, confidence and awareness, followed by open-ended questions post-training to gain feedback. All 39 training participants completed the evaluation questionnaires. This study scored 27 on the Hawker checklist.

3.2 | Training

Four studies directly reported on empirical research evaluating defined training programmes (Bose & McFiggans, 2019; Schofield et al., 2012; Willner et al., 2011, 2013). The remainder offered review of professional groups' knowledge of the MCA and training experiences and outcomes (Manthorpe et al.(2009); Sawhney et al. (2009); Shah et al. (2010); Willner et al. (2011); Samsi et al., 2012; Gough and Kerlin (2012); Schofield et al. (2012); Manthorpe and Samsi (2016); Marshall and Sprung (2016b); Morriss et al. (2017)).

Three papers report on profession-specific training (Bose & McFiggans, 2019; Lee-Foster, 2010; Schofield et al., 2012) and two (Willner et al., 2011, 2013) on mixed groups of trainees. Details of the nature of training and numbers of trainees are generally sparse. In several papers, the findings reflected a range of training types, in which training might have happened recently (Lee-Foster, 2010; Schofield et al., 2012; Willner et al., 2011, 2013) or up to 2 years previously (McCormick et al., 2017; Morriss et al., 2017; Phair & Manthorpe, 2012; Sawhney et al., 2009), in which case participants may have attended more than one training intervention. In three cases, MCA training was combined with training in related issues (communication (Lee-Foster, 2010), record-keeping (Willner et al., 2013), safeguarding and human rights (Pike et al., 2010)). Responses are varied and poorly reported.

4 | THEME 1: THE NATURE OF MCA TRAINING

Early training reported on an intervention which was at least partially based on resources provided by the Department of Health. These resources included information about the act and scenarios to illustrate points. Feedback indicated that this training was perceived as helpful. For example, social workers in specialised adult protection roles (Manthorpe et al., 2009) had experienced training based on these resources, together with a range of complementary training materials (online and face to face).

Practicalities varied with training taking place in the workplace, in training centres or online (either at work or at home). Length varied from 10 min as part of an induction programme to one or more days (Samsi et al., 2012). Most but not all training was reported to be mandatory, often with three yearly updates. Where reported, trainees preferred face-to-face, interactive, scenario-based training (Bose & McFiggans, 2019; McCormick et al., 2017).

4.1 | Positive reactions but lingering anxieties

Safeguarding leads (adult protection co-ordinators) were positive about their training but expressed anxieties about being expected to train others based on their own limited knowledge. They reported using additional resources to bolster their understanding (Manthorpe et al., 2009). This study was conducted soon after the legislation was enacted, so the participants were pioneers and would not have been able to find support from more experienced colleagues.

Mixed-profession MCA learner participants benefitted to some extent from the MCA training they received, with improvements found in most areas of knowledge (Willner et al., 2013) while specialist nurses seemed noncommittal, with the majority describing their knowledge as "fair" (Marshall & Sprung, 2016b). However, it is unclear to what degree a neutral or positive response to MCA training would result in adherence to the Act in real-world settings. Many participants described lack of confidence (Manthorpe et al., 2009; Manthorpe & Samsi, 2016; Phair & Manthorpe, 2012; Samsi et al., 2012), while others were sensitised to capacity issues, but unsure of how to implement the legislation (Samsi et al., 2012; Willner et al., 2013). As Willner et al. (2013) noted, confidence is not a reliable proxy for measuring competence. Participants in some studies (Schofield et al., 2012; Willner et al., 2013) may have demonstrated misplaced confidence while in others knowledge appeared stronger, but confidence lower (Manthorpe et al., 2009; Manthorpe, Samsi, Charles, & Heath, 2011; Marshall & Sprung, 2016b). However, Willner et al. (2013) noted that raising awareness of the legislation was a necessary first step, enabling future learning. Speech–language therapy (SLT) students in Bose and McFiggan's (2019) study reported greater awareness, knowledge and confidence. These qualities were identified immediately post-training so it is unclear whether the outcomes of training would be retained and applied in clinical practice postqualification.

Generally, the study authors conclude that participation in training improved knowledge but did not lead to corresponding improvement in application of the legislation, due to ongoing apprehension and lack of confidence. Subsequently, awareness of the limitations of training led to a reconsideration of learning approaches (Gough & Kerlin, 2012; Schofield et al., 2012; Willner et al., 2013). For example, Willner et al. (2013) suggested the role of training should only be to raise awareness, and then, online information should be complemented by access to an MCA expert, who would provide guidance and support.

4.2 | Misunderstandings and misapplications

Respondents in the 2009–2010 studies accurately predicted potential barriers to correct implementation of the MCA which were confirmed by later studies. Participants noted incongruence between the MCA and professional cultures and indicated that colleagues were unfamiliar with the legislation at the time (Manthorpe et al. (2009). Medical professionals outlined concerns about the workload of psychiatrists, delays in guidance and policy, potential misunderstandings about the nature of decision-making capacity and availability of local training (Shah et al., 2010). Trainees anticipated increased workload and feared legal implications of misinterpretation or unfamiliarity (Sawhney et al., 2009). These studies reported low response rates so conclusions might be interpreted with caution, but the doctors' fears were partially confirmed in other studies. Social care workers outlined how they would ask advice from senior members of staff, including doctors (Manthorpe et al., 2009) and multi-disciplinary staff post-training still believed capacity should be assessed by a psychiatrist (Willner et al., 2013).

Misunderstandings and misapplication of the MCA were noted in the majority of the studies. Staff lacked understanding of the definition of "capacity" (Gough & Kerlin, 2012) and how to assess it (Willner et al., 2013). Study participants often failed to abide by the principles of the act; they presumed incapacity (McCormick et al., 2017), deferred decision-making to seniors or other professionals (Manthorpe & Samsi, 2016; Samsi et al., 2012; Willner et al., 2013) and had potential to override "unwise decisions" (Willner et al., 2013). These findings may reflect limited understanding of the importance of promoting autonomy within the act and would have a disempowering impact on patients.

Some psychiatrists were reluctant (or would refuse) to discuss advance decisions to refuse treatment (Morriss et al., 2017). Nurses mistook "best interests" for a general person-centred approach (Manthorpe & Samsi, 2016) and care workers limited clients' choices (Manthorpe & Samsi, 2016). While professionals indicated that their approaches were motivated by their perceptions of patients' best interests, this willingness to override patients' choices was in conflict with the principles and guidance of the legislation and seemed to be driven more by embedded cultural beliefs of "doctor knows best," despite the empowering aim of the legislation (Jackson, 2018). For example, the above findings indicated that the right of a capacitous person to make decisions, regardless of consequences, had not been absorbed in training.

Less complex elements of the legislation also appeared to have been misunderstood. Participants were unaware of the two-step test (Willner et al., 2011). They struggled with best interests assessments (deciding what to do if making a decision on behalf of a person unable to do so) (Willner et al., 2013) and responding to fluctuating capacity (Marshall & Sprung, 2016b; Morriss et al., 2017). Phair and Manthorpe (2012) and Marshall and Sprung (2016b) reported poor awareness of advance decision-making processes and the designation of wilful neglect and ill-treatment as criminal offences, while Willner et al. (2013) identified that staff were unsure of when to involve an Independent Mental Capacity Advocate (a professional employed to contribute to decision-making for the "unbefriended") (Willner et al., 2013). These factors indicated that peoples' rights would be undermined and that training had little impact on practice change. This theme reflects, and perhaps to some extent explains, poor implementation of the legislation as identified by the House of Lords (2014).

Studies reported on a range of training approaches. Case studies (Lee-Foster, 2010; Pike et al., 2010) describe stand-alone initiatives, but make observations and share experiences that offer useful pointers for learning. Pike et al. (2010) considered the advantages and disadvantages of e-learning, concluding that it could be effective for developing basic knowledge and had benefits around flexibility and costs. They acknowledged disadvantages including lack of opportunity for discussion, poor digital literacy and inequality of access. The latter factors are supported in a recent study in which Manthorpe and Samsi (2016) identified that care home staff had not accessed available online training. Conversely, Schofield et al. (2012) found e-learning was effective for doctors and medical students. These differences may reflect access to and familiarity with technology, as well as other factors including the life-stage and family responsibilities of the participant groups and the time they would therefore have free for independent learning.

Gough and Kerlin (2012) suggest that training should involve real-life scenarios to assist practitioners in linking the legislation to their practice. Many of the papers described training in which the trainers had aimed to be creative, imaginative and challenging to engage the learners in working together or individually to solve problems using case studies or scenarios (Lee-Foster, 2010; Pike et al., 2010; Willner et al., 2013). For example, Lee-Foster (2010) developed a toolkit which participants applied to a real-life scenario drawn from their own practice and then discussed in a written assignment.

MCA training is not mandatory in all workplaces and this, together with its "stand-alone" presentation, may lead to an impression that the training is not important (Gough & Kerlin, 2012; Phair & Manthorpe, 2012). However, many of the studies reported that the MCA was taught in conjunction with related topics, including communication (Lee-Foster, 2010), record-keeping and consent (Marshall & Sprung, 2016b; Phair & Manthorpe, 2012), human rights, equality, diversity and safeguarding (Pike et al., 2010). Combining topics aided participants in understanding connections between the various aspects of their practice (Gough & Kerlin, 2012), but perceptions differ and others felt that MCA training had, unhelpfully, been "bolted on" to other topics (Phair & Manthorpe, 2012).

Some programmes used a "cascade" model, expecting trainees to then train colleagues (or at least influence their practice) and so embed the learning among their workplace teams (Gough & Kerlin, 2012), thus minimising costs of both training and the expense associated with providing replacements to fulfil trainees' roles in the workplace during their absence. Manthorpe and Samsi (2016) imply that a cascade model is congruent in workplaces with high staff turnover and hierarchical cultures. Gough and Kerlin (2012) concluded a top-down model is appropriate. However, the success of this approach is dependent on relevant staff feeling confident in sharing their knowledge. Senior staff were not always more knowledgeable on the topic than those they supervised (Marshall & Sprung, 2016b; Phair & Manthorpe, 2012) and under-confident practitioners were concerned about taking on these responsibilities (Manthorpe et al., 2009). This may have changed over time and vary across professions; speech and language therapists, for example, were keen to share their expertise (McCormick et al., 2017), and student SLT peer trainers received positive feedback (Bose & McFiggans, 2019). Therefore, it seems that knowledge transfer is dependent not only on competent, confident sharers of knowledge, but also the opportunity for those with knowledge to be heard.

5 | THEME 2: PROBLEMS IN CHANGING PRACTICE POST-TRAINING

Challenges in changing and sustaining change in practice were widely identified (Lee-Foster, 2010; Schofield et al., 2012;

Hinsliff-Smith et al., 2017), and some considered mechanisms for knowledge transfer. Two case studies demonstrated how training with follow-up activities designed to promote application in practice can be effective. Pike et al. (2010) identified difficulties with transferring safeguarding (procedures for the protection of people considered to be at risk) learning into practice pre-MCA and applied anticipatory strategies when planning MCA training. They highlighted concerns about the need for a facilitated experiential approach involving challenge of existing values and beliefs to promote reflection and enhance transfer of learning to practice. They integrated MCA training with safeguarding and human rights training to improve transferability and relevance for staff. Further steps to promote knowledge transfer included explicitly addressing the issue during training and encouraging completion of learning logs. These were designed to promote commitment to practice change and to focus conversations with supervisors. Pike et al. (2010) outlined the evidence, values and policy rationale behind a training approach yet to be evaluated. Learning transfer was successfully achieved using an assignment set post-training, together with a "toolkit" (Lee-Foster, 2010). These accounts offered detailed information on training design and suggested that training should be viewed as part of a process, embedded into organisations. While outcomes appeared positive, the information on research methods was limited and there is potential for bias in researchers evaluating the work of their own teams.

Noting the tentative and perhaps temporary nature of improvements in knowledge and confidence, many authors included recommendations for further strategies aimed towards ensuring application of learning, including clinical supervision (Gough & Kerlin, 2012; Schofield et al., 2012), supported follow-up with managers (Gough & Kerlin, 2012), in-house experts or "champions" to provide MCA guidance in practice (Willner et al., 2013), team meetings (Gough & Kerlin, 2012) and more training (Marshall & Sprung, 2016b; Phair & Manthorpe, 2012). Phair and Manthorpe (2012) suggested that MCA training should be combined with training in allied subjects such as communication skills, consent and DNAR (do not attempt resuscitation) training and be more relevant to clinicians' specialities. Consent and DNAR training relate to MCA training in that all promote autonomy and require respect of service users' decisions, some of which may be perceived as unwise. Phair and Manthorpe (2012) recommended promoting social media and Internet resources for learning and that staff should have annual updates. Willner et al. (2013) identified that staff preferred profession-specific scenarios in training, but argued that this would make release of staff more difficult. Phair and Manthorpe (2012) noted that nurses' confidence should be improved so that they could guide colleagues and identified leadership as a factor in improving practice, but cautioned against over-loading managers by ensuring clear shared responsibility. These findings appear to indicate that a range of support strategies may be required to promote learning retention and application of the legislation.

Even confident practitioners stated they would welcome extra training (Marshall & Sprung, 2016b), and Phair and Manthore (2012) reported that participants expressed preference for a range of prompts to be designed into their documentation, perhaps indicating insight into the difficulty of retaining knowledge. Manthorpe and Samsi (2016) report participants were often unable to recall what they learnt in training, an issue also noted by Marshall and Sprung (2016b). Pike et al. (2010) noted that training should not be perceived as a "one-off" but be considered a process. This was confirmed by Gough and Kerlin (2012) and Willner et al., 2013, who found that repeated training improves outcomes to some extent. Previous practice experience also seems to aid knowledge retention and confidence post-training (Marshall & Sprung, 2016b) and the opportunity to apply learning soon and often post-training appears to embed understanding more effectively (Willner et al., 2013).

5.1 | Institutionalised under-resourcing

Included literature points to brief training having limited impact on practice (Willner et al., 2011), but organisational factors led to difficulties in facilitating adequate training time. Gough and Kerlin (2012) identified barriers in health and social care environments that impede application of MCA training to practice, including staff turnover, costs of training and costs of replacing staff who are away on training. Gough and Kerlin (2012) noted that costs of releasing residential and nursing home staff are "prohibitive," while in the National Health Service Willner et al. (2013) found managers were unable to release ward-based staff for training. Medical practitioners identified high workloads as barriers (Sawhney et al., 2009; Shah et al., 2010). Pike et al. (2010) identified organisational change and the quality of staff supervision to be additional barriers.

5.2 | Hierarchy confidence and responsibility

Issues of power and authority could be seen to impact on application of the MCA in healthcare settings. Patterns of deference were mentioned in many of the studies. Care home staff deferred decision-making to senior carers and managers (Gough & Kerlin, 2012; Manthorpe & Samsi, 2016) and nurses and other staff deferred to doctors (Willner et al., 2013). Those with greater apparent power and responsibility found this uncomfortable or arduous (Manthorpe et al., 2009; Shah et al., 2010). Phair and Manthorpe (2012) found the knowledge base of matrons (nurse managers) was not strong enough to support clear guidance to colleagues. Social work safeguarding leads expressed concern about their additional responsibilities and impact on time management (Manthorpe et al., 2009). However, speech and language therapists wished to be consulted more often (McCormick et al., 2017) and expressed frustration at their perceived lack of power in contrast to that of a medical consultant. Marshall and Sprung (2016b) found nurses wished they had more confidence to enable them to challenge medical colleagues, who had more influence despite being less familiar with patients. In common with Marshall and Sprung (2016b), Phair and Manthorpe (2012) emphasised the personal responsibility of staff to update themselves, but dispute expectations that nurses should model good practice, acknowledging the difficulties of both finding time for learning and with challenging the practice of more powerful colleagues.

6 | DISCUSSION

This review identified 16 studies which used and evaluated a range of training interventions aimed at training health and social care professionals how to implement the Mental Capacity Act (Department of Health, 2005). Findings indicate that training is often poorly applied to practice and confirmed existing evidence suggesting that the legislation is not followed effectively (House of Lords, 2014) and that service users' autonomy is not respected (Taghizadeh Larsson & Österholm, 2014).

Factors which contribute to both obstructing and facilitating learning transfer were analysed in the process of data abstraction. The majority of included studies in the review provided evidence that MCA training has limited impact in real-world health and social care settings. While the studies were able to show that real-world application is poor post-training, strategies to demonstrate the opposite and evaluate successful ongoing compliance with the legislation would be difficult to design, given the many confounding factors and unquantifiable nature of training outcomes. Document audits, as conducted by Dunlop and Sorinmade (2014), could address formal recorded capacity assessment processes and evaluate compliance with other documented requirements, but would not have the scope to monitor everyday ethical decision-making carried out in practice. Proxy measurements including knowledge, confidence and testing application to scenarios were used to reflect participants' abilities to apply the legislation in practice (Bose & McFiggans, 2019; Lee-Foster, 2010; Marshall & Sprung, 2016b; Phair & Manthorpe, 2012; Schofield et al., 2012; Willner et al., 2013).

Understanding how the principles of the MCA are applied in practice seems more difficult than initial feedback on the clarity of the MCA seems to warrant. Training can be limited: most common is half a day's training every three years. Within this timeframe, trainees are required to understand not only the principles and how to apply them, but also the two-step test and mechanisms for different types of advance decision-making and the nature of new criminal offences. Further complications arise when service users have complex fluctuating conditions. On detailed assessment post-training, most participants have not retained all aspects, which means they would potentially be breaking the law and failing to uphold their service users' rights.

6.1 | Characteristics that improve training outcomes

This review focuses directly on MCA training and training outcomes, but uses some of the same sources and confirms some of Hinsliff-Smith et al., 2017 and Marshall and Sprung's (2016a) review findings, for example that the amount, quality, application and impact of training are limited, but that scenarios, when used, make learning more relevant to trainees. Marshall and Sprung (2016a) reviewed the literature around nurses' experiences of using the MCA. They identified 32 papers, seven of which are included in this review. Hinsliff-Smith et al., 2017 reviewed literature investigating application of the act. They identified 38 papers, six of which are included in this review. Both Hinsliff-Smith et al., 2017 and Marshall and Sprung et al. (2016a) conclude that improved training strategies are required to embed application of the act in practice.

Hinsliff-Smith et al., 2017 explored application of the act. In common with our review, they identified that training outcomes were not measured effectively and it appeared that knowledge was not retained so that learning could be applied. Marshall and Sprung's (2016a) review focused more broadly around the MCA; the current review aimed specifically at exploring outcomes of training. All three reviews found barriers to knowledge transfer. Hinsliff-Smith et al., 2017 suggested the problems lay within the training itself, and they considered that it was too theoretical and infrequent. Marshall and Sprung (2016a) noted barriers within the contexts of care, including paternalistic values. We suggest personal and cultural values and norms, including those related to inter-professional relationships, may impede knowledge transfer.

Training is most effective in situations when the trainee has the opportunity to apply learning soon after training. When the trainee has previous experience, training reinforces it, as does applying the act immediately after training. Within training, realistic, complex and challenging scenarios that relate to the trainees' own practice dilemmas appear to be significant in facilitating application of learning to practice. Learning through application is central to ensuring the legislation is upheld by practitioners (Willner et al., 2013) and ongoing supervision aids this process (Gough & Kerlin, 2012).

6.1.1 | Resource factors

Training is expensive (Gough & Kerlin, 2012), and with universal cuts to budgets across services (Lipley, 2018), there are scarce funds with which to pay for release of staff, cover for colleagues and the costs of a trainer and training space (Smythe, Jenkins, Galant-Miecznikowska, Bentham, & Oyebode, 2017). Studies that reported on a cascade model, designed to save money, found the "champions" and staff managers were not sufficiently knowledgeable or competent to take on the role of leading learning about the MCA (Gough & Kerlin, 2012; Phair & Manthorpe, 2012).

Online learning is perceived as a cheaper option which is open to all (Gough & Kerlin, 2012). However, not all health and social care practitioners have Internet access, they do not always find online learning effective, nor are they willing to complete online learning in their nonworking time (Smythe et al., 2017; Wu, Chan, Tan, and Wang, (2018). While benefits of online learning include flexibility and convenience, together with savings related to staffing levels and funding (Wu et al., 2018) ethical issues arise as the time-related costs have often been passed on to the nurses. Managers of under-staffed organisations with high levels of staff turnover are reluctant to fund more expensive classroom-based learning for employees who may soon change workplace (Gough & Kerlin, 2012). Phair and Manthorpe (2012), Marshall and Sprung (2016a) and Marshall and Sprung (2016b) reiterate registered professionals' responsibility to keep themselves updated. However, in the context of health and social care staff who often work unpaid overtime, it has been argued that the responsibility for MCA learning should not lie with the individual (Goodman, 2016).

6.1.2 | Cultural factors

A strong values base within a professional identity may lead to ethical and practical dilemmas for professionals. Social workers share commitment to promoting social justice and challenging oppression (Chechak, 2015) but despite this may get drawn into risk-averse practice (Murrell and McCalla (2016). Health professionals are recruited partly for their caring values (Foster, 2017) which may mean they are more naturally orientated towards "beneficence" rather than promoting autonomy in their relationships with service users. For example, despite increasing attention to the importance of family-based care and decision-making, practitioners continue to make paternalistic decisions on behalf of patients based on their feelings about what is best (Giles, Lacey, & Muir-Cochrane, 2018) . Aspects of the MCA require students to "unlearn" outdated responses to decision-making (e.g. around duty of care dilemmas) while also potentially transgressing personal and professional values that prioritise taking care of others. Some nurses, even those working in specialised areas caring for people with intellectual disabilities or dementia, struggle to limit their protectiveness towards people they perceive as vulnerable (Marshall & Sprung, 2016a). Nurses and care workers retreat from confronting this conflict in values and resolve this emotional discomfort by emphasising the person-centredness of their relationships with patients. In retreating to practice based on misunderstanding of "best interests," they risk the legal ramifications of failing to promote service users' autonomy. Short-cutting the processes of assessing capacity and following the five principles of the MCA (which promote a person's preferences over other cultural and personal values) result in illegal practice which short-changes individuals' rights to self-government.

Authors' suggestion of additional strategies to embed learning may reflect implicit acknowledgement not only of the limited nature of most training interventions but also of the nonconductive nature of practice environments to accepting and promoting the spirit and directives of the MCA. The culture of the health service is described as "paternalistic and risk averse" (Marshall & Sprung, 2016b:409). Review studies confirmed this statement (Manthorpe & Samsi., 2016; McCormick et al., 2017; Morriss et al., 2017; Willner et al., 2013), indicating that outdated underpinning cultural values and norms may need to be challenged and addressed to facilitate correct application of the MCA.

It is apparent that a wide range of factors, in addition to the quality and frequency of training, contribute to the difficulty of applying the MCA correctly. These factors are structural (under-funded organisations, low staffing levels, high staff turnover), cultural (hierarchical professional relationships, disempowered staff) and personal ("beneficent" rather than autonomy orientated values). Inability to comply with legislation not only disadvantages those whom the legislation is designed to empower, it means individuals and organisations are acting unlawfully and so are open to legal consequences.

Limitations

While the authors followed guidelines on achieving a comprehensive search, it is possible that not all evaluations of MCA (Department of Health, 2005) training have been reported or published in peer-reviewed journals. Our review process aimed to minimise risk of bias, but despite this it is possible that some bias occurred. A team approach using independent perspectives was used to promote objectivity.

Although this review focuses on legislation that applies in England and Wales, it has relevance internationally because of global legislative changes following the CRPD directive. Therefore, the implications for capacity legislation training design and evaluation are transferable.

7 | CONCLUSION

This review is the first to explore and evaluate the range of training available for health and social care professionals who need to comply with the MCA (Department of Health, 2005) to empower service users. The review authors discussed the contextual and cultural barriers to achieving successful implementation of the legislation, considering how under-resourcing and hierarchical professional relationships may undermine application of the legislation. Successful knowledge transfer and subsequent impact for people who may require support with decision-making will be dependent on development of professional relationships which empower practitioners with the confidence to advocate effectively for the rights of others. Further research is required, to explore the factors within the care environment that may constrain or facilitate application of learning from MCA training.

8 | RELEVANCE TO CLINICAL PRACTICE

NICE, 2018 suggests that further qualitative studies are required to explore the nature of effective training and the barriers to compliance with legislation following training. This review indicates that these barriers may lie partly in the culture and context of clinical practice in which the MCA is implemented. The under-resourced, hierarchical culture of health and social care environments may be impediments to correct implementation of the law. In addition, we argue that holding individuals responsible for poor practice and self-education in these circumstances is unjust. Nevertheless, the MCA is legislation and complying with it is not optional. Training recommendations should be considered in tandem with ensuring an adequately resourced, mutually supportive workplace.

As part of this culture change, identification as "learning organisations" would emphasise the key importance of the nature of the workplace in knowledge transfer for effective practice. Our findings indicate that MCA training should be interdisciplinary and face to face, involve realistic, challenging scenarios and be further embedded in practice using support from "champions." Expected training content is outlined in the recent NICE (2018) guidance. While we agree with recommendations for further research to explore best practice in training for use of the MCA, we suggest that the impact of any training is also dependent on positive changes in the workplace.

CONFLICT OF INTEREST STATEMENT

The authors report no conflict of interest.

AUTHOR CONTRIBUTIONS

Study design: CJ, FC; data collection and analysis: CJ, FC, NW, AS; and manuscript preparation: CJ FC, NW, AS.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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ORIGINAL ARTICLE

Exploring newly qualified nurses' experiences of support and perceptions of peer support online: A qualitative study

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Abstract

Aims and Objectives: To explore newly qualified nurses' support needs and their perceptions of online peer support.

Background: The experience of being a newly qualified nurse is stressful and isolating. Support from colleagues and peers can enhance perceptions of competence and confidence in newly qualified nurses, improve well-being and aid retention. However, despite initiatives such as preceptorship, support needs may remain unmet in busy clinical environments. Online support has potential to offer a partial solution to professional isolation, but there is a lack of research into how technology can support nurses' emotional and social well-being.

Design: A qualitative exploratory study was designed, employing semi-structured focus groups, analysed using thematic analysis. The study is reported in accordance with the COnsolidated criteria for REporting Qualitative research checklist.

Methods: Eight focus groups, supplemented by one individual interview, were conducted with newly qualified nurses between June 2018–January 2019.

Findings: Two main themes arose. The first was *Drowning, a lot of the time* with two sub-themes: (i) Feelings and emotions about being a Newly Qualified Nurse: 'Absolutely terrified' and (ii) Support within the role: 'Somebody you can count on'. The second was Potential advantages and disadvantages of online modality: 'Somebody is going to get in that phone!' which included three sub-themes (i) Potential advantages, (ii) Potential disadvantages and (iii) Preferences and recommendations.

Conclusions: This study demonstrates that if barriers can be overcome, then online support has potential to contribute to newly qualified nurses' well-being. Further research is needed to explore technical and ethical issues around online support and evaluate its effectiveness for newly qualified nurses.

Relevance to clinical practice: Online support has the potential to add to existing strategies to support nurses during stressful times. This may be particularly relevant when many staff are working under increased pressure due to the COVID-19 pandemic.

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KEYWORDS
nursing workforce, psychological well-being, qualitative study, resilience, role development, stress, support

What does this paper contribute to the wider global clinical community?

- Formal support mechanisms such as preceptorship have benefits, but do not address all the needs of NQNs
- Appropriate support is essential to improve the well-being and retention of NQNs,
- Online support can supplement existing support strategies for nurses
- Concerns about confidentiality and protecting their professional registration are barriers which may limit NQNs' use of online support
- Online peer support may be particularly relevant when many staff are isolated and working under increased pressure due to the global COVID-19 pandemic

1 | INTRODUCTION

The difficulty of retaining nursing staff is a global issue (World Health Organisation [WHO], 2020). The WHO recognises these challenges and has recommended strategies to improve working conditions, to retain and motivate nurses (WHO, 2020). Alongside changes, such as ensuring fair pay and safe staffing levels (WHO, 2020), alternative means of providing emotional support to newly qualified nurses (NQNs) are essential to reduce the impact of workplace stressors and to facilitate NQNs' development into confident practitioners with sustained commitment to the profession. In this first phase of a larger study, exploratory focus groups were used to explore NQNs' perceptions, experiences and feelings about their role and about online peer support for emotional and social well-being, with the aim of informing development of an online peer support intervention.

2 | BACKGROUND

NQNs may be supported in their roles through a range of transitional support programmes, such as preceptorship, although this provision is not universal (Doughty et al., 2018). Although such programmes result in increased confidence and lower attrition (Doughty et al., 2018), they do not always offer the level of support needed (Hussein et al., 2017) and retention among NQNs remains a problem (Gardiner & Sheen, 2016). Nursing involves multiple challenging experiences (Steege et al., 2017) and the transition to qualified nurse status can be overwhelming (Wildermuth et al., 2020), with metaphors like 'being thrown in the deep end' used to express the experience (Hussein et al., 2017). When support is most needed, colleagues may undermine the confidence of NQNs through rudeness or even bullying (Read & Laschinger, 2013). Consequently, NQNs may be vulnerable to early career burnout and are at particularly high risk of leaving the profession (Gardiner & Sheen, 2016; Health Education England, 2014; Maslach & Leiter, 2016). Inadequate support during transition into their new role also has associated costs to NQNs' mental health and quality of care and can impact employing organisations in terms of turnover (Webster et al., 2019). Preceptorship programmes address these problems to some extent (Whitehead et al., 2016). However, as they are not accessible to all, additional interventions are required to support NQNs for their own well-being and because of the implications for quality of care and workforce retention.

This study was conducted prior to the COVID-19 pandemic, which is experienced by nurses as extremely stressful and anxiety–provoking (Shaukat et al., 2020). There has rarely been a greater emphasis on the importance of emotional and social support for self and colleagues (Cartwright & Thompson, 2020; Lai et al., 2020). Support from colleagues can mitigate workplace anxiety (Croke, 2020), improve quality of care and result in improved job satisfaction for nurses (van der Heijden et al., 2009). The nature of support varies according to who provides it. Whilst mentoring support from senior staff is valued (Maryniak et al., 2017), more egalitarian relationships between junior colleagues can foster support in a qualitatively different manner due to the shared nature of their experiences (Green et al., 2014). However, no formal mechanisms of peer support have been identified in the literature (Webster et al., 2019; Mansour & Mattukoyya, 2019).

Nurses are familiar with online learning (Morley, 2014) and younger nurses may prefer it (Mollica & Mitchell, 2013). However, a scoping review (Webster et al., 2019) found no evidence that online support for nurses had been provided or evaluated, despite its widespread use in nurse education and with patient groups. A scoping review concluded that technology-facilitated support for nurses may help to promote their emotional and social well-being, but further evidence is required (Webster et al., 2019). Accessible smartphone technology and associated applications ('apps'), such as WhatsApp and Facebook are used informally by patients (Ganasegeran et al., 2017) and within friendship and professional groups (Morley, 2014), allowing timely exchange of information and mutual emotional support. Webster et al., (2019) found two studies indicating benefits: smartphone messaging improved well-being by offering social connection and emotional release for nurses in the Philippines (Bautista & Lin, 2017), whilst social media apps enabled support for rural midwives in South Africa (Chipps et al., 2015). During the COVID-19 pandemic, health care professionals have increasingly worked through Microsoft Teams as a form of communication and for informal support. Exploration of grey literature found peer support helped social workers cope with stress at work and improved retention (Meier, 2000). This study aimed to explore nurses' support needs and perceptions of online peer support, to address a gap in the literature and inform design of an online peer support intervention.

3 | METHOD

The study aimed to explore NQNs' perceptions of online peer support. An interpretive phenomenological approach was adopted as we were aiming to understand the lived experience of newly qualified nurses (Coule, 2013; Lincoln & Guba, 2011). In line with this epistemology, we used an exploratory qualitative methodology. The researchers adopted an open stance and aimed to be sensitive to the significance of the phenomena. We employed focus groups to gather data, using phenomenological principles by putting aside our own assumptions, questioning pre-understandings and adopting a reflective attitude (Sundler et al., 2019). A strength of this method of data collection is that it promotes interaction with others, which can be empowering and lead to richer accounts (Coule, 2013). Inductive thematic analysis was used to analyse the data (Braun & Clarke, 2014).

3.1 | Participant selection and sample

We used convenience sampling (Etikan et al., 2016). Participants needed to be NQNs working in NHS Trusts, who were not more than 18 months post-qualification. They were recruited from one large acute NHS Trust and one large mental health NHS Trust in a large conurbation, via contact with facilitators of preceptorship programmes offered by their employers. A participant information sheet was emailed to the facilitators, who forwarded it to preceptees in advance of their next preceptorship meeting. Participants were then approached face-to-face on the day of their meeting and given a paper version of the participant information sheet prior to a break. Those who chose to take part returned after the break to join a focus group. The preceptorship meetings and, therefore, also the focus groups were conducted at the participants' workplace.

Approximately half of those approached and all who consented took part in the study. The sample consisted of 25 registered mental health nurses (RMN) and 18 registered general nurses (RGN). Thirty-nine (91%) were female and participants were diverse in age and ethnicity.

3.1.1 | *Data collection*

Eight focus groups were conducted between June 2018–January 2019, each lasting about 45 minutes. In addition, one participant was interviewed on a one-to-one basis as she could not join the focus groups but was very keen to take part. Participants were assigned to a focus group based on their professional registration (adult or mental health nursing) and Trust preceptorship allocation. There were between two and eight participants per group. The focus groups were facilitated by a nurse researcher and a research assistant with a psychology degree. Both were female, with training in qualitative methodology at Masters level. They had no relationship with participants prior to the study. Participants were aware that the study was funded by the Burdett Trust for nursing, with the aim of improving retention. The interviewers explained that a previous study on nurses' well-being had raised their interest in workforce issues.

To foster trust and maintain a high level of confidentiality, minimal demographic information (gender, length of qualification, professional registration) was obtained at the start of the focus groups. A semi-structured focus group guide with prompts, was then used to initiate discussion (Table 1). The guide was based on findings from a literature review (Webster et al., 2019). Key topics included experiences, perceptions and preferences relating to online support. The focus groups and the single interview were audio-recorded, transcribed verbatim and anonymised. After reflection on the transcripts of the two initial focus groups, some questions were modified by two members of the research team, so that the guide aligned better with the research aims. Further focus groups were conducted until data saturation was achieved. Due to time constraints transcripts were not returned to the participants. Field notes were recorded following each focus group.

3.1.2 | Analysis

Inductive thematic analysis, supported by NVivo version 12 (QSR International, 2018), was used to analyse the data. This followed Braun and Clarke's (2006) six stages of becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining themes and writing up. Transcripts were initially coded independently by three members of the study team followed by discussions with an additional two members of the study team to gain consensus on the emergent themes. To ensure trustworthiness and reflexivity, the research team shared analysis of the data in regular meetings. The team included members from a range of professional backgrounds, all with experience in qualitative analysis. To enhance credibility, particular attention was paid to negative cases during the analysis (Bitsch, 2005) and the COREQ (COnsolidated Criteria for REporting Qualitative research) checklist (Tong et al., 2007) was used in reporting the study to demonstrate rigour, credibility and transparency. (Please see Supplementary file 1).

TABLE 1 Interview guide

1. What is your understanding of peer support?
2. For how long would you consider a nurse to be 'newly qualified'?
   a. What are some advantages of this label?
   b. What are some disadvantages of this label?
3. Can you tell me about some times when you have supported your peers or when your peers have supported you? What were these experiences like?
4. What experiences do you already have in online peer support? (e.g. WhatsApp, Facebook)
5. What are some of the positive features of online communication? How about negative aspects?
6. We are proposing an online peer support group for nurses who have completed their preceptorship.
   a. How might this be useful?
   b. Would you use it?
   c. When might you access it? (e.g. time of day / at work or home)
   d. How might you access it? (e.g. mobile or PC)
7. What potential problems could you foresee in accessing an online peer support group?
   a. What barriers might there be to you using an online peer support group?
8. What ground rules would be essential in an online peer support group?
9. Are you comfortable admitting to not knowing something at work?
   a. How easy is it to talk about errors as a nurse; particularly one who is newly qualified?
   b. Could you share such concerns in a confidential space online?
10. What are your thoughts about being identified in a closed and secured online peer group?
    a. What considerations would there be around remaining anonymous?
    b. What issues could there around using first names?
    c. What would you prefer?
11. What features are important in an online peer support group?
    a. How would you feel about a report function in the peer group and how might this operate?
    b. If we were to set up alerts for certain words what do you think these should be?
12. How often do you think the research team should moderate or visit the forum?
    a. What would you envision a moderator's role to entail?
13. Is there anything else you would like to talk about that you feel is important?

Thank you for taking part in this interview

3.2 | Ethical considerations

The written information sheet included the reasons for conducting the research and details on confidentiality and privacy. It informed potential participants that participation was voluntary and they were free to withdraw from the study at any time, without providing any explanation. Written informed consent was obtained from all participants. Ethical approval was received from the UK Health Research Authority on the 2nd May 2018. IRAS Project ID 241205.

3.3 | Findings

3.3.1 | Themes

Two main themes arose from analysis of the data. *Drowning, a lot of the time*, which had two sub-themes, and *The potential advantages and disadvantages of online modality: 'Somebody is going to get in that phone!'* which had three subthemes.

Drowning, a lot of the time…

This theme captured NQNs' experiences in their role and included two subthemes: *Feelings and emotions about being an NQN 'absolutely terrified'*, and *Support within the role*. This theme captures the feelings that indicated significantly more support was needed and that existing preceptorship programmes were not meeting all the needs of the nurses.

3.3.2 | *Feelings and emotions about being a NQN 'Absolutely terrified'*

The role of NQNs was discussed in seven of the eight focus groups. Content illustrated anxiety relating to the role of NQN. One nurse described feeling as if she was *'drowning, a lot of the time'* (P1, FG2). Another *'felt absolutely terrified'* (P2, FG3). In the example below, the quote reflects a sense of reality dawning:

> [I thought she was] like a drama queen, it can't be that bad. But when you qualify you realise, yeah, it's quite bad.
>
> (P1, FG9)

Some nurses described feeling as if they were play-acting, *'playing at being a nurse'* (P2, FG7), and found it hard to accept that they had achieved the new status of NQN, as here: 'There's still that, "Oh God I really am, I have really done this now, I am what I am."' (P1, FG2).

For many of the nurses, anxiety appeared to reduce over time, as they became familiar with the role:

> It’s a bit of an evolution how you’re feeling. At the beginning there is that anxiety. You are a bit out your depth, you realise the weight of the role. But every day you go to work and every day you learn something else. All the time you just build up, basically to the point when you’re not having to turn to colleagues much for answers. You know what steps to take yourself.
>
> (P5, FG2)

However, this was not the case for everyone. One nurse explained how it was *‘easier’* as an NQN than as a more experienced nurse because the “]’*weight of expectation grows as you become more experienced.’* (P3, FG2).

Over time it seems that generally the nurses adjusted as they became familiar with the demands of the role.

3.3.3 | *Support within the role: ‘Somebody that you can count on’*

This theme reflects the strategies and experiences of the NQNs as they attempted to navigate support for the early stages of their careers.

They described trying to identify *‘who was the right person to ask on the ward’* and navigate *‘the different personalities’* (P1, FG3). Where available, support from colleagues helped to relieve their anxieties:

> So very, very knowledgeable staff members, [are] taking us, as newly qualifieds, beneath their wing, which is really nice because, when it's getting hard, you always have somebody that you can count on, you know, ‘Did I do this okay, did I do this right?’, or they will give you feedback before you're even asking them, which is really nice and comforting.
>
> (P1, Solo Interview)

However, some participants described feeling challenged and unsupported by their team: *‘It's like she was just waiting for me to make a mistake and just give it to me, so I would go home really frustrated and even to a point of not wanting to go back to work.’* (P2, FG7) This lack of support meant that some of the NQNs felt it was difficult to ask for help as this risked leaving them feeling exposed to the expectation that *‘they needed to know everything now’* (P2, FG5).

The time needed for confidence to develop was not always recognised by experienced staff and this placed extra pressure on NQNs to perform perfectly:

> I don't mind being the leader, but people will actually put me in that situation of, ‘You're the qualified, you should know this.’ And I'm like, ‘Well, I literally qualified 3 weeks ago!’ So that kind of makes you nervous because I always have to be perfect. I’m always [thinking] ‘I'm not allowed to make mistakes’, so that's what makes it hard.
>
> (P1, FG3)

This was exacerbated by pressures on the ward, which limited opportunities to seek support and develop skills:

> It’s having a high workload really and not being able to do everything, and then having to get other nurses to do things that you’re not competent at yet …. and worrying you’re not going to get everything done
>
> (P3, FG9)

As they became more experienced, respondents spoke about how they were able to help other NQNs who joined the team. This helped some to recognise their own newly acquired confidence:

> When I first started, I was the only newly qualified nurse, but now some other fresh from uni newly qualifieds have come up, and it’s nice to see how I’ve progressed in myself as well and what I’ve learnt. But because I do completely get where they’re coming from. It’s nice to be able to support them and [say] ‘No, it’s okay, no one expects you to know everything, we all completely understand.’
>
> (P5, FG6)

With experience, support and time, the NQNs progressed from feeling anxious and incapable to being confident and able to both recognise their own progress and support that of others.

The potential advantages and disadvantages of online modality for peer support: ‘Somebody is going to get in that phone!’

This second theme reflected the nurses’ perceptions of online peer support and included three subthemes: *Potential advantages*, *Potential disadvantages and barriers* and *Preferences and recommendations*.

3.3.4 | *Potential advantages*

Participants in most focus groups spoke of potential advantages of being able to access an online support forum, related to benefits of connecting with other NQNs and 24-hour accessibility. The most fundamental perceived advantages were linked with the fact that the proposed online peer support forum would include others like themselves, who were also newly qualified. In several focus groups, the nurses mentioned that they would be able to ask for support from peers for issues that they might have felt foolish to raise with more experienced nurses. The context of relating to peers meant they would feel more able to express uncertainties or worries without being judged as incapable or over-anxious: ‘*I don't think you're so scared to ask questions when it's with your friends because you're all at the same point in time and stuff. It's not like anyone would think, “Oh, why did you ask that?”*’ (P2, FG3).

Participants spoke of feeling greatly reassured by the feedback received in past experiences of this sort of forum. It indicated that the worries they had were recognised by others and this helped them feel that they were part of a supportive group:

> It's great if, you know, you think, ‘Ooh, I don't know about this’, and you put it up, or ‘This happened today’ or ‘I'm feeling really- crap…does anyone else feel like that?’ And then you get all this support back.
>
> (P2, FG5)

Additionally, individuals, who belonged to a forum but who did not actively participate, described gaining social and emotional support by observing other nurses interacting and discovering they were not alone:

> Even if you don't post something yourself you can see what other people post. ‘Oh, actually I'm in the same boat as them’ and what people say about their experience, I can relate it back to myself because I'm in the same situation, and reading the comments and that and they're like, ‘Oh now I know what to do’.
>
> (P1, FG5)

Another potential advantage related to the accessibility of social media. NQNs in a number of focus groups felt this was a natural way for their generation to communicate. Forums were seen as giving access to a wider support network than would have been possible without them. One participant spoke about staff turnover on wards, which, when combined with frequent use of agency staff, meant that it was hard to develop consistent supportive relationships with their immediate ward-based team. In this context, an online forum could be a substitute. Another nurse was aware that, if she took work issues home with her, friends and family were burdened by listening to her but she felt nurses in a forum would be more understanding and sympathetic, so she would be able to offload to them:

> I just think it’s good to talk about it because sometimes you just feel so alone. You’ve had a really horrible shift and it’s just been crap and you just want to talk about it, and sometimes I go home and I talk to my husband my mum and sometimes, you can tell they are bored.
>
> (P2, FG9)

24-hour access to online support across settings was seen as beneficial, with this being placed in the context of limited supervision time. Furthermore, an online forum could be accessed with ease, when nurses had time and means to do so.

3.3.5 | *Potential disadvantages and barriers*

All the focus groups highlighted concerns or limitations regarding the provision of online support for NQNs. These tended to overshadow perceived advantages. Significant disadvantages were associated with the potential for misunderstanding and misinterpretation in social media posts on platforms such as Facebook, Instagram and Snapchat. Concerns were also voiced about the psychological impact of negative online interaction, and about professional boundaries being breached, especially in relation to confidentiality. Some barriers related to technicalities of accessing online support and finding time to use it. It was also felt that it could be hard to maintain motivation to use an online forum, especially if it became a forum for complaint and negativity with one person saying: ‘*It might just be a bundle of negatives rather than positives.*’ (P3, FG8).

The most significant drawbacks seemed to relate to anxieties around sharing information. A number of focus group participants discussed reservations about expressing personal worries with people they did not know, and some thought face-to-face contact would be preferable:

> I don’t know how comfortable I would feel talking to someone who I didn’t know, or I didn’t know what they looked like or anything like that. I think when you talk about things that you’ve gone through at work that have upset you or quite emotional things, I think it’s better to do face-to-face rather than online because then you can get some support, I think, more genuinely than you would perhaps over an online social network.
>
> (P1, FG8)

Despite the online forums allowing for anonymity, there were many concerns expressed around the potential for being misunderstood.

> And in your mind, when you are typing it, it's professional, it's fine, there's nothing to it, ‘I only meant this’. What you think the meaning is completely different from what [someone reading it might think] because they're looking at it from a different angle.
>
> (P4, FG5)

Communicating online was viewed as something that would inhibit expression, resulting in superficial discussion. Another participant went on to talk about how careful he/she is when posting online:

> I'm very mindful when I do post something, I'm making sure that I'm politically correct in what I'm saying. I try and make sure what I say is taken in the context of how I'm saying it. I mean sometimes, if I post something, I'll type it out then I'll read it again, and then I might delete a bit.
>
> (P2, FG5)

There was also a fear that posts might break confidentiality, whether these were about a clinical situation involving a patient, or how to resolve an issue connected with another member of staff. Some respondents worried this could result in perceptions that a person had acted unprofessionally, with a fear of losing their professional registration: '*In a group chat saying, "I had this patient today, they died, they had this wrong with them", and then you lose your phone. That's patient identifiable information.*' (P2, FG8).

It was also feared that voiced concerns might not lead to a sympathetic response and that unconstructive discussions might get out of control:

> That fear of the unknown. You don't know what response you're going to get from everybody else and it's kind of about judgement. Are they going to completely disagree and completely have a go at me or are they going to be supportive?
>
> *(P3, FG4)*

3.3.6 | *Preferences and recommendations*

In light of the perceived advantages and disadvantages, participants were asked for their preferences around a proposed system of online support. A number of suggestions were made, with differences of opinion apparent around the best way to proceed. In terms of size of peer group membership, opinions were mixed with some suggesting about ten participants would be an appropriate size, because small groups may be easier to contribute to: '*I think when there's a bigger group, people sort of go off topic and start talking about all sorts of things. It's probably harder to talk in the group than a smaller group.*' (P5, FG4).

However, it seemed that some were in favour of forums being larger than this, so that it would be more likely someone would relate to the issues raised by individuals:

> I think if it was open up to more people. If it's just someone you know they might not be going through the same things but if there's loads of people there's someone else wh o might have been in the same situation and can help you.
>
> (P5, FG8)

There was a diverse range of views regarding anonymity. Some felt they wanted to be completely anonymous, as here, where the participant was speaking of the associated embarrassment of asking for help: 'I probably wouldn't want to know the people. I think sometimes I would want somebody like a complete outsider that I don't know at all to help a little bit.' (P5, FG9).

Others proposed a face-to-face meeting of participants would be a helpful way of engendering trust at the start: 'So the groups to meet at least so that you can know who you are talking to.' (P2, FG7).

Participants were asked if it would be helpful for a forum moderator to introduce topics that might be relevant and again, there were mixed views. Some were in favour, as here: 'I feel like you need you guys to be sparking topics anyway because people will get notifications then it will spark more interest, people will be thinking more.' (P5, FG6), whereas others felt this would impede the flow of exchange: 'Might make it seem a bit forced, like more you're forcing conversations than just letting them happen.' (P7, FG8).

This theme was characterised by opposing and mixed reports. While online support was recognised as having potential for becoming a useful intervention, the nurses could also foresee pitfalls and were wary of further stress that might arise due to this format.

4 | DISCUSSION

It has been widely recognised that working as an NQN can be stressful and overwhelming. NQNs are exposed to high levels of responsibility, heavy workloads and both time and staff shortages (Edwards et al., 2015; Mabala et al., 2019). The qualified status appeared to lead to the NQNs feeling they were imposters, acting the role of nurse. This is a common theme in the wider literature (Masso et al., 2019). A large study conducted by Christensen et al., (2016) with nurses from Australia, New Zealand and the UK identified a direct correlation between the severity of imposter syndrome and feeling unprepared. Our findings confirmed those of these recent studies, indicating that nurses struggle during the transition period.

Our findings revealed that as participants became more familiar with the role, their confidence grew and anxiety lessened. Kramer (1974) first coined the term 'reality shock' to describe how a professional may feel when unprepared for a new role. Three stages of reality shock have been proposed: 'Doing', 'Being' and 'Knowing'. The final stage of 'Knowing' is synonymous with 'being able to answer questions instead of always asking them and finding the time and energy to assist others with workloads, instead of being consumed solely with one's own signs of progress (Duchscher & Windey, 2018; p. 231). This is congruent with our findings that once they became more experienced and grew in confidence, the NQNs were able to support newer colleagues. Peers also appeared to feel more able to express uncertainties or worries to other NQNs, without fear of being judged as incapable or over-anxious. Thereby supporting research which shows support can be especially beneficial where hierarchical differences are less apparent (Göktepe et al., 2020).

Some NQNs in the focus groups spoke of facing unrealistic expectations from more senior nurses, alongside a lack of support and guidance. There was limited recognition of the NQNs' novice status. In a recent literature review, Masso et al., (2019) commented that nurses are the only health professionals expected to be the 'finished product' after completion of their initial training. One consequence of unrealistic expectations was that the NQNs felt under pressure to appear professionally confident, even though at times they felt very unsure of themselves, as also found by Bjerknes and Bjørk (2012).

The NQNs described how they navigated their new role, working out which of their colleagues was likely to be the most helpful. In a qualitative study exploring the experience of NQNs, Kelly and Ahern (2009) found that final year students held very positive perceptions about their future role as registered nurses and what this would involve. However, after qualification, the students encountered a nursing culture in which closed groups or cliques excluded them. This was echoed in our findings. The NQNs were unprepared for the limited assistance with unfamiliar tasks they received from other registered nurses. In a literature review of NQNs' experience in the UK, Higgins et al., (2010) found that transition into the role was often difficult due to lack of support and preceptorship. NQNs may experience significant workplace stress and even bullying. This has led to the unfortunate turn of phrase 'nurses eat their young' becoming commonplace (Gillespie et al., 2017) referring to the frequent bullying within NHS organisations. However, after overcoming initial challenges, many nurses reported successfully transitioning to the role of NQN. Previous work has identified several individual characteristics essential to a successful transitional period for NQNs. These include increased resilience, competency, problem-solving and decision-making skills (Baumann et al., 2019). Our findings suggest the environment is also hugely influential. Where settings are busy and/or existing staff are not understanding, transition becomes particularly difficult. In this context, NQNs were willing to consider potential benefits of an online support environment. They were familiar with online communication through social media and learning platforms and comfortable with their use for information sharing and mutual support. However, it would be wrong to assume that all nurses are comfortable using technology, as even some from the 'digital native' generation (Koivunen & Saranto, 2018) expressed reservations about accessing resources or communicating in an online environment.

The benefits of peer support groups in general, including having things in common with group members, receiving support and feeling empowered (Delisle et al., 2017) were anticipated by the NQNs. To some extent, they identified that such benefits might compensate for gaps in existing organisational support to facilitate their transition into practice. The convenience of accessing online support at any time, from almost anywhere was noted, and indeed has been put forward as an advantage by health service providers (Panigrahi et al., 2018). However, significant barriers were identified that could undermine these gains. Aside from the pragmatic issues of the strict firewalls in practice environments, the NQNs related anxieties around how they would access forums given the time pressures at work, as also noted by Casey et al., (2018). Similarly, our participants were reluctant to contribute to an online forum in their own time. While intended to offer a new mode of support, it is possible that online provision becomes an inadvertent extension of nurses' working hours. The NQNs were concerned about having adequate time to take part, and some of their responses reflected an underlying belief that if they joined our study online group, they would be supporting the researchers, rather than receiving support themselves. Insecurities can be barriers to asking for help. In light of the recent 'clap for heroes' campaign (a UK initiative in which families clapped on their doorsteps every Thursday evening to express thanks and support for NHS workers during the first wave of the pandemic; Clap for Carers, 2020), admitting to feelings of vulnerability may conflict with the mainstream message of heroism and so feel unacceptable (Cox, 2020).

While feeling able to share feelings with colleagues can build confidence, it can be hard to find time in stressful environments (Edwards et al., 2015; Stokes-Parish et al., 2020), hard to build relationships in changing staff teams (Higgins et al., 2010) and hard to know who to feel safe with (Ten Houve et al., 2018). Sometimes experienced staff show annoyance with inexperienced colleagues' requests for guidance (Hussein et al., 2017) as was also expressed by NQNs in this study. Admitting to anxieties may reduce the likelihood of feared consequences, as colleagues with more experience may offer guidance. However, due to the unpredictable reactions of senior colleagues, many NQNs were hesitant to admit to these more senior staff that they needed help. Although online support could offer a more acceptable channel to disclose uncertainties to peers, our findings suggested it may not be any easier to admit feelings of being unsettled and insecure in the new workplace online, and such feelings may even be magnified. It is therefore important to highlight that provision of online support for NQNs does not offer a straightforward solution.

Meikle (2016) notes that for all the benefits, social media may act as a form of surveillance, in which the user loses control over how their information is shared. NQNs voiced their concerns that a digital record of communication would be kept, they worried who might access a post and that simple expressions could be misinterpreted. Some anticipated that this might threaten their nursing registration. The Nursing and Midwifery Council (NMC, 2019) provides extensive guidance about online behaviour, some of which is a response to the unedited nature of normal conversations between friends, both on and offline. As noted by some participants, their familiarity with NMC guidance and heightened awareness of the risks of spontaneous conversations would inevitably lead to self-censorship, thus limiting the potential benefits usually associated with sharing feelings in a group. NQNs highlighted both the pressures of their role and that adequate supervisory arrangements were not always in place. There was no obvious difference between RGNs and RMNs in this respect. Offering alternative support via an online forum may imply that accessing emotional support is an individual nurse's own responsibility, especially when it is legitimately transferred outside working hours. As with online learning, this may transfer work from the paid to unpaid workspace and shift responsibility from employer to employee. Such processes simultaneously fail to challenge and potentially obscure inadequate provision in the workplace. However, as part of the response to the COVID situation, many NHS organisations have recognised the importance of emotional support for staff and provided increased access to counselling services (British Psychological Society, 2020).

To summarise, the difficulties of transition to NQN status and associated feelings leave nurses requiring extensive support. Online mechanisms may contribute to this support, but significant barriers mean that further research is required to investigate whether such provision is effective.

4.1 | Limitations

Participants were recruited from two NHS Trusts in the same location which may impact on the transferability of the study findings. All researchers and the majority of participants were female, although this is representative of the nursing profession (Skills for Care, 2017). One focus group became a single interview because only one participant was able to attend. The team included an NQN on the steering group as a representative of the researched group. To promote validity and rigour, transcripts were analysed and discussed by a varied team of researchers and differences in interpretation were debated to enhance reflexivity and expose assumptions. Repeat interviews were not conducted due to time constraints. We were unable to draw conclusions about views of different age groups due to the lack of demographic data collected.

5 | CONCLUSIONS

There is a lack of research into how technology can support the emotional and social well-being of nurses. This study demonstrates that if potential barriers such as concerns about confidentiality and accessibility can be overcome, online peer support may have potential to provide help for NQNs at a time when they feel anxious and overwhelmed. Such support would require careful design to address identified concerns whilst increasing usability and benefit.

6 | RELEVANCE TO CLINICAL PRACTICE

It has been identified that NQNs need additional support during transition from student to NQN. Our study suggests that support from peers could result in improved transitions. Our findings may be relevant to the wider workforce, especially at times of heightened workplace pressures when staff may not have time for mutual support and so feel isolated. Online peer support may offer a sustainable, easily accessible intervention complementary to preceptorship programmes, to promote staff well-being and contribute towards staff retention.

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CONFLICT OF INTEREST

The authors report no conflict of interest.

AUTHOR CONTRIBUTIONS

Conception and design, acquisition of data, and analysis and interpretation of data: CJ, JO, SB, NW, PB, AS; Manuscript drafting and critical revision of important intellectual content: CJ, JO, SB, NW, PB, AS; Final approval: CJ, JO, SB, NW, PB, AS; Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; Agreed to be all aspects of the accountable for work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: all authors.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Additional supporting information may be found online in the Supporting Information section.

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OVERCOMING CHALLENGES OF CONDUCTING RESEARCH IN NURSING HOMES

Catharine Jenkins, Analisa Smythe and colleagues explore the processes, barriers and make recommendations for research in long-term care settings

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Abstract

In the UK, one third of the 850,000 people with dementia live in care homes. This article explores the process of carrying out research in nursing homes, identifying barriers and enabling factors, and making recommendations for researchers.

The authors' experiences derive from an ongoing study investigating the effect of educational interventions to promote and embed person-centred care, designed for nurses caring for the people with dementia in nursing homes.

Design issues arose from the need to use cluster randomisation which requires a large sample size, implementation fidelity, poor compliance and high numbers of participants lost to follow up. Further difficulties included gaining ethical approval, recruitment, raising concerns and the practicalities of participant retention. There are many benefits of conducting research in care homes, for the homes themselves, their staff and residents. These include training and education, networking and empowerment of staff and subsequent improved standards of care. For the research team, benefits include opportunities to contribute to an underserved setting, to advance care standards and improve nurses' working lives.

Keywords
care homes, dementia, ethical considerations, long-term care, older people, research

GLOBALLY, 13% OF PEOPLE over 60 years depend on others for support with personal care on a daily basis (Alzheimer's Disease International (ADI) 2013). For those in high income countries, care is often provided by staff in care homes, while those in low and middle income countries are more likely to be cared for by relatives at home. This situation is changing rapidly due to demographic factors and increasing urbanisation (ADI 2013). In the UK, around one third of the 850,000 people with dementia live in care homes and approximately 80% of residents have dementia (Alzheimer's Society 2015). While many residents are cared for well, there is a broad consensus that care provision for people living in nursing homes needs to be improved (Joseph Rowntree Foundation (JRF) 2012). An international taskforce identified similar concerns worldwide (Tolson *et al* 2011) and there is growing interest in carrying out research in care homes (National Institute for Health Research (NIHR) 2015).

Participation in research could improve standards of care and enhance quality of life for residents and promote professional development for staff. Additional education and networking with other care homes can be invaluable as homes can often be insular environments (Goodman *et al* 2011). Yet there is a wide range of barriers to conducting

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research in care homes at every stage, including design, obtaining ethical approval, recruitment, retention, ethical dilemmas and time pressures on staff. In addition, financial crises in the care sector may affect the conduct of research.

In this article, we report on the process of carrying out research in nursing homes, identify barriers and enabling factors and make recommendations for future researchers. Our experiences derive from an ongoing study investigating the effect of educational interventions to promote and embed person-centred care, designed for nurses caring for the people with dementia in nursing homes.

Despite the potential difficulties, research in nursing homes is worthwhile because of the need to develop an evidence base relevant to the sector, as well as to improve quality of care (NIHR 2015).

Research design

A cluster, randomised controlled trial (RCT) design was suitable for our study. Nursing homes, rather than individual staff members, were assigned to either experimental or control groups. It would not have been appropriate to randomise individual staff members or residents in the same home to control and intervention groups as this would risk staff members who were receiving the intervention influencing those allocated to the control group.

Cluster designs require a higher sample size to be adequately powered, and the analysis needs to be adjusted for clustering effects, for example, nurses in the same home have to be assigned to the same intervention because otherwise they might influence each other and contaminate the data (Woods and Russell 2014).

In our study, we needed to recruit 30 nursing homes to have sufficient power to detect a significant change in staff for our primary outcome measure of ‘burnout’ as a result of the training intervention. Recruiting the required number of homes requires significant time and resources.

In a systematic review of studies conducted in nursing homes, Spector *et al* (2013) found that many studies did not adhere to recommended guidelines for the conduct of cluster RCTs. This design requirement may hinder studies in nursing homes, yet ignoring the care home unit as a fundamental variable will produce invalid results.

Having taken into account the possible confounding effect of the nursing home as a unit, an additional threat to the validity of the study results from differences in the size of homes (Garcia *et al* 2013), which in the UK can vary from fewer than ten places to more than 150 (Royal College of Nursing (RCN) 2012). Those that are small in size are likely to vary considerably in culture, regime and governance compared with those that are larger. This means that study designs need either to restrict their recruitment to homes in a certain size range, or balance for size in randomisation. In the study, we ensured that each group had a mixture of small, medium and large homes.

A further threat to validity is high rates of staff turnover leading to high attrition rates, resulting in missing data (Garcia *et al* 2013). Care homes may also have changes in management while the study takes place, which may lead to homes withdrawing part way through a study. In addition, there may be difficulties adhering to the study protocol, for example, poor concordance with study timelines, data collection and accommodating the intervention.

A systematic review conducted by McCabe *et al* (2007) identified systemic issues specific to conducting interventions in health and care home settings, such as difficulties in training all staff members, entrenched, task-focused rather than client-focused practices and the heterogeneity of facilities.

It is difficult for care homes to release staff for training, or to take part in research generally, as not only do they have inadequate staff numbers (RCN 2012) but, as largely private, profit-making businesses, releasing staff to engage in study and research costs them money. Perry *et al* (2011) commented that the methodological quality of studies in this setting was diverse, and common limitations were the large proportion of participants lost to follow up, poor compliance with the intervention, as well as differences at baseline.

Research ethics committees

Complex ethical issues arose from our study design, including concerns about releasing staff and aiming to ensure that they and the home were not put under additional pressure. A detailed description of the intervention was required to demonstrate how it would protect, and potentially benefit, participants.

It is important to ensure equity of access to participation in research; in this study, the control group was offered the opportunity to take part in the training. Clear procedures are required to address capacity and safeguarding issues.

There are ethical issues related to including residents living in nursing homes in research, as the researcher’s presence could be perceived as intrusive, and residents may lack capacity to consent to participation. In this study, personal consultees were recruited who were able to take on the role of advising the researcher on the wishes and feelings of the person who lacked capacity.

The process of obtaining approval for a study can be daunting, and the UK research ethics system has been subjected to repeated criticisms (Tolhurst 2014). These criticisms include the requirement for duplicate submissions; submission forms that are long and complex; lengthy delays before a decision is made; inconsistency across committees; interference in study design; and a preference for, and greater understanding of, quantitative studies (Munk and Murphy 2012, Paniagua 2012, Tolhurst 2014).

The following queries might be relevant for future researchers. Subsequent to our submission to the East of England Research Ethics Committee, specific queries to us as researchers included:

- Would NHS indemnity be appropriate for research carried out in the nursing homes?
- Would site-specific assessments for non-NHS sites, for example, each nursing home, be required?
- Would the research involve adults who were unable to consent for themselves?
- How would we address issues about consent if the study included adults who may lack capacity?
- If the home was part of a larger organisation, would we be able to ensure care home managers notified homeowners?
- How would we justify selection of participants, that is, ensuring care home managers did not only approach those staff or residents who they thought 'deserved' to participate?
- Could we ensure that the home was not left understaffed while the staff were participating in the study?
- Did we have appropriate procedures in place in the event of abuse and/or malpractice or negligence being discovered or disclosed by participants?
- How could we ensure privacy and anonymity of research participants if the research was to be undertaken in public areas, for example, dementia care mapping and qualitative interviews?

Questions from the ethics committee proved useful, for example, in clarifying the research question, developing details of the intervention, responding to abuse in practice, and advice to simplify the research design.

Recruitment

Our approach to recruiting nursing homes was based on a practical online guide for researchers on how to conduct research in nursing homes (NIHR 2015). Recruitment was also facilitated by the researchers' previous experience and familiarity with nursing home settings. Our experiences taught us that the barriers to nursing home recruitment were considerable and can risk undermining a study if not planned for.

Table 1 shows the stages in our recruitment process, the barriers that arose at each stage, and successful strategies to overcome them. The team needed to be flexible, patient and creative to overcome difficulties in recruitment. The process took much longer than anticipated; there were financial implications from recruiting more widely.

It became apparent that the recruitment challenge needed to be met by the use of multiple strategies that reflected the heterogeneity of the care home sector (Davies *et al* 2014). Fostering and sustaining relationships appeared to be essential to recruitment (Goodman *et al* 2011, Garcia *et al* 2013, Davies *et al* 2014).

For each step in recruitment we recommend extensive planning that builds in time, including time to develop relationships and to be flexible in the face of unexpected hurdles. Nursing homes are more highly regulated than other healthcare settings, and staff spend significantly more time making sure that homes meet quality requirements (Hanson *et al* 2010). This may be one of the reasons why some care providers are wary of the time demands of research participation (Garcia *et al* 2013, Davies *et al* 2014).

Nursing home staff may have little interest (Davies *et al* 2014) or limited experience in taking part in research (Goodman *et al* 2011) or may mistrust researchers' motives, fearing intent to expose poor practice (Garcia *et al* 2013) rather than to improve care (Hanson *et al* 2010). The JRF (2012) identified that research focuses too often on poor practice and blame. Managers and staff members may not want their usual routines interrupted, or residents to be disturbed by the activities of a research study (Shin 2013).

In a busy home, it can be problematic for staff to find enough time to participate in research, which has to take second priority to care. These difficulties may be exacerbated as staff work shifts and weekends, and many homes have staff who work part-time or flexibly (RCN 2012). Therefore, it can be challenging to ensure that the research intervention is delivered and that data are collected on time.

Implementing the intervention

Implementation of the intervention had to take into account the pragmatics of working with staff in the constraints of the homes. This threatened implementation fidelity, which is the extent to which interventions are delivered as intended,

Table 1 **Recruitment strategies, barriers and strategies**

Recruitment strategies	Barriers and difficulties encountered	Problem-solving and strategies for success
Nursing homes were initially identified through the Care Quality Commission website	None	Not applicable
Invitation letters with reply slips and stamped addressed envelopes were sent to Birmingham nursing homes	Only 10% of homes initially approached expressed an interest in the research, which meant there were not sufficient numbers interested in Birmingham	The steering committee, including a home manager, lay people and professionals, contributed to the design of an eye-catching leaflet, as recommended by a member of the steering group The geographical area covered in the project was extended to the West Midlands
The newly designed, eye-catching leaflets were sent to all nursing homes in the West Midlands	Often there was no recollection of the leaflet or, when the leaflet was seen, staff had not found time to read it. The research team was often asked to resend the leaflet, with a reassurance that it would be read	The researchers were persistent and flexible and kept communication effective by making calls frequent but brief and demonstrated respect for the time demands and responsibilities of running the nursing home (Hanson *et al* 2010)
A follow-up phone call to the home manager was made two to four days later For the larger chains, the researchers planned to approach the head office first to ask for agreement for the care home's participation.	It was often difficult to speak to home managers as many did not return calls from the research team Some managers hesitated to take part in the study; they asked for more information or said they could not make a decision as the home was part of a chain	Liaison with individual managers was more effective than trying to contact senior managers
The team identified home managers, deputies, training co-ordinators and senior nurses	Managers were sometimes reluctant for their homes to take part due to difficulty in releasing staff, training was seen as a low priority, and availability of short and free online training alternatives	In speaking with managers about participation, it proved important to highlight the benefits of participation for the home and staff (Davies *et al* 2014). For instance, sharing findings from previous research studies on training and the way these benefited staff, residents and the standard of care in the home
	Leadership changes occurred frequently during the study recruitment period, noted by Davies *et al* (2014)	Contact with new managers was established, and additional meetings were offered to discuss the study (Hanson *et al* 2010)
Once contact had been established, managers were asked to invite potential participants – qualified nurses – to discuss whether they would like to take part in the study	There was a high turnover of qualified nurses and it was difficult to recruit the required number per home Sometimes managers did not invite staff to take part, at other times nurses were put forward but were unaware of the research The team had previously worked with care homes, but initially lacked insight into the specific needs of nursing home working environments; for example, staffing levels, diversity of provision, and changing rotas	Face-to-face contact through verbal presentations at the homes enabled researchers to build rapport Staff members reported that clear explanations of the research project through written material, that is, information sheet, training timetable, map and leaflet, and verbal presentations, aided understanding of the study and recruitment process (Davies *et al* 2014)
Members of the research team attended staff meetings in the nursing home to ensure all staff were aware of the study and could volunteer to participate	It was difficult to organise meetings at convenient times	If meetings were not in place, the manager was asked to set up a convenient time for the research team to visit the home (Goodman *et al* 2011) Following Garcia *et al*'s (2013) guidelines, it was suggested that the meeting took place at change of shift so that two sets of nurses could attend the information session and receive an information sheet

Table 1 **Recruitment strategies, barriers and strategies *(Continued)***

Recruitment strategies	Barriers and difficulties encountered	Problem-solving and strategies for success
The information sheet was followed up by a telephone call, three to four days later, to ask if staff had any questions and whether any were interested in taking part or whether they would like longer to decide	This process took longer than anticipated	The research team's approach was to avoid burdening or distracting staff in their clinical responsibilities as far as possible (Hanson *et al* 2010), for example, by being flexible and calling in the evening
A mutually convenient time to answer further questions and gain informed, written consent was arranged to meet those nurses who were interested in participating in the study, at their workplace	Nurses were often not present at the agreed times due to sickness, forgetting and non-communication	Researchers had to adjust timeframes and be flexible and accommodating The team realised it was essential to telephone in advance of every appointment to confirm
Making the training intervention attractive to participants	Some difficulty releasing staff, training seen as a low priority, and availability of short and free online training alternatives	Benefits were explained. These included 'notional credits' (equivalent to formal credits for students wanting to take standard modules), access to university, and organisational and family-friendly timings. Taster versions were offered to demonstrate the approach. Feedback about benefits of previous similar training was used to promote the training
Each home was randomised into one of three conditions	Some homes were disappointed at the long wait for the training or to be randomised to the control group, while others were relieved	Researchers explained the importance and process of randomisation in research
Those allocated to training were invited to training days	Staffing shortages meant some homes could not afford to release staff members for training during their working hours, so staff who were expected to attend, did not turn up	The team adjusted the planned timetable for the training intervention to ensure that nurses' participation did not affect management of the home (Davies *et al* 2014). Some nurses chose to attend on their days off, or before or after shifts, including night duty

with adherence to specifications in intervention manuals (Lorencatto *et al* 2014).

In this study, it was difficult to follow the protocol, adhere to agreed timelines and deliver the intervention as planned due to changes in the rota, sickness, absenteeism, organisational factors, management style and care culture (Spector *et al* 2013).

When research is conducted at the workplace, nurses may be concerned about work disruption and increased demands on their time (Cleary 2004). Cleary also discussed how researchers may be viewed by personnel as working in ivory towers and out of touch with the realities of long-term care settings. This experience was shared by the research team, for example, one participant stated: 'You're from the NHS – fairy-tale world.'

The in situ intervention in our study demanded flexibility in its application, yet also carried credibility as it involved the trainers modelling aspects of the application of knowledge in the care environment. Positive experiences as research participants encouraged the nurses to further their education and recognise their own expertise.

However, due to high staff turnover it was difficult to ensure participants remained in the study. Reasons for drop-out included pregnancy, illness, long holidays, family difficulties and leaving for new jobs. Where possible, participants were followed up in a different nursing home, with the agreement of the home manager. This may have affected the validity of the study, however, it was important to take a pragmatic approach and preferable to losing participation altogether.

Raising concerns

In the course of our study we observed high-quality care delivered by committed, caring nurses and care staff. In two of 30 homes, we became aware of neglect and teasing of residents, illegal deprivation of liberty, inadequate fire escape provision, understaffing and fraudulent use of funding.

In each of these cases the researchers had an obligation to raise concerns with the appropriate regulator, which in England is the Care Quality Commission (CQC).

The team acted on the duty to escalate concerns promptly, guided by the need to prioritise care of residents, act as advocates and be open and candid (Nursing and Midwifery Council 2015), following the framework for adult safeguarding under the Care Act 2014 and our conditions of ethical approval.

However, reporting concerns to the CQC had a number of consequences for participants and for us as researchers. During implementation, it is important to support all members of the research team. It is therefore essential to have clear agreements with the homes and protocols for reporting any concerns. In one case, the home manager made allegations about research participants (nurses) that appeared to be retaliatory.

In most of the examples in our study, nurses moved on, which made it more difficult to keep them in the research and increased 'churn' which is damaging to residents (McGilton *et al* 2014).

For researchers, once a concern has been reported to regulators, the home may withdraw its co-operation with the study. This means that the researchers will no longer have any chance of changing practice in that home and subsequent studies may be refused access (Garcia *et al* 2013).

Unanticipated ethical consequences of the research included increased risk of job insecurity for participants and staff turnover for homes. Coping with ethical issues reduced study power and validity.

Recommendations

Our experiences lead us to make these recommendations for research in care homes:

- Ensure sufficient time and financial resources.
- Ethical approval requires justification of every aspect of the study; prepare to respond to the particular questions outlined previously.
- Invest time in forming relationships with homes.
- Empathise with nursing home staff who have challenging roles, work long hours and are often taken for granted: aim to work collaboratively.
- Manage expectations: clarify timescales and the nature of interventions and advise on longer-term benefits of research.
- Be prepared to be patient, flexible, understanding resilient, to persevere and be mutually supportive.
- Adopt protocols that have built-in flexibility to adapt the intervention to different circumstances.

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- Have structures in place where you can debate and devise strategies to cope with setbacks. Our steering group included a home manager and former carer whose ideas were invaluable.
- Be aware of the possibility of poor practice and the need to respond appropriately.
- Ensure participants have a good experience so as to minimise drop-outs and promote willingness to take part in future studies. Be punctual, polite, friendly and professional.
- Hold regular meetings and provide supervision for the research team to allow time for reflection, help manage stress and ensure effective completion of the study.

Benefits

Research offers benefits for people living and working in nursing homes. For nurses, these include education, development of new skills, to have their voices heard and experiences validated, networking opportunities, profile raising, empowerment and the satisfaction of contributing to creation of knowledge. Benefits for residents also include the opportunity to have their voices heard, as well as improved standards of care and quality of life.

For researchers, benefits include the chance to make a difference to care and insight into a different world. Committing to overcoming the barriers to conducting research in care homes can contribute to advancing care standards.

Conclusion

Well-designed research studies are essential to inform the development of high-quality, person-centred care. Nursing homes should be supported and encouraged to take part. Extensive planning and preparation for ethical approval and recruitment are essential steps in the process.

The pressures on nurses working in homes can make it difficult for them to prioritise research over their professional responsibilities. Understanding their perspectives, clear communication, building relationships and being flexible, patient and creative, can help researchers recruit and support participants throughout the research process in nursing homes.

The main issues were ethical concerns and gaining ethical approval, appropriate design and recruitment, and retention of participants.

Constraints included time pressures, staff turnover and organisational cultures. However, there are opportunities to change practice in this under-researched field and improve quality of care for residents.

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Conflict of interest
None declared

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Transcultural nursing strategies for carers of people with dementia

Melissa Bunting and Catharine Jenkins investigate the effect of caring among different cultural groups and recommend culturally congruent interventions to support carers

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Abstract

Caring for a family member with dementia is stressful, and carers from all backgrounds often feel overwhelmed and under-supported. Professional and family carers' perceptions of the challenges and satisfactions of caring are influenced by culturally derived expectations. However, experiences of caring often differ from stereotypical norms.

Experiences of carer stress and beliefs about the nature and extent of support that can be expected from social networks and statutory services may differ between cultural groups in the UK, but sensitive advice, information, and emotional and practical support are universally required. Transcultural comparisons reveal similarities between carers' needs and enable identification of values-based culturally congruent recommendations that nurses can use to promote black and Asian minority ethnic carers' confidence and wellbeing.

This article, based on practice experience and a literature review, explores the effect of caring among different cultural groups and offers recommendations for culturally congruent interventions to support carers. It provides evidence-based guidance to enable nurses to meet their responsibilities for transcultural working, as laid out in the Care Act 2014. A scenario illustrates recommendations for practice.

Keywords
carer burden, carers, dementia, diversity, older people, transcultural care

PEOPLE LIVING with dementia experience a range of problems with memory, cognition, language, day-to-day orientation, planning and daily self-care (Downs and Bowers 2014). As dementias are progressive, over time those affected require increasing levels of support, which can become overwhelming for family carers (Department of Health (DH) 2010, Springate and Tremont 2014). Carers face physical, emotional and economic stressors, so require support and collaborative care from multidisciplinary health, social, financial and legal systems (DH 2010, Bekhet 2013, Royal College of Nursing (RCN) 2016). There are an estimated 670,000 families and friends from diverse social and cultural backgrounds who act as primary carers for individuals with dementia in the UK (Alzheimer's Society 2014a). These carers alleviate pressure on statutory services saving £11 billion a year (Alzheimer's Society 2014b).

This article, based on practice experience and a literature review, explores the effect of caring among different cultural groups and offers recommendations for culturally congruent carer support interventions. It provides evidence-based guidance to enable nurses to meet their responsibilities for transcultural working as set out in the Care Act 2014.

Supporting carers

Carer support is vital, not only because of the savings they provide for the state, but, more importantly, for their own wellbeing and that of the individual living with dementia. Although caring has its rewards, including job satisfaction, reciprocation of care and increased closeness to a loved one (Brodaty and Donkin 2009), carers are at high risk of depression (Kmietowicz 2013). Many become 'hidden patients', because of the mental and physical toll that providing care has on them (Brodaty and Donkin 2009). Therefore, carers' needs should be considered alongside those of people with dementia to reduce the stress on both parties (DH 2010, Kim *et al* 2012, Springate and Tremont 2014).

Dementia affects people from all backgrounds and carers are similarly diverse (Cross and Bloomer 2010). The All-Party Parliamentary Group on Dementia (APPG) (2013) found that people from black, Asian and minority ethnic (BAME) backgrounds were less likely to receive a diagnosis or formal support, while carers were not getting the support they needed (Grand *et al* 2011).

Support should be responsive to carers' needs and strengths, taking into consideration cultural norms and values (Joas and Wiegandt 2008). For example, it may be a traditional norm in the family for an older person to be cared for by a daughter-in-law (Jutlla 2015). However, it is important to ensure that this person is willing to take on the caring role, that they have accessible information in their first language or audio-recorded and clear signposting to further support (Dyson 2004).

Transcultural nursing involves focusing on the needs of individuals in their cultural context to provide culturally congruent, meaningful and beneficial care (RCN 2016). Simple, practical issues to consider may include arranging community visits to respect religious occasions and prayer times, being mindful of appropriate dress, and phrasing questions about alcohol and suicidal thoughts sensitively (Bolliger 2014).

Use of the acronym BAME risks promoting a blanket response that fails to acknowledge diverse individual needs (Butt 2006). Supporting this view, Rauf (2011) used the expression 'communities within communities' to distinguish the range of beliefs, language and cultural norms and practices found in particular groups. However, the acronym does focus attention on groups that share similar experiences of migration and racism and face particular challenges in getting the support they need (APPG 2013).

People from BAME groups are under-represented in dementia services, as are their carers (Moriarty *et al* 2011). Carers UK (2015) found 15% of BAME carers reported negative experiences of health and social care, with 10% reporting these experiences to be 'terrible'. In 2012, in England and Wales, there were 25,000 individuals living with dementia who were from a BAME background (APPG 2013), including 'invisible' white minorities such as Irish and Eastern European service users (Cemlyn *et al* 2009). It is estimated that this figure will double to 50,000 by 2026 and to more than 172,000 by 2051 (APPG 2013), meaning that the number of carers is also expected to rise (Carers Trust 2011, Prince 2015).

Carer stress

The psychosocial effect of caring in different cultures is under-explored (Institute for Research and Innovation in Social Services (IRISS) 2010). People from BAME groups tend to present to services later or at crisis point (Mukadam *et al* 2011). Across most communities, dementia is often perceived as a natural part of old age, while some minority group understandings include 'craziness' or supernatural explanations such as possession (Botsford and Harrison Dening 2015), leading to shame, isolation and reluctance to ask for help (Jutlla 2015).

Lack of a term in some languages to describe the concept of dementia is sometimes used as an explanation for late access to services at the point of crisis (Botsford and Harrison Dening 2015). However in 2007, La Fontaine *et al* found that family doctors stereotyped BAME elders and did not make their access to services easy. In 2015, Jutlla's respondents perceived that services were stigmatising, inaccessible, unsuitable and potentially damaging, echoing their previous experiences of racism. Most carers from all communities reported services were often inadequate (Newbronner *et al* 2013), but specific learning opportunities may arise from transcultural comparisons (Shim *et al* 2013).

Levels of carer stress or 'burden' vary between individuals and within cultures (Sayegh and Knight 2011, Giger 2013). This may be due to relative perceptions of dementia-related problems, some of which may transgress cultural norms more significantly in specific cultural groups. Cox (1995) found that carer stress varied between black and white carers.

In the black carer group, participants were most affected by poor physical functioning and subsequent restriction of activity, while the white carer group was more concerned about disruptive behaviour. If a behavioural symptom – for example, apathy, swearing or repeating stories – matches with cultural norms or expectations of old age, then it is much less likely to be problematic. Similarly, if caring is part of normal life, a person would not necessarily see themselves as 'a carer', and the process of identification with the role and subsequent help-seeking would take some time (Mukadam *et al* 2011). Botsford *et al* (2012) and Parveen *et al* (2011) found that spousal carers were less stressed than daughter or daughter-in-law carers, perhaps demonstrating continuity in caring between partners, or acculturation in second-generation carers (King and Christou 2008) who may, for example, prioritise further education and career development and so experience role conflict.

The extent of support from a person's social network also affects stress levels (Lamura *et al* 2008). Kim *et al* (2012) and Foster *et al* (2014) agree that the less support a carer receives from family and friends and the more hours a carer provides, the higher the level of burden experienced. 'Familism', that is, loyalty and attachment to family members, is important among South Asian cultures (Parveen *et al* 2011). However, the stereotype of 'looking after their own' is not always reflected in actual support from the extended family and so does not reduce the stress, distress or depressive symptoms experienced by individual carers (Parveen *et al* 2011). Taking on the caring role may result more from obligation than choice (Sayegh and Knight 2011).

White British participants in Parveen *et al*'s (2011) study had more support from friends, family and services. South Asian carers seemed to be motivated by cultural expectations, in comparison with white British carers whose motivation was more intrinsic (Parveen *et al* 2011). Feeling in control or having a sense of autonomy seems to be positively associated with effective coping with caring, while avoidant coping, or distancing self from the problems, is associated with perceived cultural obligation and increased stress (Sayegh and Knight 2011).

Evidence of the effect of caring on different groups is conflicting. Depression in the white British group was associated with using substances as a coping strategy (Parveen *et al* 2011). Use of substances such as alcohol may indicate poor coping mechanisms that aim to resolve, but exacerbate, low mood (Barlow 2010). Black *et al* (2013) found higher levels of unmet need and depression among non-white carers, while Skarupski *et al* (2009) found that white carers reported more depressive symptoms than black carers. Despite these apparent contradictions, learning from transcultural comparisons may reveal underlying themes that can be used to make recommendations for sustainable and culturally congruent carer support interventions.

Cultural aspects of support

La Fontaine *et al* (2007) suggested that it is important to look at similarities as well as differences between cultures. In Sussman and Regehr's (2009) study, 70% of all carers did not have regular help from family and friends, and 52% of participants wished for more regular support. Emotional and practical support from family and friends, as well as statutory services, reduces carer stress (Samia *et al* 2012, Jutlla 2015) and has a positive effect on the wellbeing of people with dementia (Brodaty and Donkin 2009).

Interventions from statutory services include educational programmes, respite, day care, carer support groups and one-to-one support (Sussman and Regehr 2009, Newbronner *et al* 2013). The Alzheimer's Society (2014a) also recommends more financial support, accessible information, more support for carers in employment, comprehensive home-support services and more involvement in decision making. These recommendations respond to the needs that carers have in common, regardless of their cultural context. The literature exploring cultural similarities and differences in caring experiences offers further insight that could make culturally appropriate interventions easier. Despite apparent differences between groups, emerging themes indicate underlying values based needs are universal, although they may be expressed differently.

Autonomy and control

The need for carers' autonomy and control was evident across the literature (Sayegh and Knight 2011, Parveen *et al* 2011, Jutlla 2015). It was shown in the importance of choosing to care and feeling confident about caring skills. Choosing to care does not mean choosing to care in isolation and without adequate support. The Care Act 2014 indicates that carers' rights are as important as those of the cared-for person. Part of the multidisciplinary team's assessment involves exploring a carer's ability and willingness to fulfil the role. An example of this is set out in the case study on page 24. The names of the people involved in this scenario have been changed to preserve their anonymity.

Brodaty and Donkin (2009) say that carers who take part in training develop confidence in their coping abilities, and tend to experience less burden and depressive symptoms, while Lopez *et al* (2012) found that self-efficacy combined with spiritual meaning is associated with lower levels of carer depression.

Understanding the nature of dementia and learning about skills can promote carer confidence. Samia *et al* (2012) found that an advanced carer training programme alleviated feelings of lack of support when caring and built confidence in coping with the demands of caring. Learning from earlier life experience can enhance caring skills and Jutlla (2015) found that experiences of migration resulted in resilience and self-efficacy, which were transferable to caring roles. Botsford *et al* (2012) suggested a similar dynamic in black carers who

Case study

Saira had been married to Ahmed for a couple of years when it became obvious that her mother-in-law, Aisha Bibi, had worsening memory problems.

Saira and Ahmed had good jobs and, as their two children attended after-school clubs, they were able to work full-time. Aisha was becoming less able to cope with her diabetes and at a family meeting, her sons agreed that between them they would take turns in looking after their mum.

Saira found she was expected to take on the majority of this role and supervise and support Aisha for three months a year. Recognising the need for support and advice, Saira contacted her GP who, after some prompting, arranged for Shanice, the practice nurse, to visit Saira and Aisha early one evening. Shanice was a good listener.

Saira opened up about the stresses she was under and could foresee in the future and became tearful.

Saira was concerned that her job was in jeopardy and that Ahmed was less supportive than she had anticipated. Shanice had developed a good network of contacts in the area and was able to refer Aisha, with her consent, to a local day care centre where staff spoke South Asian languages and where the food options met with Aisha's approval.

Shanice was able to spend time with Saira answering her questions and offering advice, while the children were chatting with grandma. Shanice gave Saira contact details for the Alzheimer's Society so that she could access further information online and they agreed that Saira would get back in contact with the practice when necessary.

became more independent following separation from family networks after migration.

'Meaningfulness', or a sense of the significance of caring, seems to be associated with autonomy. The decision to care is motivated by an individual's values. Spousal carers, who may see caring in terms of 'keeping a promise', and those with strong religious beliefs find meaning in caring and this seems to promote emotional wellbeing. Finding meaning in caring appears to be an evolving process that has a positive effect on the carer and individual living with dementia (MacKinlay and Trevitt 2012, Shim *et al* 2013).

Recommendations for practice

The Care Act 2014 legislates that carers are entitled to support that promotes their wellbeing and this is a government priority (DH 2014). Interventions to support carers should acknowledge the context of individuals in their family, cultural groups and wider society. However, austerity measures may threaten availability of statutory services (Alzheimer's Society 2014b). Nonetheless, accessible and acceptable community-based services are essential to support growing numbers of carers from BAME groups and to reduce the need for more expensive hospital or care home admission (Brodaty and Donkin 2009).

The effect of services can be enhanced for all groups by promoting congruence with cultural values. The following recommendations build on cultural understandings:

- Promote self-efficacy through carer education and reinforcing effective coping strategies. Transgression of norms by a person with dementia increases stress for a family carer.

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To minimise perception of norm transgression and reduce the effect, nurses should teach family carers about the nature of dementia, talk through problematic issues and collaborate on identifying strategies to minimise problems. Nurses should be aware of stressors that have different effects on different groups and consider culturally congruent advice. For example, if a person with dementia is not able to fulfil a previous role, the nurse could suggest more achievable alternatives, such as dusting rather than vacuuming, or watering plants rather than weeding. If behaviour communicates distress, the nurse could explore ways with the carer to meet unmet needs.

- Promote the meaningfulness of caring in the carer's own belief system. Explore reframing negative experiences as overcoming adversity, building competence and living according to deeply held values, whether spiritual or humanistic.
- Promote carers' autonomy and choices, avoiding assumptions based on cultural norms, while being sensitive to family expectations and the need to engage the wider social network to support individual carers. As carers risk isolation in group-orientated as well as individualistic cultural groups, the importance of mutual support, sharing the caring role and making use of services should be emphasised from diagnosis.
- Promote carers' resilience by reflecting on previous challenges and how they were overcome, and acknowledge the survivor identity and structure processes to develop further resilience. Explore life histories and experiences of migration to support the identity of the person with dementia and their carer, and recognise the strengths which build resilience.
- Acknowledge the effect of racism and develop culturally competent, non-discriminatory services. Listen to carers, avoid exploitation, and advocate for protection and improvement of high-quality, culturally congruent services. Challenge racism, sexism and ageism. Raise awareness in self and others of the effect of oppression and discrimination and, in collaboration with carers, structure future services to promote wellbeing in a diverse society.

Conclusion

The extent of carer stress varies within and between different ethnic and cultural groups (Springate and Tremont 2014), while cultural identity influences perceptions of 'burden' and coping styles (Sayegh and Knight 2011). This highlights the importance of adopting an individualised, culturally sensitive approach to supporting carers of people living with dementia (IRISS 2010).

Interventions delivered by culturally competent nurses and their multidisciplinary colleagues should promote congruence with cultural values, and ensure effective support and social inclusion for all service users.

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Conflict of interest
None declared

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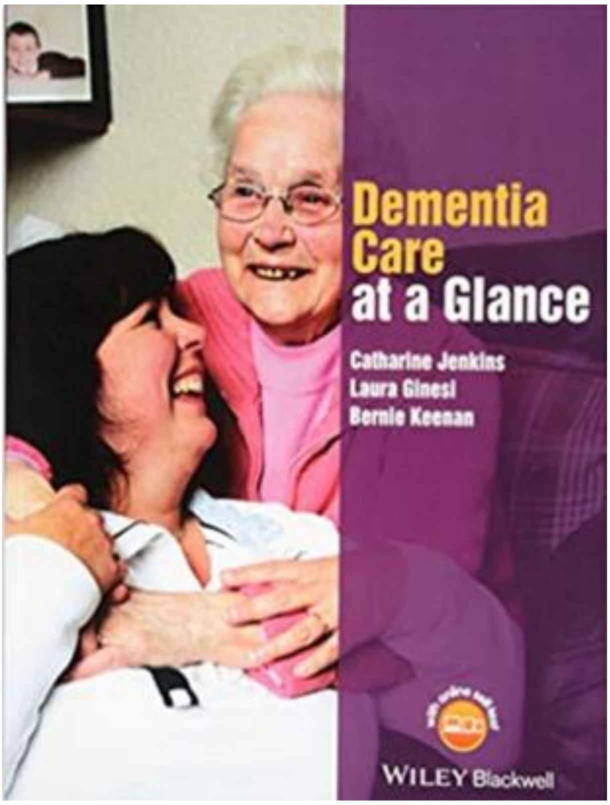

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Nursing students' experiences of delivering dementia friends sessions to peers

Linda Bale, Catharine Jenkins

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Abstract

Background Nursing students and registered nurses often feel underprepared for their roles in dementia care. Extracurricular activities offer nursing students additional opportunities for professional development. A student-academic partnership initiative was developed in which nursing students delivered dementia friends sessions to their peers before formal taught content.

Aim To explore dementia champion nursing students' experiences, identify factors that affect collaborative working and make recommendations for future student-academic partnership projects.

Method In individual and dual interviews, three students were asked about their experiences of participating in the initiative. Interviews were recorded, transcribed and analysed using a thematic analysis framework.

Findings Four themes were identified: commitment to working with people who have dementia, difficulties in taking on extracurricular responsibilities, personal development, and relationships and collaboration.

Conclusion Students were motivated by the need to provide high-quality dementia care. They identified benefits of collaborative working including development of time management, team working, leadership, communication and presentation skills. Future projects should take into account student workloads and offer rewards that are congruent with nursing students' values.

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Keywords

dementia, dementia-friendly communities, neurology, pre-registration education

NURSING STUDENTS provided dementia friends sessions for peers and university employees in a small student-academic partnership project. The aim of this initiative was twofold: to improve nursing students' and others' understanding of dementia and to aid student employability through extracurricular activities. The care of people living with dementia is central to nurses' roles, and this is covered in depth later in the nursing curriculum. However, student feedback indicated that they needed an introduction to the needs of this client group before their first placement.

The dementia friends project was a partnership between the Alzheimer's Society, academic staff partners and 12 students. The project involved recruiting students to undergo dementia champions training (Department of Health (DH) 2012, Alzheimer's Society 2013), after which the students could train others as dementia friends. Dementia friends training involves finding out more about how dementia can affect a person and then doing everyday things to help, for example, repeating information clearly and patiently as many times as needed. Students were paid for the time they spent in training, and organising and delivering any sessions in the university. The academic staff partners supported and guided the students.

Caring for people with dementia is core to nursing (Baillie et al 2015), but nursing students (Honan 2016) and registered nurses feel underprepared (Jenkins and McKay 2013). While it is important to equip student healthcare professionals with the skills to support people living with dementia through enhanced education (Banerjee et al 2017), the dementia friends initiative offers a socially

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inclusive, community-based perspective that complements classroom and practice-based learning. Dementia affects all societies (Alzheimer's Disease International (ADI) 2015) so the dementia friends sessions were open to all members of the university.

Collaborative working between industry, third sector organisations and universities has widely recognised benefits for research, creative and entrepreneurial benefits and student engagement with local communities (Jung 2011, Mason O'Connor et al 2011, Kahu 2013). While the aim of the initiative was to help nursing students prepare to care for people living with dementia, the project also offered an opportunity for the dementia champions to experience partnership work with a national charity. The purpose of this article is to report on the dementia champion nursing students' experiences of the project.

Background

The care of older people with dementia is high on the international agenda (ADI 2015) and UK government policy (DH 2012). The Prime Minister's Challenge on Dementia 2020 (DH 2015) has re-emphasised this concern and the focus now includes non-statutory responses to supporting people living with dementia through 'compassionate communities' and individuals known as 'dementia friends'. The dementia friends session is a brief, structured interactive session, designed and managed by the Alzheimer's Society (2013), with clearly outlined content and activities.

Undergraduates are encouraged to participate in extracurricular activity because of the opportunities to develop skills sought by employers including communication, team working and emotional resilience (Hinchliffe and Jolly 2011); to engage with local communities; make friends and develop a sense of the importance of peer support. Trowler (2010), Thomas (2012) and Gerrard and Billington (2014) emphasise the sense of development, belonging and well-being that students achieve because of extracurricular activities. These activities lead to improved retention and greater student satisfaction with the university experience (Hinchliffe and Jolly 2011).

Aim

The aim of this case study research was to explore the dementia champion nursing students' experiences, identify factors that affect collaborative working and make recommendations for future student-academic partnership projects.

Method

This was a small, exploratory study. As the intention was to gain in-depth understanding of students' experiences a qualitative methodology was most suitable. The initial plan was to use focus groups to encourage discussion and develop and explore alternative perspectives, but low numbers meant that this approach was adjusted to individual and dual interviews. All nine dementia champions were invited to participate and three agreed. All were second-year students, one was a mental health nursing student and two were adult nursing students. They were interviewed by the two authors, who were nurse educators and already known to the students. The authors were also dementia champions and familiar with the dementia friends sessions.

Interviews took place in 2016. Each interview lasted for approximately one hour. Students were paid for their time on the same basis as that for providing the dementia friends sessions. The students had been dementia champions for six to nine months.

Data collection

The aim was to explore students' experiences of participating in the project, including the experiences of those students who had not taken part after their dementia champions training. The invitation letter emphasised the intent to learn about barriers and enablers, so as not to intimidate students who may have felt uncomfortable about admitting to not running sessions.

A semi-structured approach was taken, using the following questions as a guide:

- What were your motivations for applying?
- How did you get on with the dementia champions training?
- How did you find the organisation of the dementia friends sessions?
- What were your experiences of providing the sessions?
- What has been the effect on you of taking part in the initiative (prompt – Any difficulties? Any benefits?).
- Would you do anything differently another time?

Data analysis

The interviews were transcribed verbatim and then analysed using Braun and Clarke's (2006) approach to thematic analysis. To minimise mutual bias, each researcher initially read the transcripts independently. Tentative themes were identified individually, before the researchers met to discuss and jointly agree on significant themes.

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Ethical considerations

Ethical approval for the study was received from the university ethics committee. All participants were fully informed and consented to be involved in the study. They were aware that they had the option to withdraw from the study at any time. Audio taped recordings and transcribed materials have been kept securely on a university network drive.

Findings

Four themes arose from analysis of the transcripts:

» Commitment to working with people with dementia.
» Difficulties in taking on extracurricular responsibilities.
» Personal development.
» Relationships and collaboration.

Commitment to working with people with dementia

The students all expressed concerns about the quality of care offered to people living with dementia. They recognised that they needed more preparation on how to work with this client group before their first placements. Placement experiences allowed them to recognise gaps in the knowledge base of registered nurses, who themselves may have had little specific dementia-related education.

In the following quotes, the students show how their emotional responses to inadequate dementia care knowledge motivated their delivery of sessions:

'I realised how much we are lacking in secondary care for people with dementia and I found it very frustrating and from that moment I've really had a "something needs to change" [attitude] and we need to be changing our practice very much in that sort of environment' (student 2).

'I wanted to do more for people who have dementia because I didn't know a lot about dementia when I started. I knew that it was a problem because there were a lot of reports and stuff going on. I felt like, from a mental health nursing perspective at that point in my training, we hadn't had anything on it. I'd already been on a dementia placement, so I felt that I sort of needed something extra and I thought this would be good for me' (student 3).

It appears that the students were motivated by compassion for people living with dementia, together with awareness of gaps in their own and others' knowledge base and practice competence.

Difficulties in taking on extracurricular responsibilities

All three students recognised that taking on additional work on top of a full-time course increased work-life pressures. Time management was an issue for all the students. Scheduling extra activities on top of a taught timetable, further reading and practice placements was challenging. Prioritisation was difficult even for students who were progressing well, but for Student 1 this was a more urgent issue. Course completion had to be the priority as failing to do so would mean having to leave the university and not qualifying as a nurse:

'The only thing that I found difficult is once you fail one thing that's a bad place to be. If I wasn't a trooper, I wouldn't be sitting here, because I failed this, I failed that, and I had three things behind. But hopefully, with the bless of God, I will be able to complete the course and I would love to do that' (student 1).

Student 3 saw the issue from a different perspective. It seems they might have prioritised delivering the sessions:

'I don't think there were many other barriers, other than having to do a university degree with it. If I didn't have to do a university degree with it, I probably would have been doing six [dementia friends] sessions a week or something, which would have been good because I have enjoyed doing them. I think that I would happily continue with it' (student 3).

Student 2 noted the time management challenges that students would face if they did not have a strong support network and used this empathy to indicate the need for staff to anticipate this issue in recruitment of future students:

'It would be good to be honest with people who are applying for it, about the time they would need to commit before they actually go on any dementia champion training. I'm fortunate enough to not have a load of backlog, but I've still found that I've had to do a lot of scheduling. For me, if I was looking to interview future champions myself, I'd be wanting to know how they were going to manage their time because it is something that I've had to. I am very lucky as I have a fantastic support network' (student 2).

The students' words reflect the demands of a nursing programme and the perhaps unanticipated extent of the extra commitment they had taken on. Their commitment is clear, but it seems that the extracurricular activity had costs for the students, as well as benefits.

Implications for practice

- **Students are motivated primarily by their commitment to practice. Initiatives should offer opportunities to develop practice-related skills and social networks that will sustain high-quality care post-qualification**
- **Considerate recruitment and organisation are important. Students should be managing existing commitments before being exposed to additional demands and projects should be timed to avoid clashes with academic deadlines**
- **Students feel underprepared to care for people living with dementia, so underpinning knowledge and skills for dementia care should be included from the beginning of nursing programmes**

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Personal development

Despite the difficulties outlined, the students generally felt positive about their abilities to overcome challenges and achieve their objectives. When asked to discuss the effect of the project the students identified positive outcomes, including receiving constructive feedback from peers and practice colleagues. Having extra knowledge and responsibilities also led to positive consequences for professional recognition and further influence:

'People are becoming quite receptive, especially now I am coming towards the end of the second year. I've sat and talked to some ward sisters who are quite happy to listen to what I have to say. So, I'm pleased with it as it's hard not to feel infectious about the subject' (student 2).

For Student 1, who was not able to take on the role as a dementia champion, the training still had a positive effect on their immediate sphere of nursing practice:

'I don't rush myself when I am dealing with them [patients with dementia]. I see them as people, I don't see them as dementia, I don't see them as confused; I see them as normal human beings. Once you do that, those people looking at you in your eyes, see you have trust and they start to think and start to recall what they used to have in their lives' (student 1).

The personal development gains were already visible to the students who had led dementia friends sessions. They could see how their new skills and confidence were preparing them for the next stages of their careers. Student 3 recognised that these abilities would soon be useful:

'We are going to jump into practice and within a year we are going to be asked to be mentors, so it's giving you some of those skills and preparing you for qualified status' (student 3).

Student 2 was also already focusing on career development beyond qualification:

'Every time I think about it I get excited and think, "OK there's not currently a role yet to employ me but I will make my own". So, employability-wise I am using this to my fullest. I am already carving my future into dementia care. Since being part of the dementia champion scheme, I've been quite active online with Twitter and I've formed a really good network of general practice nurses because I want to go into general practice but then I'm sat there and thinking I am so good with dementia [patients]. I know I want to go into general practice. How can I do both?' (student 2).

The quotes seem to indicate that the project focused the students' attention on how they might achieve their long-term objectives. They could review their experiences and see how transferable skills and networking could facilitate their greater influence on dementia care post-qualification.

Relationships and collaboration

The students acknowledged relationships with the academic staff partners, each other, practice colleagues and the university itself as influencing their experiences of the project.

Student 2 recognised how the benefits of developing a professional relationship with Student 3 led to insight that could be useful for interdisciplinary working:

'I've found it so useful to work with [name] who is a mental health nurse. Both of us were taking over the world and I said you can have a GP desk next to me and we can both be out in the community and we can do X, Y and Z together. We've already been working together around multidisciplinary and how you are a mental health nurse and how that links in with adult nursing and how our two roles are so missing without the other. So, it has really given us the opportunity to sit and talk about different things. We have sat and swapped different ideas and talked about our different course content. I've got a better appreciation of what mental health nurses do' (student 2).

Student 3 was appreciative of the opportunity to 'give back', seeming to feel that these contributions cemented their relationship with the university itself:

'I think it's done so much for me as it's made me feel engaged with the university. As opposed to just being a student, turning up doing my bit and then going home. It's made me feel like I've been able to give something back and have a sort of relationship with the university that's a bit different from just coming in and take and take and take. I feel like I've been able to support people as well, which is something that I set out to do. It's something that I would like to have done while I am here so I'm really happy and chuffed with being able to have the opportunity to do it' (student 3).

Relationships seemed to be significant for the students in creating a perception of mutual support that contributed to ongoing motivation, commitment and positive feelings about their experiences of participating in the project.

Discussion

The most significant finding from this exploratory study was that participants were motivated by wanting to make a difference to people living with dementia. Their concerns about quality of care echoed those in the literature, for example, in the need for a person-centred approach (Brooker and Latham 2016). They were seemingly unaffected by 'courtesy stigma', which is stigma that extends to those associated with a stigmatised group, as in this case with older people (Ostaszkiewicz et al 2016). Improved nurse well-being is associated with reduced risk of burnout and with higher quality patient care (Fearon and Nicol 2011). The appreciative 'cross-field' relationships they developed anticipate the mutual support that specialist dementia nurses need to sustain positive attitudes and for practitioners' long-term retention in the specialty (Chenoweth et al 2014).

None of the participants mentioned payment as driving their commitment to the project and they did not claim for a large proportion of the hours worked. As the project progressed, mutual relationships seemed to become more significant, as did the satisfaction provided by delivering the sessions and the feedback they received. They also seemed to realise that learning and skills could be applied post-qualification and that the 'platform' of expertise (Godat 2013) they were building would empower them to influence others long-term. Those who could commit to delivering sessions seemed to benefit from a boost to self-esteem, perhaps through feeling that others recognised their expertise and through a sense of contributing and therefore having improved status, in university and practice.

The findings agreed with those of previous studies in identifying the benefits of working while studying (Stevenson and Clegg 2013, Gerrard and Billington 2014), despite the difficulties of coping with various responsibilities. Mirzaei et al (2012) confirm the importance of BSc nursing students acquiring time management skills in readiness for their chosen career. Similarly, networking, leadership, communication and presentation skills were developed by undertaking the project but seem to be predicated on students' pre-existing ability to manage their academic and placement workload. Participants noted these benefits and appreciated the sense of professional recognition they gained from others and seemed able to own for themselves. Teaching others aids students' own learning and builds confidence (Ravanipour et al 2015).

Limitations

This exploratory study was based on a small sample and explored the implications of a local initiative. Further work is needed to establish how the findings will relate to those exploring and evaluating similar or larger projects. While the study is exploratory and limited by the small number of participants, the findings offer some insight into factors that may sustain or impede collaborative extracurricular activities.

Considerations for future projects

In tentatively applying these findings to planning future student-academic collaborations, it seems that emphasis should be placed on how students can contribute to quality of care rather than the 'soft skills' or financial payments gained. Professional recognition as an 'agent of change' for the client group, in this case people with dementia, seems to be the most significant factor for these participants. This has ethical implications, as the nature of the student-academic partnership project is to recognise the importance of student roles through fair payment. However, it may be that motivation related to the caring nature of nurses' roles is more powerful. Therefore, perhaps alternative or additional value-congruent forms of recognition and reward should be considered.

Further ethical concerns arose from the findings. The students could manage their own time and arrange sessions to fit around placements and their academic timetables. However, all noted the pressure and difficulties of time management and showed they were weighing up the competing needs and benefits of the project, their academic work and practice placements.

There was clearly some synthesis of learning and benefit between the group: the students felt more committed to the university, more confident in practice and gained expertise relevant to their future careers. Nevertheless, there was a risk, as expressed by Student 1, that the project could threaten the priority of qualification. In planning future projects, academic staff could consider the wider implications of extra commitments. There is a judgement to be made about the ethics of discriminating in favour of academically strong students while also ensuring equal opportunities.

Conclusion

The findings from this small study indicate that student-academic collaborative projects can achieve benefits similar to those of other partnership working opportunities. However, there are potential downsides which should be considered when planning future initiatives. Nursing students face demanding workloads and academic partners should recognise the importance of balancing extracurricular opportunities with the priority of professional qualification.

RELATED ARTICLE
Dementia Friends sessions for nursing students (Nursing Older People 2015)
rcni.com/dementia-friends-sessions

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PEER-REVIEWED

Solution-oriented learning to build resilience in mental health nursing students and recently qualified nurses

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Abstract

Increasing concerns about nursing students' mental health and the retention crisis facing nursing mean it is essential that staff working in nurse education develop effective responses to enable nursing students to acquire the skills, strategies and confidence that will sustain them throughout their education and beyond. The principles and interventions of solution-focused brief therapy can be applied in nurse education. The authors outline a solution-oriented learning (SOL) model and argue that it has the potential to build intrinsic motivation, promote deeper learning, strengthen support networks and empower nursing students. The SOL approach can be incorporated into a range of active learning experiences so that, over time, nursing students learn the SOL strategies and can use them independently to address broader personal and professional learning needs. The ability to take a positive, optimistic and structured approach may contribute to building resilience and sustaining nurses post-qualification, therefore contributing to nurse retention.

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Keywords

education, nurses, resilience, retention, solution-oriented learning

RESILIENCE HAS been identified as a key factor for nursing students' and qualified nurses' capacity to withstand challenges and succeed in their roles (Brennan 2017). It is associated with resourcefulness, calmness, adaptability and confidence. Conversely, a lack of resilience is associated with burnout, which in turn is a risk factor for intention to leave the profession (Royal College of Nursing (RCN) 2012). Resilience comprises multidimensional personal characteristics that can be developed (Brennan 2017). This article outlines how a solution-oriented learning (SOL) teaching strategy is used in a mental health nursing preregistration programme, and describes its potential to contribute to resilience-enhancing outcomes for individuals and services. SOL outcomes, with aligned teaching and assessment focused on resilience (Biggs and Tang 2011), are designed to improve nursing students' well-being and sustain them post-qualification, therefore aiding staff retention.

SOL is a teaching strategy that has grown from the philosophy and approach of solution-focused brief therapy (SFBT) developed by de Shazer and colleagues (Shennan 2014, Milner and Myers 2017). SFBT is a goal-oriented, structured therapeutic intervention in which the therapist works with the client to build on his or her existing strengths to work towards desired outcomes. The focus of SFBT is less on analysing the causes of a problem, and more on what the ideal outcome would be and the steps needed to achieve it (Milner and Myers 2017). A solution-focused orientation has better outcomes than a focus on problems for therapy (Carerra et al 2016), education (Franklin et al 2008) and coaching (Braunstein and Grant 2016), perhaps because of the empowerment implied in giving attention and positive reinforcement to the client's own ability to cope with difficulties, or resilience, and build on it.

We propose a new model of learning using a focus on solutions, in which the nurse, as an individual and as a team member, is identified as part of the context and the solution to the challenges of professional practice. As nurse educators working with mental health nursing students, we incorporate a solution-focused approach that harnesses students' own strengths as they learn. In our experience this approach leads to student ownership of their development and builds intrinsic motivation. In working together to plan for

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solutions, students need to evaluate how they respond to service users, family carers and multidisciplinary colleagues, and their own strengths, strategies and development needs. Being recipients of a person-centred, solution-oriented teaching style is empowering: students absorb the stages and interventions of SFBT, which they can use to develop their own learning and to support each other when leading teams in practice and when working with clients in practice.

Background

Nurses are caring for increasingly frail and more dependent patients, with limited resources and staff shortages (RCN 2012). These stressors have implications for nurses' mental and physical health and the quality of care they offer to service users. Nurses may find they cannot deliver care to the standard they wish to and may be concerned about levels of risk to patients (Cummings 2011). Unhappiness at work leads to high attrition rates (Good Governance Institute 2015), and newly qualified nurses experience high levels of stress and burnout (Health Education England (HEE) 2014), with resultant intention to leave or actual withdrawal from nursing (Brennan 2017). Nurse turnover is damaging for the nurses who leave and for their colleagues who remain; it has negative implications for patient experiences and is costly for organisations (HEE 2014).

Reports have highlighted ongoing concerns about students' mental health (Brown 2016, Unite Students 2016). Poor student mental health is associated with failing to complete the course, hazardous drinking and suicide (Brown 2016). Patterns of poor mental health among healthcare workers are repeated internationally: Carod-Artal and Vazquez-Cabrera (2013) identified global studies that echo UK and European findings of high levels of emotional exhaustion and depersonalisation, with low levels of personal accomplishment. Educators' duty towards students' well-being does not only apply while they are studying: it also involves preparation for their professional well-being, with implications for their future retention in the profession.

There are ethical considerations to promoting resilience and we are not suggesting that nurses should be prepared to be ever-more resilient to be able to cope with ever-higher demands. Instead, we suggest that resilience should incorporate professional self-respect and assertiveness, empowering nurses to articulate the conditions required for high standards of care, and that skills to support resilience can be embedded throughout the curriculum.

Solution-oriented learning teaching strategies

We teach preregistration mental health nurses about the recovery model and nursing responses to meeting the needs of adults with serious mental health problems and dementia. In addition, we prepare students for the transition to becoming a qualified nurse. Students express fears about maintaining their values and commitment, knowing that their mentors, who may show signs of burnout (HEE 2014) were in their positions only a few years previously. The aim of the SOL approach is to build resilience for individual well-being, culture change and sustainable practice. Students gain from having an effective therapeutic skill set that is role-modelled in their relationships with teaching staff which, over time, they learn to use more effectively on themselves and each other. This is also demonstrated by teaching staff who model how a solution-oriented approach can guide and support through a range of challenging situations. The implications of emotional labour (Edward et al 2017) and mutual support strategies are incorporated into 'trigger situations' that are explored together with students. A trigger situation is a scenario that reflects a real-world nursing dilemma, in which managing one's own physical and emotional reactions is as central to success as responding to service users' needs for safety or therapeutic intervention. For example, 'The aunt of a distressed service-user phones to say his mother has recently died. She says she cannot face telling him, saying, 'he'll go ballistic' so requests the nurses do so. What would you do and why?'

In this way, professional abilities and interpersonal skills are combined at levels of increasing complexity through the learning experience (Phumeechanya and Wannapiroon 2014). Table 1 shows an example of how SOL might work in practice and focuses on gaining consent for personal care from a patient with dementia. We see SOL as improving the well-being of students and service users, while having the potential to be embedded throughout the programme.

Working together to find solutions has an extensive evidence base, but its potential is under-explored in health education. The solution-oriented approach is more than problem-based learning reworded. Linguistic choices have deeply embedded emotional consequences that drive behaviour (Marrero et al 2017): a deliberate and positive orientation to 'solutions' is designed to lead to optimism and commitment, while the strategy itself provides a structured approach

Implications for practice

- Nursing education should incorporate ways of learning that help to build students' well-being and resilience so they are well equipped to enter the nursing profession
- Educators' duty towards students' well-being applies not only while they are studying, but also involves preparation for their professional well-being, with implications for their future retention in the profession
- Solution-oriented learning harnesses students' strengths as they learn and has the potential to build intrinsic motivation, promote deeper learning, strengthen support networks and empower nursing students

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to achieving goals. Benefits of working together to solve problems include ‘deeper learning’ (Dolmans and Gijbels 2013), bridging the theory-practice gap (D’Sa and Bhaduri 2013), improved long-term retention of content and improved clinical skills and reasoning (Prosser and Sze 2014). Emotional intelligence is enhanced through aiding students to work autonomously, feel competent and related to others, and be intrinsically motivated and self-regulating (Dolmans and Gijbels 2013, D’Sa and Bhaduri 2013). Students develop lifelong learning skills (Prosser and Sze 2014) and essential soft skills, including team working, communication and interpersonal skills (Cooper and Carver 2012). SOL is not well known in health education, but has had positive outcomes in sustainability education, where structured active experiential learning has empowered students to learn how to think strategically and ethically (Wiek and Kay 2015), with a focus on creatively finding solutions.

Alignment of learning outcomes, teaching content and assessment are well established (Biggs and Tang 2011); in addition in the solution-oriented approach, we model professional values and interpersonal approaches that we hope students will demonstrate with service users. We take a person-centred approach, based on the work of Rogers (2004), aiming to relate to students with empathy, genuineness and unconditional positive regard. So we respond to classroom issues using skills drawn from professional practice, including those of person-centred counselling (Rogers 2004), solution-focused therapy (Shennan 2014) and motivational interviewing (Lundahl et al 2013).

TABLE 1. Learning communication skills for effective working relationships – an example from nurse education

Year 1: Gaining consent for personal care when a service user has dementia	
Solution-focused therapy intervention	Teaching intervention – small group work
‘Miracle question’ to identify student-centred learning outcome	Teaching staff ask: ‘If you woke up tomorrow and a miracle had happened and you were excellent at gaining consent with people with dementia, how would it look to someone watching? What would it feel like? What little things would you/your mentor notice first?’
Scaling questions and coping questions	Teaching staff ask: ‘On a scale of one to ten, where are you in your ability to gain consent? Respond accordingly, for example, so even though you have not yet had much experience, you are already developing the skills to get to five. What are you doing to get there? How would you get to six?’
What were your previous solutions?	Students are asked to consider how they would feel if someone came up and began a personal care task without asking permission. How might they respond? How would the student try to address this situation in practice? Role play in pairs, for example, being reluctant to have one’s hair brushed and gaining consent
Looking for exceptions, compliments, future-oriented questions, doing more of what works	When did it go ok? What did you do, what skills did you use? What positive feedback could you give and receive? Teaching staff model the approach, for example: ‘I noticed that even though your service user looked angry, you stayed friendly, calm and pleasant as you approached them’
What else do you (students/teaching staff) need to know?	What are your next steps for learning? How could you build your expertise and support your colleagues to do the same?
Solution-focused therapy intervention	Teaching intervention – small group work

Learning needs identified by nursing students primarily relate to the requirement to deliver safe, effective person-centred care in a team-oriented approach. But in small group work, nursing students also learn to give and receive constructive criticism, to notice each other’s signs of stress, and to adjust their supportive responses so that they can work together effectively. They learn to learn, but they also learn to teach, regularly sharing knowledge in seminars, presentations and small group work. Other examples of our SOL activities include working with experts by experience to explore the theory-practice link (Maher et al 2017), and working with actors to practise specialist communication skills needed for working with people with dementia. Students practise articulating a point of view, listening to complex arguments, assertiveness and prioritisation skills, all of which contribute to their ability to manage workloads and liaise with a range of colleagues.

In identifying and working towards solutions together, the students come to rely on each other and build strong friendships. Having a social network of trusted colleagues is essential in building resilience (Burdick 2015) and promoting staff retention (Read 2014). In this way students can mutually contribute to one another’s long-term professional well-being.

In more formal structured sessions aimed at employability, students reflect on their own anxieties, strengths and weaknesses as they approach qualification. They research strategies that will empower them in addressing their perceived difficulties, including those on delegation, team working, having difficult conversations, challenging others and negotiating compromises as they transition into practice and develop towards leadership roles.

While successful recruitment is essential for organisations, it is equally important to retain experienced staff. Nurses leave the profession because of feelings of isolation, threatened

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burnout and feeling overwhelmed by the demands of their jobs (HEE 2014). Having confidence in one's ability to cope lessens anxieties and promotes feelings of autonomy, therefore reducing stress (Cummings 2011). Solution-oriented outcomes should, therefore, target development of the interpersonal skills, problem-solving ability and self-esteem needed to respond positively to stressful situations, to manage emotions effectively, respond assertively to unrealistic or unsafe expectations and learn through adversity.

Recommendations

We propose a student-centred SOL model that reflects a collaborative approach to identifying learning goals and constructing the steps required to achieve them, based on the principles and steps of SFBT:

- Identify a learning outcome: ask a 'miracle question' – for example 'If you woke up tomorrow and everything was as good as it could possibly be, what would it be like? - and generate discussion around ideal outcomes and the skills, abilities and experiences that will result.
- Identify students' existing strengths, based on scaling questions, exceptions and previous solutions.
- Generate optimism by exploring small steps and facilitate learning through relationships based on Rogerian values and person-centred communication skills.
- Provide a 'soft scaffold' in which support is offered, adjusted or removed according to students' needs and developing confidence as they work through the steps that contribute to achieving the desired solutions and learning, while formally and informally using SFBT techniques.
- Focus on the future – explore how this learning is transferable and what new learning is required.

Conclusion

We argue that the SOL model has potential for long-term benefit in addressing students' well-being and retention of qualified nurses. It aligns values, skills and knowledge together in learning outcomes, with taught content that reflects nursing students' needs alongside those of service users, and assessment strategies that reinforce expectations of professional, practical and emotional competence.

Further work is needed to develop and evaluate the SOL model for nurse education. There is an ethical and business case for incorporating long-term resilience preparation into preregistration nursing courses using an SOL approach. Lesson plans can be adjusted to incorporate the interpersonal skills and group experiences that will benefit students' emotional well-being, while laying the foundations for confident, capable, supportive and sustainable practice post-qualification.

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