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Abstract

Background

'Experts by experience' (EBE) involvement in professional healthcare education programmes contributes to developing students' caring skills by supporting students' understanding of the lived experience and reality of service-users' situations. Also, involvement in healthcare education is a beneficial experience for EBEs themselves. This study aimed to explore specifically older people's experiences and perceptions of their involvement of EBE in gerontological education to generate insight into their understanding of this experience.

Methods

In this qualitative study, EBEs contributing to delivery of healthcare professional education programmes at a UK university took part in focus groups (n=14) to discuss their views and experiences of involvement in EBE teaching. Data were analysed using open coding.

Findings

Four themes emerged from the data, suggesting that older EBEs' involvement in education may be beneficial for their wellbeing. The four themes were: 'contributing to improved care', 'having a purpose', 'being included', and 'feeling appreciated'.

Conclusions

Findings support the requirement for nurse educators to develop EBE programmes that involve older people, not only as a teaching strategy for students, but also as a method of promoting the health and wellbeing of the older EBEs.

Originality

There is limited research regarding specifically older EBEs' experiences of involvement in gerontological education. This is an important area of study because involvement in education may constitute a means of engaging in social, community, and voluntary activities for older people, which recent UK health policies advocate as methods of promoting and facilitating healthy ageing.

Introduction

It is well recognized that globally, the population is ageing. In the United Kingdom (UK), the percentage of people over the age of 65 years is set to increase from the current figure of 18% to 26% over the next 40 years (Office of National Statistics, 2019). Many older people live healthy and independent lives. However, many others live with one or more long-term medical conditions, frailty and/or disability (Kingston, et al., 2018). The impact on longevity and multi-morbidity is illustrated by the fact that older people are the primary users of health and social care. Currently in England, approximately half of all hospital admissions involve people over the age of 65, while 67% of all social care clients are aged over 65 years (Health Foundation, 2018). These documents acknowledge that one of the most significant drivers for modification to health and social care services is the changing demography.

In the UK, questions about the quality of care for older adults have been a public concern for a number of years (Francis, 2013; Cavendish, 2013; Age UK, 2018). In response, numerous initiatives have been introduced which aim to provide care tailored to the needs of older people. These include, movement towards integrated care systems; recognising and accounting for frailty; focusing on healthy ageing; promoting personalised care planning; and equipping the health and social care workforce with skills to care for older people with complex multi-morbidities (National Institute for Health Research, 2017; NHS England, 2019a). Within this context, this study suggests that the employment of older people as Experts by Experience (EBE) in nurse education can support implementation of some of these initiatives. While it is well documented that EBE education activities supports workforce development, this study also suggests EBE may be a means of providing personalised support, and health and wellbeing promotion for older people engaged in EBE activity.

Background

A plethora of evidence (for example Lathlean et al., 2006; Turnbull and Weeley 2013; Suikkala et al., 2016; Picton et al., 2019; Happell et al., 2019) suggests that EBE involvement in health and social care education can contribute to the development of students' caring skills by supporting students' understanding of the lived experience and reality of service-users' situations. Suikkala et al.'s (2016) study specifically considers older EBE involvement. The study found that the approach contributed to healthcare students' understanding of multi-morbidity and functional decline challenges that older patients face, and students' sensitivity to the care preferences of older people increased.

Although most research investigating EBE in education focuses on learner outcomes, a number of studies do consider the experiences and perceptions of EBEs themselves. The literature that is available proposes that in general, involvement in health and social care education is a beneficial experience for EBEs. For example, Lathlean et al.'s (2006) study of approaches to engage EBEs in education, and Frisby's (2001) exploration of EBEs with mental health conditions conclude that EBE activity can be empowering. Muir and Laxton (2012) suggest EBEs find involvement in medical students' practice assessment is rewarding for those involved. Abe et al.'s (2010) survey of SPS found that involvement in that EBE approach is highly satisfying. Plaksin et al.'s (2016) literature review of the benefits and risks of EBE involvement found that EBE activity leads to improved health and wellbeing behaviours, and increased social and relationship-building activities.

Although overall, EBE involvement can be beneficial for those undertaking the activity, there are some risks. EBEs can experience 'performance' stress (Bokken et al., 2004; Harvey et al., 2011) and they can become fatigued or exhausted during EBE activity (Denny et al., 2006; Lathlean et al, 2006), although Lathlean et al.'s study concludes that stress and fatigue are not long-lasting.

Although a number of studies exploring EBE involvement in education have been undertaken, there is a dearth of research regarding specifically older EBEs' experiences of involvement in gerontological education. This is potentially an important area of study because on one hand, older people have particular vulnerabilities in that they have an increased likelihood of having experienced ill health themselves, may be more susceptible to fatigue, or may have disabilities or sensory impairment that affect their involvement. On the other hand, however, older EBEs' involvement in education may constitute a means of engaging in social, community, and voluntary activities for them, which recent health policies advocate as methods of promoting and facilitating healthy ageing and improved quality of life for older people (NICE, 2015a; 2015b; NHS England, 2016). Therefore, the aim of this study was to explore older people's experiences and perceptions of their involvement of EBE education with a view to generating insight into their understanding of this experience.

Methodology and methods

The study aimed to explore the complexities of perception and experience. A qualitative research approach was therefore deemed appropriate. Denzin and Lincoln (2000) proposed that qualitative methods yield rich, in-depth knowledge of how individuals think, experience and behave within given contexts. Approval to undertake the study was granted by the Faculty of Health and Life Sciences Ethics Committee, Northumbria University.

A UK university had developed a pre-registration nursing module and continuing workforce development modules for nurses and allied healthcare professionals that aim to equip students with the knowledge and skills to provide quality care for older people. EBE involvement was integral to these modules, and took the form of three approaches:

- Older people narrate their experiences of illness, caring, and health and social care provision (narrative approach).
- Older people discuss their participation in wellbeing initiatives.

- Older people roleplay patients in a variety of health and social care settings (Standardised patient simulation (SPS)).

Twenty EBEs contributed to module delivery, and all were invited to take part in the study. Fourteen individuals agreed to participate. Individuals who agreed to participate were provided with information about the study, and if they decided to take part they were asked to complete a consent form. Participants were allocated unique identifier codes, which supported anonymity of data. Data collection took place in university classrooms. All participants were familiar with these settings, and felt at ease in these rooms.

Participants were invited to take part in two focus group interviews. All participants were invited to the first focus group interview, and ten attended. This focus group discussion enabled participants to share their diverse experiences. They were invited to discuss their motivations to participate in this EBE innovation, their views on older people's involvement in EBE teaching, and their experiences of EBE. In acknowledgement that participants were involved in EBE teaching in different ways, a series of second focus group interviews were arranged which reflected the nature of the involvement of group members in EBE teaching. There were two interviews with those involved in narrative discussion (ND); one interview with those involved in discussing wellbeing initiatives (WBI); two interviews with those involved in SPS. These discussions explored participants' reasons for participation, what they considered would be the outcomes of their participation, challenges encountered with regard to participation, and their reflections on their experiences.

Table 1: Participant details

INSERT TABLE 1 HERE

Interviews were audio-recorded and transcribed verbatim. Individual research team members open coded the data. In order to validate coding, other team members independently re-coded data. During a team meeting, coding outcomes were compared and

variations and similarities were discussed. This informed the process of collapsing codes into larger categories, and theme development. This allowed elucidation and description of participants' experiences of EBE, whilst creating meaningful themes.

Findings

Four themes emerged from the data analysis. These were 'contributing to improved care', 'having a purpose', 'being included', and 'feeling appreciated'.

'The chance to put things right': Contributing to improved care

Participants who were engaged in narrative discussions and SPS said a significant motivator for becoming EBEs was to improve health and social care for older people. These participants recounted episodes of care they had experienced and considered as examples of poor care. By becoming involved in the education of student nurses, they felt they were contributing to the development of a workforce with better understanding of what older patients require from care:

> I was so angry and upset when my husband died and the things that went wrong. And at that particular point I thought, if ever I get the chance to try and influence the way that students are taught and put things right (ND1)

Some participants reported that engaging in EBE education could be an emotional experience, as it could bring back painful memories of their own experiences:

> And you could almost feel…you could get upset, really. You could get a little bit upset. Because you sort of remember (SPS3).

However, they continued to contribute because they considered themselves as change agents, and their involvement as an effective method of developing students' care practices and ultimately improving care for older people:

> You are a drained at the end of the day. I go home whacked out. In fact, [wife] has said once or twice, "Pack it in", you know. But, no, I would never do that. But anyway, it's, it's quite thrilling to be able to do something like that…you can see it coming out [students' caring behaviours] (SPS2).

> You've put everything into it. But it is satisfying. You know, to see that person that you're actually interacting with change throughout the time you're with them (ND3).

Those engaged in workshops and seminars where they discussed their participation in wellbeing initiatives viewed their involvement as a means of demonstrating that most older people live well and require preventative healthcare to maintain their health. This group were concerned that older people are portrayed and perceived by society as dependent, disabled and frail. This group were particularly keen to challenge this perception. Some wanted to dispel this stereotype by exposing students to well older people, who they felt constituted the majority of older people. By doing so, they suggested students would see that ageing is a normal part of life:

> But most older people, haven't got illnesses…dementia. So we've got to make the students aware that old age is not a funny thing. You've got to understand that it's a slow progress. Everybody is an individual, and you've got to just go with the flow. And just let students understand that everybody gets old (WBI1)

Others felt that increasing frailty and the onset of chronic conditions were part of getting old, but felt EBE provided an opportunity to demonstrate older people can live well despite such challenges. They wanted the students to have understanding of abilities and capabilities rather than focusing only on the impact of disease:

> To show the students, rather than a person with dementia, what they can't do – was to show what they can do - to maybe change people's perception of older people and people with dementia (WBI4)

'I can get up and come and do things': Having a purpose

Many participants viewed EBE as a means of engaging in purposeful activity. For example, some viewed EBE activity as a method of continuing, or returning, to work:

> I didn't want to retire. When I was 65, I didn't want to stop working. I had to. It's nice that I don't have to stop working. I can get up and come and do things (SPS1).

> I kind of thought when I was made redundant, I've got all this thing here, what am I going to do with it? So it's nice to have that outlet (ND3).

For other participants, EBE was a means of engaging in achievable activities. These participants explained that in circumstances where frailty, long term conditions or disability were inhibiting their physical or cognitive ability, some of their favoured hobbies and activities were no longer possible. However, these limitations did not impede EBE engagement:

> He'll [partner] be off out walking somewhere…And I can't do walking anymore, so this is really something I *can* do and enjoy (SPS1).

For some SPS participants, SPS facilitated engagement with the interests and aspirations of their younger days. For these participants, EBE was not a type of work, but an opportunity to pursue activities and personal ambitions that had been unfeasible during their parenting or working lives. One SPS participant explained how SPS offered an opportunity to fulfil a long held dream of acting:

> A long time ago there was these drama groups going on, and I thought, "That's great, that. I wouldn't mind doing that". But I never got round to it. But now I've fulfilled my ambition (SPS2).

'We're not treated like outsiders': Being included

Many participants talked about the comradeship and sense of belonging that EBE involvement afforded. Although they enjoyed and valued the company of their EBE peers, they also very much valued the reintegration with the 'working world', particularly inclusion in the teaching team, that EBE involvement brought:

> They treat us like a member of staff. Like a colleague, which is nice. We're not treated like outsiders (SPS1).

This sense of belonging was not restricted to belonging to the teaching team. Some participants expressed affinity and affiliation with the university. This was not expressed in terms of belonging by virtue of working there, but by an emotional connection with the institute itself:

> I think of the university as my university (ND1)

Other participants referred to the university as an abstract term representing academia or an 'ivory tower'. Some of these participants previously had had no contact with universities, perceiving these institutions as being beyond their reach. Some had knowledge of universities because their grandchildren or other young family members attended universities, something of which they were very proud. For this group of participants, association with, and indeed belonging to the concept of 'university' led to feelings of prestige and immense pride, enhancing their own sense of self-worth.

> To think that the university thinks that I've got any that's worth listening to (WBI3).

'I'm made to feel like we've done good work': Feeling appreciated

Many participants remarked upon students' and staffs' appreciation of their EBE engagement:

> And then at the end, they [students] were very, very enthusiastic…and thanked us (SPS4).

The participants interpreted this appreciation as evidence that their EBE contribution was valued by students:

> And the fact they appreciate it at the end shows that it is important for them (SPS2)

One participant suggested that this appreciation was an indication that his contribution was valuable: 'I'm made to feel like we've done good work' (SPS3). Feeling appreciated led participants to derive a sense of accomplishment. They used words such as 'achievement', 'success' and 'satisfaction' to illustrate how they felt.

Some participants articulated concern that older people are viewed as a 'burden' on society. However, the appreciation of staff and students appeared to indicate to participants that their contribution to supporting learning was a kind of recompense:

> And I feel as though I've given something back (SPS3).

> It's the fact that you're putting something back, you know. And you are acknowledged as doing that, and people appreciate what you do (WBI5).

Discussion

The findings of this study indicated that involving older people in EBE education has personal wellbeing benefits. All participants enjoyed the EBE activities, but involvement also had a profounder significance for them. Some responses inferred that EBE engagement facilitated 'making sense' of experiences of illness and the care they received. For example, some participants reflected on their experiences of inadequate care as a stimulus to improve future care. They conveyed to students the effect of poor care on older patients and their families, and by doing so, felt that they were contributing to the development of caring and compassionate nurses. This desire to generate 'good' from 'bad' experiences motivated these participants' continued contribution, in spite of the fatigue and upset involvement could cause them. Other participants' EBE involvement was more about developing students' understanding that age is simply one stage in the life course – a stage that most people experience, and is thus 'normal'. These groups of participants were keen to demonstrate that by virtue of the experiences and knowledge they have accumulated over a life time, older people are able to make a valuable contribution to society, although they may need support and opportunities to do so. This finding aligns with Tornstam's (2005) symbolic interactionist

theory of gerotranscendence - the idea that as people age, they transcend the 'limited' views they held in their earlier days, becoming less self-focused, more 'connected' to the natural world, and more accepting of life events. Tornstam argues that ageing is a natural development process towards maturity and 'wisdom'. Wisdom in this context is defined as older people's reflections on their cumulative experiences resulting in toleration of life's ambiguities and challenges, consequently leading to a desire and faculty to offer valuable counsel.

Gerontological research recognises that older people are at high risk of experiencing social losses. Although in recent decades, there has been an increase in family reliance on older relatives for childcare support and financial support (Wellard, 2012; Scanlon et al., 2019), according to Wellard (2012), this has not significantly mitigated the reduced recognition for their contributions to society that many older people experience. Fingerman et al. (2013) suggest this may be because older people are less likely to work, less likely to engage in intensive parenting, and more likely to be viewed as out-of-touch with contemporary social issues, resulting in loss of familial and societal roles as provider or advisor. Older people are also liable to experience the death of peers and significant others, and are at increased risk of frailty, chronic disease and disabilities, which according to Krause (2007; 2010) reduces capability to participate in both social and solo favoured activities. As a result, some older people are at risk of social isolation, and lowered self-esteem, which can have significant negative impacts upon physical and psychological health (Krause, 2007; 2010; Eakman, 2013).

A number of health and social care initiatives acknowledge this situation, and attempt to redress it. Nolan's 'senses framework' (Nolan et al., 2004; 2006) proposes that quality of life for older people is optimised when they experience care and support that facilitates senses including belonging, significance, achievement, purpose and continuity. Recent health and social care policy and guidelines require that older people should be supported to access

opportunities to engage in social groups, volunteering, community activities and cultural activities with the aims of promoting social interaction, meaningful activity, feelings of worth and achievement (NICE, 2015a; 2015b). Recognition of the health and wellbeing benefits of these opportunities and activities has led to the introduction of social prescribing, defined as 'empowering people with social, emotional or practical needs to find solutions which will improve their health and wellbeing' (NHS England, 2019b).

Although the focus of social prescribing is on the use of services provided by voluntary, community and social enterprise sectors, this study suggests that in many ways, engaging older people in EBE education was a kind of social intervention. Being involved in EBE education enriched participants' social network and engagement with activities that they considered to have purpose and value, and were meaningful to them. EBE involvement also facilitated participants' reflection upon their life course, in that it provided connections to their past lives and activities, and also supported them to look forward. For example, some participants viewed EBE activity as a way of returning to work, or regaining social roles involving advising and supporting others. This activity enabled some to extend their working life, which is actively being encouraged by the UK government. Some participants embraced EBE activity because it provided an opportunity to achieve ambitions and aspirations that they thought had passed them by. For these participants, the activity offered a link with the past, and a sense of continuity.

However, in some cases, ageing and disability meant that participants were no longer able to carry on with activities they had enjoyed in the past. In these instances, EBE involvement provided new interests with achievable outcomes. For older people with long term conditions, disabilities and frailty, total recovery is not an option. A number of studies (for example, Brooks Bouson, 2016; de Lange, 2017), using Frank's (1995) seminal discussion of illness narrative typologies, suggest that care cultures that focus on recovery and rehabilitation i.e 'restitution' may not be helpful for this group of people, as they may

experience feelings of failure, and feel their life has stagnated, because they are unable to recover the health and/or abilities they have lost. However, if people are introduced to new opportunities and activities which are achievable, then they may be prompted to view illness as a means of gaining experience which can be used, and approach illness as an impetus for modifying and developing aspirations, and exploring new possibilities and roles. This appears to have been the case for some participants in this study, whose involvement in EBE signified capability and a focus on what they could achieve, rather than what they could no longer do.

EBE involvement gave many participants a sense of not only being part of a team, but belonging to a community. A number of studies (for example, Seeman, 2000; Holt-Lunstad et al., 2010; 2015; Shor et al. 2015), and acknowledged by social prescribing initiatives (NHS England, 2019b), propose that this brings health and wellbeing benefits. These include social support, social interaction, identity, belonging, and opportunities to engage in meaningful activity. In this study, participants' responses suggested that they often feel marginalised as 'outsiders' in society, but that being part of the teaching community facilitated a sense of belonging. Belonging to a community that provides a public service was important to them, as it enabled them to contribute in very positive ways to the functioning of society. Being identified with the university was particularly significant to some. These participants inferred that because they viewed the concept of 'university' with awe and admiration, belonging to, and being identified with it was something to be deeply proud of. Since Tajfel's (1971; 1982) seminal work in the 1970s and 1980s on social identity theory, it has been widely acknowledged that the personal identity and self-perception of individuals is strongly influenced by their affiliations and interactions with groups or communities. According to Hogg (2016), this can have a profound impact on the sense of self, including perceptions of self-worth, and status position within society. For participants in this study, whose responses suggested they previously felt marginalised as 'outsiders' because of their

advancing age, affiliation with the university, and engagement in university activities, repositioned them in society to a position widely acknowledged as prestigious and highly valued.

Being appreciated by teaching staff and students was central to cultivating participants' feelings of belonging. On a more tangible level, participants saw the university as a place of work, but of work that was recognised and appreciated by others as being important, influential and valuable. Studies of motivation in volunteering by Haski-Leventhal et al. (2016) and Hogg (2016) conclude that many older people value opportunities to continue to contribute to, as well as appropriate from, society, and be recognised as participating in this 'give and take' process. Thompson (2016) proposes that appreciation and reassurance is necessary to identify that work is acknowledged, particularly for groups that have low self-esteem resulting in part from low societal value, as appreciation is integral to building positive self-perception, and life satisfaction. Recent policy supporting older people's involvement in volunteering and work not only acknowledges the importance to older people of continuing to contribute, but also the importance of being recognised as contributors by society. Such policies acknowledge that stereotypical views of older people as 'burdens' on society are damaging, in that they can lead to social and health inequalities (NICE 2015a; 2015b).

Conclusion

If older people are to be involved in EBE education, it is important that educators understand how older people experience and view the activity. This study suggests that although engaging in the activity can be fatiguing for older people, nevertheless many wellbeing benefits arise. Findings support the requirement for nurse educators to develop EBE programmes that involve older people, not only as a teaching strategy for students, but also as a method of promoting the health and wellbeing of the older EBEs. Nurse educators

support students' understanding of contemporary health and wellbeing issues, and effective ways of promoting health and managing care. Supporting older people to maintain independence, social wellbeing and mental health wellbeing are high on contemporary health and care agendas, so EBE may be a useful method of not only teaching students about these issues, but actually demonstrating a social intervention in action. In the future, if education institutions link with community and voluntary sector organisations, it may be possible to include EBE activity on social prescribing activity lists, however, further research in this area is warranted.

Limitations

This study's findings are based upon the responses of a small number of EBE participants located in one university in England. The insights and new perspectives offered by this study should therefore be considered by further studies in other contexts.

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Table 1: Participant details

Participants			Focus groups					
Participant	**Gender**	**Age**	**General**	**ND 1**	**ND 2**	**WBI**	**SPS 1**	**SPS 2**
ND1	F	60-69	X	X				
ND2	F	>80	X	X				
ND3	M	70-79			X			
ND4	F	60-69			X			
WBI1	M	>80	X			X		
WBI2	M	70-79	X			X		
WBI3	F	>80	X			X		
WBI4	F	>80	X			X		
WBI5	F	70-79	X			X		
SPS1	M	>80	X				X	
SPS2	M	60-69	X				X	
SPS3	F	70-79	X				X	
SPS4	F	60-69						X
SPS5	F	70-79						X