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Older people's involvement in healthcare education: Views and experiences of older experts by experience

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4 **Title: Older people's involvement in healthcare education: Views and experiences of**
5 **older experts by experience**
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8

9 **Abstract**
10

11 **Background**
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15 'Experts by experience' (EBE) involvement in professional healthcare education
16 programmes contributes to developing students' caring skills by supporting students'
17 understanding of the lived experience and reality of service-users' situations. Also,
18 involvement in healthcare education is a beneficial experience for EBEs themselves. This
19 study aimed to explore specifically older people's experiences and perceptions of their
20 involvement of EBE in gerontological education to generate insight into their understanding
21 of this experience.
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29 **Methods**
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33 In this qualitative study, EBEs contributing to delivery of healthcare professional education
34 programmes at a UK university took part in focus groups (n=14) to discuss their views and
35 experiences of involvement in EBE teaching. Data were analysed using open coding.
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40 **Findings**
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43 Four themes emerged from the data, suggesting that older EBEs' involvement in education
44 may be beneficial for their wellbeing. The four themes were: 'contributing to improved care',
45 'having a purpose', 'being included', and 'feeling appreciated'.
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50 **Conclusions**
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53 Findings support the requirement for nurse educators to develop EBE programmes that
54 involve older people, not only as a teaching strategy for students, but also as a method of
55 promoting the health and wellbeing of the older EBEs.
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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.

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4 Although a number of studies exploring EBE involvement in education have been
5
6 undertaken, there is a dearth of research regarding specifically older EBEs' experiences of
7
8 involvement in gerontological education. This is potentially an important area of study
9
10 because on one hand, older people have particular vulnerabilities in that they have an
11
12 increased likelihood of having experienced ill health themselves, may be more susceptible to
13
14 fatigue, or may have disabilities or sensory impairment that affect their involvement. On the
15
16 other hand, however, older EBEs' involvement in education may constitute a means of
17
18 engaging in social, community, and voluntary activities for them, which recent health policies
19
20 advocate as methods of promoting and facilitating healthy ageing and improved quality of life
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22 for older people (NICE, 2015a; 2015b; NHS England, 2016). Therefore, the aim of this study
23
24 was to explore older people's experiences and perceptions of their involvement of EBE
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26 education with a view to generating insight into their understanding of this experience.
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30 **Methodology and methods**

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33 The study aimed to explore the complexities of perception and experience. A qualitative
34
35 research approach was therefore deemed appropriate. Denzin and Lincoln (2000) proposed
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37 that qualitative methods yield rich, in-depth knowledge of how individuals think, experience
38
39 and behave within given contexts. Approval to undertake the study was granted by the
40
41 Faculty of Health and Life Sciences Ethics Committee, Northumbria University.
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44

45 A UK university had developed a pre-registration nursing module and continuing workforce
46
47 development modules for nurses and allied healthcare professionals that aim to equip
48
49 students with the knowledge and skills to provide quality care for older people. EBE
50
51 involvement was integral to these modules, and took the form of three approaches:
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53

- 54 • Older people narrate their experiences of illness, caring, and health and social care
55 provision (narrative approach).
- 56
- 57
- 58
- 59 • Older people discuss their participation in wellbeing initiatives.
- 60

- 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

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

11 Four themes emerged from the data analysis. These were 'contributing to improved care',
12 'having a purpose', 'being included', and 'feeling appreciated'.
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17 ***'The chance to put things right': Contributing to improved care***

18 Participants who were engaged in narrative discussions and SPS said a significant motivator
19 for becoming EBEs was to improve health and social care for older people. These
20 participants recounted episodes of care they had experienced and considered as examples
21 of poor care. By becoming involved in the education of student nurses, they felt they were
22 contributing to the development of a workforce with better understanding of what older
23 patients require from care:
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33 I was so angry and upset when my husband died and the things that went wrong.
34 And at that particular point I thought, if ever I get the chance to try and influence
35 the way that students are taught and put things right (ND1)
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38

39 Some participants reported that engaging in EBE education could be an emotional
40 experience, as it could bring back painful memories of their own experiences:
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42
43

44 And you could almost feel...you could get upset, really. You could get a little bit
45 upset. Because you sort of remember (SPS3).
46
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48 However, they continued to contribute because they considered themselves as change
49 agents, and their involvement as an effective method of developing students' care practices
50 and ultimately improving care for older people:
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52
53

54 You are a drained at the end of the day. I go home whacked out. In fact, [wife]
55 has said once or twice, "Pack it in", you know. But, no, I would never do that. But
56 anyway, it's, it's quite thrilling to be able to do something like that...you can see it
57 coming out [students' caring behaviours] (SPS2).
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4 You've put everything into it. But it is satisfying. You know, to see that person
5 that you're actually interacting with change throughout the time you're with them
6 (ND3).
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10 Those engaged in workshops and seminars where they discussed their participation in
11 wellbeing initiatives viewed their involvement as a means of demonstrating that most older
12 people live well and require preventative healthcare to maintain their health. This group
13 were concerned that older people are portrayed and perceived by society as dependent,
14 disabled and frail. This group were particularly keen to challenge this perception. Some
15 wanted to dispel this stereotype by exposing students to well older people, who they felt
16 constituted the majority of older people. By doing so, they suggested students would see
17 that ageing is a normal part of life:
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27 But most older people, haven't got illnesses...dementia. So we've got to make
28 the students aware that old age is not a funny thing. You've got to understand
29 that it's a slow progress. Everybody is an individual, and you've got to just go
30 with the flow. And just let students understand that everybody gets old (WB11)
31
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36 Others felt that increasing frailty and the onset of chronic conditions were part of getting old,
37 but felt EBE provided an opportunity to demonstrate older people can live well despite such
38 challenges. They wanted the students to have understanding of abilities and capabilities
39 rather than focusing only on the impact of disease:
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45 To show the students, rather than a person with dementia, what they can't do –
46 was to show what they can do - to maybe change people's perception of older
47 people and people with dementia (WB14)
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50 ***'I can get up and come and do things': Having a purpose***
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52 Many participants viewed EBE as a means of engaging in purposeful activity. For example,
53 some viewed EBE activity as a method of continuing, or returning, to work:
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4 I didn't want to retire. When I was 65, I didn't want to stop working. I had to. It's
5 nice that I don't have to stop working. I can get up and come and do things
6 (SPS1).
7
8

9 I kind of thought when I was made redundant, I've got all this thing here, what am
10 I going to do with it? So it's nice to have that outlet (ND3).
11
12

13 For other participants, EBE was a means of engaging in achievable activities. These
14 participants explained that in circumstances where frailty, long term conditions or disability
15 were inhibiting their physical or cognitive ability, some of their favoured hobbies and
16 activities were no longer possible. However, these limitations did not impede EBE
17 engagement:
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24 He'll [partner] be off out walking somewhere...And I can't do walking anymore, so
25 this is really something I *can* do and enjoy (SPS1).
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27

28 For some SPS participants, SPS facilitated engagement with the interests and aspirations of
29 their younger days. For these participants, EBE was not a type of work, but an opportunity to
30 pursue activities and personal ambitions that had been unfeasible during their parenting or
31 working lives. One SPS participant explained how SPS offered an opportunity to fulfil a long
32 held dream of acting:
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39 A long time ago there was these drama groups going on, and I thought, "That's
40 great, that. I wouldn't mind doing that". But I never got round to it. But now I've
41 fulfilled my ambition (SPS2).
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48 ***'We're not treated like outsiders': Being included***

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50 Many participants talked about the comradeship and sense of belonging that EBE
51 involvement afforded. Although they enjoyed and valued the company of their EBE peers,
52 they also very much valued the reintegration with the 'working world', particularly inclusion in
53 the teaching team, that EBE involvement brought:
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4 They treat us like a member of staff. Like a colleague, which is nice. We're not
5
6 treated like outsiders (SPS1).
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9 This sense of belonging was not restricted to belonging to the teaching team. Some
10
11 participants expressed affinity and affiliation with the university. This was not expressed
12
13 in terms of belonging by virtue of working there, but by an emotional connection with
14
15 the institute itself.
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17
18 I think of the university as my university (ND1)
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21 Other participants referred to the university as an abstract term representing academia or an
22
23 'ivory tower'. Some of these participants previously had had no contact with universities,
24
25 perceiving these institutions as being beyond their reach. Some had knowledge of
26
27 universities because their grandchildren or other young family members attended
28
29 universities, something of which they were very proud. For this group of participants,
30
31 association with, and indeed belonging to the concept of 'university' led to feelings of
32
33 prestige and immense pride, enhancing their own sense of self-worth.
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35
36 To think that the university thinks that I've got any that's worth listening to (WBI3).
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41 ***'I'm made to feel like we've done good work': Feeling appreciated***
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43 Many participants remarked upon students' and staffs' appreciation of their EBE
44
45 engagement:
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48 And then at the end, they [students] were very, very enthusiastic...and thanked
49
50 us (SPS4).
51

52
53 The participants interpreted this appreciation as evidence that their EBE contribution was
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55 valued by students:
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58 And the fact they appreciate it at the end shows that it is important for them
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60 (SPS2)

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4 One participant suggested that this appreciation was an indication that his contribution was
5 valuable: 'I'm made to feel like we've done good work' (SPS3). Feeling appreciated led
6 participants to derive a sense of accomplishment. They used words such as 'achievement',
7
8 'success' and 'satisfaction' to illustrate how they felt.
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12
13 Some participants articulated concern that older people are viewed as a 'burden' on society.
14 However, the appreciation of staff and students appeared to indicate to participants that their
15 contribution to supporting learning was a kind of recompense:
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18

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

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21
22 It's the fact that you're putting something back, you know. And you are
23
24 acknowledged as doing that, and people appreciate what you do (WB15).
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27

28 **Discussion**

29 The findings of this study indicated that involving older people in EBE education has
30 personal wellbeing benefits. All participants enjoyed the EBE activities, but involvement also
31 had a profounder significance for them. Some responses inferred that EBE engagement
32 facilitated 'making sense' of experiences of illness and the care they received. For example,
33 some participants reflected on their experiences of inadequate care as a stimulus to improve
34 future care. They conveyed to students the effect of poor care on older patients and their
35 families, and by doing so, felt that they were contributing to the development of caring and
36 compassionate nurses. This desire to generate 'good' from 'bad' experiences motivated
37 these participants' continued contribution, in spite of the fatigue and upset involvement could
38 cause them. Other participants' EBE involvement was more about developing students'
39 understanding that age is simply one stage in the life course – a stage that most people
40 experience, and is thus 'normal'. These groups of participants were keen to demonstrate that
41 by virtue of the experiences and knowledge they have accumulated over a life time, older
42 people are able to make a valuable contribution to society, although they may need support
43 and opportunities to do so. This finding aligns with Tornstam's (2005) symbolic interactionist
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4 theory of gerotranscendence - the idea that as people age, they transcend the 'limited' views
5
6 they held in their earlier days, becoming less self-focused, more 'connected' to the natural
7
8 world, and more accepting of life events. Tornstam argues that ageing is a natural
9
10 development process towards maturity and 'wisdom'. Wisdom in this context is defined as
11
12 older people's reflections on their cumulative experiences resulting in toleration of life's
13
14 ambiguities and challenges, consequently leading to a desire and faculty to offer valuable
15
16 counsel.
17

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19 Gerontological research recognises that older people are at high risk of experiencing social
20
21 losses. Although in recent decades, there has been an increase in family reliance on older
22
23 relatives for childcare support and financial support (Wellard, 2012; Scanlon et al., 2019),
24
25 according to Wellard (2012), this has not significantly mitigated the reduced recognition for
26
27 their contributions to society that many older people experience. Fingerman et al. (2013)
28
29 suggest this may be because older people are less likely to work, less likely to engage in
30
31 intensive parenting, and more likely to be viewed as out-of-touch with contemporary social
32
33 issues, resulting in loss of familial and societal roles as provider or advisor. Older people are
34
35 also liable to experience the death of peers and significant others, and are at increased risk
36
37 of frailty, chronic disease and disabilities, which according to Krause (2007; 2010) reduces
38
39 capability to participate in both social and solo favoured activities. As a result, some older
40
41 people are at risk of social isolation, and lowered self-esteem, which can have significant
42
43 negative impacts upon physical and psychological health (Krause, 2007; 2010; Eakman,
44
45 2013).
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48
49 A number of health and social care initiatives acknowledge this situation, and attempt to
50
51 redress it. Nolan's 'senses framework' (Nolan et al., 2004; 2006) proposes that quality of life
52
53 for older people is optimised when they experience care and support that facilitates senses
54
55 including belonging, significance, achievement, purpose and continuity. Recent health and
56
57 social care policy and guidelines require that older people should be supported to access
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4 opportunities to engage in social groups, volunteering, community activities and cultural
5
6 activities with the aims of promoting social interaction, meaningful activity, feelings of worth
7
8 and achievement (NICE, 2015a; 2015b). Recognition of the health and wellbeing benefits of
9
10 these opportunities and activities has led to the introduction of social prescribing, defined as
11
12 'empowering people with social, emotional or practical needs to find solutions which will
13
14 improve their health and wellbeing' (NHS England, 2019b).
15
16

17 Although the focus of social prescribing is on the use of services provided by voluntary,
18
19 community and social enterprise sectors, this study suggests that in many ways, engaging
20
21 older people in EBE education was a kind of social intervention. Being involved in EBE
22
23 education enriched participants' social network and engagement with activities that they
24
25 considered to have purpose and value, and were meaningful to them. EBE involvement also
26
27 facilitated participants' reflection upon their life course, in that it provided connections to their
28
29 past lives and activities, and also supported them to look forward. For example, some
30
31 participants viewed EBE activity as a way of returning to work, or regaining social roles
32
33 involving advising and supporting others. This activity enabled some to extend their working
34
35 life, which is actively being encouraged by the UK government. Some participants embraced
36
37 EBE activity because it provided an opportunity to achieve ambitions and aspirations that
38
39 they thought had passed them by. For these participants, the activity offered a link with the
40
41 past, and a sense of continuity.
42
43
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45 However, in some cases, ageing and disability meant that participants were no longer able
46
47 to carry on with activities they had enjoyed in the past. In these instances, EBE involvement
48
49 provided new interests with achievable outcomes. For older people with long term
50
51 conditions, disabilities and frailty, total recovery is not an option. A number of studies (for
52
53 example, Brooks Bouson, 2016; de Lange, 2017), using Frank's (1995) seminal discussion
54
55 of illness narrative typologies, suggest that care cultures that focus on recovery and
56
57 rehabilitation i.e 'restitution' may not be helpful for this group of people, as they may
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4 experience feelings of failure, and feel their life has stagnated, because they are unable to
5 recover the health and/or abilities they have lost. However, if people are introduced to new
6 opportunities and activities which are achievable, then they may be prompted to view illness
7 as a means of gaining experience which can be used, and approach illness as an impetus
8 for modifying and developing aspirations, and exploring new possibilities and roles. This
9 appears to have been the case for some participants in this study, whose involvement in
10 EBE signified capability and a focus on what they could achieve, rather than what they could
11 no longer do.
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23 EBE involvement gave many participants a sense of not only being part of a team, but
24 belonging to a community. A number of studies (for example, Seeman, 2000; Holt-Lunstad
25 et al., 2010; 2015; Shor et al. 2015), and acknowledged by social prescribing initiatives (NHS
26 England, 2019b), propose that this brings health and wellbeing benefits. These include
27 social support, social interaction, identity, belonging, and opportunities to engage in
28 meaningful activity. In this study, participants' responses suggested that they often feel
29 marginalised as 'outsiders' in society, but that being part of the teaching community
30 facilitated a sense of belonging. Belonging to a community that provides a public service was
31 important to them, as it enabled them to contribute in very positive ways to the functioning of
32 society. Being identified with the university was particularly significant to some. These
33 participants inferred that because they viewed the concept of 'university' with awe and
34 admiration, belonging to, and being identified with it was something to be deeply proud of.
35 Since Tajfel's (1971; 1982) seminal work in the 1970s and 1980s on social identity theory, it
36 has been widely acknowledged that the personal identity and self-perception of individuals is
37 strongly influenced by their affiliations and interactions with groups or communities.
38 According to Hogg (2016), this can have a profound impact on the sense of self, including
39 perceptions of self-worth, and status position within society. For participants in this study,
40 whose responses suggested they previously felt marginalised as 'outsiders' because of their
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4 advancing age, affiliation with the university, and engagement in university activities,
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6 repositioned them in society to a position widely acknowledged as prestigious and highly
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8 valued.
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11 Being appreciated by teaching staff and students was central to cultivating participants'
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13 feelings of belonging. On a more tangible level, participants saw the university as a place of
14
15 work, but of work that was recognised and appreciated by others as being important,
16
17 influential and valuable. Studies of motivation in volunteering by Haski-Leventhal et al.
18
19 (2016) and Hogg (2016) conclude that many older people value opportunities to continue to
20
21 contribute to, as well as appropriate from, society, and be recognised as participating in this
22
23 'give and take' process. Thompson (2016) proposes that appreciation and reassurance is
24
25 necessary to identify that work is acknowledged, particularly for groups that have low self-
26
27 esteem resulting in part from low societal value, as appreciation is integral to building
28
29 positive self-perception, and life satisfaction. Recent policy supporting older people's
30
31 involvement in volunteering and work not only acknowledges the importance to older people
32
33 of continuing to contribute, but also the importance of being recognised as contributors by
34
35 society. Such policies acknowledge that stereotypical views of older people as 'burdens' on
36
37 society are damaging, in that they can lead to social and health inequalities (NICE 2015a;
38
39 2015b).
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45 **Conclusion**

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47 If older people are to be involved in EBE education, it is important that educators understand
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49 how older people experience and view the activity. This study suggests that although
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51 engaging in the activity can be fatiguing for older people, nevertheless many wellbeing
52
53 benefits arise. Findings support the requirement for nurse educators to develop EBE
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55 programmes that involve older people, not only as a teaching strategy for students, but also
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57 as a method of promoting the health and wellbeing of the older EBEs. Nurse educators
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4 support students' understanding of contemporary health and wellbeing issues, and effective
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6 ways of promoting health and managing care. Supporting older people to maintain
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8 independence, social wellbeing and mental health wellbeing are high on contemporary
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10 health and care agendas, so EBE may be a useful method of not only teaching students
11
12 about these issues, but actually demonstrating a social intervention in action. In the future, if
13
14 education institutions link with community and voluntary sector organisations, it may be
15
16 possible to include EBE activity on social prescribing activity lists, however, further research
17
18 in this area is warranted.
19
20

21 **Limitations**

22
23 This study's findings are based upon the responses of a small number of EBE participants
24
25 located in one university in England. The insights and new perspectives offered by this study
26
27 should therefore be considered by further studies in other contexts.
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Working with Older People

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