People with dementia as peer workers, challenges and benefits: a thematic analysis and nominal groups study.

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Abstract

Background: There are national initiatives to involve service users in service delivery. However, programmes employing people with dementia as peer support workers (PSWs) in memory services are in their infancy. This study is the first to explore the challenges and benefits to staff and peers involved in such a programme.

Method: Focus groups, structured based on nominal groups methodology were run with PSWs and clinical staff from two memory services. In total there were 12 participants, with

three focus groups: PSWs alone (n=3); staff members alone (n=6); and PSWs and staff members combined (n=6). Data were analysed through thematic analysis of recorded session content and the ranking of themes inherent in a nominal groups approach.

Results: Perceived benefits of the PSW programme were similar for staff and PSWs and included personal benefits for PSWS and stereotype reduction for staff. More challenges were reported by staff than PSWs, but both groups agreed that role definition and dealing with the cognitive deterioration inherent in dementia were key issues.

Conclusions: The PSW programme does have benefits for involved staff and PSWs. However, the challenges identified highlight the need for careful and consensual setup and consideration of power dynamics, with agreed roles and clear guidelines to deal with cognitive deterioration.

Key Words: Dementia, Memory Clinics, Qualitative Research, Quality of Life

Running title – Peer support workers in dementia services

Introduction

The employment of peer support workers (PSWs), where people with a condition are employed in a service supporting others with that condition(Mowbray et al., 1998) is widely established within mental health services (Resnick and Rosenheck, 2008). Such initiatives are likely to benefit those with dementia (Keyes et al., 2014) but they and work evaluating them are in their infancy (Keyes et al., 2014).

In other client groups, benefits include more positive staff attitudes towards services (Dixon, Hackman and Lehman, 1997), reduction of hospital readmission rates (Forchuck et al. 2005), and service users feeling more understood (Corrigan, 2006). PSWs experience increased self-esteem, purposeful activity, use of skills, friendship and wellbeing as well as the rewards of helping others, normalisation and stigma reduction (Mowbray, Moxley, & Collins 1998; Yuen & Fossey, 2003).

Challenges for PSWs (e.g. Gates and Akabas, 2007) include disappointment in performance and lack of support (Mowbray et al., 1998) whereas PSW role definition, accountability and the management of boundaries present challenges for staff (Gates & Akabas, 2007; Repper & Carter, 2011).

Work evaluating PSW programmes in other patient groups is informative but may not directly relate to people with dementia as while there are commonalities, such as experience of stigma (Milne, 2010, Mak et al., 2007), there are also differences. In particular, dementia is associated with more severe, generally progressive, cognitive impairment (Wright and Persad, 2007, Prince et al., 2011). No study has investigated the challenges and benefits of PSW programmes to the PSWs with dementia and the staff who work with them and this is the focus of the current study.

Methods

Participants

Participants were PSWs (N=4) and staff (N=8) employed within two memory services in the UK. PSWs were concurrently patients and employees of the programme and roles included co-facilitating groups, assisting in memory cafes, conference presentations and designing service materials. Staff included admiral nurses (AN), psychologists (Psy), a deputy manager (DM), a dementia advisor (DA) and an occupational therapist (OT). Staff: PSW ratio across both services was 29:5.

Procedure

Three focus groups were run using nominal groups (NG) methodology (Delbecq and Van de Ven, 1971). This methodology was chosen as it has been adapted for use with people with dementia (Dening et al., 2012) and enables structured evaluation of the varied views expressed within the groups (Dening et al., 2012). All participants gave informed consent. Ethical approval was not required as the study was a service evaluation.

Three structured groups- NG 1 (PSWs only, n=3); NG2 (Staff only, (2 ANs, 1 Psy, 1 DM, 1 DA, 1 OT)) and NG 3 (staff (1 Psy, 1 OT) and peers, n=4) - lasting between 1.5 and 2.25 hours, were facilitated by two facilitators, AM and JMS. They were audio-recorded with detailed notes taken. The combination of mixed and non-mixed groups of staff and PSWs was chosen to allow some assessment of whether the discussions differed when both parties were or were not present. (Dening et al., 2012).

Each of the three groups consisted of five stages:

1) Silent generation of ideas (10 minutes): Participants wrote down benefits and challenges of the PSW programme.

2) Group discussion of ideas (30 minutes minimum): Ideas were generated and written on a flipchart to facilitate a structured, time-limited conversation (Van de Ven and Delbecq, 1972).

3) Further silent generation of ideas (10 minutes).

4) Discussion and generation of common themes (30 minutes minimum).

5) Ranking of themes (10 minutes): The five most important benefit and challenge themes were individually ranked by participants (high = 1, low = 5).

Data Analysis

As suggested by Dening et al. (2012), two approaches to analysis were taken to enhance content and face validity of the emerging themes.

1.. Thematic analysis of detailed session notes and audio recordings

Detailed session notes and audio recordings were analysed using Braun and Clarke (2006)'s six phases of thematic analysis. After coding for units of meaning, key emergent themes were developed jointly by two authors (AM and JMS). Respondent validity was demonstrated through giving participants a summary of the analysis, which all validated as an accurate reflection of their views.

2. Collation and ranking of themes within each group

The highest ranking theme for each individual was given a score of 10 with the lowest scored as 2. Theme scores were summed to give an overall 'rank score' for each theme.

Results

Thematic analysis

Three emergent 'benefit themes' and four emergent 'challenge themes' were identified through the thematic analysis.

Benefit themes

Theme: Quality of life

A prominent theme was the positive impact of the programme on PSWs' quality of life. PSWs emphasised features of wellbeing, engaging in stimulating activities and experiencing enjoyment and achievement within a positive environment. The PSW programme was also normalising of experience and facilitated the learning of new skills, enhancing a sense of meaning and purpose:

" my life would be dull without it(…,,) If I was sitting at home, I'd just be playing solitaire" PSW1 (NG1).

 PSWs also emphasised the social connections given by the work:

"...being here makes me feel like I'm not an isolated idiot" PSW 3 (NG3)
and the positive experience of reciprocity:

"It's not just a benefit going out, but also a benefit coming in" PSW 4 (NG3)

Theme: Peers adding value to the service

All groups agreed that PSWs made a valuable contribution to service development, delivery, and research activities. PSWs' expertise in lived experience, and the fact that they increased diversity of ideas within the service were particularly valued, as illustrated in the quote below:

"we are not all mental health professionals…people relate to people differently…more scope, different views, different ideas." Staff member 1 (NG2).

Staff also highlighted that the PSW program increased the profile of the service:

"It's good PR… it's got a lot of press…" Staff member 6 (NG2)

<u>Theme: Reduction of stigma associated with dementia</u>

Participants discussed a shift in stereotypical and stigmatising representations of dementia. For PSWs this included reinforcement of there being *"life after diagnosis" (PSW1, NG1)*. For staff, PSWs were seen as *"examples of living well with dementia" (Staff member 7, NG3),* challenging negative preconceptions about the abilities of those with a diagnosis, which were further challenged through contact and joint work with PSWs:

"it helped me to start from a position of assuming capability, skills…" (Staff member 4, NG2).

Challenge themes

<u>Theme: Lack of role definition</u>

Some staff were unclear about the PSWs' specific day-to-day roles within the service:

"The time when I see them is when they are having their food…there's nothing negative ……….it's just questioning the purpose of their role…" Staff member 2 (NG2).

While PSW's themselves expressed the desire to have more opportunities, to get involved and to put their ideas forward:

"More please! … I'd like more to do" PSW3 (NG3)

<u>Theme: The challenge of working with clients as colleagues</u>

Working with clients as colleagues changed the 'them and us' dynamic, but also led to difficulties managing PSWs' dual roles as patients and members of staff.

"They are still on my caseload and I work with them as well" Staff member 3 (NG2).

A subtheme within this was the role of power. PSWs reported hesitancy about communicating anything negative about the programme because they *"[did] not want to offend"* (PSW 2, NG1). Staff reported concerns about power more directly:

> *"I think there's a real power imbalance…I treat them quite different and act quite different to how I would act with any other member of staff." Staff member 4 (NG2)*

A second subtheme was the challenge of managing PSWs' practical and emotional needs. Staff discussed the challenge of managing professionalism, with PSWs requiring prompting to come to work and having difficulties arriving on time. Both staff and PSWs also highlighted the role's emotional challenges, including potential exposure to negative experiences such as discrimination. PSWs highlighted how hearing about experiences of dementia was sometimes upsetting;

"When I went to these conferences there were people talking about…the end result of dementia, you know, how they get uh, locked up in homes and things like this! I find that all very depressing…" PSW 1 (NG3).

They also discussed how their own experiences of dementia could make such stories more difficult to hear. Staff discussed the challenge of managing these negative impacts on PSWs as well as potential risk issues raised by PSWs when they were both colleagues and clinicians to them.

Theme: Resource limitations

Resource limitations and cost to the service were particularly an issue for staff, who discussed some concerns about the cost of the project and also that the project was not necessarily a service priority. Staff felt they needed to focus on other activities than the PSW project with one consequence being that that they did not have time to recruit or support large numbers of workers. This was noticed by PSWs themselves, who reported that there were not enough PSWs.

Theme: Considering disease progression among PSWs

Staff and PSWs raised concerns about disease progression including the increased physical and cognitive effort involved on the part of peers as disease progressed as well as the potential loss of role and relationships when it was no longer possible for peers to continue work. Although staff discussed that they might be able to use their clinical skills to manage this, there was concern about the effects of turning an empowering experience into one that was disabling:

' You're working? But actually, no, you're a bit far gone now. What does that feel like for the person?" Staff member 5 (NG2)
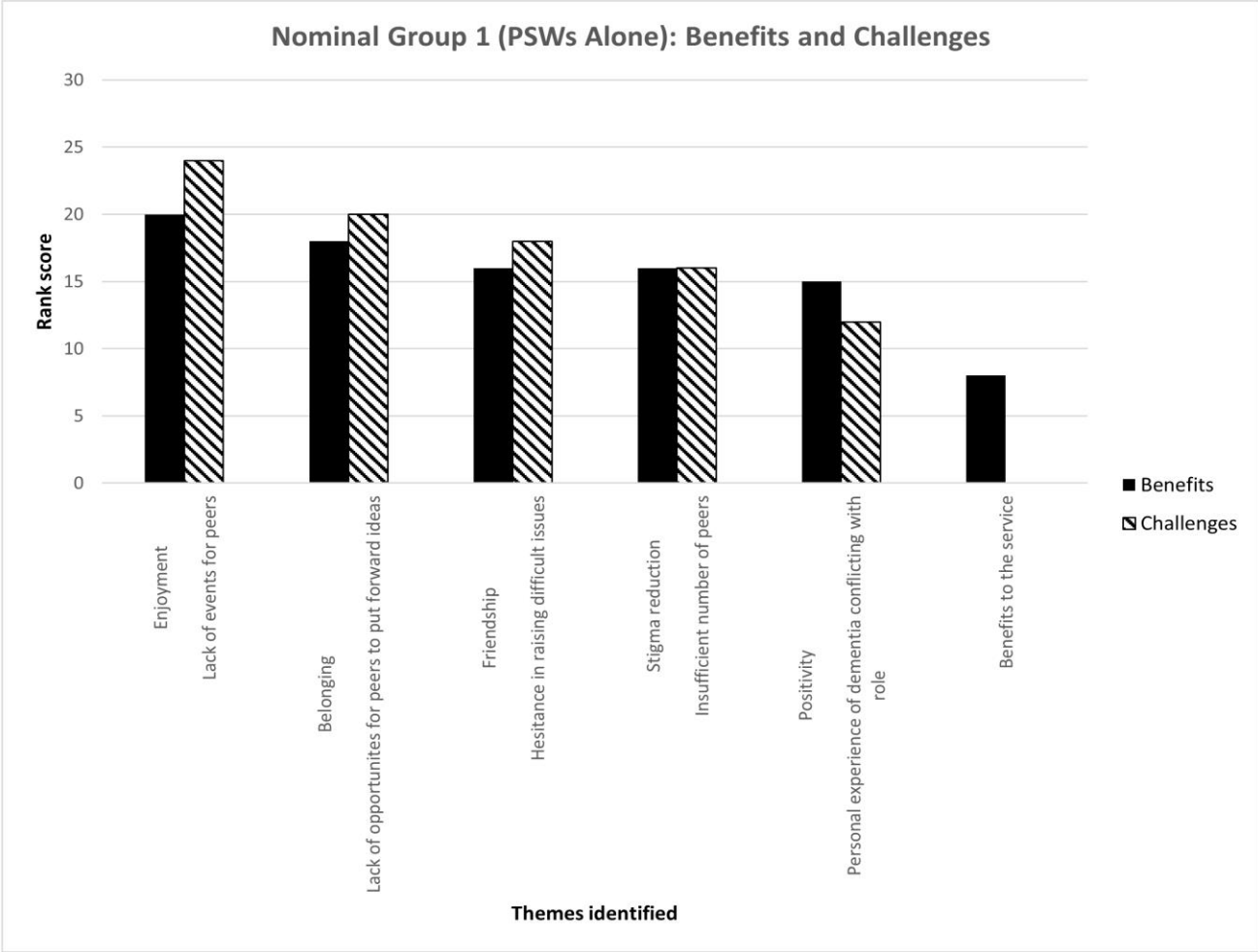
Although this was a significant challenge, PSWs reported faith in the service's ability to manage role changes with sensitivity:
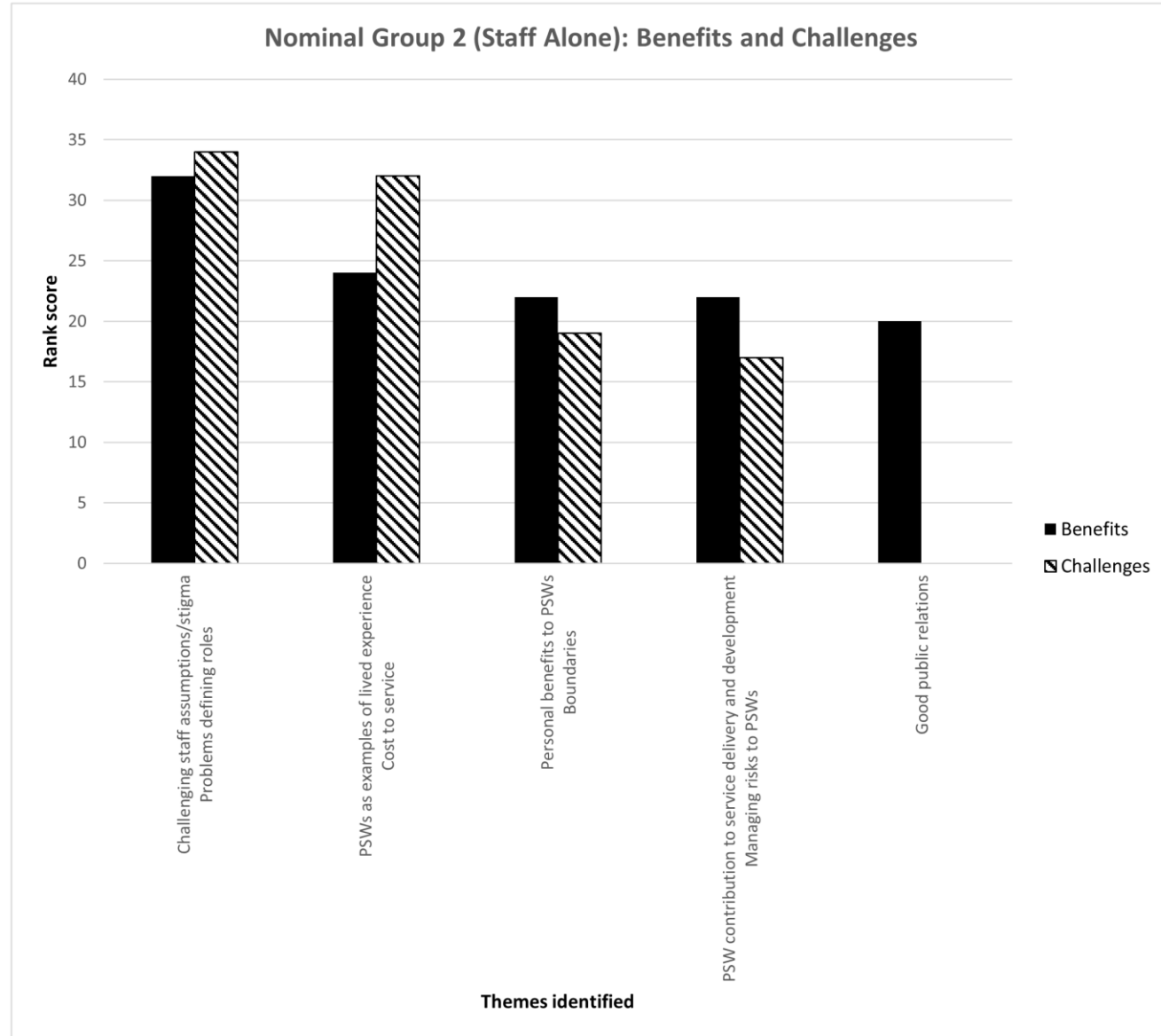
"If they sort of say well, "ha ha, we don't want you any more", then it would be, well, it wouldn't happen!" PSW 4 (NG3).

Ranked themes

Graphs of theme rankings from the NG process are given in figures 1-3. Table 1 shows the cross-tabulation of ranked themes (generated in the NGs) with emergent themes (generated by thematic analysis). All ranked themes are associated with an emergent theme providing

evidence of face and content validity. It was noticeable that while all three emergent benefit themes were represented by ranked themes from all groups, ranked items representing emergent challenge themes differed across groups; lack of role definition was not discussed in the mixed group, with 'limited resources' and 'working with clients as colleagues' represented across all groups, but from different perspectives. The challenge of 'considering disease progression' was only raised when PSWs and staff were in a group together.

Nominal Group 1 (PSWs Alone): Benefits and Challenges

■ Benefits
◨ Challenges

Rank score

Themes identified

Enjoyment
Lack of events for peers
Belonging
Lack of opportunites for peers to put forward ideas
Friendship
Hesitance in raising difficult issues
Stigma reduction
Insufficient number of peers
Positivity
Personal experience of dementia conflicting with role
Benefits to the service

Nominal Group 2 (Staff Alone): Benefits and Challenges

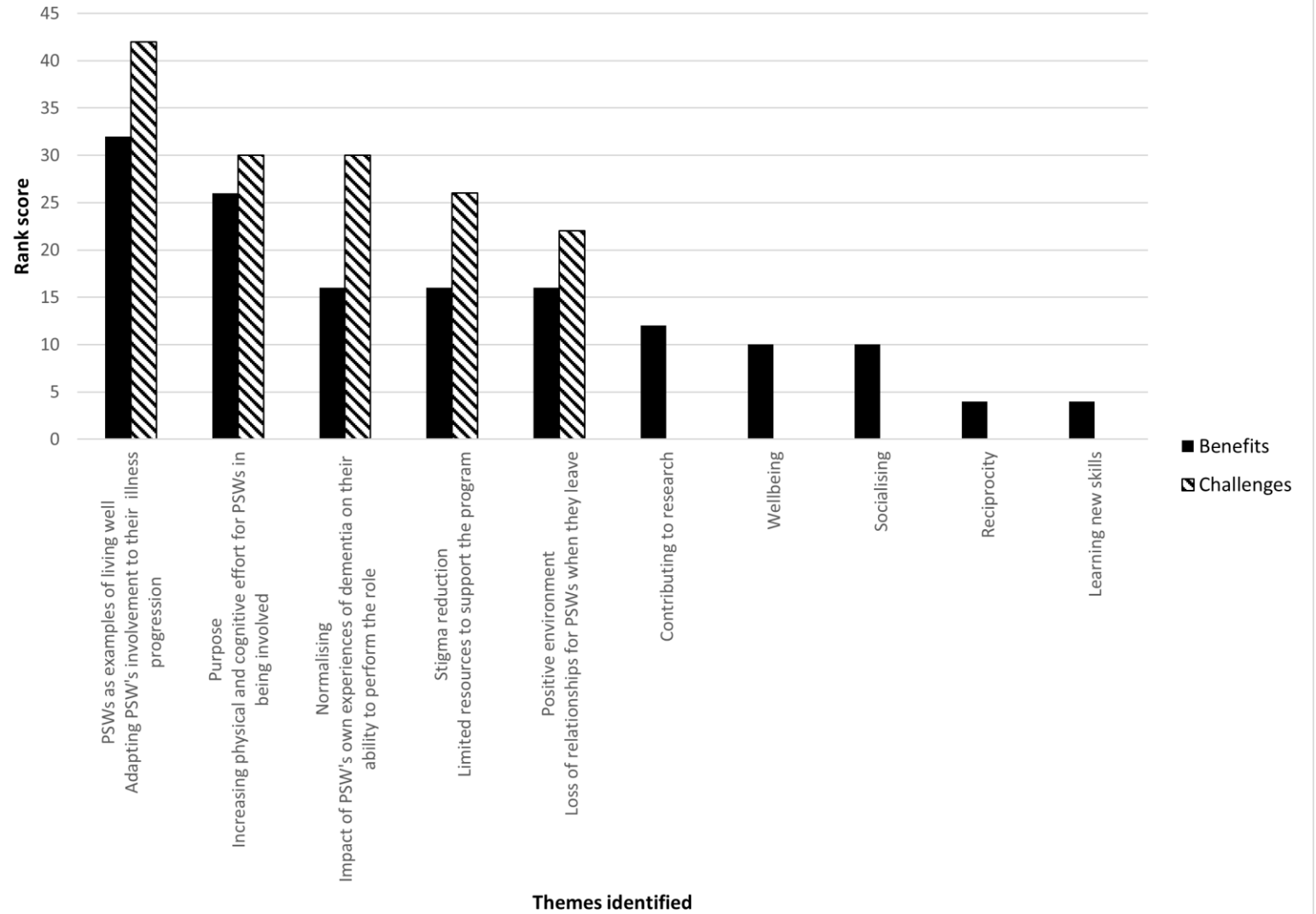Nominal group 3 (Staff and PSWs): Benefits and Challenges

Table 1 Crosstabulation of emergent themes from thematic analysis with ranked themes generated in each group

Emergent theme[*]	Nominal group	Ranked themes[**] (ranking[§])
Benefits		
Quality of life	PSWs	Enjoyment (1), belonging (2), friendship (3), positivity (5)
	Staff	Personal benefits to PSWs (3)
	Both	Purpose (2), normalising (3), positive environment (5), wellbeing (7) socialising (8), reciprocity (9), learning new skills (10)
Peers adding value to the service	PSWs	Benefits to the service (6)
	Staff	PSW contribution to service delivery and development (4), good public relations (5)
	Both	Contributing to research (6)
Reduction of stigma	PSWs	Stigma reduction (4)
	Staff	Challenging staff assumptions/stigma (1), PSWs as examples of lived experience (2)
	Both	PSWs as examples of living well (1), stigma reduction (4)
Challenges		
Lack of role definition	Peers	Lack of events for peers (1), lack of opportunities for peers to put forward ideas(2)
	Staff	Problems defining roles (1)
	Both	-
Working with clients as colleagues	Peers	Hesitance in raising difficult issues (3), personal experience of dementia conflicting with role (5)
	Staff	Boundaries (3) managing risks to PSWs (4)
	Both	Impact of PSW's own experiences of dementia on their ability to perform the role (3)
Resource limitations	PSWs	Insufficient number of peers (4)
	Staff	Cost to service (2)

	Both	Limited resources to support the program (4)
Disease progression among PSWs	PSWs	-
	Staff	-
	Both	Adapting PSWs' involvement to their illness progression (1), Increasing Physical and cognitive effort to PSWs in being involved (2) Loss of relationships for PSWs when they leave (5)

Note * 'Emergent theme' refers to a theme from the thematic analysis; ** 'Ranked theme refers to theme ranked within the nominal groups process; § 'ranking' refers to ranking of theme within the nominal group in terms of numbers endorsing it (high ranking means more people endorsed it) '-' indicates where no ranked themes representing that particular emergent theme were generated in that group.

Discussion

This is the first study to investigate the challenges and benefits of a PSW programme to staff and PSWs. Three 'benefit' and four 'challenge' themes were identified through thematic analysis with evidence of content and face validity provided through nominal group rankings. Reported benefits of increased quality of life, stigma reduction and contribution to service delivery were similar to those found in mental health PSW programmes (Mowbray et al., 1998). Benefits such as 'life beyond diagnosis' and a sense of meaning and reciprocity echo those found where people with dementia take part in self-help networks (Clare et al., 2008, Keyes et al., 2014)

In terms of challenges, the difficulty of working with clients as colleagues, and the lack of clear PSW roles, is also similar to mental health (Repper and Carter 2011). However, while mental health PSWs tend to report feeling overwhelmed (Mowbray et al., 1996), PSWs with dementia reported the opposite, wanting more opportunities. Also, uniquely to this setting, both staff and PSWs reported concerns about how to adjust or end a PSW's role upon significant deterioration. In general, the challenge themes suggested that if PSWs are over-

exposed to negative experiences, under-utilised, and asked to leave due to disease progression, such programmes could actually increase stigmatisation.

Power emerged as an issue in our study; PSWs reported hesitancy in raising difficult issues, and only reported certain challenges (lack of events/opportunities, insufficient peers) when not in the presence of staff. This may be because stigmatized groups who have less power have difficulty speaking up (Kaiser and Miller, 2003). By contrast, some issues (costs to service, risk issues) were only discussed when staff were on their own. This is perhaps because, as a more powerful majority group they were worried about offending PSWs (Goncalo et al., 2015). However, it is important to note that mixed groups were also generative, with the issue of disease progression only being raised in this format.

This was an initial study of a novel area. There was a small sample size (reflective of the small number of services operating such programmes), which limits generalizability. The UK based, inner-city, memory services in this study may not be representative of other areas and countries and PSWs and staff involved in the study were self-selecting, possibly biasing results and not reflecting the experiences of these groups as a whole.

Although replication in a larger sample, with assessment of impact on service users is recommended, this study does provide preliminary evidence that PSW programmes have benefits for people with dementia. In the light of the challenges, we suggest that such programmes need to be well resourced and set up. From the outset, there should be clarification of peer and staff roles and how disease progression might be managed. We also suggest that there should be explicit discussions about power relationships.

Conflict of interest

None.

Description of author's roles

J. Stott designed the study, wrote the paper and supervised A Mwale and J. Sweeney in data collection. J. Sweeney contributed to study design, data collection, data analysis and edited the manuscript for important content. L. Koschalka contributed to study design, data analysis and edited the manuscript for important content. L. O'Connor contributed to study design, analysis and edited the manuscript for important content. A. Mwale contributed to study design, data collection, data analysis and writing of the paper.

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Appendix 1 Figure legends:

Figure 1. Ranking of benefits and challenges: nominal group 1 (PSWs alone)

Figure 2. Ranking of benefits and challenges: nominal group 2 (staff members alone)

Figure 3. Ranking of benefits and challenges: nominal group 3 (PSWs and staff members)

Appendix 2