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The perspectives of people with dementia on day and respite services: a qualitative interview study

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Abstract

Respite services have traditionally been viewed as services for carers mainly. Perhaps as a result, the perspectives of people with dementia have been largely ignored. In this study, we consider these perspectives in relation to day and respite services, and contextualise them in light of Kitwood's prediction that person-centred care would be adopted only superficially by such services. Convenience sampling was employed and semi-structured interviews were conducted with six community-dwelling people with dementia. A thematic analysis was conducted and four themes were identified: 'acceptability of service characteristics', 'meaningful engagement', 'personhood' and 'narrative citizenship'. The findings suggest that day services were more acceptable than residential respite, though some people would prefer home-based models, if available. 'Meaningful' engagement must be individually defined; however purposeful and reciprocal activity was commonly invoked as meaningful. 'Personhood' and 'narrative citizenship' were quintessential markers of quality care; while some people experienced personhood being bestowed upon them, others reported distinct instances of malignant social psychology, discrimination and stigma. In conclusion, an implementation gap may still persist regarding person-centred care in some respite services, based on the perspectives of people with dementia. Delivering the vision for care outlined here would require greater flexibility in service provision, more resources and more one-on-one staff–client time. The fundamental shift in thinking required by some staff relies on us supporting them to develop a greater self- and shared cultural-awareness around dementia.

Keywords: dementia; respite; reciprocity; acceptability; personhood; narrative citizenship

Background

The World Health Organization (2017) has advised that we take public health action in terms of improving dementia prevention, awareness and care, in light of ageing populations globally. These actions are also reflected in national dementia

strategies internationally, along with another key objective of supporting people with dementia to remain living in their own homes for as long as possible. One of the often-cited ways to delay/reduce institutionalisation for people with dementia is to ameliorate any strain experienced by their carers, through the provision of respite services, which are intended to provide a break in care-giving for the carer (Maayan *et al.*, 2014).

A number of respite models exist, including traditional residential respite provided in care homes, day services provided in the community and other in-home models of care, which can also serve to provide a break in care-giving. A recent systematic review by Vandepitte *et al.* (2016) on the effectiveness of respite services for people with dementia and carers indicated that while there is some evidence that day services reduce carer 'burden', the evidence regarding residential respite is mixed, but there is some evidence of unexpected adverse outcomes for both the person with dementia (reduced sleep quality) and the carer (increased 'burden', 'distress') as a result of using residential respite services. Overall, there was insufficient evidence to draw any conclusions about the effectiveness of in-home and other community-based respite models.

A qualitative systematic review and meta-ethnography synthesising the perspectives of key stakeholders in relation to respite services for dementia indicated that the acceptability of these services can be quite low, particularly from carers' perspectives, across respite service models (O'Shea *et al.*, 2017b). A number of key areas for service development were identified including (a) supporting initial access and the transition to service use, (b) having a flexible, responsive person-centred care approach, (c) providing meaningful activity for the person with dementia, and (d) supporting dyad restoration (*i.e.* ensuring mutual benefit for the dyad from service use). The concept of 'dyad restoration' suggests that respite services should adopt a different approach and that 'respite' for the carer alone is not an adequate service aim. The psycho-social, personhood and physical needs of the person with dementia must be met also by respite services and the carer must trust that this is a core service goal, in order for them to let go and experience a restorative psychological break.

Kitwood (1995) defined a new 'person-centred' dementia care which began a paradigm shift, away from the biomedical perspective on dementia and towards a more holistic perspective on the needs of a person with dementia, over and above their physical needs. He argued that care must meet the psycho-social and 'personhood' needs of people with dementia also, with personhood being defined as something that is both conferred and experienced relationally, *i.e.* 'a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (Kitwood, 1997: 8). One of Kitwood's main concerns was that person-centred care, if adopted at all, would only be done so superficially, through the strategic use of discourse and window-dressing. He warned of the potential danger that care practices and culture would not change accordingly, in a way that could serve to truly support and maintain the personhood of people with dementia in care settings:

It is conceivable that most of the advances that have been made in recent years might be obliterated, and that the state of affairs in 2010 might be as bad as it

was in 1970, except that it would be varnished by eloquent mission statements, and masked by fine buildings and glossy brochures. (Kitwood, 1997: 133)

The views of people with dementia have long been lacking in relation to the service development literature, with informal family carer perspectives conventionally given precedence, because these proxy accounts were seen as more reliable (Cantley *et al.*, 2005; Lloyd *et al.*, 2006; Pison-Young *et al.*, 2012; Murphy *et al.*, 2015). O'Shea *et al.* (2017b) highlighted that, to date, the perspectives of people with dementia are not at all clear in relation to respite and day services and the care provided within them. The lack of this discourse in itself indicates a lack of citizenship for people with dementia; their voice is often absent because gatekeepers decide who is, and who is not, suitable to participate in research. The omission of the perspectives of people with dementia from research to date has likely compromised our ability to develop respite services in a way that ensures the personhood and citizenship of people with dementia are supported.

It is our intention in this paper to explore, through the lens of personhood, how people with dementia experience respite and day services, and the care provided to them in these settings. Specifically, we seek to understand if people with dementia feel that their personhood is being supported and maintained in these settings. This is imperative, because we can only really know what 'person-centred' dementia care should look like in practice, from understanding the perspectives of people with dementia; this is the real test of the validity of Kitwood's warning about implementation. The aim of this study was to develop an understanding of the perspectives of people with dementia on the range of respite services (incorporating residential respite, day services and in-home services).

Methods

Study design

The research presented in this paper was conducted as part of a wider qualitative semi-structured interview study conducted in the Republic of Ireland between July 2017 and March 2018, with a range of key stakeholders [N = 35, *i.e.* people with dementia (n = 6), carers (n = 9), frontline staff (n = 7), managers (n = 8) and policy makers/academics (n = 5)], on the range of respite services. While the objective of the larger study is to explore and synthesise the perspectives of multiple stakeholders, the researchers felt that given (a) the lack of published data representing the perspectives of people with dementia on this particular topic, and (b) the richness of the present data, it would be valuable to give this perspective a platform of its own.

The research is underpinned by a subtle realist perspective, *i.e.* that the researcher's perspective is certainly influenced by his or her own position and experience in the social world, however, phenomena do exist independent of the researcher's mind, and are knowable through the research process (Hammersley, 1995). This perspective holds that once the researcher is aware of their own position and how it might influence the research process, they can make claims about the

validity of their representation, while also recognising that other perspectives on the phenomenon are possible.

The present study is presented in line with the Consolidated Criteria for Reporting Qualitative Research guidelines (COREQ), a 32-item checklist by Tong *et al.* (2007) (see the Appendix).

Recruitment and sampling

Six people with dementia were recruited through two day services, a respite service and a public health nurse, using convenience sampling, but with a view to representing a range of socio-demographic characteristics (e.g. male/female, age range, dementia type, urban/rural, spousal/child relationship; see Table 1 for interviewee characteristics). The nurse managers served as gatekeepers to this population. It is not known how many people with dementia were asked by these gatekeepers to participate in the study, or how many people refused. The researcher was contacted only when a client was interested in hearing more about the study. The only inclusion criterion for the study was a recorded formal diagnosis of dementia. Five of the six people with dementia were using, or have in the past used, at least one respite service model. The sixth interviewee had early onset dementia, and had not yet used formal services, but has recent (within the previous ten years) experience of caring for her own mother with dementia who used both day services and residential respite services, and wanted to share her unique perspective on respite services as someone with early onset dementia looking towards the need for support in the future. We felt this was relevant because there are diverging perspectives around the appropriateness of general services for those with early onset dementia (Keady and Nolan, 1997; Reed *et al.*, 2002), and there is evidence, albeit limited, from the perspectives of people with early onset dementia that the perceived acceptability of older adult day services is low (Beattie *et al.*, 2004).

Data collection

Following piloting and modification, a semi-structured interview schedule was developed for use based on the existing literature in this area (for basic schedule topic areas, see Figure 1). This schedule was used flexibly; the participants were encouraged to continue with whatever narratives were meaningful to them, through prompts, based on the questions they were asked in relation to respite services. The interviews were recorded using a digital audio recording device (Olympus, VN-750). Field notes were made after each interview.

Cross-sectional interview data were collected face-to-face for all participants by the first author, a female PhD researcher, with no prior relationship with the interviewees. Interviews ranged from 20 to 65 minutes in duration. Just one interview took place in a participant's home, and he requested that his daughter be present. The other five took place within the service through which the interviewee had been recruited; these participants were interviewed alone. With a view to maximising interviewee responses, the researcher spoke to the primary carer prior to the interview to understand key aspects of the person's biographical history (family life, occupation, hobbies/interests), as well as information about their life now,

Table 1. Interviewees' demographic information

| Pseudonym | Sex | Age | Age at diagnosis | Diagnosis | Dementia severity | Marital status | Living arrangements | Ethnicity | Services used |
|-----------|--------|-----|------------------|--------------------------|-------------------|----------------|---------------------|---------------|----------------|
| John | Male | 80 | 74 | Alzheimer's disease | Mild | Married | Wife, 81; urban | White Irish | DS, RR, IH, HH |
| Anna | Female | 66 | 64 | Fronto-temporal dementia | Moderate | Married | Husband, 71; rural | White Irish | DS, RR, IH, HH |
| Adam | Male | 80 | 74 | Alzheimer's disease | Moderate | Widowed | Son, 44; urban | White Irish | DS, RR, HH |
| Cora | Female | 86 | 82 | Alzheimer's disease | Moderate | Widowed | Friend, 76; rural | White British | DS, RR, HH |
| Noelle | Female | 58 | 56 | Alzheimer's disease | Mild | Married | Husband, 60; urban | White Irish | None |
| Bill | Male | 74 | 70 | Vascular dementia | Moderate | Divorced | Daughter, 37; urban | White Irish | DS, RR, HH |

Notes: DS: day services. RR: residential respite. IH: in-home/domiciliary services. HH: home help.

Can you tell me about your own experience of [service name]?

What is this service like?

Did you like the service when you first came? Why/why not?

Do you like the service now? Why/why not?

What do you think about the staff here?

How are you treated by the staff here?

What kinds of things do you do here?

Do you enjoy the activities?

How could we make this place better for you?

What could staff do to improve your experience?

Have you used other services? Respite? Services at home? Day services? (as applicable – loop back to the top)

Is there anything else you would like to tell me about the service?

Have you questions for me?

Figure 1. The basic interview schedule.

including their interests and skills, to facilitate communication and interpretation throughout the interviews, and to help build familiarity and rapport with the person (as described in Murphy *et al.*, 2015).

Approach to interviewing

The interviewer took a postmodern, empathic approach to interviewing participants (Fontana and Prokos, 2007) which does not hold neutrality or detachment as a goal. Interviewers adopting this approach position themselves as advocates and partners in the study, who aim to use the results to advocate for changes in policy and practice (Fontana and Prokos, 2007). The interviewer explained her reasons for conducting the research, and why the topic was important to her. Genuine empathic inquiry and responding is key and can facilitate a disarming of any pre-conceived power dynamics, leading to a deeper understanding of the perspectives of participants (Josselson, 2013).

This was achieved here through (a) asking open, interviewee-centred questions (for examples, see Figure 1) and (b) responding empathically and in flexible ways to interviewee responses (e.g. through summarising, paraphrasing and mirroring their narrative back to them, to check understanding). Transcripts were not

returned to participants, however, validation was sought from each participant throughout the interview, and again near the close of the interview to ensure that they felt they had been given sufficient opportunity to disclose their perspectives to their satisfaction. The interviewees were each thanked and it was made clear to them that they had made a valuable contribution to the research by sharing their personal experiences and perspectives (as advised in Murphy *et al.*, 2015).

Data management and analysis

Directly after the interviews, the audio files were saved to an encrypted, password-protected hard-drive under an assigned code, to ensure that confidentiality and anonymity were upheld. Data were stored and managed using the NVivo 11 program.

Inductive thematic analysis was employed for this analysis, as described by Braun and Clarke (2006). The data were transcribed verbatim by the first author from digital audio recordings, and information which might make interviewees personally identifiable was removed to preserve anonymity. The transcripts were read and reread to gain familiarity with the data, before the coding process began. At this point, initial memos were made to begin the audit trail.

NVivo 11 was used to support the coding process and manage the data for analysis. The first author coded all six transcripts and met regularly with a senior member of the team (KI) not involved in the interviewing process to discuss the codes and the potential themes. This was to ensure rigour through triangulation, to challenge the researcher's assumptions and to encourage a high degree of reflexivity throughout the analytic process. Codes were compared and contrasted iteratively, and were explored and compiled to form cohesive, rich and well-defined themes. In relation to data saturation, here defined as 'the point in coding when you find that no new codes occur in the data' (Urquhart, 2012), data saturation was reached. At the final iterations of the coding process, no new or anomalous codes were being identified that did not fit within working categories. Particular attention was paid to identifying positive and negative cases in relation to each theme.

Ethics

Ethical approval for the study was obtained from the Dublin City University Research Ethics Committee (DCUREC/2017/018). Potential participants met with the researcher, and were given study information (either visual or written) detailing the study aims and procedures, and a consent form. The family carers of the people with dementia all gave proxy written consent. Written consent through a signature, or a tick, in the case of the visual consent forms, was also obtained from people with dementia where possible. Even though either, or both, proxy and self-consent was obtained, the researcher also used the 'process consent method' (Dewing, 2007) throughout the interview process; the language, behaviour and body language of the person with dementia was monitored continuously for signs that they were no longer happy to participate, and in that event, the interview was brought to a conclusion.

Results

The analysis revealed four major themes which will be discussed below: (a) acceptability of service characteristics, (b) meaningful engagement, (c) personhood and (d) narrative citizenship.

Acceptability of service characteristics

For a number of interviewees, attending day services was enjoyable, convenient in terms of food and transport, and good value for money:

It's very nice ... I really like it here. (Anna)

For €12 it's well worth it ... we get our coffee and tea and a bun in the morning and then we get our lunch and a dessert and coffee or tea after that ... and we get a bus ... I think it's terrific and I'd love to come more often but I can't because of the waiting list. (Cora)

However, for some other interviewees, including Noelle, a 58 year old with early onset dementia, neither day service nor residential respite models are acceptable. She believes that these services are designed for older adults, a group into which she does not fit. She maintains that staff would not be capable of meeting her needs as a younger woman with dementia:

I know they [staff] wouldn't know what to do with me ... sure they are used to dealing with much older people in a certain way ... but I know they wouldn't know what to do with me.

Furthermore, she is concerned that by attending day care or respite, she would inevitably witness people who are far more advanced in their dementia, which would cause her undue stress and anxiety about her future:

It would make me feel terrible about what is happening to me, and would give me a vision of what might be to come for me in years to come and I do not want to fear what might be even more by seeing all that.

In particular with residential respite, Noelle feels that the 'back and forth and upheaval' of it would be 'traumatic' for her, a belief that was borne out of her personal experience of caring for her mother with dementia in recent years.

These more negative sentiments about residential respite were also echoed by Bill and John, who having experienced respite admissions, now refuse to use this service. John cited an unsavoury 'coldness' to the environment as a core reason for his negative attitude. Both Bill and Noelle indicated that they would prefer to receive respite care and support in their own homes:

I can't see why I have to ... 'you must go to day centre' ... I don't want to ... and when there's so much to do at home ... I don't want that respite ... I don't want to go and stay anywhere ... I need to have my own thing here [indicating at home, interview conducted in his sitting room]. (Bill)

Well I would want someone to come to the house maybe, and help me to bake and do washing and maybe we could go for a walk with the dogs. (Noelle)

For some interviewees, social engagement was important, and indeed was the main appeal of using services outside the home:

I do like chatting to people ... no matter what happens if you have social contact it's very very good ... I get on very well with everybody ... coming here cheers me up and it gets me out of the house and I'm meeting people all the time, different types of people ... we must have a laugh ... if we don't have a laugh we have nothing ... and we have many laughs here ... the craic is good. (Adam)

However, the level or type of engagement was unsatisfactory to some. John, Bill and Anna felt at times that they could not meaningfully socially engage those around them, particularly those who are less able to communicate verbally. Here, John notes how he carries this dissatisfaction home to his wife:

I do [like coming here] if I can learn from them but some people don't speak much ... I find that silence is deafening sometimes ... I would like something a bit more discerning and be surrounded by people who can say we didn't like this or that today ... I come home and say to my wife that I tried to talk to four or five different people at the table and they don't say anything so I find myself complaining to her at home about the quality of the course [day service].

Meaningful engagement

For all interviewees, how their time is occupied when in respite care was important to them.

John reported his dissatisfaction with a recent residential respite stay in terms of the lack of activity or engagement that he experienced over the course of the week:

It was unbelievable there ... I had nothing to do all day only walk around in a circle.

However, the experience of activity and engagement in day services was more positive overall. Adam and Cora were both satisfied with the level and type of engagement they experienced in their respective day services. For them, 'meaningful' engagement was largely about having something to participate in socially or creatively, as a group. In this way, activities such as bingo, painting and dance were seen as enjoyable ways to feel a part of something bigger, which for Adam, is 'a good way to pass away the time'.

While participation and being part of a group defines 'meaningful' engagement/activity to some, others place more value on activities that stimulate their personal values and interests. Anna spoke repeatedly about the importance of being 'kept busy'. Interestingly, when asked if she is 'kept busy' at the day service she attends, she said that she is not kept busy in the way that she would like (*i.e.* gardening, embroidery, making curtains, cleaning). This indicates the importance of staff exploring what is meaningful for each individual person.

A number of interviewees further defined what 'meaningful' engagement meant to them, beyond occupation, participation and catering to personal interests. John, Cora, Bill, Adam and Noelle all spoke about being engaged in way that gave them a sense of *purpose*. This was not a common experience for them in either day services or residential respite, but many of them, in the context of being asked about what they want from service use, reflected on times when they previously felt purpose in their lives.

Bill, who worked as a horticulturist before his diagnosis, described how it used to feel to have others ask for his help and expertise, and to feel a sense of reciprocity. He is not asked to share his knowledge at the day service, despite there being a garden that clients have access to:

Before, I'd have a lot of people asking me if I'd come over and have a look at this and that in the department ... I'd still have a person say to me what do you think? I used to love that actually ... there are a lot of people out there actually and they would go around and they say to me please come over and I'd give them what they need ... but it's a thing that I used do outside of the thing now.

Similarly, when John was asked what he would like to get out of service use, he went on to describe a time when he was able to contribute professionally in such a way that helped economies in the Middle East, and how he went on to write a book about it, 'some feedback to leave behind':

Ten years earlier the markets in the Middle East laid up ... they were drawing blanks where they used to make money ... they thought how can we do this ... and then we said our piece [him and his team from Ireland] and they more or less agreed with us then ... and they discovered weaknesses ... we helped them discover why ... I wrote a book about it afterwards ... I decided I should leave something behind in terms of the literature.

While Bill and John described how they felt purpose based on what they could offer to others professionally, Adam and Noelle recalled finding purpose through caring for their children, as this gave them a valued role, and an increased sense of self-worth:

I just love when they come home from school and [names] from college at the weekends and I feed them all up and I send them away again with enough food for a small army and I know they love that and I just feel ... am feel that they need me as their mom but I also kind of ... when I cook and bake for them I feel like I'm not just some useless and helpless person that they feel sorry for ... like I matter and you know I can do something for them still. (Noelle)

When Noelle looks ahead to needing more support as her dementia progresses, she links this with her need to 'feel useful', which is something she did not see staff attempt to do when her mother was using day services.

Personhood

For four of the interviewees it was greatly important to them that they were treated with kindness, care and understanding by staff. For two people, Adam and Cora, this was their experience of staff in day services:

Oh they are very very nice people and it's nice to be nice ... it costs us nothing. (Adam)

The people all the staff are terrific ... the two boss ladies are fantastic ... very kind and careful and helpful. (Cora)

However, this was far removed from the experiences of the others. One man, John, explained how the way he is spoken to sometimes by staff makes him feel 'not worthwhile counting' and 'not a person', which is a clear statement of him experiencing damage to his personhood and self-esteem. He describes reflecting on the effects of this type of treatment when he returns home from his day service, where he ruminates on negative interactions with staff, deepening his feelings of rejection and further eroding his personhood:

I began to say at home last night ... how do I feel about this experience ... do I feel rejected? and the answer is yes ... do I feel that I didn't ... that my opinion was not worth taking ... the answer is yes.

John goes on to clarify that not all staff fail to treat him as 'a person'; some staff are nice sometimes, but his sense is that this can be 'superficial' and that there is a lack of authenticity or genuineness to many of their interactions. He experiences this as a lack of respect:

They're not even trying to meet the needs of the customer ... they're leading everyone up/down the pathway ... it needs to be more sincere ... but it's not at all ... there's no real respect, it's like I don't matter.

Noelle also had a negative experience of staff in respite and day services, in terms of how her mother was treated. She felt that her mother's dignity was compromised in these services because staff saw her as 'less than', compared to people without dementia, and she refuses to endure this treatment when it comes to her eventually needing more support:

I would honestly rather sit at home on my own than go somewhere and be made to feel helpless and senile and like I am less than other people ... no way in the world will I ever do that ... I think staff could do with understanding that I want to be seen and understood and treated the same as they would treat their sisters and their friends and anyone else in the world who doesn't have this thing [dementia] ... I don't want to be made to feel different.

Her hopes for respite service development in this respect is that she would like home-care, provided by staff who see and respect her as a whole and complex person with many identities, roles and strengths. She does not want a service that infantilises her, or otherwise wears away her personhood and sense of self:

I want that carer to have the cop on to know that I am still a person ... I pray to God that they wouldn't treat me like a child or like I'm less than an adult woman, a mother, a wife, a skilled baker ... that would kill me ... unless ... unless that person had the right attitude and I knew that they respected me ... they would need to see me and I would need to feel that they held me in some esteem.

Interestingly, Noelle, like John, also mentioned how she values genuineness in her interactions with others, and feels that since her diagnosis, even when people are trying to be kind and encouraging, she senses that they are sometimes *plámásing* (Irish term denoting disingenuous praise) her. She notes this is not something she would value in respite or support service staff either: 'I don't want to feel like it's a condescending thing I just hate that feeling'.

Narrative citizenship

Another way in which the care approach was considered by interviewees was in terms of how their agency and citizenship were sometimes challenged. Some interviewees reported feeling silenced by staff because they were not given the opportunity to communicate their stories, motivations, and/or their care needs and preferences.

Cora talks throughout the interview about how her favourite drink is milk, but the day service staff 'quibble' and 'get cross' at her when she asks for it. She says they often 'stop' her and tell her not to ask again, but describes how she opportunistically takes power back, leading her to see herself as a renegade of sorts:

I love milk ... I'm addicted to it ... and at 86 and half so what? Sometimes when they are not looking I get the kitchen woman to give me some ... I'm a rebel!

John depicts his experience of feeling stripped of his narrative agency and autonomy by staff in a much more distressing light. He describes two incidents: in the first, he wanted to move his chair in a circular group set-up, but he was 'blocked' by staff. He felt they had not even tried to understand why he wanted to move it, because they did not give him the opportunity to explain his motivation. This blocking of his narrative agency by the staff 'frustrated' and 'humiliated' him, and he was surprised to find himself lashing out physically:

There were two staff one day who decided to teach me a lesson ... and eh ... I could move my seat ... so I could move it but not a certain distance because they threatened to block me ... and that in a sense is threatening to block my ideas ... and eh ... and that turned out nasty ... I got so annoyed with her ... do you see this stick here? I used this with both of them [staff members] ... I mean I didn't ever think it would come to that.

The second incident was centred on his food choices being ignored by staff. While Cora's solution was to be a 'rebel' in secret and at opportune times, John wanted to affect real change and challenge the 'hierarchy'. His plan was to 'mobilise' a group of people to affect this change with him:

You can be certain ... there will be something signed by me ... and signed by at least half a dozen others ... to say why we are not attending.

However, he came to realise that he would face obstacles in recruiting his peers, because of the difficulties of co-constructing a joint narrative with them, and so he devised an alternative plan to take his grievance directly to the manager, by posing a question designed to appeal to her human empathy:

One of the weaknesses of the whole thing ... the man next to me had the same five chips I had ... no meat ... no fish on his plate either ... he didn't seem to object. I tried to suss him out 'are you satisfied'? I couldn't draw it out of him.

The lady in charge the manager inside ... I will channel her because she's the one person who is in charge of the whole set-up ... and they ignored our choices ... and why? and ask if she were in my shoes what would she do about it?

In terms of what services must do to address this issue, he says staff need to be educated on the importance of asking clients' preferences and giving them choice over their care. He noted that they must 'survey their clients' so that they do not continue to make 'a mistake of the market':

Nobody asked the right questions ... therefore they are all losing out on an opportunity of learning from us ... but it isn't easy to educate people to do that ... but what do they like ... how do you know they like it ... when did you last ask them?

In this way he is calling for at least the opportunity for co-construction and negotiation of a narrative around not only his own care preferences, but those of his peers also.

Two other interviewees highlighted how dementia is framed in stigmatising ways by society and within health and social care services, and how people can internalise that stigma as part the dementia experience:

I really do feel more sensitive to how people see me ... now I just assume that people feel sorry for me sometimes. (Noelle)

This stigma and disempowerment can be constructed through certain meta-narratives that society and services use to tell the story of dementia. Two stigmatising meta-narratives are outlined below around the infantilisation of people with dementia ('like a child'), and discrimination based on perceived abnormal cognition and behaviour ('they went mad').

Noelle had witnessed how her mother had been stigmatised and disempowered through infantilisation by respite and day service staff; it made her guilt as a carer worse and now has made her cautious about service use, fearing the same stigma would be dealt to her:

Those places have the feel of a crèche to them ... it would crush me to be made to feel like I was just being cared for like a child ... I used to feel awful dropping mum there

and listening to the god awful tone they would use talking to everyone there ... like they were talking to children.

Anna outwardly stigmatises other people with dementia in her day service, even though she herself has a diagnosis and has some awareness of this. Mid-interview, she points down the room to another client and declares 'she's a pity, isn't she', shaking her head. When later asked broadly about the other people attending the service she refers to them on a number of occasions as 'mad', but indicates that it does not affect her much: 'I didn't take any notice anyway, I was only laughing at them.' This indicates how deeply entrenched the stigmatising meta-narratives are around dementia, and how the drive to dissociate from that can be amplified in a group/service setting.

Discussion

The aim of this study was to develop an understanding of the perspectives of people with dementia on respite services. The four major themes ('acceptability of service characteristics', 'meaningful engagement', 'personhood' and 'narrative citizenship') are discussed below. We also consider the findings in the context of Kitwood's (1997) warning around the superficial implementation of person-centred care, as outlined at the outset.

The findings indicate that day services are more acceptable to people with dementia than residential respite admissions, but for some people with dementia, the preferred location of care is in their own home. This preference for home-based models of respite by some people with dementia has also been reported in the recent *Rethinking Respite* report by the Older People's Commissioner for Wales (2018). However, given that the Irish government is spending more than twice as much on residential care than on community-based care for people with dementia, and that home-care of any kind is not provided on a statutory basis in Ireland, service recalibration will likely be challenging (O'Shea *et al.*, 2017a; O' Shea *et al.*, 2018). It is worth noting that service acceptability was particularly poor for the interviewee with early onset dementia; having been exposed to day and respite services as a carer for her own mother, the thought of needing support for herself from these services is not one that she can even bear to contemplate. For those who felt day services were a good fit, they cited the importance of factors such as good food, transport and perceived value for money. They also cited the importance of the social milieu of the facility, particularly the communicative abilities of other people attending the service. This corresponds with the findings by Rokstad *et al.* (2017) and Strandenaes *et al.* (2018) who interviewed people with dementia about their experiences of day care; food, transport and social engagement were all noted as significant factors influencing service acceptability. It is important to indicate that the interviews presented here were a once-off snapshot, and that what is acceptable in terms of service provision to people with dementia may, or may not, change over time as the dementia progresses. Therefore, it is important that respite service staff and family members check in with people with dementia regarding service acceptability over time, as views and preferences are likely to change.

Meaningful engagement represents different things to each person with dementia in relation to respite services. For some, this is something that is participatory and/or plays to their personal interests. For others, this is about doing something that they feel is of value to others, which gives them a sense of purpose and reciprocity, thus increasing their self-worth. Other studies have also reported that what is considered 'meaningful' activity is different for each person (Brataas *et al.*, 2010; Rokstad *et al.*, 2017; Strandenaes *et al.*, 2018), and that identifying each individual's motivation for engaging in activity is important for matching a person with activities that will ultimately be meaningful, satisfying and beneficial to them (Han *et al.*, 2016). The *Rethinking Respite* report (Older People's Commissioner for Wales, 2018) noted that people with dementia value being 'productive' and 'making a contribution'. Interestingly, the findings here about giving to others and nurturing children as examples of 'purposeful' activity seem to echo Erikson's (1993) concept of 'generativity', the seventh of his eight stages of human development. Generativity is defined as the concern to nurture, guide and ensure the wellbeing of future generations and, ultimately, to leave a lasting legacy, and when negotiated successfully, this strengthens the self (Erikson, 1993; Villar, 2012). These findings suggest that if services and supports are serious about providing person-centred care, they must focus a great deal of resources and attention on creating opportunities for reciprocity for people with dementia, whereby the latter can maintain a sense of engagement and purpose through giving.

The final two themes, 'personhood' and 'narrative citizenship', are closely linked, in that they speak to what people with dementia want the care approach in these settings to look like, and how they want to be seen and treated by service providers. This brings us to the question outlined in the introduction regarding the validity of Kitwood's warning, over 20 years ago, about how person-centred care will only be superficially adopted by services, through discourse and window-dressing. The findings indicate that 'malignant social psychology' or behaviours that serve to undermine personhood (Kitwood, 1997) continue to persist in services and are felt deeply by some people with dementia, despite the widespread rhetoric that 'person-centred care' is now care-as-usual. Specifically, participants highlighted incidences where they have felt their personhood and self-esteem were diminished through the damaging effects of one or more of the following malignant social psychologies: disempowerment, infantilisation, stigmatisation, invalidation, imposition and disparagement. While some people with dementia in this study did indeed experience personhood as being bestowed upon them in day services, others clearly outlined damaging intersubjective experiences with staff. A more nuanced finding in the present study is that some more positive interactions with staff were not perceived to be genuine, and people with dementia sensed shallowness in their interactions, which can be experienced as a lack of respect. This, in particular, seems to speak to Kitwood's warning about superficiality in the implementation of the person-centred approach. These findings validate the assertion by Mitchell and Agnelli (2015) that Kitwood's work remains highly relevant to this day because of the difficulty we continue to have in terms of delivering care that is satisfactory to people with dementia and that supports their personhood.

The notion of 'narrative citizenship', which could be considered an operational element of a person-centred approach to care, was also a hugely important theme

in this study. 'Narrative citizenship' is a novel concept in the context of respite care for people with dementia. According to Baldwin (2008), supporting narrative citizenship is about 'maximising the opportunities for narrative expression for people with dementia'. He notes that narrative expression need not be linguistic, and that stories can also be articulated through movement and/or more artistic expression. In our study, interviewees reported feeling disempowered and stigmatised, in part because staff sometimes denied them opportunities to co-construct their narrative, and in part because of the larger stigmatising meta-narratives around dementia and people who live with dementia. These findings evoke the theoretical work of Gilleard and Higgs on the 'othering' of older adults, where 'choice, autonomy, self-expression' are lost and citizenship is therefore diminished (Gilleard and Higgs, 2010; Higgs and Gilleard, 2014). This discursive 'othering' is likely maintained by the continued dominance of a biomedical framing of dementia in the media and in health and social care settings, which fosters the flawed idea that once a person is diagnosed with dementia, their abilities and rights regarding autonomy, including decision-making capacity, are inevitably diminished (O'Shea *et al.*, 2017a). It is also worth noting the work of McColgan (2005) on how resistance strategies are often employed by people with dementia who are 'subject to rules and restrictions which are not of their choosing'. This seems especially relevant in light of some of the self-constructions of people with dementia here as 'rebel' and challenger of the 'hierarchy', in response to having their agency slighted by staff. McColgan (2005) described how such strategies are used in particular to reject certain constructions/labels and the group control asserted over them by staff, and to create a sense of personal space, territory (with particular reference to seating arrangements, as in this study), home and routine. It is clear from these findings in the present study that some people with dementia are capable of and want to be active agents, but that staff do not always create opportunities for them to co-construct their narrative(s) in a way which would empower them to achieve the outcomes they want.

The failure of some staff to support the personhood and narrative citizenship of people with dementia in an authentic way highlights that Kitwood was justified in being concerned about the implementation of a person-centred care approach. The findings are also consistent with those of a qualitative study by Kirkley *et al.* (2011) who have also validated Kitwood's prediction in a respite setting, but from the perspectives of service providers. The authors noted that although participants spoke about person-centred care as a positive thing, there was a wide range of understandings around the concept, many lacking depth. The authors concluded that some providers would describe their service as being person-centred, but they have not made the necessary cultural shift to implement this care approach in practice. In contrast, Rokstad *et al.* (2017) and Strandenaes *et al.* (2018) have reported on people with dementia's experiences of day services, which detailed only positive interpersonal experiences with staff. Both of these studies report on experiences with day services in Norway which were designed specifically for people with dementia, and at that time were enrolled in a wider 24-month trial investigating effectiveness and costs. Perhaps these purposefully designed centres being investigated in this way contributed to more person-centred practices.

We have to be careful not to colonise the views of the people with dementia represented here, or to suggest that service development should be based on these findings, given that the small group of people with dementia interviewed here was quite homogenous. However, the perspectives here do demonstrate that for some people with dementia, person-centred care is not experienced and that personhood is sometimes assailed, perhaps unwittingly, by staff. While it is not clear from the present study what the specific barriers to implementing person-centred care were, it is worth turning to theory to understand how we might begin to conceptualise and tackle this situation. Kitwood (1990) has previously observed that staff in health and social care services are constricted in their ability to provide authentically person-centred dementia care because they essentially operate on a sort of 'double-think', *i.e.* their practice is influenced by two paradoxical schemas. The first comes from what he called the 'standard paradigm', referring to the biomedical model, into which formal carers are trained. This, he says, is typically nihilistic and focuses on the neuropathology of the disease, not the person. The second schema is the staff members' own natural human inclination which is often (but not always) towards empathy for other people; this allows windows of 'more optimistic and less deterministic' thinking and practice regarding dementia (Kitwood, 1990: 179). However, he notes that the influence of the biomedical model tends to prevail, despite the 'great deal of goodwill, kindness and commitment' (1990: 186), in large part because of the 'the lack of inter-subjective insight' and critically, the absence of widespread 'moral education' for staff (Kitwood, 1990, 1998). Kitwood noted that very high levels of empathy and imagination, as well as flexibility in thinking, are critical in interactions with people with dementia, in terms of supporting and maintaining their personhood, and that these complex skills 'do not feature strongly in the training of professionals' (1990: 185). Health and social care staff can therefore lack insight that they are not seeing people with dementia as fellow human beings, deserving of genuine empathy and unconditional positive regard in interpersonal interactions. Consequently, through their behaviour and styles of interaction, staff can unintentionally propel the types of 'malignant social psychology' that diminish the self-worth and personhood of people with dementia (Kitwood, 1990; Kitwood and Bredin, 1992). We would suggest that in addition to this, there are a range of organisational pressures that reduce staff time and capacity to be person-centred, including large volumes of administrative work and physical care tasks, often in the context of being under-staffed, which significantly impact staff morale, and in turn their ability to be consistently person-centred in their interpersonal approach to care. Future research should investigate the organisational barriers and facilitators relating to the implementation of person-centred care, including managing culture change, in the context of respite service development.

Person-centred dementia care is now a central aim of national policy documents and dementia strategies worldwide, and there is a near consensus that this should be considered the dominant care paradigm of our time. While many services may indeed provide consistently person-centred care, this study shows that an implementation gap may still persist in some services. It is clear that we have to make a concerted effort to address any shortcuts that have been taken, to make it appear as if the implementation work has been done. It is time that we heed Kitwood's

warning; we must consider deeply how we can build the type of self and shared organisational awareness necessary among all health and social care staff and management, to facilitate the fundamental cultural shift required to embed person-centred care in the organisational cultures of all respite and day services.

Additionally, it is worth noting that there have been calls for a fundamental shift in how we conceptualise 'respite' and services which aim to provide respite (O'Shea *et al.*, 2017c), because the term 'respite' speaks only to the experience of the carer and their need for a break, and the term is associated with the use of other terms which stigmatise people with dementia and position them as burdensome. Therefore, it is questionable whether or not this term 'respite' has any use going forward to guide the development of services in line with the principles of person-centred care. The language we use is central to guiding service development, and the findings here support the notion that the term 'respite' cannot encompass the clear, nuanced vision for person-centred dementia care that people with dementia possess, and here state they are not always experiencing in practice. It seems likely that the continued use of this value-laden term is hindering the implementation of person-centred care, as the stigmatising tenets underpinning this word 'respite' trickle down into the experiences of people with dementia in care settings. O'Shea *et al.* (2017c) proposed 'restorative care' as alternative nomenclature, and this may be fitting to speak to the experiences and perspectives of both members of the dyad, given the findings in the present study. The people with dementia here are calling on us in some respects to support and *restore* their personhood, narrative citizenship and sense of purpose, through the provision of person-centred care.

Some limitations must be noted for this study. This was a small study with a sample of just six people with dementia. All participants were white Irish/British, and English was their primary language. The findings therefore do not speak to experiences of ethnic minorities who might have very different perspectives on, and experiences of, the range of respite services. Furthermore, it is possible that gatekeepers within services were biased towards providing access to people with dementia who they perceived would have more positive perspectives on services. We also must note that we did not collect data on the length of service use, and so it is not clear how this factor might differentially influence perspectives across the range of services. However, there was a considerable degree of variation in the sample in terms of some other socio-demographic characteristics (sex, age, cause of dementia, living arrangements, marital status), and it was the first of its kind to explore the perspectives of people with dementia on the range of respite services available in Ireland. This is important because these are services which historically have been conceptualised as being for the benefit of carers only, and the voices of people with dementia have been accordingly disregarded up to this point.

Conclusions

Again, we must reiterate that do not wish to colonise the views of a small number of people with dementia. However, the perspectives here indicate that at least for some people with dementia, respite services have low acceptability, and that the care approach is sub-optimal. Day services and in-home services may be more

acceptable to some people with dementia than residential respite services that take people out of their home for prolonged periods. Regarding the care approach, it might be useful for service providers to focus on understanding what meaningful or purposeful activity means for people with dementia. This could include creating opportunities for people with dementia to take on valued roles, so that they can feel a sense of reciprocity and purpose, which many people outlined here would particularly enrich their lives. Regarding the care approach, some, but not all, people with dementia represented in this study are still experiencing ‘malignant social psychology’, or behaviours that serve to undermine personhood. For these people with dementia, person-centred care is not simply about care being individualised, it is about staff *genuinely* respecting, validating and meeting personhood needs in every interaction, and providing opportunities for purposeful engagement, narrative agency and citizenship. Authenticity is important because some people with dementia can sense when staff are being disingenuous. While some services may be providing person-centred care, others may still require cultural change, in line with the vision for care outlined here by people with dementia. This type of change, where necessary, will involve educating staff on dementia and their framing of it, on communication skills and the importance of narrative, and on how to be more self-aware and reflexive in dementia care practice. A greater degree of flexibility and responsiveness should be allowed and encouraged by management in this situation; delivering care underpinned by personhood and citizenship will certainly require that people with dementia receive more time and attention from staff on a one-to-one basis. Future research must continue to explore health and social care service development in line with the principles of person-centred care with more people with dementia, in particular using co-design approaches.

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Appendix

Consolidated Criteria for Reporting Qualitative Research (COREQ): 32-item checklist (developed by Tong et al., 2007)

| Item number | Guide questions/description | Page number on which reported |
|---|--|-------------------------------|
| Domain 1: Research team and reflexivity: | | |
| Personal characteristics: | | |
| 1. Interviewer/facilitator | Which author/s conducted the interview or focus group? | 4 |
| 2. Credentials | What were the researcher's credentials? (e.g. PhD, MD) | 4 |
| 3. Occupation | What was their occupation at the time of the study? | 4 |
| 4. Gender | Was the researcher male or female? | 4 |
| 5. Experience and training | What experience or training did the researcher have? | 4 |
| Relationship with participants: | | |
| 6. Relationship established | Was a relationship established prior to study commencement? | 4 |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? (e.g. personal goals, reasons for doing the research) | 6 |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/facilitator? (e.g. | 6 |

(Continued)

(Continued.)

| Item number | Guide questions/description | Page number on which reported |
|--|--|-------------------------------|
| | bias, assumptions, reasons and interests in the research topic) | |
| Domain 2: Study design: | | |
| Theoretical framework: | | |
| 9. Methodological orientation and theory | What methodological orientation was stated to underpin the study? (e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis) | 3 |
| Participant selection: | | |
| 10. Sampling | How were participants selected? (e.g. purposive, convenience, consecutive, snowball) | 4 |
| 11. Method of approach | How were participants approached? (e.g. face-to-face, telephone, mail, email) | 4 |
| 12. Sample size | How many participants were in the study? | 3 |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | 4 |
| Setting: | | |
| 14. Setting of data collection | Where were the data collected? (e.g. home, clinic, workplace) | 4 |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | 4 |
| 16. Description of sample | What are the important characteristics of the sample? (e.g. demographic data, date) | Table 1 |
| Data collection: | | |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | 4 & 6 |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | 4 |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | 4 |
| 20. Field notes | Were field notes made during and/or after the interview or focus group? | 4 |
| 21. Duration | What was the duration of the interviews or focus group? | 4 |
| 22. Data saturation | Was data saturation discussed? | 7 |
| 23. Transcripts returned | | 6 & 7 |

(Continued)

(Continued.)

| Item number | Guide questions/description | Page number on which reported |
|------------------------------------|---|-------------------------------|
| | Were transcripts returned to participants for comment and/or correction? | |
| Domain 3: Analysis and findings: | | |
| Data analysis: | | |
| 24. Number of data coders | How many data coders coded the data? | 7 |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | N/A |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | 7 |
| 27. Software | What software, if applicable, was used to manage the data? | 7 – NVivo |
| 28. Participant checking | Did participants provide feedback on the findings? | 6 & 7 |
| Reporting: | | |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? (e.g. participant number) | Yes and yes |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | Yes |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | Yes |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | Yes |

Note: N/A: not applicable.

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