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## **Self-reported benefits for care-partners of attending a person-centred dementia cafe.**

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### **Abstract**

Informal care-partners of individuals with dementia are often referred to as the invisible patient, with their needs under-represented in research. The physical, mental and emotional responsibilities of caring for someone with dementia can be both rewarding and challenging. This qualitative study explored if attending a dementia café positively impacted on care-partner well-being. The co-designed café adopted a person-centred approach, valuing members unique abilities, and contributions. Results showed that the café provided a safe environment where individuals could be themselves. Participants found a sense of belonging, camaraderie and friendship, which enhanced their sense of well-being and maintained their selfhood and dignity.

### **Introduction**

Approximately 35 million people worldwide are living with dementia and most of the care provided is by informal or family care-partners (Prince, 2015) who are widely considered to be the cornerstone of dementia care support (Alzheimer Disease International, 2016). In the UK, where this study is based, 850,000 people are living with dementia, with this figure likely to be over 1 million by 2025 (Prince et al, 2014) with an estimated 670,000 people caring for someone with dementia (Lewis et al, 2014). Whilst it is appreciated that this role is generally very rewarding (Stansfeld, 2017) it is also well documented that informal care-partners of individuals living with dementia can be under considerable physical, mental and emotional challenges which can lead to poor health outcomes (Cheng, 2017). Indeed, many care-partners are themselves older people, with their own health problems to deal with alongside their caring responsibilities (Farina et al, 2017). Evidence further suggests that providing care to someone with dementia also has significant financial costs to the individual (Michalowsky et al, 2018) whilst generating massive savings to society, with the UK Government suggesting that care-partners provide £10.1 billion per annum of unpaid dementia care (Wittenberg et al, 2019).

Needs associated with providing care, such as managing behavioural and psychosocial symptoms are often not met by care services (Stirling et al, 2010; Dal Bello-Haas et al, 2014), which is particularly worrying considering that care is provided by family and friends over the course of many years (Greenblat, 2012). In the UK, policy directives promote that people living with dementia should be supported to stay at home for longer and to live positively (DoH, 2012; DoH, 2016, Alzheimer Association 2017) Certainly, formal systems of care would not

be able to cope without care-partners providing unpaid care at home (Farina et al, 2017) estimated at around 35 hours per week of care (Murray et al, 1999). There is a contingent need to support care-partners (Schulz and Eden, 2016) and National strategic dementia plans have underlined this (Robertson et al, 2016). The UK's National Institute for Health and Care Excellence commended that care-partners receive training, education and tailored support throughout the dementia journey, recognising their invaluable role. (NICE, 2018). Whilst the UK Department of Health and Social Care developed a 'carers strategy' for all those involved in caring roles (DoH, 2018) and specifically acknowledged the care-partner role in the Prime Ministers Challenge on Dementia 2020 (DoH, 2016). On the Global stage, the World Health Organization, emphasized the vital need to support care-partners, to circumvent the negative consequences which can be associated with caring for an individual living with dementia (WHO, 2012; WHO, 2017). The need therefore for services for people living with dementia and their care-partners that enhance wellbeing and quality of life are essential; one example of this is the dementia, or Alzheimer's café.

### **Dementia cafés**

The Alzheimer café concept emerged in 1997 in the Netherlands (Miesen and Blom, 2001) with the approach soon being developed and replicated across the world (Fukui et al, 2019). The original ethos of the Alzheimer Café was to create a meeting place for people living with dementia and their care-partners to provide support to '*companions in distress*' (Miesen and Blom, 2001:5). With the emphasis on dealing with the distress associated with dementia, it aimed to provide information, encourage the sharing of experience, and promote emancipation for both the person living with dementia and their care-partner (Miesen, 2004). From this original concept, memory café's were developed, which differed in the fact that they were often run by healthcare professionals, designed to offer support and advice on an individual level, often providing a drop-in facility (Light and Delves, 2011).

The café movement now has many different names and is often referred to in a more generic way as a dementia café, with names becoming interchangeable. However, in essence these are all social groupings with supportive and educational elements. A variety of models have evolved, adapting to local needs and structured towards the needs of service users in the local area (Halley et al, 2005) and becoming more culturally appropriate (Dow et al, 2011). The concept of a dementia café embodies the socially supportive environments that have been recommended by national and international dementia strategies for those living with dementia and their care-partners (For example NICE, 2018). Dementia cafés recognise the need to focus on the skills and capacities the person living with dementia retains, rather than those they have lost. From the care-partner perspective, dementia cafés provide them with a socially inclusive network of individuals who have experienced or are experiencing similar circumstances. This approach brings positive benefits as people share experiences and support one another (Pratt et al 2005) promoting the vision of living positively with dementia. Indeed, evidence suggests that dementia cafés facilitate social inclusion and prevent isolation for people living with dementia and their care-partners (Dow et al, 2011; Teahan et al, 2020) by enabling social connections (McFadden and Koll, 2014).

### **The development of a person-centred café**

Over the past five years academics at a University in the North-West of England worked in unison with people living with dementia, their care-partners and former care-partners to co-design a café style group based on a person-centred approach. The aim was to provide a safe, welcoming environment to provide stimulation, fun, support and promote an ethos of

inclusivity, often teaching new skills. Sessions aimed to be informative, relaxed and enjoyable, and took a person-centred approach to those living with dementia and their care-partners and former care-partners. Sessions were planned jointly with academics and members, based on what members wanted to do, or learn about, with presenters also having first-hand experience of dementia. For example, members wanted to celebrate Chinese New Year, so a local person who was known to some members was invited to host a session, going on to provide an interactive, and fun afternoon that included Chinese cuisine, art, culture and history. Underpinning the café structure with the ethos of co-design, which meant that sessions were also co-delivered, with members and staff often jointly facilitating the café, showcasing interests, hobbies or talents. Crucially, the drive of the café was to provide person-centred support, focussing on the individual, and not the dementia, and aimed to combine attributes of both the Alzheimer and memory cafes (Innes et al, forthcoming). When naming the group, members expressed strong opinions, that the group did not have the word dementia in its title, as it was felt that the emphasis should be on living positively, and not be stigmatised by the negative connotations surrounding dementia. Being person-centred meant that there were no power differentials, enabling everyone who wanted to be involved, to plan, facilitate and evaluate the sessions. This allowed members to feel valued and respected, with their views used to shape the service into a group which offered meaningful support. The group was advertised in local shops, organisations, support groups to promote its membership.

### ***The concept of Wellbeing***

The concept of wellbeing is described as a positive state of mind and body, of feeling safe, able to cope and having a sense of connection with people, communities and the wider environment (DoH 2010:12). Staricoff (2004) suggests that a person can be physically ill, yet still maintain a state of wellbeing, since it is a state of acceptance of what is in the mind, body and spirit. The UK Department of Health (2014:6) state that: '*Wellbeing is about feeling good and functioning well and comprises an individual's experience of their life; and a comparison of life circumstances with social norms and values*'. Furthermore, the UK Department of Health's (2014) description of wellbeing posits that it exists in two dimensions, with a subjective or personal perspective, based on life satisfaction and an objective perspective, based on assumptions about fundamental human needs and rights. In contrast, Daykin et al (2016) identified wellbeing to have personal, cultural and social dimensions.

Taking a psycho-social stance, Tom Kitwood conceived wellbeing and personhood differently from previous models and moved away from the emphasis on medical and behavioural factors (Kitwood, 1997). Rather, the importance of personhood and person-centred care is fundamental to achieving wellbeing (Kitwood and Bredin, 1992). Kitwood (1997:19) defines personhood as 'a standing or status that is bestowed upon one human being, by others, and implies recognition, respect and trust'. Using this definition of personhood Kitwood (1997) described a person's 'wellbeing' as being enhanced by the presence of recognition, respect and trust received from others, or in the absence of such behaviours, that 'illbeing' can occur. Kitwood (1997: 19) conceptualised that individuals have five psychological needs: inclusion, attachment, comfort, identity, and occupation, that when met will promote wellbeing. Designing services around the principles of personhood seeks to create an inclusive environment which situates people equally, facilitating reciprocal trust and altruism through validation and acceptance (Trivers, 1971).

Kitwood's approach to person-centred care is widely used to support personhood for people living with dementia (Wadham et al., 2016). However, informal care-partners can themselves frequently experience social isolation due to their caring responsibilities and reluctance to engage in social situations because of unpredictable behaviour (Nay et al., 2015). Utilising Kitwood's (1997) concept of person-centred care and personhood in designing the café approach and as a lens to guide data analysis, this research acknowledges the needs of care-partners and former care-partners. It also draws on the relational nature of Kitwood's (1997) work on personhood, and its exploration of social interaction, roles and relationships (Tolhurst et al., 2014). Indeed, the psycho-social needs of experiencing an enriching environment which promotes self-worth and sense of purpose is also reflected in Nolan et al's (2006) work on relationship-centred care. As such Kitwood's conceptualisation can also be applied to those who provide care and support to those living with dementia.

## **Methods**

### **Study aims.**

This paper explores the impact of regular attendance at a person-centred café for care-partner wellbeing. The wider study reported elsewhere (Innes et al forthcoming) examined the primary intended benefit to those living with dementia. In using Kitwood's (1997) psycho-social concept of personhood and wellbeing to analyze the data, our intention is to draw upon the emotional and relational aspects of being a current or former care-partner for someone living with dementia.

### **Study design**

Findings in this paper were taken from a larger study based on a co-designed café informed by a person-centred approach with people living with dementia, their care-partners and former care-partners. This paper describes the data collected from the care-partners and former care-partners only. The duration of the study was shortened from 12 months to 8 months (August 2019- March 2020) due to the Coronavirus pandemic. This paper will focus on the experiences of attending eight café sessions for three current care-partners and five former care-partners. Interviews conducted prior to the sessions sought to gain an in-depth understanding of what participants expected from the cafés and follow up interviews explored their experiences and views of attending the eight sessions that took place up to March 2020. Eight care-partners consented to taking part in the study. Three were current care-partners (Two were female and one was male) and five former care-partners (All were female). Three interviews were conducted as a dyad with the person living with dementia, however, only the care-partner data is included in this paper. The age range for participants was 50- 80 years. All interviews at both time periods lasted between 30 minutes and one hour and were digitally recorded and transcribed verbatim.

The café was free of charge to attend and hosted at the author's University. All authors took part in the larger study (Innes et al, forthcoming) with authors 1, 3 and 4 involved in data collection, and author 2 leading on all areas of co-design.

The evaluation process was discussed and co-designed with people living with dementia, care-partners, and former care-partners who belonged to the University's Dementia Hub, and carried out by academics who worked within the Hub, and had experience of working with people living with dementia.

## **Ethical concerns**

Ethics approval for the study was granted by the University Research Ethics Committee [HSR1718-0620n 28<sup>th</sup> April 2018]. Due to social distancing measures introduced as a result of the COVID-19 pandemic, further ethical approval was obtained on 06/04/2020 to complete the follow up semi-structured online using conferencing software or by telephone.

## **Inclusion criteria**

To be included in the study, participants had to have an interest in participating in [SID's] café for a twelve-month period and agree to taking part in pre and post interviews by the named researchers. Not all people attending the café participated in the study.

## **Recruitment**

The group was publicised at locally run dementia support groups, carers groups and several network events. Many of the participants had attended previous groups which took place within the university setting and had helped to co-design the new café format and wanted to be involved in its evaluation. All participants were given information about the study in paper format at least one-week before the study to allow time for clarification and questions. Process consent was followed throughout the study (Dewing, 2008).

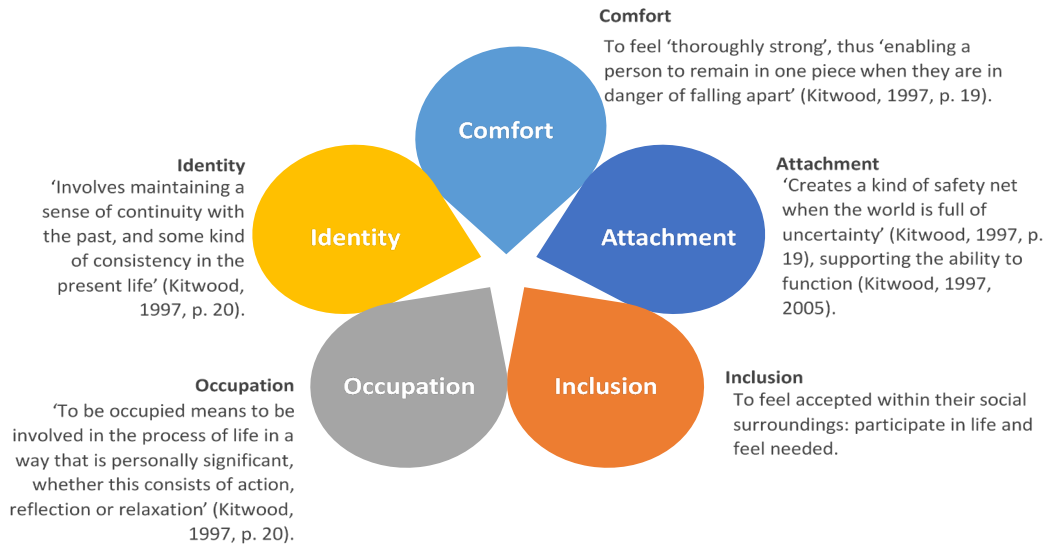
## **Interviews**

Semi-structured interviews were used where the researcher adopted conversational style to encourage interviewees to speak in-depth about their experiences. A topic guide exploring issues such as their experiences of dementia, expectations for attending the group, and preferences for activities were sought in pre-session interviews. Whilst post intervention interviews centred on their subjective experiences, impacts and benefits to their personal wellbeing resulting from attending the sessions. This facilitated a consistent approach across all interviews. However, as previously mentioned post intervention interviews could not take place face-to-face due to the Covid-19 pandemic. This may have impacted upon the participant responses.

## **Data analysis**

All interviews were transcribed verbatim and anonymised. Researchers used the 6-step approach by Braun and Clarke (2006) to thematically analyse the data. Interviews were conducted by LC and LM, with transcripts repeatedly read and re-read, with NVivo software used to code the data. Initial themes were generated and reviewed by the research team for coherence and credibility. Primary themes and sub themes were then refined and viewed through the lens of Kitwood's (1997) concept of personhood, and thematically 'mapping' the analysis (Braun and Clarke, 2006). All themes were discussed amongst the researchers and amended until a consensus was reached. The last part of the analysis, according to Braun and Clarke's (2006) is demonstrated in selecting extracts to report on which best represent the themes, and overall study.

**Figure 1 An adapted diagram illustrating Kitwood's (1997) 5 Psychological needs:**



## Findings

Kitwood (1997) asserts that personhood and subsequently wellbeing is achieved when the psychological needs of inclusion, attachment, comfort, identity, and occupation are met. Whilst Kitwood's (1997) work was based on a person-centred approach to caring for people living with dementia, his thoughts on wellbeing are equally pertinent to the care-partners and former care-partners, as the following analysis demonstrates, focusing on the person's uniqueness and their needs. Kitwood (1997) theorised that the depersonalisation which occurs for those diagnosed with dementia undermines their personhood. We contend that this is often true for their care-partners, who become invisible as a result of the dementia in another. It is therefore vital that care-partners (like those living with dementia) remain connected to sources which have always generated feelings of being valued, respected and needed, such as occupation or identity, which are too often neglected. In presenting these findings, we are mindful, that the positive experiences discussed here, may also be connected to the general ethos of the co-designed café, and that members who attended the sessions were either aware of, or had contributed to the development of [anonymized] café. Some participants had attended earlier versions of the café and expressed a desire to be involved with the design and research. Kitwood's (1997) concept of personhood has been used as a lens, to guide and present these findings.

### Inclusion

Kitwood (1997:20) described inclusion as: 'To feel accepted within their social surroundings and participate in life and feel needed'. Participants viewed inclusion as being extremely important to them. Their need to feel included was perhaps magnified because they had often experienced feeling isolated and lonely as they were confronted with challenging behaviour in the person they cared for, and consequently feared being judged by others. This meant that they often chose not to leave their homes and socialise with others. The following quote is

particularly pertinent as a former care-partner spoke about not wanting others to judge the person she cared for.

*FCP04: Well, I was in denial... Oh, there's nothing wrong with him, he's perfectly alright, he's just got Alzheimer's, ... I really didn't want people to know that he could be like that, because he just wasn't like that.*

One participant commented that she had attended other dementia support groups, which had labelled the person she cared for as having dementia, and she had perceived that this stopped them both being seen as individuals. She compared these experiences to the person-centred approach used in [SID's] café.

*CP07: We have been to a couple of places where there's still a little bit of the stigma attached, ..., because that's all they harp on about and they keep throwing the word dementia in your face a lot of the time. And to me, that's wrong, we need to get away from that, and like I say, just see that individual and look at what can they actually do, what can they provide... They don't see dementia here, they just see the person.*

*CP06: We found it quite difficult at first. We kept going to these places in [locally], but they were mainly elderly people that just were falling asleep. Well, you can't put people with dementia there, there was no stimulus. At [SID's] café all ages go, and there's all sorts of things going on.*

Participant's spoke about the need for themselves and the person they cared for feeling included and accepted by others. This was often experienced by being included in 'banter' and interactions which went on within the groups, which also gave them a sense of normality.

*CP07: I like it because of the camaraderie, the peer support, the fact that people are going through exactly what you're going through or have been through it, and also for the fact that you're not judged... I think, as a carer, the banter and what you can have with the other carers gets you through.*

Whilst this was an enjoyable part of the session, attendance at the café often resulted in generating conversations beyond the session, and acted as a catalyst for interactions and discussions after the café had finished.

*CP08: It's about stimulating rather than saying do you remember so and so, this is something we thought you might be interested in... offering you something that might be the trigger... bringing something to mind that you've not thought of for a long time. And I think that's wonderful, because we can't do that at home and we just do the same old, same old.*

Participants spoke of the lasting benefit of the café sessions which positively impacted their wellbeing, by providing stimulation once they left the session. For current care-partners this was particularly important and was seen as a way of improving the quality of life for those living with dementia. Inclusion was also perceived as being part of the group, and of those whom they cared for and not feeling different or disadvantaged because of the diagnosis of dementia. For those actively caring for someone living with dementia [SID's] café allowed them to relax and socialise, in the knowledge that they were in a non-judgemental environment, where the person, not the dementia was seen.

### Attachment

Attachment is defined by Kitwood (1997:19) as the creation of 'a kind of safety net when the world is full of uncertainty', supporting the ability to function. For the participants in this study, the camaraderie and peer support, provided by other members of [SID's] café reflected their



need for attachment by allowing them a safe environment, where individuals could share experiences, at different stages of the dementia journey. This allowed people to see how others have coped and give them confidence and hope for the future. Friendship was central to participants' attendance at the group and was reported as something very valuable impacting positively on other areas of their lives. However, it was acknowledged that friendship was built up over time and was perhaps an unexpected benefit from attending the group.

*CP07: The friendships that I've actually got from here, when [person living with dementia] was in hospital... these are the same people who came every day to see if I was OK...I think if I hadn't have come here, then I wouldn't have had that because the friendships are very strong, and I think that's what you find.*

*FCP05: ...that camaraderie and the amount of respect, the mutual support, the understanding, the empathy, it's massive, and when you're really, really struggling, to have that safety net of knowing that you can walk in there and people in that room truly understand and truly care is priceless.*

One participant spoke of his feelings of belonging and safety which he and his wife had experienced at the café. The feelings of safety were derived from the physical environment, the presence of familiar people and the fact that groups were run in a non-threatening manner where confidentiality was respected, it was important to participants that they could be honest, and share their experiences, giving them the feeling that they were not alone. Sharing similar life experiences seemed to be a factor which created trust through empathy and understanding.

*CP06: It's a fact that [person living with dementia] is never really comfortable in a lot of places, but she is here. We have been to other groups and it doesn't seem...it seems a bit cold in other groups. But for some unknown reason, which could be because of the actual people that are there, it's quite warm and that's what is the biggest difference out of it. ...You can get things off your chest. You can be open. Because other people are in the same position as you it's fine, so it's like releasing something out of a drawer... because you know that that group of people are in the same position as you.*

Peer support was seen as an important aspect in increasing wellbeing and building self-esteem, giving them an opportunity to share their experiences with others who had first-hand experience of living with dementia. Support from peers was seen as offering both practical and emotional support to the care-partners, helping them cope with their everyday lives of caregiving while providing a sense of social connection. Participants spoke of the importance of shared experience, understanding and openness. All the care-partners attached value to being able to talk, laugh and interact with others in a social setting, which perhaps offered a respite from their caring responsibilities and the pressure they felt in other situations.

## Comfort

Kitwood (1997:19) described comfort as feeling 'thoroughly strong', thus 'enabling a person to remain in one piece when they are in danger of falling apart'. In this study, participants described the strength they acquired from the support of their friends and social networks which they had gained from [SID's] café attendance, and how this gave them the strength to deal with the shock when they received the initial diagnosis. Kitwood's description of everything 'falling apart' is particularly apparent in the first exemplar a former care-partner describes the fear when they first heard the diagnosis of dementia and the comfort of finding support.

*FCP03: You become so isolated and become so fearful, you don't know what's ahead of you, this is probably one of the most traumatic things you can possibly ever go through, and to know that you can come to a place where you can bring the person that you're looking after and anything goes, and I mean anything.*

For others the diagnosis brought a need for information in a bid to alleviate symptoms and improve the quality of life for the person living with dementia. This coping mechanism gave them some comfort and strength in that they were actively trying to help.

*FCP02: I had no knowledge, no understanding of the illness, how it would affect the person, how it would affect the family and the wider circle of people. It came as a shock initially, I think I was in denial because I think most people are.... This is the man that had looked after me for 30 years, you know, and I felt as though I was failing him because I didn't know enough.*

Reflections from former care-partners portrayed the uncertainty that participant's experienced at not knowing what to do when confronted by the diagnosis of dementia. All the former care-partners described their personal need to find out about dementia, conceived as both a way of coping with the diagnosis, and a way to move forward. Six participants spoke about their reactions to hearing the diagnosis. On occasions they described the circumstances and details of when they heard the diagnosis for the first time, and the ways they dealt with the news. For some, this was a confirmation of their own suspicion's, for others, it was a complete shock. For one person it was a relief, that they were being given an explanation for the array of symptoms sometimes dismissed by health care professionals.

*FCP05: I was still fighting for some kind of diagnosis and then in the end I said – because it was always me – I said, look, we need to sort this out, something is going on, can we have a meeting with the GP as a family.... Having been vilified by so many professional people, finally, finally somebody saw what I was dealing with. And it was such a relief.*

Five participants reflected upon this diagnostic period as a time where they coped by using denial. Denial was experienced through the pretence of carrying on as if nothing was occurring, almost a defiance that the diagnosis of dementia would not be allowed to alter the lives

*FCP02: My attitude was, I'm not going to let this change me, affect me, and basically, it was the worst decision I ever made. Once I realised that this is going to change our lives, it was...I wouldn't say it was easier, but it was a bit more bearable*

Participants spoke of the fear and isolation as they 'fought' for a diagnosis, an explanation for what was going on. Each person identified their personal struggles, and their need to find ways to cope with the changing situation. Whilst there was obvious distress as they retold their stories, there was an acknowledgement that they had gained strength from others, and learnt ways to cope from people who had shared experiences. Kitwood's (1997) imagery of feeling strong in the face of adversity aptly encompasses the participants experiences.

It was apparent from the interviews that those currently caring for a person with dementia chose not to talk about the impact of receiving a diagnosis of dementia in the same way as former care-partners. This may be because the person living with dementia was present in the interview, which could have influenced what was articulated, or perhaps they perceived what was occurring in the present as the more important issues to comment upon.

### Identity

Identity, according to Kitwood 'involves maintaining a sense of continuity with the past, and some kind of consistency in the present life' (Kitwood, 1997:20). For care-partners and former

care-partners, identity was a central issue, as they often felt invisible, as the focus was generally on the person with dementia. Reclaiming their identity, and building their lost self-confidence were the empowering attributes of attending the café.

FCP01: *...It's also belonging to the club and getting out and getting the confidence to do things on my own, which I'd never done before in my life.*

FCP05: *You do feel part of something, you feel that your opinions are of value and that you have something to contribute*

CP06: *And we all seem to come together, you know, with the sense of like having fun and...which is what you need for circumstances like ours, you know...And it doesn't matter who you are, or what, if you have a diagnosis or not, we're all the same, we're all the same, on a par with each other, and that's what you want*

Care-partners spoke about the increased confidence they have observed in themselves and in the person living with dementia, and how feeling supported by other members of the group had a positive impact on their wellbeing. [SID's] café also helped participants to have a sense of belonging and prevent the social isolation they had previously experienced as they now had others in a similar position or who had experience similar issues in the past to talk to and share tips and strategies with. Identity and belonging are often closely linked, and this is seen in the exemplars. Identity is perhaps a pivotal issue for care-partners, who may have felt they had become 'invisible', with their needs often overlooked. Being part of a group, having a purpose and feeling valued emerge from this theme strongly, and are interwoven throughout the analysis.

### Occupation

Kitwood (1997:83) describes occupation as '*being involved in the process of life that is personally significant and which draws on a person's abilities and powers.*' Former care-partners articulated the need to have a purpose, and this is particularly poignant when their role as a care-partner is removed when the person passes away. Attendance at [SID's] café allowed former care-partners to reflect upon challenges they faced when caring for someone with dementia, and benefit from ongoing support from peers. They also saw the café as a way to contribute to dementia care in a positive way, and whilst their input was initially for altruistic reasons, the support they gave was reciprocated, and deemed mutually beneficial to their wellbeing.

FCP01: *And the help and support that people with dementia, and also the carers, what they need. And I feel as though it's given me a voice to speak on their behalf.*

CP07: *...having been here and starting here and coming to the groups here has opened all the other doors for what I'm involved in, which then [the person living with dementia] gets involved with. So again, a lot of what I go to, people don't see the dementia because we're working against that, we're actually trying to reduce the stigma and trying to make it a more positive experience rather than negative, but through being here, that's opened that door.*

CP06: *...we do a lot to help other people, ...raising awareness of dementia and how to interact with people.*

Participants spoke of the ways they had been involved in the group activities; raising dementia awareness and supporting other care-partners and those living with dementia, giving them a sense of purpose, and sense of belonging, reducing the social isolation which many of them had experienced prior to attending [SID's] café. Participants also spoke of their increased self-belief, which allowed them to speak to a wider audience or fundraise. The analysis of this data

also showed that the themes of occupation and identity, and inclusion and attachment often overlapped, and participants comments could conceivably have been placed under multiple themes. An example of this would be when participants spoke of feeling isolated prior to becoming involved in the group, which over time changed to represent the importance of belonging and friendships, which were also interconnected with identity and purpose.

## **Discussion**

Findings demonstrate the positive impact that the person-centred café had on the wellbeing of care-partners and former care-partners. The findings suggest that the café offered a safe environment, where support was reciprocal, and helped them to better cope with their everyday lives (Brooker et al, 2017). In facilitating peer support, creating social networks, and often friendships (Greenwood, 2017), [SID's] café provided longer term support and reduced social isolation for participants (Dow et al, 2011). Care-partners and former care-partners also articulated the uncertainty which they encountered when faced with the diagnosis of dementia, and the strength which they felt they got from attending groups (Greenwood, 2017). [SID's] café allowed them a safe and welcoming environment, in which they could reflect upon the challenges they had faced (Teahan et al, 2020). The study also found that former care-partners still required on-going support, and this was successfully achieved by attending the café group. The needs and voices of former care-partners are largely absent from research, so this study makes an important contribution to the literature. The findings demonstrate the important contribution former care-partners have in supporting and building capacity for current care-partners and raising dementia awareness.

As well as explicitly linking with Kitwood's model of person-centred care (e.g. occupation is emphasised in this model), these experiences support a sense of identity. A sense of purpose, achievement and significance are all mentioned as key to positive relationships, identity and an enriching environment (Nolan et al, 2006; Van Gennip et, 2014). Within this study, the importance of being able to engage alongside others in activities that were personally relevant, enjoyable and meaningful was clearly linked with a sense of identity and wellbeing. The centrality of peer support allowed participants a sense of attachment, and also inclusion, which in turn facilitated a sense of purpose, and occupation. Being involved in a social group, which led to friendships, reflects evidence that suggests that the opportunity to socialise with others experiencing life in similar ways can reduce social isolation and lead to informal peer support networks (Dow et al., 2011; Takechi et al, 2019; Wiersma and Denton, 2016). It is also interesting that being a member of [SID's] Café offered opportunities for community engagement activities, raising awareness of the condition. Teahan et al (2020) argues that such community engagement activities have the potential to reduce stigma as community members see people living with dementia and their care-partners engaging in usual ways.

## **Conclusion**

Findings from this study, suggest that attendance at a person-centred café can have a positive impact on self-reported wellbeing of care-partners, by meeting the psychological needs of inclusion, attachment, comfort, identity, belonging and occupation, as defined by Kitwood (1997). However, we also acknowledge that the positive experiences which were articulated by participants may be interconnected with the participants involvement in the co-design process of [SID's] café. We consider that the contribution to this process may have increased participants self-worth and sense of personhood and could in itself have helped to increase self-reported wellbeing. Many of the findings in this study were interlinked, with past emotions such as fear and isolation being replaced by friendship and acceptance. Indeed, friendship

and peer support contributed to participants feelings of inclusion, belonging and attachment and as such the friendships forged by participation in the cafés and as such can be clearly seen as part of maintaining personhood and wellbeing articulated by Kitwood (1997).

Findings from this study demonstrate the importance of being able to engage alongside others in activities that were personally relevant, enjoyable and meaningful were clearly linked with a sense of identity and wellbeing. For care-partners and former care-partners maintaining, or reimagining a sense of purpose, by attending [SID's] café appeared to give them an identity, which had sometimes become lost through the process of caring, or the death of the person they cared for. We would also suggest that the person-centred approach used in [Sid's] café offered positive benefits to the wellbeing of care-partners and as such is similar to Teahan et al (2020) research on Irish participants at a café session. Our findings also offer important evidence that former care-partners need ongoing support and opportunities to reflect on challenges they encountered whilst caring for someone with dementia. In this way the issue of 'the invisible patient' can be addressed. The person-centred model evaluated in this study allowed former care-partners to rekindle their identity, self-belief and sense of purpose, in a safe and supported environment.

Study findings reflect the broader literature on dementia cafes which demonstrate the positive impact which they have on care-partner wellbeing, through increasing a sense of belonging through peer support (Lee et al, 2020) reducing loneliness (Tseklevs et al, 2020), social isolation ( Akhtar et al, 2017) and reducing carer burden by promoting new coping strategies (Teahan et al, 2020). However, this study differed from being purely an evaluation of a generic dementia café, as it centred on enacting Kitwood's principles of person-centred, and as such was created through co-design, co-facilitation and evolved through consensus and partnership working. The architects of [Sid's] café were people living with dementia, care-partners, former care-partners and academic staff, all of whom had expert knowledge of dementia. We would therefore contend that the process of developing [Sid's] cafe is an example of excellence in practice, which resonates strongly with the recommendations from national and international dementia policy and strategy, which all call for a person centred approach, tailored to individual needs, with informational, and psychosocial support to optimise wellbeing.

Finally, in keeping with the ethos of the co-designed process, all findings were shared with members of the café, and have been used as part of the ongoing development of [SID's] café.

## **Study Limitations**

This study acknowledges that the sample is not representative in terms of ethnicity, despite every effort in recruitment, which perhaps reflected extant literature concerning the representation of individuals that are described as 'hard to reach' and who don't engage with community services or events, preferring to utilise more familiar services such as faith institutions (Parveen et al, 2017).

COVID-19 lockdown impacted the study, as services could no longer be delivered in a face-to-face context. Nevertheless, participants clearly articulated that the person-centred café was beneficial to their sense of wellbeing and personhood.

The study involved participants having the decision to be interviewed as dyads. We acknowledge that this may have stifled some care-partner responses, as indicated in the results section. On the other hand, this may have given confidence to the dyad partnership, to enable greater openness.

The study involved some participants who had been involved in the co-design of [SID's] café. We acknowledge that this might have affected their experiences. Furthermore, to mitigate any risk that participants felt the need to respond in a particular way, because they had been involved in the co-design process, author 1, who had led the co-design process was not involved in data collection.

### **Statement of ethical approval**

Ethics approval for the study was granted by the University Research Ethics Committee [HSR1718-0620n 28<sup>th</sup> April 2018]

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### **Statement of conflict of interest**

No conflict of interest was reported

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