Aging & Mental Health

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/camh20

A participatory approach to understand what might be most meaningful to people living with dementia in a positive psychology intervention

Victoria Jackman, Emma Wolverson, Chris Clarke & Catherine Quinn

To cite this article: Victoria Jackman, Emma Wolverson, Chris Clarke & Catherine Quinn (08 Jan 2024): A participatory approach to understand what might be most meaningful to people living with dementia in a positive psychology intervention, Aging & Mental Health, DOI: 10.1080/13607863.2023.2299967

To link to this article: https://doi.org/10.1080/13607863.2023.2299967

AGING & MENTAL HEALTH
https://doi.org/10.1080/13607863.2023.2299967

Routledge
Taylor & Francis Group

A participatory approach to understand what might be most meaningful to people living with dementia in a positive psychology intervention

Victoria Jackman[a], Emma Wolverson[a,b], Chris Clarke[c] and Catherine Quinn[d,e]

[a]School of Psychology and Social Work, University of Hull, Hull; [b]Dementia UK, London, UK; [c]Tees Esk & Wear Valleys NHS Trust, UK; [d]Centre for Applied Dementia Studies, University of Bradford, Bradford, UK; [e]Wolfson Centre for Applied Health Research, Bradford, UK

ABSTRACT

Objectives: This study aimed to understand which character strengths are most important for people living with dementia and therefore which strengths-based psychological interventions could be most meaningful and acceptable.

Methods: A participatory design, utilising Delphi methodology, was incorporated into an iterative three stage framework: (1) literature reviewed for Positive Psychology (PP) interventions and patient public involvement to define the character strengths; (2) modified Delphi ($N = 10$) identified which character strengths are most important for living with dementia; (3) focus groups ($N = 14$) explored which PP interventions are most acceptable and meaningful. Qualitative data from the focus groups was analysed using thematic analysis.

Results: Love, kindness and humour were deemed the most important character strengths for living with dementia. Qualitative data from the focus groups was captured in three superordinate themes: (1) lack of opportunity not capacity; (2) key considerations of PP interventions for people living with dementia; and (3) potential benefits of PP interventions.

Conclusions: Love, kindness and humour come naturally to people with dementia, but people may lack social opportunities to use these strengths. Therefore, a PP intervention promoting positive emotion, social relationships and connection to one's values appears most meaningful and acceptable as this may provide a social context to use and maintain these strengths.

ARTICLE HISTORY
Received 13 July 2023
Accepted 12 December 2023

KEYWORDS
Dementia; character strengths; positive psychology intervention; coproduction

Introduction

Supporting individuals to live well with dementia is an international priority (Gauthier et al., 2022). Despite the negative discourses that surround dementia (Alzheimer's Research UK, 2019), people with dementia can have positive experiences, actively seek these out and grow through the adversity they face (Wolverson et al., 2016). Individual experiences of living well with dementia inevitably vary based on: psychological characteristics, physical health and fitness, level of social engagement and connectedness, ability to have independence, quality of relationships and role in society (Quinn et al., 2022). Broadly, such positive psychological resources are predictors of living well with dementia (Lamont et al., 2020). More specifically, qualitative research reveals the importance of the strengths people may draw on to face and fight the condition, whilst maintaining a sense of personal identity and growth (Wolverson et al., 2016). For example, people living with dementia can utilise humour to actively maintain wellbeing (Hickman et al., 2018). Maintaining a positive outlook can contribute to couples' resilience to live with the challenges dementia brings (Conway et al., 2020).

Accordingly, in seeking to develop interventions that grow an individual's resources and strengths to improve wellbeing (Csikszentmihalyi & Seligman, 2000), a positive psychological framework could be helpful. Positive psychology (PP) is 'devoted to the study and theory of the processes and conditions that contribute to flourishing or optimal functioning across groups, institutions, and individuals' (Gable & Haidt, 2005, p. 103). More recent developments of 2nd wave PP approaches recognise the dialectical interplay and interdependence between positive and negative experiences (Lomas & Ivtzan, 2016). This approach resonates with living with dementia whereby individuals strive to balance their responses to challenges whilst actively seeking positive experiences (Wolverson et al., 2010; Wolverson et al., 2016). This is consistent with affect balance approaches in dementia, whereby an individual's wellbeing can be predicted by their experience of positive emotions relative to negative emotions within discrete time periods (Kolanowski et al., 2022). Utilising a PP framework in dementia research is not to deny the hardships people may face (Bartlett et al., 2017) but aims to enhance our understanding of what it means to maintain well-being in living with dementia.

Consequently, PP interventions could be helpful to support people with dementia to live well as, broadly, they aim to promote wellbeing by enhancing positive affect, meaning and engagement (Duckworth et al., 2005). PP interventions are effective at improving wellbeing in older adults (Ho et al., 2014; Salces-Cubero et al., 2019), with multi component interventions generally being most effective across a range of populations (Carr et al., 2021). Currently, few PP interventions have been evaluated with people living with dementia, although qualitative research suggests gratitude diaries are perceived

---

CONTACT Victoria Jackman victoriajackman07@gmail.com

Supplemental data for this article can be accessed online at https://doi.org/10.1080/13607863.2023.2299967.

as acceptable and useful (Pearson et al., 2021). Furthermore, humour interventions for people living with dementia in a residential setting have shown positive benefits, including increasing happiness and reducing agitation (Low et al., 2014). Therefore, enhancing such strengths might be helpful in improving wellbeing.

From a PP perspective, the Character Strengths and Virtues (CSV) framework (Park et al., 2004) could be of relevance to understand how people living with dementia could be supported to live well. This PP framework delineates 24-character strengths that contribute to wellbeing, categorised around six virtues: wisdom and knowledge, courage, humanity, justice, temperance and transcendence (Park & Peterson, 2009). Character strengths are 'positive traits reflected in thoughts, feelings and behaviours' (Park et al., 2004, p. 603), that form the core characteristics of these virtues (Park & Peterson, 2009). Character strengths have been utilised in the design and development of strengths-based interventions to improve wellbeing outside of dementia, since they show a strong relationship with different models of wellbeing (Wagner et al., 2020).

People living with dementia should be actively involved in designing and evaluating interventions. As such participatory approaches are now a priority within dementia research (Vernooij-Dassen et al., 2021; Innovations in Dementia, 2023). Past research in dementia has typically centred on involving carers and professionals (Burton et al., 2019), instead of those actually living with dementia. This may be because people with dementia have been seen as incapable of consenting or being actively involved in research (Dementia Action Alliance, 2017). However, studies that actively involve people living with dementia in designing psycho-social interventions report that interventions are more personalised and tailored to the needs of the people using them (Dodd et al., 2021), highlighting the benefits of this approach.

Participatory research naturally sits within current approaches to the systematic development and evaluation of complex interventions (see Skivington et al., 2021). Typically, interventions are decided upon by research teams following a review of research evidence and theory (e.g. Cotelli et al., 2012; Spector et al., 2003). However, a strength of participatory approaches lies in combining the knowledge of the research evidence and theory brought by the researcher with the lived experiences, preferences and choices of people living with dementia (Gove et al., 2017). As such, this research took a foundational and participatory stance to understand what components of a PP intervention may be important, combining the research evidence with the subjective preferences and insights of people living with dementia. The following two research questions were posed: (1) from the perspective of people living with dementia which character strengths are deemed most important to live well with dementia? (2) for these identified character strengths, which strength-based interventions would be most meaningful and acceptable to people living with dementia?

Method

A participatory, modified Delphi design was incorporated within an iterative three stage framework (see Figure 1) that centred on generating qualitative data. Based on the approach used by Yates et al. (2020) these stages involved (1) evidence gathering and Patient and Public Involvement (PPI), (2) modified Delphi and (3) focus groups. This was an iterative approach so as to allow new insights to be incorporated across the stages, combining research evidence with the voices of people living with dementia. There are different approaches to involving people living with dementia actively in research, with INVOLVE (2012) describing these as consultation, collaboration and user controlled. This study predominantly used consultation, whereby people living with dementia were consulted systematically at each stage.

Stage 1: evidence gathering and patient and public involvement

Aim: To review the evidence for existing character strength-based interventions and to co-produce definitions of the character strengths.

Stage 1a: systematic literature review

A systematic literature review was undertaken to review the evidence base regarding existing character strength-based interventions that have been used with older adults which highlighted pre-existing PP interventions exist for older adults targeting hope, humour, gratitude, spirituality and forgiveness, with overall positive evidence of effectiveness. Results are published elsewhere (Jackman et al., 2023). Relevant interventions were used in stage 3 to seek participants opinions on these.

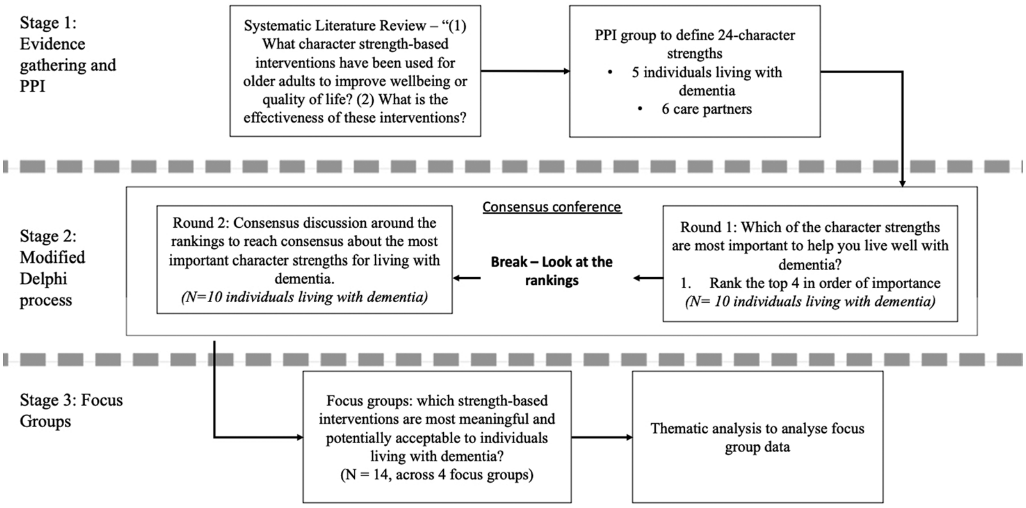

Figure 1. Outline of the research procedure.

Stage 1b: patient and public involvement

An established dementia specific PPI group in the North of England was approached and agreed to help develop accessible and meaningful resources for the research. The group was comprised of five people living with dementia and six care partners. Care partners were family carers and were included at this stage because they were members of the established PPI group and enabled the gathering of broad perspectives on the meanings of character strengths in relation to dementia. Researchers (VJ, EW) attended the PPI group to seek consultation about how to define the 24-character strengths in a way that is meaningful to people living with dementia. This involved all members of the group being given 24 cards, each with a character strength, their synonym(s) (taken from Park et al., 2004) and definition on (defined by Park & Peterson, 2009). They were asked to collaboratively discuss each of the 24-character strengths, synonyms and definitions. Individuals then chose their preferred synonym from the list and together group members created and agreed definitions of each strength in the context of living with dementia. The definitions written by the PPI group were compared to Park and Peterson (2009) by the research team. For critical thinking, forgiveness and humility, the definition used by Park and Peterson (2009) was used alongside the PPI groups for greater clarity and understanding. These definitions were then used for the subsequent research stages and can be seen in the supplementary material.

Stage two: modified Delphi process

Aim: Multi-modal PP interventions typically target three strengths (e.g. Salces-Cubero et al., 2019). Therefore, the aim of the modified Delphi was to refine the 24-character strengths down into the strengths deemed most important for living with dementia. This was to ensure the focus of an intervention would be relevant to this population.

Design: A participatory research design utilised a modified Delphi method. A modified Delphi is often used when there is a lack of available evidence coupled with a need to bring together expert opinions and insights to gain consensus around a research question (Powell, 2003). Modified Delphi is a widely used approach in clinical research (Jorm, 2015) and has been adapted as an accessible method to involve people living with dementia (Morbey et al., 2019). The Delphi comprised two rounds, where each round informed the next and participants could see the answers from the previous round, in line with common modified Delphi designs (Barrett & Heale, 2020). This methodology supported people living with dementia to take an expert by experience position and come to a systematic agreement across the two rounds about the most important character strengths for living with dementia. The most important character strengths identified formed the content of subsequent focus groups.

Participants: Members of a dementia self-advocacy group based in Yorkshire (United Kingdom) were approached January 2022 and an overview of the study was shared. The group subsequently agreed and confirmed their interest in participation. Participant inclusion criteria can be seen in Table 1.

Table 1. Participant inclusion criteria for stages 2 and 3 of the study.

Inclusion criteria	Justification
Fluent in English speaking and reading.	The researcher only speaks English, and they need to ensure sound understanding of the character strengths.
Identify themselves as living with dementia.	No confirmation of their dementia diagnosis was sought, but by recruiting through charities supporting people living with dementia there is the assumption individuals will be living with dementia.
Living in a community setting	The strengths relevant to individuals living in community settings may differ to individuals residing in a residential setting.
Able to give informed consent	To ensure ethical completion and participation. See the ethics section for considerations around capacity.
Able to participate in interviews (either as a group or one to one)	To be able to provide the data required for the study.

Procedure: The lead researcher attended a group session prior to data collection to explain the research and share the information sheet, allowing participants time to read and consider it. On the day of data collection (one month later), the study was re-explained, and participants were given a further chance to ask questions. Informed consent was recorded. All participants completed a demographic information form.

The two-round modified Delphi was completed in one 3-h session, with a break. All four researchers facilitated the session.

Round 1: Participants formed small groups with one facilitator, and each participant was given 24 cards. Each card had one character strength alongside its definition (defined in stage one). Participants were then asked individually to pick and then rank the four strengths they deemed most important for living with dementia (1 = most important; 4 = least important). All participants' rankings were collated by the researcher(s) and then displayed to allow all participants to see how the strengths had been rated by other participants.

Round 2: All participants came together for a consensus discussion (Yates et al., 2020), allowing participants to discuss the rankings of the character strengths, with the aim to resolve discrepancies. There is not a standard definition of consensus, with most studies using a priori of 50-97% (Nasa et al., 2021), therefore, 50% agreement was used as the lower limit to conclude consensus. Discussions focused on those character strengths that were collectively ranked the highest. Character strengths with no rankings were excluded. All participants were invited to discuss these rankings, justifying their choice in ranking. A final vote was then taken, by asking participants to raise their hands to indicate the strengths that were most important to them for living with dementia. This ensured at least 50% consensus about the most important character strengths for living with dementia.

Stage three: focus groups

Aim: Focusing on the strengths deemed most important for living with dementia (stage two of the study), the aim of stage three was to understand which strength-based interventions could be most meaningful and acceptable.

Design: A qualitative research design, utilising focus group methods.

Participants: The aim was to conduct 3–6 focus groups as this is usually deemed sufficient to reach at least 90% of themes for a given topic (Guest et al., 2016). Seven dementia charities across the Yorkshire region of the UK were approached *via* email. In line with the UK Alzheimer's Society's guidance, the aim was to recruit 3–6 participants for each focus group (Alzheimer's

Society, n.d). After charity leads had discussed participation with their groups, three of the six groups agreed to participate, with this forming four focus groups overall, given the large number of people attending one group. Participant inclusion criteria can be seen in Table 1.

Procedure: A resource booklet was created as a discussion guide and visual aid. This included the following questions for each strength: (1) Do you agree that x [character strength] is important for living with dementia? (2) What helps you to keep showing x? (3) If you have been invited to a group and they were going to focus on x, what would you want it to involve or look like? (4) How could services support you to show x? Evidence based interventions targeting the most important character strengths (identified in the literature review in stage one) were also briefly summarised and presented in the booklet. Where character strengths had no established interventions for older adults, separate scoping searches were done to identify and describe interventions used with any population.

At the beginning of each focus group, the information sheet was shared with each participant, participants were given a chance to ask questions and informed consent was recorded. All participants provided demographic information to contextualise the data. Focus groups were semi-structured and lasted approximately 60 minutes. Each focus group was audio recorded and transcribed.

Data analysis

Reflexive thematic analysis was used to analyse the qualitative data from the focus groups since the research aimed to understand subjective perspectives and analyse patterns across the qualitative data set (Braun & Clarke, 2021). The six phases identified by Braun and Clarke (2021) were followed, using an inductive approach (see Table 2). An ontology of critical realism and a contextualism (Madill et al., 2000) epistemology informed the analysis.

Ethical considerations

The study received ethical approval by the Faculty of Health Science Research Ethics Committee at the University of Hull (FHS419). All materials used were reviewed by people living with dementia prior to the start of the study to ensure accessibility. In line with the UK Mental Capacity Act (Department of health, 2005), capacity was assumed upon meeting the participant. The lead researcher completed informal capacity assessments during the consent process by looking at each person's ability to sufficiently take in, understand, and weigh up and then communicate a decision about participating. This was continually monitored throughout the study. All participants were deemed to have the capacity to consent to take part.

Table 2. The six phases of thematic analysis (Braun & Clarke, 2021).

Six phases:	Procedure
Familiarising yourself with the dataset	Audio recordings were listened too and transcribed. Transcripts were read and re-read. Initial analytic ideas were recorded.
Coding	Transcripts were read and interesting/ meaningful segments were identified with a code label.
Generating initial themes	Based on these codes, patterns were sought, and initial themes were derived. Interpretation of the data from the researchers fed into the process.
Developing and reviewing themes	Through consultation with the secondary researchers, the themes were revised and developed across several iterations.
Refining, defining and naming themes	Brief summaries were written for each theme to ensure a coherent story is told. This led to further refinement through further discussions with the secondary researchers.
Writing up	The themes were written up and embedded within the wider report.

Researcher context

In line with a contextualism epistemology, the researcher's context is important to consider in generating meaning from the data and knowledge produced. The lead researcher is a white British, middle class, young female who is outside of the participant group and, at the time of undertaking the research, was a Trainee Clinical Psychologist. The researchers each had personal and/or professional experiences of dementia. The lead researcher attended the monthly sessions at the dementia self-advocacy group involved in stage two, in order to build relationships with the participants involved in this stage. All participants in stage three were unknown to the researchers prior to data collection.

Results

Participants

A total of 24 people living with dementia participated within the research, with ten being involved in stage two of the study, and 14 in stage three of the study. Participants were different across each stage. See Table 3 for demographic details.

Stage two: modified Delphi process

The results from round one (the individual rankings) can be seen in Table 4, whereby rankings were reversed scored (i.e. a ranking of 1 received 4 points and a ranking of 4 received 1 point). Following the consensus discussions, love, kindness and humour met the pre-defined consensus criteria of 50% as being perceived to be the most important character strengths for living with dementia.

Table 3. Participant demographics for stages 2 and 3 of the study.

Measure		Stage 2 ($N=10$)	Stage 3 ($N=14$)
Gender	Male	7	7
	Female	3	7
Age (years)	65–70	2	2
	71–75	3	7
	76–80	3	3
	81–85	2	1
	>86	0	1
Ethnicity	White British	9	13
	Other white background	1	0
	Asian British	0	1
Time since diagnosis	<1 year	3	5
	1–2 years	4	3
	3–4 years	2	4
	5–6 years	1	1
	7–8 years	0	1

Table 4. Results from round 1 (rankings; 1 = most important = 4 points; 4 = least important = 1 points).

Character strength	Rankings	Points	Consensus
Love	1, 1, 1, 1, 1, 2,3	25	80%
Kindness	1, 2, 2, 3, 3, 3	16	70%
Honesty	1, 2, 2	10	
Self-control	2, 3, 3, 4	8	
Humour/playfulness	2,4, 4, 4	6	50%
Creativity	1, 4	5	
Forgiveness	3, 3	4	
Gratitude	2, 4	4	
Humility	1	4	
Teamwork	1	4	
Bravery	3, 4	3	
Faith/purpose	2	3	
Love of learning	2	3	
Openness to experience	4, 4	2	
Perseverance	3	2	
Optimism	4	1	
Critical thinking		0	
Wisdom		0	
Zest/Vitality		0	
Social intelligence		0	
Fairness		0	
Leadership		0	
Prudence		0	
Wonder		0	

Table 5. Summary of themes.

Superordinate theme	Subordinate theme
Lack of opportunity not capacity	'It's part of your nature': relevance of character strengths training 'I wish I didn't have the label': opportunities to use character strengths
Key considerations of PP interventions for people living with dementia	'We are all individuals': acceptability of character strength interventions. 'Being around people is very important': relevance of group interventions. 'You've got to have some fun': a key aim of interventions
Potential benefits of PP interventions	

Stage three: focus groups

Focus groups one and two involved participants attending groups at the same dementia charity, with focus groups three and four involving participants from different charities.

Thematic analysis

Three superordinate themes and five subordinate themes were identified and are summarised in Table 5. They are reported in detail below.

Theme: lack of opportunity not capacity

Participants perceived love, kindness and humour to be universal traits meaning they also saw themselves remaining able to experience and draw on these in living with dementia, although acknowledged the barriers due to the reduced social experiences brought about by their diagnosis of dementia.

1. Sub-theme- *'It's part of your nature':* relevance of character strength training

   Love, kindness and humour were all viewed as innate character strengths that are important '*whether you have got dementia or not'* –P9. There was a common opinion that people with dementia do not lose the capacity or ability to use these character strengths and they hope to continue to use them; *'And long may I keep doing that [showing kindness]'* –P9. Thus, interventions aiming to 'train' or 'teach' strengths were not perceived as meaningful because participants felt strongly that love, kindness to others and humour *'come naturally'* -P8 and are trait like. Therefore, interventions that falsely create humour, such as groups where you tell jokes and funny stories, were not perceived as helpful as *'I don't think you manufacture it [humour]. Its either there or its not'* -P9. Furthermore, participants did not anticipate benefits in the counting kindness intervention, as *'Well I don't think there is any need in writing it. If you are doing kindness, you are doing kindness. Making a record of it, for what? You are not proving to somebody what you have done, kindness is kindness out of kindness and I'm helping her and him or anyone, so this is out of kindness'* –P11. This highlights how participants perceived themselves as able to engage in these strengths naturally and spontaneously, and therefore do not need 'teaching' to use them.

   However, participants identified that self-kindness was different and they felt did not occur as naturally. It was acknowledged *'That's [self-kindness] a lot more difficult'* -P2. When individuals thought of kindness, they defined it as caring for others and that being their priority; *'we're too busy looking after others aren't we? [barriers to self-kindness]'* –P3. Indeed, for many participants caring for others has been an important role throughout their life and therefore did not appear to be a specific barrier for people living with dementia. *'Oh, I've always looked after the elderly, or someone who's got a broken leg'*-P1. Self-kindness appeared to be an alien concept, with participants finding the term difficult to grasp: *'How would you define being kind to yourself?'* -P10. This highlights how an intervention aiming to teach self-kindness may be more meaningful to people living with dementia.

2. Sub-theme – *'I wish I didn't have the label'*: opportunities to use character strengths

   Participants viewed their diagnosis of dementia as a barrier in being able to continue to use innate strengths, describing a loss of relationships and meaningful roles within their lives. Negative social experiences (e.g. *'When I go up to people and say I have dementia. They don't want to talk to me'*-P13) meant that some participants had withdrawn from social contexts or tried to conceal their diagnosis as *'I wish I didn't have the label [dementia]. You see, when you write forms you have to put it on. But then people don't want anything to do with you.'* –P14. Participants also identified that other people perceived them as not capable, e.g. *'Yes… well… the thing is…when you get diagnosed with dementia. People don't understand it. You see I used to be a secretary but as soon as they found out I have dementia, well they wouldn't let me do it anymore. I wasn't even able to be on the committee. I can still do things, just some things take me longer'* -P14.

   Providing people living with dementia the opportunity to lead interventions was seen as meaningful as they can give back to others. For example, *'through the*

NHS [National Health Service] I volunteer and I run a class…it was good…[in the group] there is about 4 of them who live by themselves, so it is a benefit to them'-P9. Therefore, as perceived stigma surrounding the diagnosis of dementia contributed to the lack of opportunity to continue to use their strengths participants viewed interventions that help people connect to their local community as meaningful, as '*having things on each day to be involved in would be good' – P12.*

Theme: Key considerations of PP interventions for people living with dementia

In considering what PP interventions might need to include to increase wellbeing in people living with dementia, participants felt interventions should be flexible and personalised. Although, two common components that were deemed important were that they should involve enjoyment ('fun') and connection with others.

3. Sub-theme – *'We are all individuals'*: acceptability of character strength interventions

   In discussing the interventions that exist currently to promote love, kindness and humour, there were individual differences in the acceptability of these interventions, based on participants' personality and interests. For example, one participant commented about a humour intervention *'No, I'm not that type of person [to tell funny stories]'*-P1, whereas others enjoy *'sharing some jokes'* – P11. Participants stated it is important that interventions are flexible and adaptable as people living with dementia should be seen as individuals as *'Everyone is different'* –P6. Therefore, in ensuring that a PP intervention is meaningful for people living with dementia, it would be important to connect with individuals' interests and hobbies: *'I actually think it's finding the interests of the person as well. Trying to keep them interacting with things. It's no good you trying to force something on somebody, because we're all individuals'* -P10. This highlights how there is not one PP intervention that is consistently seen as acceptable and meaningful.

4. Subtheme – *'Being around people is very important'*: Relevance of group interventions

   A common element that was deemed meaningful for a PP intervention was spending time with others, as group-based interventions were consistently seen as '*important'* -P11. This was because love, kindness and humour were all seen as occurring within relationships, as *'you do don't you, you laugh between you'*-P3. Furthermore, being with others allows people to use their strengths, as well as providing opportunities for these strengths to be experienced, creating a sense of reciprocity: *'When you come to a group like this, you have to sort of be kind, and expect people to be kind back. It moves in two directions'*-P2. Given that *'being around people is very important'* –P12 all participants felt that a group format to delivering PP interventions would be beneficial for people living with dementia. However, *'I actually think I had a bad start when I was diagnosed. They put me in with people who are a way lot older than me and they were more advanced. It's that sort of thing that puts people off' – P10.* Therefore, group interventions may be most beneficial if the group consists of like-minded individuals, as their *'likes have got to be connected' – P9.*

5. Subtheme – *'You've got to have some fun'*: a key aim of interventions.

   Participants also spoke of the importance of any intervention being fun, with this being a key criterion when discussing the acceptability of interventions *'Oh, I wouldn't mind. It [laughter yoga] could be fun'* -P4. Furthermore, in participants experiences this is what has kept them going back to interventions they have been a part of: *'The group you know, they just started laughing, it was real fun…and its good. They keep coming to it. They feel the benefit of it, they like it. In fact, one guy said can you come every day. Its basic exercise, nothing tiring but it's fun'* -P9. The importance of having fun was particularly important in the context of living with dementia as *'none of us know what's ahead do we'* -P5. Therefore, there was a sense of making the most of each day as *'you've got to have some fun haven't you. There is no point in sitting there and thinking, uh, I have this in my head, you can do things, do things while you can'* –P7. Therefore, this highlights the importance of PP interventions encouraging playfulness and being enjoyable.

Theme: Potential benefits of PP interventions.

Throughout the focus groups, participants made a link between expressing love, kindness and humour, and this increasing their wellbeing, *'bring[ing] you alive a bit'* –P3. Such strengths may help to buffer against negative emotions and bring a sense of acceptance in living with dementia rather than to *'dwell on things'*-P4 and maintain a sense of identity, e.g. *'Especially when you are living with dementia, it [love] helps you keep your life happy and more of you. So, I think it's more of a necessity as well.'*-P11. Furthermore, the benefit of engaging with these strengths was considered to positively influence a person's emotion and behaviour, e.g., *'love makes you more content, it makes you happy sort of thing. So, without love you are going to start being depressed, and not want to be involved in things or do things'*-P10. Therefore, showing love, kindness and humour could contribute to enhanced wellbeing when living with dementia, with these strengths being seen as *'important'* –P12 and *'good for you'* –P1.

Discussion

This study aimed to capture the voices of people living with dementia in the design phase of a dementia-specific multi-component PP intervention. This research highlights how people living with dementia have important opinions and insights about what interventions are likely to be helpful for increasing their wellbeing and illustrates that people living with dementia can actively participate in the systematic design of such interventions.

In stage two, love, kindness and humour were seen as the most important character strengths for living with dementia. This is consistent with previous findings whereby love has been described as the most important strength for people living with dementia (McGee et al., 2023) and maintaining personhood (Kitwood, 1997). Humour has consistently been seen as an active strength that helps people with dementia to live well, maintain positive relationships, and help buffer against adversity (Hickman et al., 2018; Wolverson et al., 2016). Kindness has received less attention in the dementia literature and therefore little is known about its role in contributing to wellbeing when living with dementia. The results from this study highlight kindness to others is felt to be spontaneous and that showing kind acts towards others could help to increase positive emotions. Peterson and Park (2020) detail a structure of character which places the 24-character strengths along two dimensions of self vs other, and heart vs head. Love, kindness and humour all fall into the heart and other oriented quadrant. It is possible that as people living with dementia begin to encounter cognitive challenges (head-orientated), the heart orientated strengths become increasingly important for their wellbeing.

This study identifies that love, kindness to others and humour are seen as occurring naturally to people living with dementia. Participants placed emphasis on being able to continue to use these strengths, as they have been important throughout their life. Participants highlighted that spontaneously showing self-kindness was more difficult, therefore a self-kindness intervention could be meaningful to people living with dementia to improve wellbeing. As participants found the term self-kindness somewhat ambiguous, psychoeducation about what this means may be important. Within the PP literature, self-kindness interventions are not seen to be effective at increasing wellbeing, with the focus on kindness to others being more valuable (e.g. Haydon et al., 2022). However, evidence is emerging that developing self-compassion helps to foster self-kindness and reduce self-criticism for people living with dementia when coping with the challenges dementia brings, for example when forgetting things (see Craig et al., 2018). Therefore, since clinical approaches to working with dementia are often deficit focused (Grand et al., 2011), it could be important for psycho-social interventions to incorporate self-compassion and kindness, especially since this is valued by people living with dementia and is a key mechanism in increasing wellbeing (Schotanus-Dijkstra et al., 2016).

In understanding what helps individuals to show love, kindness and humour, there were individual differences in the acceptability of potential interventions. This highlights the importance of the person-activity fit (Lyubomirsky & Layous, 2013) as PP interventions may only increase an individual's wellbeing if there is concordance between a person's needs and the social context within which an appropriate intervention is conducted. The findings highlight how PP interventions might help individuals to connect to what is important to them, potentially to maintain a sense of their identity (Wolverson et al., 2016). As such, PP interventions for people living with dementia will need to be person centered (Mitchell & Agnelli, 2015). Therefore, it would be important to conduct a holistic assessment of needs with people living with dementia, to aid the delivery of person-centered psychological support (Edvardsson et al., 2010).

Social interaction was deemed important within a multi-component PP intervention focused on love, kindness and humour as these strengths were perceived as relational. Therefore, group formats may be most beneficial, which is in line with pre-existing psychosocial interventions, whereby social interaction may actively contribute to intervention efficacy (Dugmore et al., 2015). One possible reason for this is that social interaction can increase cognitive reserve and therefore contributing to increased brain health in individuals living with dementia (Sommerlad et al., 2019). Furthermore, groups can increase the enjoyment of interventions. For example, Spector et al. (2011) details how group cognitive stimulation therapy was deemed as fun as it was characterised by laughing and smiling between participants, which kept people returning to the group. This is important in dementia since social stigma can negatively impact an individual's wellbeing (Pratt & Wilkinson, 2003) and people living with dementia have an increased risk of social isolation, particularly after the impact of COVID-19 (Curelaru et al., 2021). Therefore, engaging in a group allows increased connection with others and social inclusion (Osman et al., 2016). This highlights the importance of clinical services continuing to offer group interventions (e.g. reminiscence therapy) as is recommended in the NICE guidelines (NICE., 2018).

Strengths, limitations and future research

This study used an innovative participatory research design as being creative in research is important to allow people living with dementia to be actively involved (Phillipson & Hammond, 2018). Our study aligns with Morbey et al. (2019) in highlighting the importance of accessibility in the writing of items to be ranked. Hence PPI was essential initially to define the character strengths. Furthermore, providing participants with tangible resources for the first round was an effective way for participants to independently engage with the materials and express their opinions. This contrasts with a usual modified Delphi whereby participants need to hold in mind large amounts of information to assign a value to them (Yates et al., 2020). However, there is still much to learn about how to conduct a modified Delphi most effectively with people living with dementia. Some participants experienced fatigue by the consensus discussion and therefore it could have been beneficial to complete it over two sessions. This highlights how a modified Delphi can be effectively used with this population but requires careful planning and adaptations.

Context is important to consider when generating meaning from the findings, particularly as a contextualism epistemology was taken (Madill et al., 2000). The sample as a whole comprised of individuals who regularly attend groups and was a volunteer sample. Therefore, as they identified love, kindness to others and humour come naturally, it is unclear whether this same finding would be shared by other people living with dementia. It is possible that the individuals in this study already had a relatively high level of wellbeing, and a limitation of this work is this was not something that was objectively measured. Furthermore, as participants were regularly attending groups, it is possible this contributed to the finding that a PP intervention should take place in a group setting, whereas a group may not suit everyone. Due to the limited sample, future research is needed to capture more voices, particularly those from marginalised groups as presently there are health inequalities for people living with dementia (UK Dementia Research Institute, 2022). For example, it would be helpful to understand whether similar character strength-based interventions would be valued by those from a global majority, who are twice as likely to be diagnosed with Alzheimer's Disease, yet less likely to access support from services (Alzheimer's Society, 2020). Therefore, future research is needed to develop interventions that are meaningful across cultural contexts.

The scope of this research meant that the evidence base was identified, and the initial concept of a character strength-based intervention was seen as feasible and acceptable to people living with dementia. However, future research is now needed to co-design a character strength-based intervention that is specific to people living with dementia, particularly since there are few character strength-based interventions focused on love, kindness and humour that have been designed and evaluated with older adults (Jackman et al., 2023). Therefore, using the Medical Research Council's framework as a guideline (Skivington et al., 2021), future research is needed to continue this development and feasibility phase of co-designing an intervention. Some important elements to consider may be around the acceptability of online versus face-to-face delivery, frequency and duration of the intervention and the potential involvement of care partners.

Conclusion

This study highlights key components of what is valued by people living with dementia in a PP intervention. It was revealed that love, kindness and humour are important strengths for living well with dementia, and therefore an intervention focused on these may be most meaningful. The findings revealed that a PP intervention needs to provide a social context that facilitates the use and expression of these strengths, that provides opportunity for enjoyment and positive emotion and opportunities to build positive relationships in a person-centered way. Focusing on people's strengths could support people to live well with dementia whilst facilitating a move away from deficit-focused discourses.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References

Alzheimer's Research UK. (2019). *Dementia Attitudes Monitor 2018: Wave 1*. Dementia statistics. https://www.dementiastatistics.org/wp-content/uploads/2019/02/Dementia-Attitudes-Monitor-Wave-1-Report.pdf#zoom=100

Alzheimer's Society. (n.d). *Dementia-Friendly Focus Groups*. Retrieved December 7, 2021, from https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/dementia-friendly-focus-groups

Alzheimer's Society. (2020, September 30). *Improving dementia and Alzheimer's support in Black communities*. https://www.alzheimers.org.uk/blog/improving-dementia-support-black-communities

Barrett, D., & Heale, R. (2020). What are Delphi studies? *Evidence-Based Nursing*, *23*(3), 68–69. https://doi.org/10.1136/ebnurs-2020-103303

Bartlett, R., Windemuth-Wolfson, L., Oliver, K., & Dening, T. (2017). Suffering with dementia: The other side of "living well. *International Psychogeriatrics*, *29*(2), 177–179. https://doi.org/10.1017/S104161021600199X

Braun, V., & Clarke, V. (2021). *Thematic analysis: A practical guide*. Sage.

Burton, A., Ogden, M., & Cooper, C. (2019). Planning and enabling meaningful patient and public involvement in Dementia Research. *Current Opinion in Psychiatry*, *32*(6), 557–562. https://doi.org/10.1097/yco.0000000000000548

Carr, A., Cullen, K., Keeney, C., Canning, C., Mooney, O., Chinseallaigh, E., & O'Dowd, A. (2021). Effectiveness of positive psychology interventions: A systematic review and meta-analysis. *The Journal of Positive Psychology*, *16*(6), 749–769. https://doi.org/10.1080/17439760.2020.1818807

Conway, L., Wolverson, E., & Clarke, C. (2020). Shared experiences of resilience amongst couples where one partner is living with dementia—A grounded theory study. *Frontiers in Medicine*, *7*, 219. https://doi.org/10.3389/fmed.2020.00219

Cotelli, M., Manenti, R., & Zanetti, O. (2012). Reminiscence therapy in dementia: A review. *Maturitas*, *72*(3), 203–205. https://doi.org/10.1016/j.maturitas.2012.04.008

Craig, C., Hiskey, S., Royan, L., Poz, R., & Spector, A. (2018). Compassion focused therapy for people with dementia: A feasibility study. *International Journal of Geriatric Psychiatry*, *33*(12), 1727–1735. https://doi.org/10.1002/gps.4977

Csikszentmihalyi, M., & Seligman, M. (2000). Positive psychology. *The American Psychologist*, *55*(1), 5–14. https://doi.org/10.1037/0003-066X.55.1.5

Curelaru, A., Marzolf, S. J., Provost, J.-C., & Zeon, H. (2021). Social isolation in dementia: The effects of covid-19. *The Journal for Nurse Practitioners: JNP*, *17*(8), 950–953. https://doi.org/10.1016/j.nurpra.2021.05.002

Dementia Action Alliance. (2017, May 15). *Launching the dementia statements*. https://www.dementiaaction.org.uk/news/23236_news_launching_the_dementia_statements

Department of health. (2005). *Mental Capacity Act 2005*. https://www.legislation.gov.uk/ukpga/2005/9/contents

Dodd, E., Ismail, S., Christopher, G., Wildschut, T., Sedikides, C., & Cheston, R. (2021). Nostalgic conversations: The co-production of an intervention package for people living with dementia and their spouse. *Dementia (London, England)*, *21*(2), 489–502. https://doi.org/10.1177/14713012211047350

Duckworth, A., Steen, T., & Seligman, M. (2005). Positive psychology in clinical practice. *Annual Review of Clinical Psychology*, *1*(1), 629–651. https://doi.org/10.1146/anurev.clinpsy.1.102803.144154

Dugmore, O., Orrell, M., & Spector, A. (2015). Qualitative studies of psychosocial interventions for dementia: A systematic review. *Aging & Mental Health*, *19*(11), 955–967. https://doi.org/10.1080/13607863.2015.1011079

Edvardsson, D., Fetherstonhaugh, D., & Nay, R. (2010). Promoting a continuation of self and normality: Person-centred care as described by people with dementia, their family members and Aged Care Staff. *Journal of Clinical Nursing*, *19*(17–18), 2611–2618. https://doi.org/10.1111/j.1365-2702.2009.03143.x

Gable, S. L., & Haidt, J. (2005). What (and why) is positive psychology? *Review of General Psychology*, *9*(2), 103–110. https://doi.org/10.1037/1089-2680.9.2.103

Gauthier, S., Webster, C., Servaes, S., Morais, J., Rosa-Neto, P. (2022). *World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support*. Alzheimer's Disease International. https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf

Gove, D., Diaz-Ponce, A., Georges, J., Moniz-Cook, E., Mountain, G., Chattat, R., & Øksnebjerg, L. (2017). Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging & Mental Health*, *22*(6), 723–729. https://doi.org/10.1080/13607863.2017.1317334

Grand, J., Caspar, S., & MacDonald, S. (2011). Clinical features and multidisciplinary approaches to dementia care. *Journal of Multidisciplinary Healthcare*, *4*, 125–147. https://doi.org/10.2147/jmdh.s17773

Guest, G., Namey, E., & McKenna, K. (2016). How many focus groups are enough? Building an evidence base for nonprobability sample sizes. *Field Methods*, *29*(1), 3–22. https://doi.org/10.1177/1525822X16639015

Haydon, M., Walsh, L., Fritz, M., Rahal, D., Lyubomirsky, S., & Bower, J. (2022). Kindness interventions for early-stage breast cancer survivors: An online, pilot randomized controlled trial. *The Journal of Positive Psychology*, *18*(5), 743–754. https://doi.org/10.1080/17439760.2022.2093786

Hickman, H., Clarke, C., & Wolverson, E. (2018). A qualitative study of the shared experience of humour between people living with dementia and their partners. *Dementia (London, England)*, *19*(6), 1794–1810. https://doi.org/10.1177/1471301218805895

Ho, H., Yeung, D., & Kwok, S. (2014). Development and evaluation of the positive psychology intervention for older adults. *The Journal of Positive Psychology*, *9*(3), 187–197. https://doi.org/10.1080/17439760.2014.888577

Innovations in Dementia. (2023). *The dementia enquirers gold standards for co-research*. https://bit.ly/3YQ7sj6.

INVOLVE. (2012). *Briefing notes for researchers: Involving the public in NHS, public health and social care research*. National Institute for Health Research. https://www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEBriefingNotesApr2012.pdf

Jackman, V., Wolverson, E., Clarke, C., & Quinn, C. (2023). A systematic review of character strength based interventions designed to improve wellbeing in older adults [manuscript in preparation].

Jorm, A. (2015). Using the Delphi expert consensus method in mental health research. *The Australian and New Zealand Journal of Psychiatry*, *49*(10), 887–897. https://doi.org/10.1177/0004867415600891

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press.

Kolanowski, A., Zhu, S., Haitsma, K., Resnick, B., Boltz, B., Galik, E., Behrens, L., Eshraghi, K., & Ellis, J. (2022). 12-month trajectory and predictors of affect balance in nursing home residents living with dementia. *Aging & Mental Health*, *26*(8), 1686–1692. https://doi.org/10.1080/13607863.2021.1947964

Lamont, R., Nelis, S., Quinn, C., Martyr, A., Rippon, I., Kopelman, M., Hindle, J., Jones, R., Litherland, R., & Clare, L. (2020). Psychological predictors of 'living well' with dementia: Findings from the ideal study. *Aging & Mental Health*, *24*(6), 956–964. https://doi.org/10.1080/13607863.2019.1566811

Lomas, T., & Ivtzan, I. (2016). Second wave positive psychology: Exploring the positive–negative dialectics of wellbeing. *Journal of Happiness Studies*, *17*(4), 1753–1768. https://doi.org/10.1007/s10902-015-9668-y

Low, L., Goodenough, B., Fletcher, J., Xu, K., Casey, A., Chenoweth, L., Fleming, R., Spitzer, P., Bell, J., & Brodaty, H. (2014). The effects of humor therapy on nursing home residents measured using observational methods: The smile cluster randomized trial. *Journal of the American Medical Directors Association*, *15*(8), 564–569. https://doi.org/10.1016/j.jamda.2014.03.017

Lyubomirsky, S., & Layous, K. (2013). How do simple positive activities increase well-being? *Current Directions in Psychological Science*, *22*(1), 57–62. https://doi.org/10.1177/0963721412469809

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology (London, England: 1953)*, *91 (Pt 1)*(1), 1–20. 1 https://doi.org/10.1348/000712600161646

McGee, J., McElroy, M., Meraz, R., & Myers, D. (2023). A qualitative analysis of virtues and strengths in persons living with early stage dementia informed by the values in action framework. *Dementia (London, England)*, *22*(1), 46–67. https://doi.org/10.1177/14713012221131857

Mitchell, G., & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard (Royal College of Nursing (Great Britain): 1987)*, *30*(7), 46–50. https://doi.org/10.7748/ns.30.7.46.s47

Morbey, H., Harding, A., Swarbrick, C., Ahmed, F., Elvish, R., Keady, J., Williamson, P., & Reilly, S. (2019). Involving people living with dementia in research: An accessible modified Delphi survey for core outcome set development. *Trials*, *20*(1), 12. https://doi.org/10.1186/s13063-018-3069-6

Nasa, P., Jain, R., & Juneja, D. (2021). Delphi methodology in healthcare research: How to decide its appropriateness. *World Journal of Methodology*, *11*(4), 116–129. https://doi.org/10.5662/wjm.v11.i4.116

NICE. (2018). *Dementia: Assessment, management and support for people living with dementia and their carers*. https://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109

Osman, S., Tischler, V., & Schneider, J. (2016). 'Singing for the brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers. *Dementia (London, England)*, *15*(6), 1326–1339. https://doi.org/10.1177/1471301214556291

Park, N., & Peterson, C. (2009). Character strengths: Research and practice. *Journal of College and Character*, *10*(4), 1–10. https://doi.org/10.2202/1940-1639.1042

Park, N., Peterson, C., & Seligman, M. (2004). Strengths of character and well-being. *Journal of Social and Clinical Psychology*, *23*(5), 603–619. https://doi.org/10.1521/jscp.23.5.603.50748

Pearson, M., Clarke, C., & Wolverson, E. (2021). The meaning and experience of gratitude for people living with dementia. *Dementia (London, England)*, *21*(1), 335–352. https://doi.org/10.1177/14713012211040675

Peterson, C., & Park, N. (2020). Character Strengths and Virtues: Their role in wellbeing. In Donaldson, S. I., Csikszentmihalyi, M., Nakamura, J. (Eds.), *Applied Positive Psychology* (pp.49–63). Routledge.

Phillipson, L., & Hammond, A. (2018). More than talking. *International Journal of Qualitative Methods*, *17*(1), 160940691878278. https://doi.org/10.1177/1609406918782784

Powell, C. (2003). The delphi technique: Myths and realities. *Journal of Advanced Nursing*, *41*(4), 376–382. https://doi.org/10.1046/j.1365-2648.2003.02537.x

Pratt, R., & Wilkinson, H. (2003). A psychosocial model of understanding the experience of receiving a diagnosis of dementia. *Dementia*, *2*(2), 181–199. https://doi.org/10.1177/1471301203002002004

Quinn, C., Pickett, J., Litherland, R., Morris, R., Martyr, A., & Clare, L. (2022). Living well with dementia: What is possible and how to promote it. *International Journal of Geriatric Psychiatry*, *37*(1), 1–7. https://doi.org/10.1002/gps.5627

Salces-Cubero, I., Ramírez-Fernández, E., & Ortega-Martínez, A. (2019). Strengths in older adults: Differential effect of savoring, gratitude and optimism on well-being. *Aging & Mental Health*, *23*(8), 1017–1024. https://doi.org/10.1080/13607863.2018.1471585

Schotanus-Dijkstra, M., Pieterse, M. E., Drossaert, C. H. C., Walburg, J. A., & Bohlmeijer, E. T. (2016). Possible mechanisms in a multicomponent email guided positive psychology intervention to improve mental well-being, anxiety and depression: A multiple mediation model. *The Journal of Positive Psychology*, *14*(2), 141–155. https://doi.org/10.1080/17439760.2017.1388430

Skivington, K., Matthews, L., Simpson, S., Craig, P., Baird, J., Blazeby, J., Boyd, K., Craig, N., French, D., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidelines. *BMJ (Clinical Research ed.)*, *374*, n2061. https://doi.org/10.1136/bmj.n2061

Sommerlad, A., Sabia, S., Sing-Manoux, A., Lewis, G., & Livingston, G. (2019). Association of social contact with dementia and cognition: 28 year follow-up of the Whitehall II cohort study. *PLoS Medicine*, *16*(8), e1002862. https://doi.org/10.1371/journal.pmed.1002862

Spector, A., Gardner, C., & Orrell, M. (2011). The impact of cognitive stimulation therapy groups on people with dementia: Views from participants, their carers and group facilitators. *Aging & Mental Health*, *15*(8), 945–949. https://doi.org/10.1080/13607863.2011.586622

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial. *The British Journal of Psychiatry: The Journal of Mental Science*, *183*(3), 248–254. https://doi.org/10.1192/bjp.183.3.248

UK Dementia Research Institute. (2022). *Diversity and dementia. How is research reducing health disparities?* https://ukdri.ac.uk/uploads/UK-DRI_Dementia_Health_Inequalities_Report_2022.pdf

Vernooij-Dassen, M., Moniz-Cook, E., Verhey, F., Chattat, R., Woods, B., Meiland, F., Franco, M., Holmerova, I., Orrell, M., & de Vugt, M. (2021). Bridging the divide between biomedical and psychosocial approaches in Dementia Research: The 2019 Interdem manifesto. *Aging & Mental Health*, *25*(2), 206–212. https://doi.org/10.1080/13607863.2019.1693968

Wagner, L., Gander, F., Proyer, R. T., & Ruch, W. (2020). Character strengths and PERMA: Investigating the relationships of character strengths with a multidimensional framework of well-being. *Applied Research in*

Quality of Life, *15*(2), 307–328. https://doi.org/10.1007/s11482-018-9695-z

Wolverson, E., Clarke, C., & Moniz-Cook, E. (2010). Remaining hopeful in early-stage dementia: A qualitative study. *Aging & Mental Health*, *14*(4), 450–460. https://doi.org/10.1080/13607860903483110

Wolverson, E., Clarke, C., & Moniz-Cook, E. (2016). Living positively with dementia: A systematic review and synthesis of the qualitative literature. *Aging & Mental Health*, *20*(7), 676–699. https://doi.org/10.1080/13607863.2015.1052777

Yates, J., Stanyon, M., Challis, D., Coleston-Shields, D., Dening, T., Hoe, J., Jawahar, K., Lloyd-Evans, B., Moniz-Cook, E., Poland, F., Streater, A., Trigg, E., & Orrell, M. (2020). Developing a model of best practice for teams managing crisis in people with dementia: A consensus approach. *BMC Psychiatry*, *20*(1), 505. https://doi.org/10.1186/s12888-020-02899-0