

The Meaning and Experience of Gratitude for People Living with Dementia

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Introduction

A key priority in dementia care is the development of interventions and support systems that enable people who are experiencing dementia to 'live well' (Department of Health, 2009; Banerjee, 2010). The term 'live well' has not been clearly defined in dementia care but is thought to be linked to well-being, life satisfaction, quality of life, participation in activities and expression of positive emotions (Clare et al., 2014). People with dementia seek to actively maintain positive emotional and relational experiences likely to relate to living well (Wolverson, Clarke & Moniz-Cook, 2010; Dalby, Sperlinger & Boddington, 2012; Harris, 2013) but further research is necessary to better understand these experiences and how they can be supported by dementia care systems.

Positive psychology, the science of positive traits and experiences (Seligman & Csikszentmihalyi, 2000) provides one framework for understanding the assets and strengths that might enable people to live well with dementia (see Clarke & Wolverson, 2016). One of the concepts encompassed by a positive psychology perspective is gratitude. Gratitude is variously defined as a positive emotion involving a benefactor and a beneficiary, a trait, a character strength, or a celebration of any person, activity, event, situation or state that is considered to be free or undeserved (Emmons & McCullough, 2004; Peterson & Seligman, 2004; Roberts, 2004; Steindl-Rast, 2004; Wood, Froh & Geraghty, 2010).

Existing research involving people not living with dementia indicates that gratitude and thankfulness are related to lower levels of stress and depression, increased life satisfaction and improved health (see Wood, Froh & Geraghty, 2010). Evidence also indicates that gratitude has positive, reciprocal effects on relationships (Lambert, Clark, Durtschi, Fincham & Graham, 2010; Bartlett, Condon, Cruz, Baumann, & Desteno, 2012). Research with both clinical and non-clinical samples indicates that interventions to foster gratitude (e.g. keeping gratitude diaries or writing letters of thanks; Seligman, Steen, Park & Peterson, 2005) increase well-being on a range of measures including life satisfaction, optimism, perceived stress and depression (Cheng, Tsui & Lam, 2015; Kerr, O'Donovan & Pepping, 2014).

Gratitude also correlates with increased post-traumatic growth (Peterson, Park, Pole, D'Andrea & Seligman, 2008) suggesting that gratitude can emanate from experiences of trauma or adversity. Gratitude and well-being or quality of life are related across a range of physical health conditions (see Ruini & Vescovelli, 2013; Eaton, Bradley & Morrissey, 2014). Recent research also indicates that gratitude is a relevant concept in the lives of older people (Melin-Johansson, Eriksson, Segerbäck & Boström, 2014; Hörder, Frändin & Larsson, 2013) and positive psychology interventions which incorporate gratitude can improve well-being in older adults (Ramirez, Ortega, Chamorro & Colmenero 2014; Ho, Yeung & Kwok, 2014).

To date, there is only serendipitous evidence that gratitude may be a relevant construct in dementia, and further research is warranted. A review of the qualitative literature relating to positive experiences in dementia (Wolverson, Clarke & Moniz-Cook, 2016) reported that gratitude and thankfulness form a key theme in people's lived experiences. A review of the positive aspects of caregiving in dementia also indicated that people living with dementia communicate feelings of gratitude to others (Lloyd, Patterson and Muers, 2016) and mutual appreciation is part of a process of sustaining couplehood in dementia (Hellstrom, Nolan & Lundh, 2007). Such findings suggest that gratitude is experienced by, and has meaning for, people with dementia, and it may therefore be associated with well-being. The lived experience of a chronic illness is likely to differ depending on the particular illness experienced (Sheilds et al., 2015) and, since living with dementia carries specific risks to personhood and relationships (Kitwood, 1990) gratitude may take on different meanings and functions in this context. A more thorough understanding of the meaning and functions of gratitude has implications for both the measurement of psychosocial outcomes (see Clarke et al., 2020) and the design of interventions. The primary aim of this study was therefore to explore the subjective meaning and experience of gratitude for people living with dementia.

A secondary aim was to explore the use and acceptability of gratitude diaries amongst people with dementia. This aim was incorporated for two key reasons. Firstly, diaries offer a way to record subjective experiences on a prospective and day-to-day basis and potentially provide flexibility in data collection (see Morrell-Scott, 2018) which is particularly important when people with dementia are experiencing changes in their cognitive and language abilities and may therefore have difficulty articulating themselves in conventional research interviews (Hubbard, Downs & Tester, 2003; Bartlett, 2012). However, the value of gratitude diaries as a data collection method to allow people with dementia to report on lived experiences of gratitude as they occur has yet to be explored. Secondly, exploring the usability and acceptability of the gratitude diaries has implications for the potential application of this method as a Positive Psychology Intervention (PPI; see Seligman, Steen, Park & Peterson, 2005) in dementia. To date, this has not been researched but the gratitude diary method has been shown to be an effective well-being intervention for older people (Killen & Macaskill, 2015) and in clinical settings (Ducasse et al, 2019).

Therefore, this study sought to answer the following research questions:

- 1. What is the meaning and experience of gratitude for people living with dementia?***
- 2. How acceptable and usable are gratitude diaries for people living with dementia?***

Held (2002) questions whether positive psychology research may unrealistically mandate positive emotions and experiences in the midst of adversity. However, the aim of this study was not to create a single discourse around how gratitude might be experienced and it was not expected or assumed that people living with dementia should feel grateful for their experiences, rather the aim was to create an opportunity to explore experiences that might otherwise be overlooked.

Methods

Design

This was a mixed-methods QUAL+ quan study (Johnson & Onwuegbuzie 2004) using an exploratory convergent approach (see Moseholm & Fetters, 2017) in which the approach is qualitatively framed and enhanced using quantitative findings (Johnson, Onwuegbuzie & Turner, 2007). In accordance with Johnson and Onwuegbuzie (2004) 'QUAL' refers to qualitative data and 'quan' to quantitative data. 'QUAL' is capitalised to emphasize that the research was driven by qualitative methods. Qualitative data were collected using semi-structured interviews and diaries in order to address the primary research question. Both qualitative and quantitative data were gathered and integrated to address the secondary research question. This centred on using free-response questions and Likert scales to explore the acceptability and usability of a diary for recording experiences of gratitude.

Sampling

A purposive sampling strategy was adopted to recruit a relatively homogenous participant group, in line with the requirements of Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2008). Individuals were included if they were living in the community and reported receiving a diagnosis of dementia a minimum of 3 months previously, to allow for adjustment to the diagnosis (Vernooij-Dassen, Derksen, Scheltens & Moniz-Cook, 2006). Participants were included if they were able to consent and felt comfortable answering questions about their experiences. Participants were excluded if they reported having received a dementia diagnosis before the age of 65, as young-onset dementia may bring different experiences to dementia occurring later in life (Green & Kleissen, 2013). Participants were recruited via community-based dementia services and support groups.

Data Collection

Ethical approval was granted by a local branch of the UK NHS Health Research Authority Ethics Committee (*details removed to ensure blinding*). Participants provided written informed consent to take part and for anonymised data to be included in publications. All participants took part in an interview conducted by the first author. Interviews were guided by a semi-structured interview schedule, comprising open-ended, exploratory questions. Self-reported demographic details were collected to contextualise the data.

Interviews were conducted at the homes of participants, or in community support settings (n=1). Interviews were audio-recorded and transcribed verbatim by the first author. Four participants chose to have their spouse present during the interview, but any speech of spouses was excluded from the analysis, as the research focus was on the individual meaning and experience of gratitude for people living with dementia. The mean length of interviews was 46 minutes (range: 19 - 90 minutes).

Following the interview, participants were invited to keep a gratitude diary, recording up to three things for which they felt grateful each day, over the course of 7 days. The diary structure was based upon a 'counting blessings' paradigm (Emmons & McCullough, 2003). Each page of the diary included a statement to help orientate the participant to the purpose of the diary and how to use it. Participants were prompted to think back over the day and write down up to 3 things, large or small, that they felt grateful for. An example diary page can be found in Appendix A.

Participants were offered the option of keeping a paper diary or submitting their diary entries via email; all participants who consented to keeping a diary chose to keep a paper diary. Participants were also offered the option of text or email reminders sent daily to prompt diary completion. None of the participants requested this support. After completing the diary participants were invited to complete a short Diary Evaluation Questionnaire, based on other studies which have assessed usability (Kerssens et al., 2015) and existing usability questionnaires (Lund, 2001; Brooke, 1996). They were asked to respond to Likert Scale questions regarding ease of use, confidence using the diary, and whether they would continue to use the diary.

Data Analysis

Quantitative data regarding acceptability and usability of the diaries were summarised using descriptive statistics, with averages (mean values) calculated for the responses to Likert Scale questions on the Diary Evaluation Questionnaire. The interview data and gratitude diary entries were collated to create qualitative case studies, analysed according to the principles of IPA (Smith et al., 2009) which has previously been used to analyse interview and diary data as a single dataset (e.g. Smith, 1999). IPA is concerned with understanding individual lived experiences within their wider contexts as well as the meaning of the data set as a whole (Smith, Flowers & Larkin, 2009). It is well-suited to exploring the meaning of a particular phenomenon for a group of individuals within a mixed-methods paradigm (Mayoh & Onwuegbuzie, 2015).

Each case study was analysed according to a cyclical process involving the following stages (see Smith et al., 2009; Larkin & Thompson, 2012):

1. Reading transcripts and diary entries together in full multiple times to increase data familiarity.
2. Line-by-line examination of each case study, using three levels of exploratory analytic coding: content-based, linguistic and conceptual.
3. Identification of patterns and themes for each participant.
4. Beginning to look for commonalities and differences across participant accounts. Generating initial codes and detailing codes with supporting quotes as evidence.
5. Returning to the original data and refining the codes, exploring and testing out how the codes fit together.
6. Development of initial themes by the first author, which were checked and shaped in collaboration with the second and third authors.
7. Developing an 'interpretative account' drawing together participant experience, the meaning of this data in this context, and the experience, understanding and psychological knowledge of the research team.

Quality Assurance and Reflexivity

Within an IPA approach, researchers are influenced by their own beliefs, ideas and assumptions whilst trying to make sense of the participants making sense of their experiences (a process known as the 'double hermeneutic'; Smith & Osborn, 2008). The research team had both family experience of dementia and experience of employment supporting those living with dementia. The research team held a belief that dementia brings many changes and challenges for individuals and families, but that it is also possible to live well with dementia, enjoying experiences and exhibiting strengths.

It was believed that gratitude may potentially be present in the lives of people with dementia, however it was not assumed that this would be the case.

To support transparency and coherence (Yardley, 2000) the first author kept a reflective journal (see Wall, Glenn, Mitchinson & Poole, 2004) during the process of data collection and analysis, which was regularly reviewed by the second and third authors, offering opportunities to mitigate the impact of researcher beliefs on an emerging understanding of the data and the shaping of themes. The cyclical data analysis process described above enabled in-depth engagement with and thorough analysis of the data, demonstrating commitment and rigour (Yardley, 2000).

Results

Sample

Eight participants (5 male and 3 female) took part in this study, in line with guidelines that recommend a sample size of 4-10 participants for IPA research (Smith et al., 2009). Participants self-reported a diagnosis of dementia. They were recruited through community groups in the North of England (n=5), a charity led community group (n=1) and word of mouth (n=2). Six participants lived with a spouse. Participants were aged between 71 and 80 years (mean age 74 years) and the self-reported time since diagnosis ranged from 18 months to 5 years. All participants identified themselves as White British and five identified themselves as religious. Further details of participant demographics are presented in Table 1.

Table 1. Participant Characteristics.

Pseudonym	Gender	Type of Dementia (self-reported)	Returned a Gratitude Diary
Harry	Male	Frontotemporal	Yes
Lilian	Female	Vascular	Yes
James	Male	Unknown	Yes
Robert	Male	Alzheimer's Disease	Yes
Eric	Male	Mixed	No
Thomas	Male	Mixed	Yes
Dorothy	Female	Frontotemporal	No
Anne	Female	Alzheimer's Disease	Yes

The Meaning and Experience of Gratitude

Gratitude was experienced by all participants, with specific examples of gratitude discussed in interviews and recorded in diaries. Two connected superordinate themes and seven subthemes emerged from the data (see Figure 1). The findings indicate two overarching aspects of gratitude – gratitude that was experienced and demonstrated interpersonally, and a sense of gratitude linked to experience of life more generally, demonstrated through a grateful attitude. The relative prominence of these two gratitude domains varied in the accounts of participants. Most participants focused on the interpersonal experience and expression of gratitude for the support received from others. The two gratitude domains are presented as overlapping, as discussions of gratitude for life and a life lived included experiences shared with significant others. Experiences of gratitude were

balanced against challenges resulting from the experience of living with dementia and ageing. Arrows in the diagram represent this tension.

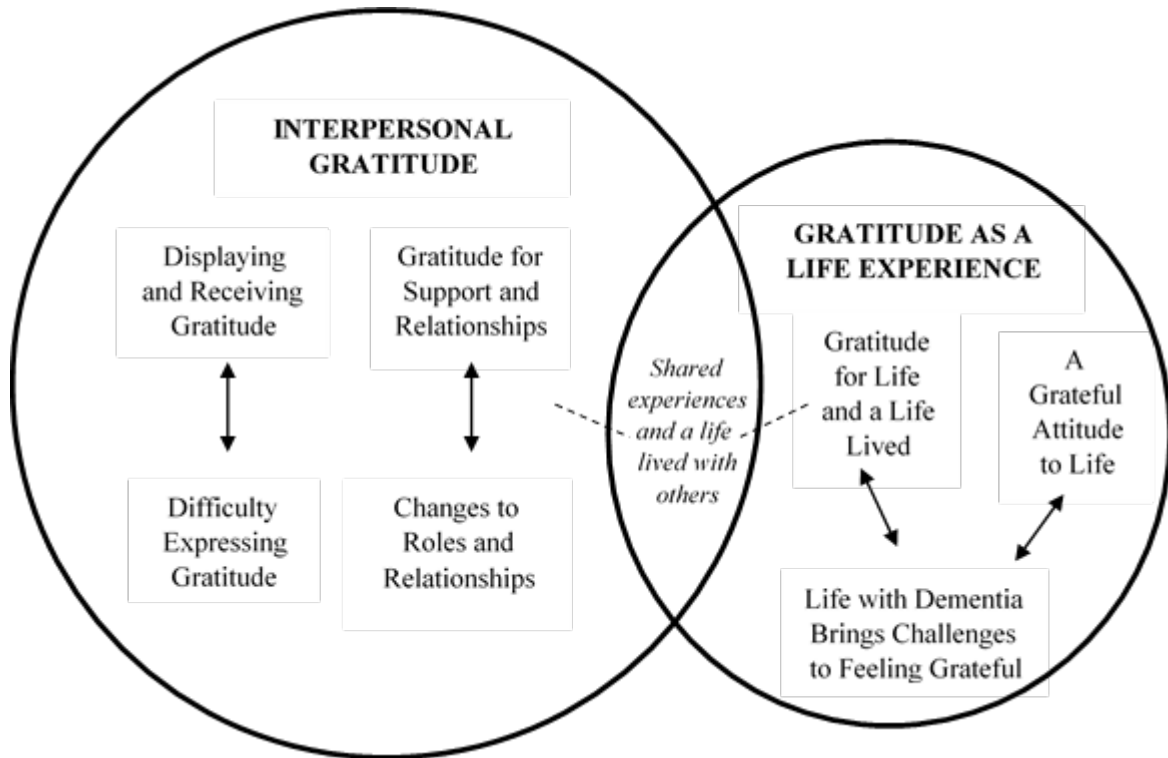


Figure 1. A diagrammatic representation of study themes.

INTERPERSONAL GRATITUDE

This superordinate theme encompassed four subthemes. A felt sense of gratitude towards others and the display of gratitude towards others were held in tension with the difficulties of changing relationships and challenges to the expression of gratitude.

Gratitude for Support and Relationships

Gratitude for support and relationships emerged as the most dominant subtheme. It was discussed at length within interviews and diary entries and assigned explicit importance by participants. Gratitude was defined as being thankful toward the people *'behind me'* (Eric) and *'there for you'* (Robert) and for *'the help that you receive'* (Thomas). Lilian described family as the *'main thing'* and Anne spoke about gratitude for family being *'most important'*, with gratitude diary entries echoing gratitude experienced for *'friends'* and *'family time'* (Harry) *'my wife'* and *'my children'* (James). Dorothy, who spoke little of her biological family, had found a family in those who supported her in the community and to whom she was grateful: *'they class me as their nanna'*. Participants' choice of language as they described feeling *'very'* and *'extremely'* grateful for *'everybody'* and *'everything'*

others did communicated the strength and scope of their gratitude to those around them. Some participants reported increased gratitude towards others, feeling *'even more...gracious to people since I've been diagnosed with dementia'* (Robert).

Participants spoke of the importance of knowing other people were there, spending time with others, and attending groups with other people who were living with dementia, which meant having *'fun'* (Lilian) and feeling like *'one of the crowd'* (Anne). Participants communicated that without others *'we'd be lost'* (Robert) and *'I don't know where we'd be'* (Eric). There was a sense that participants' resilience was attributed to those around them and the support received:

'I'm doing okay coping with it...but only because I've got (wife) here all the time' (Thomas)

Changes to Roles and Relationships

Whilst all participants conveyed experiences of gratitude for the support of others, the accounts of some suggested that receiving support was also difficult. Changed social roles led to a sense of increased dependence and decreased autonomy, which posed challenges in the experience of gratitude due to a sense that one might be *expected* to feel grateful for the support offered by others: *'I think everybody should be thankful for what they get'* (Eric). Harry expressed gratitude for the extensive support of his family but he also expressed concerns about being a *'burden'* or *'nuisance'*. This was also evident in his use of passive language, which conveyed a sense of powerlessness as he spoke of the possibility of one day being *'sent somewhere'* or *'farmed out'* to a residential home. For Thomas, it was a change to receive help and support, as someone who had *'always been a helper'*. Lilian spoke about formal help she received with her physical care and finding it difficult to be satisfied with this:

'You never think anybody has to do anything like that for you because...I've always done me [sic] own' (Lilian)

Gratitude was also impacted by the loss of loved ones. Harry spoke of struggling with gratitude following the loss of his wife, which left him wondering where his life was going. For Dorothy, the loss of her partner meant losing a hugely important part of her life and led her to question what she had to be thankful for. Those in the community who offered her support played a crucial role in gratitude - without them she felt gratitude may not have been possible:

'Without these, people in here (community group) I haven't got nothing to be grateful for...Cause I'd be sat on me own all in that bungalow all by meself [sic] 24 hours a day' (Dorothy)

Participants' experiences of gratitude toward others were therefore balanced against the difficulties brought about by decreased independence and autonomy and the loss of close relationships.

Displaying and Receiving Gratitude

In addition to a felt sense of gratitude, for many participants the communication of gratitude to others through words and actions was a salient aspect of their relationships. For some, displaying

gratitude was straightforward; Dorothy described the expression of gratitude through physical affection (e.g. hugs) as *'just natural'*, whilst Robert said he would *'just thank them...that's it. No difficulty about it'*. Thomas identified his gratitude as an important part of reciprocity in his relationship with his wife: *'I don't expect (wife) to-to give all this help, without me thankin' 'er.'* Acts of gratitude varied for different participants. Lilian spoke of kissing and hugging family members and support staff, whilst Harry and Anne spoke of being more reserved and expressing gratitude primarily through words.

Some participants placed emphasis on the gratitude received *from* others, for *'cooking a lovely meal'* (Lilian) and for helping at support groups: *'people come up to me and say...they appreciate what...I do'* (Robert), suggesting the importance of reciprocity in the expression of gratitude. Participants discussed ways in which they gave back to others through mentoring, taking part in research, and raising awareness, and valued their inclusion within the present study: *'it's nice to give something back'* (Harry). Thomas expressed a sense of gratitude for his dementia diagnosis itself, as it meant he had more to give:

'There aren't all that many of us that have got what I've got, so, in a way I'm thankful for that even...because people are interested in listening to me.' (Thomas)

Difficulty Expressing Gratitude

It felt important to participants that they were able to communicate their gratitude to others. However, it was not always possible to match the internal feeling with the expression of gratitude. When sharing their gratitude for support received within the community, Thomas and Dorothy did not feel it was possible to communicate gratitude in a way that would be commensurate with the support provided by others, feeling unable to *'thank them enough'* for what they had done. At times, Lilian would forget to express her thanks to others and felt *'upset'* by this. For Harry, fronto-temporal dementia was like having a *'switch'* in his brain which changed his mood and could either facilitate or hinder the expression of gratitude. Harry's difficulty finding the words to express his feelings and experience mirrored his difficulties communicating gratitude to others:

'I am extremely grateful, obviously...to them (family) but I say it doesn't, it doesn't, it doesn't come out as well from their side of the fence as it should' (Harry)

GRATITUDE AS A LIFE EXPERIENCE

The second superordinate theme encompassed three subthemes relating to a process of continuing with life and looking back on a life lived with gratitude, balanced with changing abilities and negative emotions experienced in living with dementia.

A Grateful Attitude to Life

Gratitude was described as a natural and innate part of living and as such, participants often found it difficult to articulate and define the experience. Regarding the interview, Robert commented that:

'Sometimes they're hard questions to answer...you never look at anything like that...you just carry on with your life'

Gratitude was experienced as part of a general attitude to life that continued in spite of dementia because it was part of one's identity, part of *'how you are'* (Lilian). For Eric, a change to his grateful attitude would be at odds with his sense of self: *'I try to have a good attitude at everything I do!...if I did change it...it wouldn't be me'*. A grateful approach allowed people to carry on with their lives with a *'smile'* *'laugh'* and *'joke'* (Eric) and maintain a sense of hope and resilience: *'I carry on life as normal...just carry on and hope for the best'* (James).

Gratitude for Life and a Life Lived

Participants expressed gratitude to be alive and to still be engaging with activities and interests. Harry shared his gratitude for *'treats'* (food) and *'entertainment'*, Lilian expressed gratitude for her ability to continue cooking and singing, and Anne for walks *'in the fresh air'* and *'drumming'*. Diary entries of *'waking up'* and *'another day'* indicated that for James, being alive was something to feel grateful for. In the experience of gratitude, participants balanced what they could continue to do with what they were no longer able to:

'Thankful that I can still listen to the (football) match on the radio, now that I can no longer go in person' (Harry)

For some participants, gratitude emerged from looking back at life and feeling satisfied with their opportunities, experiences, family life and career. This also encompassed a life shared with spouses, with James, Robert and Lilian all expressing their gratitude for over fifty years of marriage. For both Harry and James, having lived a life which they could look back on with satisfaction was also related to their *'working class'* origins and experiencing a sense of achievement. This process appeared to hold individual meaning and be easier for some than others to draw gratitude from, as for Eric, looking back at life was linked to dwelling on difficulties he had experienced in the past: *'I don't look back now, I've got to look forward'*.

Life with Dementia Brings Challenges to Feeling Grateful

Whilst participants shared the importance of carrying on and engaging with life, the experience of living with dementia raised difficulties and challenges in terms of experiencing and expressing gratitude fully. Three participants stated that their sense of gratitude did not extend to dementia itself, and for Anne, periods of forgetfulness and disorientation were characterised as *'bad days'*, when she found gratitude less accessible. Though participants spoke of their gratitude for activities and experiences in their daily lives, they were aware that their abilities, and the opportunities available to them were changing, resulting in feeling *'frustrated'* (Harry, Anne and Robert). Participants also experienced changes to their physical health and for Dorothy, wider problems as part of ageing were contributing to feeling *'anxious'* and *'depressed'*. Comparisons between self and others emerged as an important process in approaching life with a sense of gratitude despite the challenges of dementia, feeling *'lucky'* for what one had (Harry, Robert, Thomas and Lilian). This sense of luck helped participants maintain a positive outlook and keep going in the knowledge that things could be worse:

'Knowing that there's other people that's worse off than me that haven't got family around them, and you just appreciate what you've got' (Robert)

Use and Acceptability of the Gratitude Diary

Seven participants agreed to complete a gratitude diary. Six diaries were completed; five were returned to the researcher by post and one was collected in person. Table 2 displays details of diary completion. Figure 2 displays the average responses on the Diary Evaluation Questionnaire to the questions regarding ease of use, confidence and plans to continue using the diary, where a rating of 1 = strongly disagree, and a rating of 5 = strongly agree.

Table 2. Details of Diary Completion

Number of Participants who:	Returned a Diary	6
	Accepted Offer of Researcher Reminders	0
	Completed the Diary Evaluation Questionnaire	4
Diary modality:	Paper	6
	Email	0
Mean number of entry spaces used (of 21 spaces available)		12 (range 6-20)
Mean number of days on which entries were recorded (of 7 days)		5 (range 2-7)

INSERT FIGURE 2 HERE

Figure 2. Mean ratings of questions on the Diary Evaluation Questionnaire (n=4).

Qualitative Feedback Regarding Diary Use

Three participants reported benefits from using the diary, including reflecting on what they were grateful for, feeling better when thinking about the support received from others, and enjoying the experience of writing down feelings. Two participants responded that their difficulties with vision and writing made keeping the diary difficult and stated that family members supported them. One participant shared that on some days he felt pressured to think of things to write; for another, the presence of her granddaughter helped with keeping the diary as she had enjoyed her visiting. Four participants did not make any comments about possible improvements to the diary format; one participant suggested that the experience of keeping the diary would be easier if the questions were easier to understand. Three participants recorded extra comments that expressed their positive experiences of having taken part in the study and their hopes for the study outcomes.

Discussion

The primary aim of this study was to explore the meaning and experience of gratitude for people living with dementia. We also aimed to explore the usability and acceptability of gratitude diaries for people with dementia. Overall, the findings indicate that gratitude holds subjective meanings and value for people living with dementia in the community, supporting previous serendipitous findings (Wolverson, Clarke & Moniz-Cook, 2016; Hellstrom, Nolan & Lundh, 2007). Findings relating to the primary aim of the study will be discussed in full prior to findings relating to the secondary aim, which are discussed at the end of this section.

Participant experiences of interpersonal and generalised gratitude were balanced against acknowledged psycho-social challenges associated with the progression of dementia, echoing findings that living with dementia can involve an interplay between difficulties, losses, strengths, and positive coping (De Boer et al., 2007). Both changed abilities and changes to social roles and opportunities affected the experience of gratitude for participants, mirroring the ways in which both individual and social factors impact on the lived experience of dementia more generally (Kitwood, 1990; Patterson, Clarke, Wolverson & Moniz-Cook, 2018).

Participants' accounts indicated that gratitude was experienced in relation to others and displayed to others through performative actions and words. These findings are in accordance with definitions of gratitude as a social emotion (Roberts, 2004) and suggest this aspect of gratitude is particularly meaningful for people living with dementia. Relationships were of central value to participants, supporting findings that people living with dementia assign family roles high importance (Cohen-Mansfield, Parpura-Gill & Golander, 2006) and value maintained reciprocal relationships (Harris, 2013). The experience of gratitude in dementia may be shaped by the meaning dementia holds for roles and relationships, where the balance of relationships may change significantly. The findings indicate that for some, changed roles and abilities and an increased reliance on support may result in a sense of feeling 'in debt' to others or of being unable to reciprocate actions and display gratitude as desired. In the wider literature gratitude has been conceptually linked to indebtedness (Komter, 2004) defined as 'a state of obligation to repay another' (p4; Greenberg, 1980) but there is evidence that these concepts are differentiated by personal factors such as motivation and expectations (Tsang, 2006; Watkins, Scheer, Ovnicek & Kolts, 2006). A relationship between interpersonal

gratitude and indebtedness may exist in the experience of dementia but could be influenced by factors such as the experience of current and previous reciprocity in relationships.

Despite cognitive changes, participants experienced gratitude for past and present experiences and demonstrated a grateful attitude. These findings correspond to a broad definition of gratitude as 'transpersonal' (experienced generally towards the universe; Steindl-Rast, 2004) and are related to conceptualisations of gratitude as a character strength (Wood, Froh & Geraghty, 2010). The experience of gratitude for a life lived fits with life review theories whereby ageing prompts the processing and integration of conflicts and experiences over the life span, as we determine whether or not we have achieved our life goals (Erikson, 1995, Butler, 1963). McAdams & Bauer (2004) propose that gratitude in later life may challenge perceptions of needing to repay favours, with Erikson's final life stage prompting older adults on reaching this life stage to 'simply be thankful that one has been blessed with life' (p95). As such, the experience of gratitude in the wider sense may not be linked to indebtedness in the same way as the experience of interpersonal gratitude might, as the wider gifts of life may be viewed as being bestowed by the universe rather than being directly linked to interpersonal relationships with others.

For the participants in this study, comparison to others appeared linked with the experience of transpersonal gratitude and a corresponding sense of feeling lucky for what one had experienced in life or was still able to do now. Social comparison has been found to have positive outcomes in other chronic illnesses (Arigo, Suls & Smyth, 2012) and luck has been linked to gratitude and social comparison, with a sense that things could have been different (Teigen, 1997). Participants also described a grateful attitude to life which was linked to their sense of self. In holding onto a sense of identity, people living with dementia experience a tension between continuity and change in their sense of who they are (Caddell & Clare, 2011). The findings suggest that the preservation of felt and expressed gratitude interacts with self-identity, a possibility that should be explored in future research.

It is important to consider the connections and differences between the aspects of gratitude reported in this study. There was an overlap between gratitude for life and for relationships, with participants expressing gratitude for relationships over their lifetime and their shared experiences. Within the wider literature, Steindl-Rast (2004) proposes a continuum of gratitude, ranging from gratitude experienced towards other people to gratitude towards the universe. König and Glück (2014) discuss how boundaries between broad and narrow conceptions of gratitude can blur "if someone is grateful to his/her partner for a whole life lived together" (p655). Further research is required to explore potential relationships between the interpersonal and transpersonal aspects of gratitude identified in this study, in order to build an understanding of how levels of gratitude (McCullough, Tsang & Emmons, 2004) might interact in living with dementia. Research should also explore the relationship between gratitude and related constructs such as spirituality (Emmons & Kneezel, 2005) and hopefulness (McCullough, 2002) in dementia, to inform the application of interventions based on a positive psychology approach more generally.

The secondary aim of this study was to explore the acceptability and usability of gratitude diaries. The findings indicate that it is possible for people living with dementia to use diaries to record their experiences of gratitude, as demonstrated with other clinical and non-clinical groups (see Wood, Froh & Geraghty, 2010; Killen & Macaskill, 2015). This also highlights how people with dementia can

engage with creative methods of data collection (see Bartlett, 2012). Moreover, these findings suggest the feasibility of developing and testing specific gratitude diary interventions in dementia. Engagement with the diary method did vary, and participants spoke of the importance of having support from others to remind them to keep the diary and to compensate for difficulties with vision or writing, indicating the importance of adapting data collection methods to meet the needs of individuals.

Limitations and Implications

Within this study only a small number of voices were heard, and all participants were of a similar age and identified as White British. Sampling was purposive and the sample represents a connected, active and supported group of individuals living with dementia, which is likely to influence the findings, especially when gratitude was discussed in a social context and was experienced in relation to others. The findings of this study indicate the importance of future research exploring the meaning of gratitude within a more demographically diverse sample, including for people of different ethnicities and faiths. Further research is also needed to explore the meaning and experience of gratitude across the contexts of different care relationships and care settings, for example with non-community dwelling individuals who do not have the same level of access to support and opportunities. Future research could also explore the relational element of gratitude from the perspective of family members and spouses. The present study took a cross-sectional design, and further research would be required to explore what gratitude means to people who are living with dementia over time. There may be value in using qualitative longitudinal approaches in this area, which may offer opportunities to gather meaningful data by having chance to build a relationship with the person living with dementia over time and have repeated conversations on the topic of gratitude.

The finding that gratitude was primarily experienced as interpersonal emphasizes the importance of fostering meaningful relational experiences, strengthening social bonds and facilitating emotional expression in dementia care, through development of relationship-centred care approaches (see Nolan, Ryan, Enderby & Reid, 2002; Ryan, Nolan, Reid & Enderby 2008). Future research should explore the potential costs associated with fostering gratitude (see Wood, Froh & Geraghty, 2010), such as the inadvertent fuelling of feelings of indebtedness, and consider why some people experience indebtedness and others do not. Fostering reciprocity in relationships in dementia may help to reduce feelings of indebtedness and social expectations relating to gratitude. Social interventions such as gratitude visits – writing a letter of thanks and sharing it with someone else (Seligman, Steen, Park & Peterson, 2005) – may build upon gratitude by strengthening relationships, and may in turn support a sense of reciprocity and relational balance. Supporting individuals to be involved with research (in line with the activism movement; Bartlett, 2014) may help to maintain an overall sense of reciprocity and agency that could combat indebtedness.

The finding that gratitude also holds a broader meaning in dementia supports future research exploring the impact of interventions that promote a grateful approach to life and foster gratitude for experiences beyond the interpersonal. Gratitude diaries could be trialled as an intervention in dementia care for fostering and supporting gratitude. Mindfulness exercises that involve savouring the moment have been linked to resilience and happiness in older adults (Smith & Hanni, 2019) and

may enable recognition of grateful feelings as they occur in dementia. The use of life story techniques (Butler, 1963) may foster a sense of gratitude for a life lived through encouraging individuals to review and make sense of their lives as a whole.

On reflection, the font-size of the diary text could have been increased and visual prompts (such as the use of images to support text) could have been added to support understanding of the written instructions. Future research is likely to benefit from the co-production of gratitude diaries with people living with dementia with respect to wording and design, prior to further comparative testing in research and/or implementation in clinical practice. Options for augmenting a diary for clinical use include developing individualised prompts on each page, avoiding complex written questions and incorporating an individualised page at the start of the diary that is completed with an individual or a couple, supported by a healthcare worker. This could include space to note the personal meaning of gratitude as well as examples of events or experiences that somebody might include in their diary (which wasn't done as part of this preliminary research to avoid leading the participants, but in practice could helpfully prompt people living with dementia toward personal sources of gratitude). The experience of doing this jointly with a care partner or healthcare worker would likely increase confidence in understanding and using the diary and reduce reliance on episodic recall of events on the part of the person with dementia.

Conclusions

Overall, the findings of this study indicate that gratitude is a meaningful, multidimensional concept for people living with dementia, the complexity of which should be explored more through further research. The findings highlight the potential feasibility of developing and testing gratitude interventions aimed at increasing the well-being of people living with dementia. However, the social context around the experience of gratitude in dementia may be pivotal. The findings reinforce the importance of supporting people who are living with dementia to maintain social connections and reciprocal interactions, through extending opportunities that foster a sense of agency and involvement so as to foster experiences of meaningful gratitude as opposed to feelings of indebtedness.

Abbreviations Used

IPA (interpretative Phenomenological Analysis)

NHS (National Health Service)

PPI (Positive Psychology Intervention)

QUAL + quan (Qualitative and quantitative)

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Appendix A

Gratitude Diary Instructions

This is your gratitude diary. You are asked to write in here each day for one week, starting a new page each day. Do not worry if you forget to write in the diary or miss some days. There are many things in our lives, both large and small, that we might be grateful about. Think back over the past day and write down on the lines below up to three things in your life that you are grateful or thankful for. It doesn't matter if you can't think of three things.

1. _____

2. _____

3. _____

