

THE UNIVERSITY OF HULL

**Considering an Alternative Perspective: An Exploration of the Meaning and  
Experience of Gratitude for Individuals Living with Illness.**

being a Thesis submitted in partial fulfilment of the requirements for the degree of  
Doctor of Clinical Psychology

in the University of Hull

by Martha Jane Pearson, BSc (Hons) Psychology, University of York

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## Acknowledgements

*This thesis is dedicated to Ida Pearson.*

Firstly, I would like to express my gratitude to those who took part in this study. Thank you for your openness and honesty in sharing your stories and experiences with me. Thank you for welcoming me into your homes and for allowing me to witness moments where gratitude was expressed to your family members. You thanked me for the opportunity to be part of the study, and I hope that through conducting this research I have helped to carry your voices and experiences forward so that people can learn more about what it is like to live with dementia.

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## Overview

This portfolio thesis consists of three parts: a systematic literature review, an empirical paper and a set of related appendices. The thesis as a whole considers what gratitude means and how it is experienced by individuals living with a diagnosis of a chronic condition.

The first section is a systematic literature review that explores how gratitude is experienced by individuals living with a diagnosis of cancer, and critically examines how gratitude as a concept is understood and discussed within the cancer literature. Eighteen papers were reviewed. The data were synthesised using a meta-ethnographic approach, which took a critical interpretivist stance to consider how findings were structured and interpreted by researchers. The findings indicate that people living with cancer encounter positive experiences related to gratitude, which have multiple aspects, and co-occur with difficult experiences. The findings are discussed within the context of wider literature, and the implications for future gratitude research are considered.

The second section of the portfolio is an empirical study that explores the meaning of the concept of gratitude for people who are living with dementia in the community, and the experience of this concept. A secondary aim of the study was to explore the usability and acceptability of a diary as a data collection method for this group. The research used a mixed-methods approach, primarily collecting qualitative data using interviews and diaries, and analysing this using Interpretative Phenomenological Analysis. Secondary quantitative data were collected via a questionnaire and summarized using descriptive statistics to assess the usability of the diary method. Eight participants aged over 65 and living in the community were interviewed, and six of these participants kept a gratitude diary for a week following interview. Two

superordinate themes and seven subthemes emerged from the data. These findings indicate that gratitude has meaning as a multidimensional construct and is experienced in life with dementia, influenced by and balanced with the changes of dementia and ageing. Descriptive statistics indicate that a diary may be an acceptable method of data collection for this group. The findings are discussed in the context of wider literature, and the implications for dementia care generally and the specific application of positive psychology interventions are discussed.

The third section consists of a set of appendices relating to both the systematic literature review and the empirical paper. Also contained within these appendices are a reflective statement and an epistemological statement, which consider the researcher's experience of conducting the research and the philosophical position and assumptions underlying the research.

**Total Word Count: 40,096** (including tables, appendices and references)

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## **Part One: Systematic Literature Review**



**The Experience and Conceptualisation of Gratitude in Cancer: A Systematic  
Literature Review and Critical Interpretive Synthesis**

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Please see Appendix A for the instructions for contributors

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## **Abstract**

### **Objective**

Cancer is a life-threatening illness, which brings with it many challenges. The positive psychology movement has led to exploration of the positive experiences of people living with cancer, and specific constructs such as gratitude have been linked with well-being in the context of illness-related adversity. Furthering knowledge of the experience of gratitude in cancer could inform further development of interventions to support people living with cancer. The present review aimed to synthesise and critically examine the literature relating to the experience of gratitude for people living with cancer.

### **Method**

A systematic search of the literature was conducted using the electronic databases PsycINFO, MEDLINE and CINAHL Complete. Eighteen papers were included in the review. The data were synthesised using a meta-ethnographic approach, which took a critical interpretivist stance to consider how findings were structured and interpreted by researchers.

### **Results**

The papers reviewed indicate that people living with cancer encounter positive experiences relating to appreciation, gratitude and thankfulness, which were conceptualised in various ways within the literature. Aspects of these experiences include enhanced appreciation of being alive, changed perspectives on life, and appreciation of support. These experiences co-occurred with and arose from challenges and difficult experiences.

## **Conclusions**

This review provides preliminary evidence of the meaning and experience of gratitude for cancer patients and critically examines how these experiences are discussed in the literature. The findings highlight the importance of further study regarding the experience of gratitude in cancer and the development of gratitude based clinical interventions to improve well-being in cancer.

**Keywords:** gratitude, cancer, appreciation, post-traumatic growth

## **Introduction**

Cancer can be viewed as both a life-threatening illness and a chronic illness that can recur and which is associated with profound psychosocial challenges (Hewitt, Rowland & Yancik, 2003). Discourses around cancer are changing, with movement from ‘victim’ narratives towards the use of terms such as ‘survivor’ (Ristovski-Slijepcevic & Bell, 2014). With people living longer following a diagnosis of cancer, the focus of research has expanded to include developing psychosocial interventions to support self-management, and enhance well-being (Mustafa, Carson-Stevens, Gillespie & Edwards, 2013; Bradt, Dileo, Magill & Teague, 2011). There are over one hundred types of cancer (National Cancer Institute, 2016) and different cancers can raise specific challenges for individuals. For example, the association between smoking and lung cancer can lead to patients diagnosed with lung cancer feeling stigmatised and blamed, whilst breast cancer can challenge experiences of female sexuality (Chapple, Ziebland & McPherson, 2004; Emilee, Ussher & Perz, 2010). Despite these differences, there has been a tendency for research to examine cancer as a single phenomenon, and there is evidence that the lived experience of cancer is qualitatively different from the lived experience of other chronic illnesses such as Human Immunodeficiency Virus or Chronic Kidney Disease (Sheilds et al., 2015).

### **A Paradigm Shift: Positive Psychology and Gratitude**

There is a growing understanding that a struggle with challenging experiences and loss may result in positive psychological change known as post-traumatic growth (Calhoun & Tedeschi, 2001) and that people who have been diagnosed with cancer report positive consequences of their experiences (Willis, Lewis, Ng & Wilson, 2015; Moreno & Stanton, 2013; García-Rueda, Carvajal Valcárcel, Saracíbar-Razquin, & Solabarrieta,

2016). Positive psychology perspectives, which involve the study of strengths, positive traits and experiences (Seligman & Csikszentmihalyi, 2000) offer ways to understand and conceptualise the positive psychological changes that can occur in the context of illness and the factors that maintain and promote overall well-being. Researchers have begun to investigate the links between specific positive emotions and well-being and the effects of fostering experiences of gratitude (Sin & Lyubomirsky, 2009).

Lambert, Graham and Fincham (2009) asked laypeople to think of the characteristics that came to mind when thinking about gratitude, and found that appreciation, thankfulness, gratefulness, and expressing thanks were considered central to the concept, suggesting that gratitude may be discussed using multiple terms. Gratitude can be conceptualised variously as a positive emotion, a trait, a character strength, and a celebration (Emmons & McCullough, 2004; Wood, Froh & Geraghty, 2010; McCullough, Tsang & Emmons, 2004; Wood, Maltby, Stewart, Linley & Joseph, 2008; Peterson & Seligman, 2004; Steindl-Rast, 2004). A summary of gratitude conceptualisations is shown diagrammatically in Appendix B. Research into the relationships between gratitude and other constructs indicates an association between gratitude and different areas of well-being such as lower levels of psychopathology, higher hedonic and eudaimonic well-being, better relationships, and improved physical health outcomes (Wood, Froh & Geraghty, 2010). Gratitude may also play an important role in coping and long-term adjustment to disaster, acting as a protective factor against Post Traumatic Stress Disorder (Israel-Cohen, Uzefovsky, Kashy-Rosenbaum & Kaplan, 2015; Lies, Mellor & Hong, 2014). Although the evidence base is largely cross-sectional, Wood, Maltby, Gillett, Linley and Joseph (2008) conducted two longitudinal studies which indicate that gratitude is a causal factor in reducing stress and depression and improving perceived social support over time. There has been a corresponding

interest in evaluating the effects of gratitude-based interventions, which include keeping gratitude diaries, engaging in contemplation tasks and writing letters of thanks (Seligman, Steen, Park & Peterson, 2005). Overall, gratitude interventions have been found to increase well-being on a range of measures including life satisfaction, optimism, depressive symptoms, perceived stress and happiness, in both clinical and non-clinical populations (Chan, 2013; Cheng, Tsui & Lam, 2015; Froh, Sefick & Emmons, 2008; Kerr, O'Donovan & Pepping, 2015; Sergeant & Mongrain, 2011; Watkins, Uher & Pichinevskiy, 2015).

### **Gratitude in Cancer**

Although there is some evidence of a link between gratitude and well-being in cancer, research in this area has been limited. Studies indicate that for women living with breast cancer, gratitude is positively associated with well-being and affects positive social outcomes such as high quality relationships (Ruini & Vescovelli, 2013; Algoe & Stanton, 2012). Otto and colleagues (2016) studied the effects of fostering gratitude in women with early stage breast cancer, finding that those who completed a weekly letter-writing intervention reported a significant decrease in death-related fear of cancer recurrence compared to control participants. Whilst such research highlights the potential positive role played by gratitude in living with cancer, there is a very limited understanding of what gratitude means for people living with cancer, and a lack of clarity regarding how gratitude has been conceptualised in relation to living with cancer. It has been assumed that gratitude will hold the same meaning for individuals living with cancer as it does more generally, but it is possible that gratitude holds different meaning for people faced with life-threatening adversity. If greater clarity can be reached around the meaning of gratitude in cancer then future research into the applicability of gratitude interventions for this clinical group will be better informed.

Accordingly, this review aimed to answer the following questions:

1. *How is gratitude experienced by people who have been diagnosed with cancer?*
2. *How have experiences relating to gratitude in cancer been framed and understood by researchers?*

## **Methods**

### **Search Strategy**

A systematic search of existing qualitative literature was conducted in January 2017, using the electronic databases PsycINFO, MEDLINE and CINAHL Complete. These databases were chosen to cover a broad range of disciplines likely to be involved in research into the lived experience of cancer. The reference lists of included papers were scanned for any further relevant papers.

Given that there is no consensus on a single definition of gratitude and gratitude is discussed in multiple ways, a search strategy was designed to include literature relating to a broad definition of gratitude which included terms related to ‘gratitude’, ‘gratefulness’, ‘appreciation’ and ‘thankfulness’ (Lambert, Graham & Fincham, 2009).

Search terms were defined in three areas:

1. Terms relating to gratitude: gratitude OR grateful\* OR thank\* OR appreciat\*  
(TITLE, ABSTRACT AND SUBJECT TERMS)
2. Terms relating to cancer: cancer\* OR neoplasm\* OR oncolog\* OR tumo\*  
(ABSTRACT)

3. Terms relating to the study type and focus: qualitative OR interview\* OR experience\* OR narrative\* OR phenomenolog\* OR "focus group\*" OR perspective\* OR view\* OR thought\* OR opinion\* OR attitude\* (ABSTRACT)

The following limiters were applied:

- English language only
- Peer-reviewed journals only (this limiter was not applied to the database 'MEDLINE' as all articles stored within this database are peer reviewed).

### **Inclusion and Exclusion Criteria**

Tables 1 and 2 show the inclusion and exclusion criteria for papers alongside the rationale for each criterion.

**Table 1.** The inclusion criteria and their rationale.

| <b>Inclusion Criterion</b>   | <b>Rationale</b>  |
|--|---|
| The identified study aimed to explore the lived experiences of adults with cancer from the perspective of the individual | To find papers which explored the lived experience of adult cancer  |
| The study was qualitative in nature  | To access accounts of lived experience  |
| The paper was empirical – not autobiographical, a commentary, reflection or review                                       | So as to only include empirical findings as opposed to personal views or secondary data                                     |
| The paper was written in the English language  | To find papers which were written in the first language of the researcher, as there was no budget available for translation |
| The study was published in a peer reviewed academic journal  | To find papers which had been reviewed by other researchers and as such were deemed good enough quality to be publishable   |



|  |   |
|--|---|
| The study included sufficient qualitative data relating to gratitude, where sufficient data was defined as one or more themes relating to gratitude, illustrated by at least two quotes for each theme, and/or three or more quotes from different themes which made reference to aspects of gratitude | To include papers with findings of sufficient depth in relation to the aims of the review |
|--|---|

**Table 2.** The exclusion criteria and their rationale.

| <b>Exclusion Criterion</b>   | <b>Rationale</b>  |
|--|---|
| The paper was a duplicate of another paper   | To ensure only one copy of each paper was included in the review  |
| The study recruited a mixed participant group where it was not possible to differentiate between the perspectives of individuals living with cancer and perspectives of other groups (e.g. staff, family or another illness group) | To ensure the data being examined related solely to the experiences of people who had been diagnosed with cancer  |
| The study specifically recruited participants with comorbid conditions e.g. HIV and cancer   | To explore the lived experience of cancer as evidence suggests it may be qualitatively different from the lived experience of other illnesses (Sheilds et al., 2015)  |
| The study did not aim to directly access the views of people living with cancer (e.g. analysis of blog posts was excluded)   | So as to only include empirical studies with the aim of accessing and exploring the experiences of people living with cancer through direct questions and methods   |
| The study recruited a child sample or sample of adults who experienced childhood cancer  | To include the lived experiences of people who had been diagnosed with cancer in adulthood only. Childhood cancer brings with it unique challenges, with children developing different types of cancer to adults, receiving different treatments, and treatments having different ongoing and late effects which continue to emerge throughout adulthood (National Cancer Institute, 2017). |

### **Quality Assessment**

Methodological quality was assessed by the first author using the methodology checklist for qualitative studies created by the UK National Institute for Health and Care Excellence (NICE; 2016) and a subset of papers were rated by a peer researcher. A copy of the checklist is shown in Appendix C. In the case of studies that employed a mixed

methodology, only the qualitative aspects of the study were evaluated using the checklist, as these findings alone were included in the review. The quality assessment was not used as part of the inclusion strategy for the review, as for an interpretive review it is considered important to include papers which discuss the concept of interest, regardless of methodological quality (Dixon Woods et al., 2006). The checklist was used to critique the quality of the research papers in the areas of design and methods, reflexivity, clarity and depth of reporting, and the quality of analysis.

### **Data Synthesis**

The content of all study themes and subthemes relating to gratitude, and any quotes from other themes that related to gratitude were extracted using a bespoke data extraction form (see Appendix D). The data were synthesised using a meta-ethnographic approach (as described by Noblit and Hare, 1988) within which a critical interpretivist stance was adopted (Dixon Woods et al., 2006). Critical interpretive synthesis aims to go beyond summarising a body of data, to create new ideas, critique included studies and consider what a body of research means as a whole. This approach was chosen to explore the possibility that gratitude appears in accounts of lived experience even when it is not directly explored or conceptualised as such by researchers, with findings potentially emerging serendipitously from an exploration of lived experience or positive experiences more generally. Researcher interpretations and definitions of positive experiences in cancer and of gratitude are key to understanding the experience of gratitude in cancer. These understandings will likely be shaped by the broad range of existing conceptualisations of gratitude in the wider literature (see Emmons & McCullough, 2004; Wood, Froh & Geraghty, 2010). As such, it was considered important to consider the impact of the questions asked, the stance taken by researchers and the way in which findings were framed.

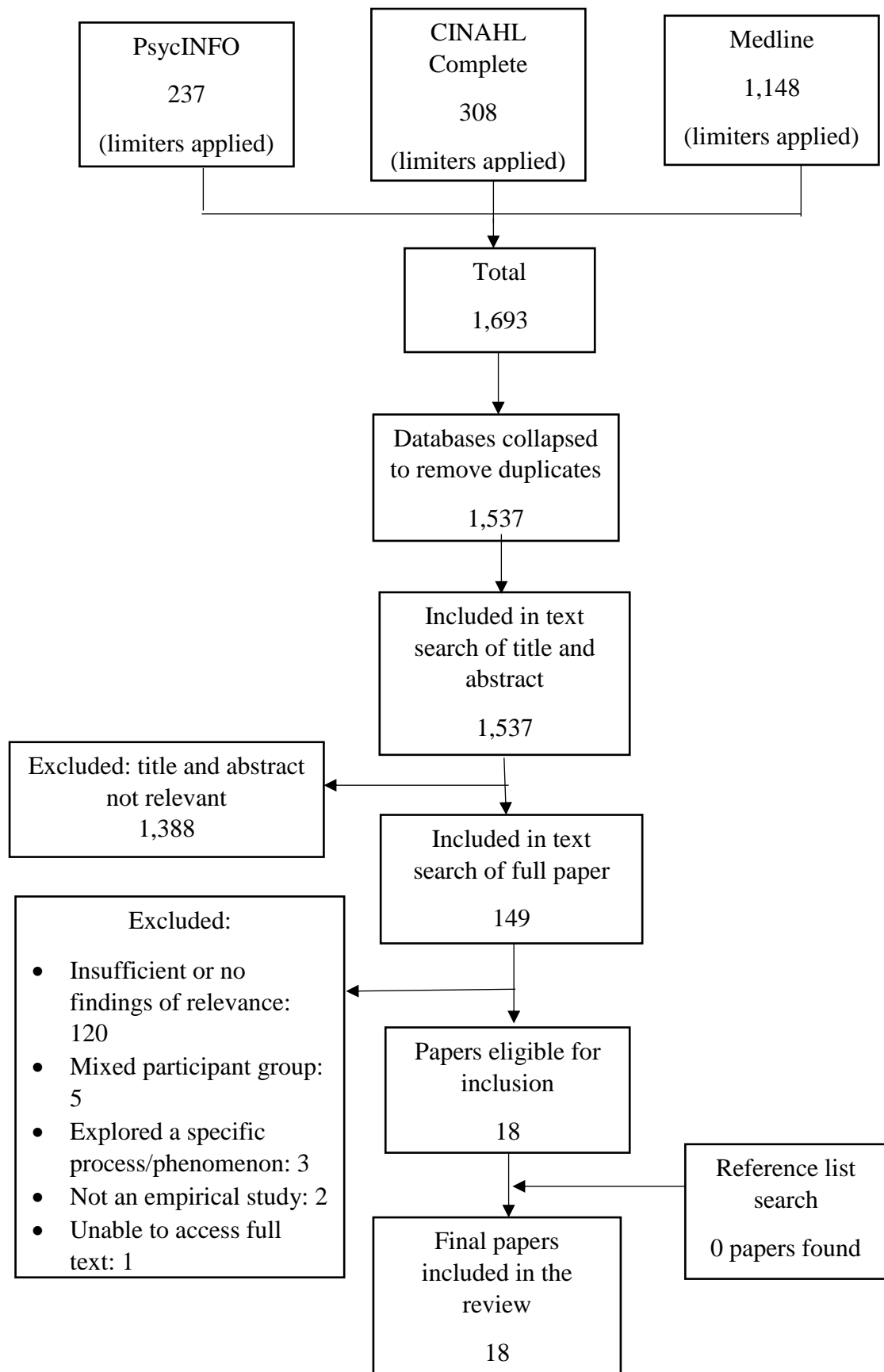
The subsequent steps were followed by the researcher in the process of data synthesis:

1. A process of familiarisation with the data through reading and re-reading of the included studies
2. Recording of initial descriptive codes based on the content of the data
3. Re-reading and refining codes
4. Finding links across the studies
5. Identifying and exploring contrasting and complex findings
6. Generating initial themes based on the codes and the relationships between studies
7. Testing out and refining the themes by examining their fit with the original data
8. Exploring each theme within its context, considering the discourses used to frame the data which contributed to each theme
9. Synthesising the overall findings.

## **Results**

### **Identification of Relevant Studies**

Eighteen papers from the electronic search met the inclusion criteria for the review. The process of selecting the papers is outlined in Figure 1.



**Figure 1.** A PRISMA flow diagram outlining the stages involved in the identification of relevant studies.

## **Characteristics of Included Studies**

Table 3 details the main characteristics of the included studies along with the relevant findings extracted for analysis. Fifteen of the studies reviewed were qualitative in nature, and three used a mixed methods approach (Bulkley et al., 2013; Kucukkaya, 2010; Munoz et al., 2016). The modal location of the studies was North America, with seven conducted in the USA and two in Canada. The other nine studies were conducted across Europe (UK, Northern Ireland and Turkey) Asia (Taiwan, Iran, Japan and Singapore) and Australia. The reported ages of participants ranged from 21 (Munoz et al., 2016) up to 82 years (Davidge et al., 2010). Nine studies had mixed gender samples, eight recruited female participants only and one study recruited male participants only (Cheng et al., 2013). Sample sizes ranged from as small as eight (Cebeci, Yangin & Tekeli, 2012; Komura & Hegarty, 2006; Prince-Paul, 2008) to as large as 92 (Bulkley et al., 2013) with a mean sample size of 20. The overall sample for this review totalled 365 cancer patients.

The participants included in the different studies had a range of cancer diagnoses including breast cancer (Cebeci et al., 2012; Davies et al., 2016; Lacey, 2002; Mehrabi et al., 2015; Tsuchiya, Horn & Ingham, 2013; Kucukkaya, 2010) mixed diagnoses (Ang et al., 2016; Komura & Hegarty, 2006; Prince-Paul, 2008; Sinding, Barnoff & Grassau, 2004; Munoz et al., 2016) head and neck cancer (Nund et al., 2014; Semple & McCance, 2010) oral cancer (Cheng et al., 2013) metastatic cancer (Lin, 2008) cervical cancer (Clemmens et al., 2008) rectal cancer (Davidge et al., 2010) and colorectal cancer (Bulkley et al., 2013). Nine studies did not report the period of time post-diagnosis in which the study took place, and the figures provided by other studies

ranged from immediately post-diagnosis (Kucukkaya, 2010) up to 28 years post-diagnosis (Clemmens, Knafl, Lev & McCorkle, 2008).

In ten studies participants had completed treatment, whilst in three studies the sample was mixed in terms of ongoing and completed treatment (Komura & Hegarty, 2006; Kucukkaya, 2010; Tsuchiya et al., 2013). Two studies did not provide clear treatment details (Lin, 2008; Sinding et al., 2004) and in individual studies participants were undergoing chemotherapy (Cebeci et al., 2012) were transitioning from hospital to home care (Ang et al., 2016) or were enrolled in a hospice programme (Prince-Paul, 2008) at the time of recruitment. Twelve studies provided marital and offspring information, whilst four studies offered no information about social support (Davigde et al., 2010; Komura & Hegarty, 2006; Nund et al., 2014; Prince-Paul, 2008). In one study, details of familial caregivers were provided (Ang et al., 2016) and one study asked participants to rate their own social support on a scale of high, moderate and insufficient, in which 67% rated their support as high and 26% rated their support as moderate (Kucukkaya, 2010).

The majority of the studies (14) used interviews only to collect data and two studies combined interviews with other techniques (Lin, 2008; Komura & Hegarty, 2006). Two of the mixed methods studies used open-ended questionnaires to gather qualitative data (Kucukkaya, 2010; Bulkley et al., 2013). The modal data analysis method used was a thematic approach, as used in 5 studies (Ang et al., 2016; Nund et al., 2014; Tsuchiya et al., 2013; Munoz et al., 2016; Mehrabi et al., 2015). Phenomenological approaches (Cheng et al., 2013; Davies et al., 2016; Lacey, 2002; Prince-Paul, 2008) and content analysis approaches (Clemmens et al., 2008; Komura & Hegarty, 2006; Kucukkaya, 2010; Cebeci et al., 2012) were each used in 4 studies. Other approaches included

grounded theory (Davidge et al., 2010) narrative analysis (Lin, 2008) cognitive mapping (Semple & McCance, 2010) content analysis and card sort techniques (Bulkley et al., 2013) and a qualitative analysis and participatory action research approach (Sinding et al., 2004).

**Table 3.** The Characteristics of Studies Included in the Review.

| <b>Authors, Date of Publication and Location</b> | <b>Relevant Aims</b>  | <b>Sample</b>   | <b>Methodological Approach</b>   | <b>Relevant Findings</b>  |
|--|---|---|--|---|
| <b>QUALITATIVE STUDIES</b>                       |   |   |  |   |
| <b>Ang et al. (2016)<br/>Singapore</b>           | To explore the experiences of care transition of patients with cancer and their caregivers. | Purposive sample of 12 caregivers and 12 patients with cancer (9 female, 3 male, aged 28-74 years, mean age 53 years).                      | Data collected using face-to-face interviews and analysed using thematic analysis.                                   | Subtheme ‘Ability to Self-Care’ within the theme ‘Appreciating the Transition Care’   |
| <b>Cebeci et al. (2012)<br/>Turkey</b>           | To explore the experiences of women living with breast cancer during treatment.             | Purposive sample of 8 women (aged 30-47 years, mean age 38 years) diagnosed with breast cancer and in the process of cancer treatment.      | Data collected using semi-structured, in-depth interviews (lasting between 1 and 2 hours) and analysed thematically. | Subtheme ‘Greater Appreciation of Life’ within the theme ‘Changes’<br><br>Quote from the subtheme ‘Changes in Understanding the Value of Health’ within the theme ‘Changes’ |
| <b>Cheng et al. (2013)<br/>Taiwan</b>            | To explore the experiences of middle-aged men living with oral cancer.                      | Purposive sample of 9 men, aged 47-65 years (mean age 55 years) who had undergone tumour resection surgery and completed cancer treatments. | Data collected using in-depth interviews and analysed according to Colaizzi’s phenomenological method (1978).        | Theme: ‘Appreciating Support from Family and Friends’   |
| <b>Clemmens et al. (2008)<br/>USA</b>            | To describe the quality of life experiences of long-term survivors of cervical cancer.      | Intensity sample of 19 women with a diagnosis of cervical cancer, aged 29–64 years (mean age 50 years).                                     | Data collected using semi-structured interviews and analysed using qualitative content analysis.                     | Theme: ‘Renewed Appreciation of Life’   |



| <b>Authors, date of publication and location</b> | <b>Relevant Aims</b>   | <b>Sample</b>   | <b>Methodological Approach</b>   | <b>Relevant Findings</b>   |
|--|--|---|--|--|
| <b>Davidge et al. (2010)</b><br><b>Canada</b>    | To explore patient experiences following sacral resection as part of surgery for advanced rectal cancer. | 12 patients, 6 male, 6 female, aged 32-82 years (median age 61 years) diagnosed with rectal cancer. All had undergone sacral resection.   | Data collected using semi-structured interviews and analysed using grounded theory.  | Theme: ‘Patients’ Gratitude to be Alive’   |
| <b>Davies et al. (2016)</b><br><b>USA</b>        | To explore the lived experience of women following mastectomy.   | Purposive sample of 10 women with breast cancer aged 35-76 years (mean age 59 years) who had experienced mastectomy within the last 6-12 months.  | Data collected using in-depth interviews and analysed using a phenomenological approach.   | Theme: ‘Gratitude’   |
| <b>Komura and Hegarty (2006)</b><br><b>UK</b>    | To explore cancer patients’ experiences of positive life changes.  | 8 patients from a cancer support group. 6 participated in a group discussion (3 men, 3 women, no further details provided). 5 participated in interviews (2 men, 3 women, aged 50-67 years, mean age 59 years). | Data collected through group discussion and semi-structured interviews, and analysed using a method of content analysis based on the seven types of positive life changes (Petrie et al., 1999). | Theme: ‘Greater Appreciation of Health and Life’                                       |
| <b>Lacey (2002)</b><br><b>USA</b>                | To explore the lived experience of patients with breast cancer using decisional support aids.            | Purposive sample of 12 women, aged 38–68 years (mean age 54 years) diagnosed with and treated for breast cancer and disease free at the time of interview.  | Data were collected using interviews (length 30–75 minutes) and analysed using Colaizzi’s (1978) phenomenological method.  | Theme: ‘Appreciating the Importance of Family and Friends’ Support in Decision Making’ |

| <b>Authors, date of publication and location</b> | <b>Relevant Aims</b>  | <b>Sample</b>   | <b>Methodological Approach</b>  | <b>Relevant Findings</b>   |
|--|---|---|---|--|
| <b>Lin (2008)<br/>USA</b>                        | To explore how Chinese immigrants with metastatic cancer search for meaning at the end of their lives.        | Purposive sample of 12 Chinese immigrants from China and Taiwan with a diagnosis of metastatic cancer (aged 37-70 years, no mean age or gender information provided). | A topical life history method employed utilising life story and in-depth interviews (interviews lasted approximately 3 hours each). Data analysed using narrative analysis. | Quotes from the themes: 'Compassion and Love', 'Empowerment and Peaceful Dying' and 'Readjustment and Transcendence'   |
| <b>Mehrabi et al. (2015)<br/>Iran</b>            | To explore the post-traumatic growth experiences of women with breast cancer.                                 | Purposive sample of 18 women diagnosed with breast cancer (aged 31-65 years, no mean age reported) who had completed treatment 3-6 months earlier.                    | Data collected using semi-structured, in-depth interviews and analysed using thematic analysis.   | Theme: 'Appreciation of Life', including subthemes 'Attitude Improvement' and 'Re-evaluation of the Meaning of Life'<br><br>Subtheme: 'Thanksgiving' within the theme 'Spiritual Prosperity' |
| <b>Nund et al. (2014)<br/>Australia</b>          | To explore the experience of living with dysphagia following non-surgical treatment for head and neck cancer. | Maximum variation sample of 24 patients who had received radiotherapy treatment for head and neck cancer. 20 male, 4 female, aged 43-71 years (mean age 57 years).    | Data collected using in-depth, semi-structured interviews (lasting between 20 minutes and 2 hours). Data analysed using thematic analysis.                                  | Theme: 'Altered Perceptions and Changes in Appreciation of Food'   |

| <b>Authors, date of publication and location</b>      | <b>Relevant Aims</b>   | <b>Sample</b>  | <b>Methodological Approach</b>   | <b>Relevant Findings</b>   |
|---|--|--|--|--|
| <b>Prince-Paul (2008)<br/>USA</b>                     | To explore the meaning of social well-being, as an element of quality of life, for individuals at the end of life.   | Purposive sample of 8 terminally ill patients living in a hospice. 3 male, 5 female (aged 44-74 years; mean age 61 years).   | Data collected using in-depth semi-structured interviews (which lasted an average of one hour) and analysed using Giorgi's (1971) descriptive phenomenological method.   | Theme: 'Gratitude'<br><br>Quotes from the themes: 'Losses and Gains of Role Function', 'Meaning of Relationships With Family, Friends, and Co-workers', and 'Meaning of Relationship With God or a Higher Power' |
| <b>Semple and McCance (2010)<br/>Northern Ireland</b> | To explore the experiences and support needs of parents with head and neck cancer who have young children.   | 12 cancer patients with children under the age of 16 at the time of diagnosis who had completed treatment. 10 men and 2 women (age not reported).  | Data were collected using in-depth interviews and analysed using cognitive mapping techniques.   | Theme: 'Increased Appreciation of Life'  |
| <b>Sinding et al. (2004)<br/>Canada</b>               | To explore the experiences of lesbians diagnosed with cancer. The subset of findings relating to the experience of cancer care are reported in this paper. | 26 lesbian women diagnosed with breast and/or gynaecological cancer aged 36-72 years ('average' age is reported as 50 years although the type of average calculation used is not specified). | The study took a participatory action research approach. Data were collected using face-to-face and telephone interviews (approximately 90 minutes long) and analysed in line with principles of qualitative analysis (Seale, 1999). | Theme: 'Gratitude for Receiving Equitable Care/Readiness to Fight for Equitable Care'  |

| <b>Authors, date of publication and location</b> | <b>Relevant Aims</b>  | <b>Sample</b>  | <b>Methodological Approach</b>  | <b>Relevant Findings</b>   |
|--|---|--|---|--|
| <b>Tsuchiya et al. (2013)<br/>Japan</b>          | To explore positive change experienced by breast cancer survivors.                    | 10 women diagnosed with breast cancer (aged 39-69 years, mean age 53 years) who had undergone breast surgery and attended self-help groups.  | Data collected using semi-structured interviews (2 hours in length) and analysed using thematic analysis.   | Theme: 'Increased Appreciation of Life' including subthemes 'Appreciation of Family and Friends' and 'Appreciation of Nature'<br><br>Quote from the subtheme 'Awareness of Self' within the theme 'Self-development' |
| <b>MIXED METHODS STUDIES</b>                     |   |  |   |  |
| <b>Bulkley et al. (2013)<br/>USA</b>             | To investigate the spiritual well-being of colorectal cancer survivors with ostomies. | Of a total sample of 283 colorectal cancer patients with ostomies who had survived at least 5 years post-diagnosis, 92 participants provided qualitative data (52 male, 40 female; mean age 71 years). | Qualitative data were collected using an open-ended question about the biggest challenge of living with an ostomy. Data were analysed using content analysis and a card sort technique. | Theme: 'Appreciate Life More/Second Chance'<br><br>Quotes from the themes: 'Strength Through Religious Faith' and 'Helping Others Helps Me'  |
| <b>Kucukkaya (2010)<br/>Turkey</b>               | To explore the experience of positive changes for Turkish women with breast cancer.   | Of a total sample of 84 women with a diagnosis of breast cancer aged 30-60 years (no mean age reported) the qualitative data was analysed  | Qualitative data were collected using open-ended questionnaires and analysed using content analysis.  | Theme: 'Greater Appreciation of Life'  |

|  |  | for the 42 women who reported positive change in their life following illness (no further demographics provided).  |  | Subtheme 'Increased Appreciation of Personal Worth' within the theme 'Changes in Self Perception' |
|--|--|--|--|---|
| <b>Authors, date of publication and location</b> | <b>Relevant Aims</b>   | <b>Sample</b>  | <b>Methodological Approach</b>   | <b>Relevant Findings</b>  |
| <b>Munoz et al. (2016)<br/>USA</b>               | To explore the experience of cancer and health-related quality of life among young adults from racial and ethnic minorities. | Purposive sample of 31 racial and ethnic minority young adults, 20 female and 11 male (age 21-39 years, mean age 33 years) with different diagnoses of cancer. | Qualitative data were collected using semi-structured interviews conducted by telephone (lasting 19-57 minutes, mean length 38 minutes). Data were analysed using thematic analysis. | Theme: 'Appreciation for Life'  |

## **Methodological Quality Assessment**

The methodological quality of the included studies was assessed by the first author, using the NICE (2016) checklist for qualitative studies. A subset of papers were checked by a peer researcher. Differences in overall ratings occurred for two papers (Bulkley et al., 2013; Clemmens et al., 2008) and were discussed to reach a consensus. Table 4 shows the overall methodological quality ratings for each of the included papers, and a summary table containing an overview of the methodological quality in key areas can be found in Appendix E.

Overall, the papers were judged to be lacking in reflexivity, with inadequate discussion of the relationship between researcher and participant, or consideration of the impact of the values, approach and biases of the researcher(s), with only two papers discussing issues of reflexivity explicitly (Davies et al., 2016; Prince-Paul, 2008). The papers also varied in the richness of data presented and in the detail of theme discussion, although the inclusion criteria for the review meant that all papers must provide a relevant theme illustrated by at least two quotes, or a minimum of three relevant quotes across multiple themes. Whilst in general the methods and approach of the studies appeared appropriate, not all studies gave a clear rationale for the study design and methods. However, this may indicate a limitation in reporting rather than a failure to consider the theoretical basis of an approach.

**Table 4.** The overall methodological quality ratings of papers included in the review.

| <b>Methodological Quality Rating</b>   |  |   |
|--|--|---|
| -  | +  | ++  |
| <i>Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter</i> | <i>Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter</i>  | <i>All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter</i>                               |
| No studies were assigned to this category  | Ang et al., 2016<br>Davidge et al., 2010<br>Davies et al., 2016<br>Komura & Hegarty, 2006<br>Kucukkaya, 2010<br>Lin, 2008<br>Mehrabi et al., 2015<br>Munoz et al., 2016<br>Sinding et al., 2004<br>Tsuchiya et al., 2013 | Bulkley et al., 2013<br>Cebeci et al., 2012<br>Cheng et al., 2013<br>Clemmens et al., 2008<br>Lacey, 2002<br>Nund et al., 2014<br>Prince-Paul, 2008<br>Semple & McCance, 2010 |

### **Synthesis of Findings**

Table 5 displays the themes and subthemes resulting from the synthesis. The studies relevant to each subtheme are listed. Appendix F contains a summary of the use of gratitude terminology by authors (in naming themes) and by participants (in direct quotes) for the themes ‘Experience of Life’ and ‘Relationships and Support’. The language used to discuss ideas varied by theme, but overall the term ‘appreciation’ was most frequently used by authors and in the available participant quotes. It appeared that some authors used gratitude terminology to frame findings when participants themselves did not use this language – however it is not possible to conclude whether this was the case as the reviewer only had access to a subset of participant quotes.

**Table 5.** Aspects of Gratitude in Living with Cancer: Themes and subthemes of the synthesis, listed alongside the relevant studies.

| Theme                            | Subtheme                | Related Studies   |
|----------------------------------|-------------------------|---|
| <b>Experience of Life</b>        | <i>Attitude to Life</i> | Bulkley et al., 2013; Cebeci et al., 2012; Clemmens et al., 2008; Komura & Hegarty, 2006; Kucukkaya, 2010; Lin, 2008; Mehrabi et al. 2015; Munoz et al., 2016; Prince-Paul, 2008; Semple & McCance, 2010; Tsuchiya et al., 2013   |
|                                  | <i>Being Alive</i>      | Bulkley et al., 2013; Cebeci et al., 2012; Davidge et al., 2010; Davies et al., 2016; Kucukkaya, 2010; Mehrabi et al., 2015; Prince-Paul, 2008  |
| <b>Relationships and Support</b> | -                       | Ang et al., 2016; Bulkley et al., 2013; Cheng et al., 2013; Lacey, 2002; Lin, 2008; Prince-Paul, 2008; Sinding et al., 2004; Tsuchiya et al., 2013  |
| <b>Growth and Challenge</b>      | -                       | Ang et al., 2016; Bulkley et al., 2013; Cebeci et al., 2012; Cheng et al., 2013; Clemmens et al., 2008; Davidge et al., 2010; Davies et al., 2016; Komura & Hegarty, 2006; Lacey, 2002; Lin, 2008; Mehrabi et al. 2015; Munoz et al., 2016; Nund et al., 2014; Prince-Paul, 2008; Semple & McCance, 2010; Sinding et al., 2004; Tsuchiya et al., 2013 |

### **Theme 1: Experience of Life**

This overarching theme comprises two subthemes: a cognitive reappraisal of values, priorities and approach to life, and a sense of gratitude for being alive, which may follow the former cognitive change. The authors who discussed appreciation in the context of wider life experience used the term appreciation to refer to positive change, where enhanced value was given to life or an element of life.



*Subtheme: Attitude to Life*

The idea discussed in the greatest depth across studies relates gratitude to a change in life perspective following a diagnosis of cancer. Many studies reported a sense of increased appreciation for life in general (Mehrabian et al., 2015; Cebeci et al., 2012; Prince-Paul, 2008; Semple & McCance, 2010; Munoz et al., 2016; Bulkley et al., 2013; Kucukkaya, 2010; Clemmens et al., 2008; Komura & Hegarty, 2006). Studies reported participant experiences of changed attitudes and perceptions of life, with cancer bringing a sense of increased understanding about what was valuable and important in life (Mehrabian et al., 2015; Clemmens et al., 2008; Kucukkaya, 2010; Komura & Hegarty, 2006; Munoz et al., 2016; Lin, 2008; Semple & McCance, 2010).

“It is like smelling the roses – stop and smell the roses. Your values change. You value drinking and going out with your mates and working, doing whatever else. Then you step back from that and say, ‘Hold on’. Everybody thinks kids are important, but it makes them doubly important.” *Semple and McCance (2010)*.

*Theme: Increased Appreciation of Life, p1286*

Participants spoke of specific attitudinal changes, such as an enhanced appreciation of health (Mehrabian et al., 2015; Cebeci et al., 2012; Komura and Hegarty, 2006; Lin, 2008) and a greater sense of self-worth (Kucukkaya, 2010). Studies also reported findings relating to increased appreciation of and gratitude towards nature. In one study it was reported that every participant expressed gratitude towards nature and spoke of ‘amazement’ at its beauty (Prince-Paul, 2008) while in another study participants spoke of finding greater beauty in their surroundings:

“I was very surprised at such beautiful scenery around me. I think this is my change. ‘Till I developed BC [breast cancer] I realised neither that the sky was so blue nor that Mt Fuji could be seen from my place.’” *Tsuchiya et al. (2013). Subtheme: Appreciation of Nature, p111*

Mehrabi and colleagues (2015) interviewed women who identified with the Islamic faith, and most experienced a sense of spiritual growth following their experience of cancer. Within this, participants thanked God for their health and for everything they valued in their lives:

"I realized the value of my properties and all things that I have in my life and getting cancer reminded me to thank God" *Mehrabi et al., (2015). Theme: Spiritual Prosperity, Subtheme: Thanksgiving, p1243*

Changed attitudes and perspectives emerged across studies, therefore suggesting that these experiences may occur for people living with cancer who have different demographic, social, illness and treatment characteristics. The studies drawn together under this theme explored the experiences of cancer patients across a range of countries (USA, Canada, Turkey, UK, Iran, Japan and Northern Ireland) although individual studies were conducted with largely culturally and ethnically homogeneous samples. However, Munoz and colleagues (2016) reported that their study theme ‘Appreciation for Life’ was more prevalent within the ethnic-racial group ‘Asian/Pacific Islander’ than Black Hispanic or non-Hispanic groups. The authors found that Asian participants in the study reported higher emotional well-being scores than other groups, and speculated

that benefit finding may be related to positive psychosocial well-being following treatment.

Of the 11 studies supporting this subtheme, 9 papers had approached the research from a positive stance, either looking specifically for growth and positive change (Komura & Hegarty, 2006; Kucukkaya, 2010; Mehrabi et al., 2015; Tsuchiya et al., 2013) exploring experiences of well-being and quality of life (Bulkley et al., 2013; Clemmens et al., 2008; Munoz et al., 2016; Prince-Paul, 2008) or exploring how participants made meaning from their experiences (Lin, 2008). In 9 studies included under this theme, researchers used variants of the word ‘appreciation’ to frame findings, using the umbrella of appreciation of life to encompass a number of different subtheme titles such as ‘Attitude Improvement’, ‘Appreciation of Nature’ and ‘Positive Changes in World View’ (Kucukkaya 2010; Mehrabi et al., 2015; Tsuchiya et al., 2013).

#### *Subtheme: Being Alive*

This subtheme relates to wider experiences of gratitude and appreciation which encompassed a sense of feeling grateful for life itself and appreciating being alive whilst also having cancer. Participants (and researchers) spoke of the joy found in life, with participants expressing thankfulness for life on earth and being alive still (Prince-Paul, 2008; Cebeci et al., 2012; Davidge et al., 2010) and for the feeling of having a ‘second chance’ to live (Bulkley et al., 2013; Clemmens et al., 2008; Kucukkaya, 2010). In two studies, women who had received mastectomy surgery spoke of the relatively low importance of losing a breast in the wider context of their experience of being able to live (Davies et al., 2016; Cebeci et al., 2012):

“I lack a breast, but this is not the end of life, I am alive.”

*Cebeci et al. (2012). Theme: Greater Appreciation of Life, p410*

For some participants, surviving cancer and being alive was attributed to a higher being (Bulkley et al., 2013; Mehrabi et al., 2015):

“I always thank God for my living. Always have faith, love, and hope.”

*Bulkley et al. (2013); Theme: Strength Through Religious Faith, p2517*

This subtheme was represented for several illness groups including women with a diagnosis of breast cancer (Cebeci et al., 2012; Davies et al., 2016; Kucukkaya, 2010; Mehrabi et al., 2015) terminally ill cancer patients (Prince-Paul, 2008) those with a diagnosis of rectal cancer (Davidge et al., 2010) and individuals who had survived colorectal cancer (Bulkley et al., 2013). Researchers recruited participants immediately following surgery (Davies et al., 2016) interviewed individuals living with terminal cancer in a hospice (Prince-Paul, 2008) and recruited a sample for which the average age was 71 years (Bulkley et al., 2013). The finding of gratitude for being alive in these samples suggests that contexts such as recently undergoing and surviving major surgery, living as an older adult with a major illness, or living as an individual who is contemplating the end of life may foster the experience of gratitude for being alive.

Five of the seven studies within this subtheme are also included within the subtheme ‘Attitude to Life’ (Bulkley et al., 2013; Cebeci et al., 2012; Kucukkaya, 2010; Mehrabi et al., 2015; Prince-Paul, 2008) indicating that experiences of gratitude in these areas co-occur and could be linked. The conceptualisation of findings in this subtheme differed from that of ‘Attitude to Life’ in terms of greater variation in the terminology authors and participants used to discuss gratitude for being alive. Terms relating to

gratitude, appreciation and thankfulness were all used by participants and researchers to discuss joy at being alive, suggesting that gratitude for life may be discussed in different ways and exists as a broad experience.

## **Theme 2: Relationships and Support**

Several studies presented themes and subthemes relating to the appreciation of others, with these findings reported across a range of cancer groups. Women living with breast cancer, middle aged men with oral cancer and hospice residents with varied cancer diagnoses all spoke of the importance of, and their appreciation for support from, family, friends and colleagues in helping them through the challenges of cancer (Tsuchiya et al., 2013; Cheng et al., 2013; Lacey, 2002; Prince-Paul, 2008):

“The power of family unity, and support, from my friends, uh, friends who were concerned about me helped me out...er, I felt grateful that I was surviving thanks to the support from people around me...My family and friends, well, owing to them I am here I think.”

*Tsuchiya et al. (2013). Subtheme: Appreciation of Family and Friends, p111*

However, the potential negative experiences of changes to relationships such as increased dependence, and the interplay between these elements and positive experiences were also highlighted in one study:

“It was no problem for me physically before and now I have to depend on my wife for the physical part...I tell her all the time how much I love her, how much

I appreciate what she's doing. It's still hard though." *Prince-Paul (2008).*

*Theme: Losses and Gains of Role Function, p368*

Breast cancer patients who had moved home following hospital treatment appreciated visits from nursing staff which helped them to feel reassured and gain confidence in caring for themselves (Ang et al., 2016). Gratitude for formal care was also expressed in the accounts of lesbian women living with a diagnosis of cancer (Sinding et al., 2004). Participants spoke of positive experiences of interacting with staff who showed acknowledgement and acceptance of their female partners. The study authors discuss this experience as occurring in the context of attitudes that are homophobic or prejudiced in favour of heterosexual couples, suggesting that this may result in gratitude for receiving care that is equal to the care that would be expected by heterosexual people.

"It made such a difference to me that she went to [my partner] first. Just that, in legitimization of who we are, because she would have for sure gone to my husband if I were married, right? It just normalizes it, and you've got so much to deal with emotionally."

*Sinding et al. (2004). Theme: Gratitude for Receiving Equitable Care/Readiness to Fight for Equitable Care, p182*

Whilst the studies discussed above summarized participant experiences using the terms 'appreciation' and 'gratitude', a study of the experiences of Chinese immigrants living in the US with metastatic cancer included participant experiences relating to the appreciation of family and friends under the theme of compassion and love (Lin, 2008).

It was reported that compassion and love helped with finding meaning in life after cancer, and participants spoke of appreciating the love they were shown by their families and the visits made by their friends. One individual appeared to appreciate his friends visiting particularly because of the context of cultural beliefs in which they did this:

“I have many friends who support me. They come to visit me. I appreciate them very much. In general, Chinese people are afraid to visit cancer patients. But the meaning is related to the fact that people are afraid of getting a negative impact from cancer patients; that is, they are afraid of getting bad luck. But those of my friends are not afraid to come to visit me. I feel very warm about their visiting.” *Lin (2008). Theme: Compassion and Love, p253-254*

Findings from two particular studies indicated that appreciation and gratitude for relationships and support in cancer were related to religious experiences. One participant was quoted as making reference to ‘*the Lord*’ as a source of support alongside family and friends (Lacey, 2002) and two participants spoke of their experiences of thankfulness in the context of their relationships with God and with their spouses (Prince-Paul, 2008).

‘I’m so thankful...God has been good. My wife is a wonderful, beautiful person...she’s been through every dark hour with me.’ *Prince-Paul (2008). Theme: Gratitude, p369*

Authors framed findings around relationships and support using the terms ‘appreciation’ and ‘gratitude’. Participants themselves used the language of appreciation, but also

spoke of feeling *'thankful'* and giving *'thanks'* to the people around them and to God (Bulkley et al., 2013; Prince-Paul, 2008; Tsuchiya et al., 2013). Half of the studies listed within this theme had explored specific experiences in which others, both professional health workers and family members, are particularly involved (Ang et al., 2016; Lacey, 2002; Sinding et al., 2004) which may explain why findings relating to gratitude for others emerged within these studies.

### **Theme 3: Growth from Challenge**

This theme relates to the context in which positive experiences of appreciation, gratitude and thankfulness were framed and discussed. Studies contextualised findings alongside the challenges of cancer, including the difficulties of surgery and treatment (Lacey, 2002; Davidge et al., 2010; Cheng et al., 2013) side effects, illness and changed abilities (Nund et al, 2014; Mehrabi et al., 2015; Cheng et al., 2013; Ang et al., 2016; Clemmens et al., 2008) and loss of the breasts (Cebeci et al., 2012; Davies et al., 2016). The way in which positive changes were presented suggests that they may be experienced or interpreted as emerging in response to adversity, with the challenges of cancer acting as a catalyst for the fostering and expression of aspects of gratitude, as illustrated by the quote below:

“...the sad part about it is I think it took cancer to make me realize a lot of things in my life, to appreciate a lot more of the things that I didn't appreciate before...I wish I could just pick everybody up and say, look, I don't want you to go through what I went through but I want you guys to see what I see now. Start appreciating everything.” *Clemmens et al. (2008) Theme: Renewed Appreciation of Life, p901*



In one study, appreciation was used to frame both positive and negative elements of experience. Nund and colleagues (2014) reported a theme relating to changed appreciation of food. Here, the most common experience for participants was of eating being a necessary task and no longer bringing pleasure after cancer surgery. However, the authors also reported that some participants who were long-term post-treatment experienced an increased appreciation of food with their enjoyment having been lost and then regained, and treatment status may influence the experience of appreciation. These two opposing areas of experience are illustrated by the quotes below:

“The only satisfaction I get from food ...is that I won’t die from hunger.”

“I have got more of an appreciation...I appreciate food more now than I ever did, because I got it taken away.”

*Nund et al. (2014). Theme: Altered Perceptions and Changes in Appreciation of Food, p286*

This co-existence of negative and positive experiences can also be seen in the context of other themes drawn out by researchers. Included papers reported themes relating to gratitude in amongst themes relating to negative experiences and difficulties. For example, other themes reported include ‘Living with Losses (loss of the breast and of one’s hair)’ (Cebeci et al., 2012) ‘Continuous Disturbance and Turmoil’ (Cheng et al., 2013) ‘Significant Chronic Pain Related to Sacrectomy’ (Davidge et al., 2010) ‘Discomfort’ (Davies et al., 2016) ‘Suffering and Impending Death’ (Lin, 2008) and ‘Ongoing Struggles’ (Clemmens et al., 2008). The only paper reviewed which did not refer to the difficulties of cancer within the discussion of themes relating to appreciation and gratitude, or within other reported themes, was that of Kucukkaya (2010), whose study specifically focused on positive experiences. Experiences of gratitude,

appreciation and thankfulness in cancer co-occurred with, and may arise from, the challenges and difficulties of the illness.

## **Discussion**

This review aimed to gather and interpret data relating to the meaning and experience of gratitude for people who have received a diagnosis of cancer. The findings indicate that for people who are living with or who have lived with cancer, gratitude may encompass a range of experiences including an enhanced appreciation of life experiences, thankfulness towards God, and appreciation of support from others. These findings contribute to evidence of positive experiences in cancer (Willis, Lewis, Ng & Wilson, 2015; García-Rueda, Carvajal Valcárcel, Saracíbar-Razquin, & Solabarrieta, 2016; Hefferon, Grealy & Mutrie, 2009; Jim & Jacobsen, 2008). Gratitude appeared to co-exist with and emerge from the difficulties of cancer, in accordance with post-traumatic growth perspectives in which positive psychological change results from a struggle with challenging life experiences and loss (Calhoun & Tedeschi, 2001).

Exploration of the lived experience of gratitude has been limited, but the present findings show similarity to experiences of gratitude among patients with spinal cord injury (Chun & Lee, 2013). These similarities may be attributable to both cancer and spinal cord injury involving a major life change that requires treatment and surgery, which results in a change of perspective or increased awareness of what one has. However, the findings of this review differ in some ways from those which emerged from an analysis of the gratitude diary entries of older adults, for whom gratitude was more focused on experiences which related to autonomy, environmental mastery, and

self-acceptance (Killen & Macakskill, 2015). Thus, illnesses such as cancer may affect the experience of gratitude in unique ways.

This review also aimed to critically explore the way in which gratitude and related concepts were presented within the literature. The findings indicate that gratitude has been understood in multiple ways and is referenced using a range of terminology within the cancer literature, as it has been in the wider literature relating to gratitude (see Roberts, 2004; Emmons & McCullough, 2004; Wood, Froh & Geraghty, 2010; McCullough, Tsang & Emmons, 2004; Peterson & Seligman, 2004; Steindl-Rast, 2004). Appreciation was the term most commonly used by researchers and presented within participant quotes, and was used to refer to a range of experiences. This corresponds to a broad definition of appreciation as an acknowledgement of the value of something and experience of a positive connection to it (Adler & Fagley, 2005). Cancer patients' use of the term 'thankful' to express gratitude towards others may also fit with a definition of thankfulness as gratitude in relation to others (Steindl-Rast, 2004) whilst discussion of feelings of gratitude for being alive corresponds to broad definitions of gratitude as 'transpersonal' and experienced generally towards the universe (Steindl-Rast, 2004). None of the studies reviewed aimed to explore gratitude specifically, and gratitude may have emerged as holding different meanings or importance if participants had been asked directly about their experiences of the construct. It is not possible to know the extent to which the findings reflect the lived experience of cancer and the extent to which they are shaped by theories and measures of gratitude. There are criticisms of the extent to which researcher conceptualisations of gratitude fit with layperson conceptualisations (Morgan, Gulliford, & Kristjánsson, 2014) and these considerations point to the need to explore gratitude specifically in cancer.

The findings of this review are shaped by the positions and knowledge of researchers. The majority of studies were conducted in Western cultures, and the interpretation of findings will be shaped by Western ideas of ‘positive change’ and definitions of ‘growth’ (see Matsui & Taku, 2016). Terms relating to gratitude may hold different meanings in different cultures or be used more commonly in some cultures than others (for example, studies reviewed in which the term ‘gratitude’ was used to frame findings were all conducted in North American countries). Gratitude has different meanings in different countries and cultures, with some evidence that gratitude may be experienced as more wholly positive in the US than in other countries such as the UK (Morgan, Gulliford, & Kristjánsson, 2014) and Japan (Kotani, 2002). Thus, future research is needed to explore the meaning of gratitude in cancer for people from different cultural backgrounds. The findings of this review may not translate as well outside Western, particularly Northern American, cultures.

Measures of gratitude have been created based upon the theoretical and empirical study of gratitude (e.g. McCullough, Emmons & Tsang, 2001). These measures have been developed for general use, and so it is important to consider their fit with the findings of the present review when considering the measurement of gratitude in cancer populations. Appendix G contains a table which maps the review findings onto pre-existing gratitude measures, and indicates that the subthemes ‘Attitude to Life’ and ‘Relationships with Others’ map most clearly onto measures. Religious thankfulness is referenced in the Appreciation Scale (Adler & Fagley, 2005) as part of the subscale ‘Ritual’, suggesting that gratitude to God is part of the way gratitude is demonstrated or displayed. This fits with the results of the present review in which religious

thankfulness was subsumed within wider themes ‘Being Alive’ and ‘Relationships with Others’ because some of the participants who experienced gratitude for experiences in these areas expressed this towards God. These findings indicate that pre-existing measures of gratitude may be used to measure the experience of gratitude in cancer.

### **Strengths and Limitations**

This review offers a useful summary of how cancer patients may experience aspects of gratitude, appreciation and thankfulness, and is valuable for furthering an understanding of the lived experience of cancer. This review also critically explores how concepts and ideas are used by researchers to frame experiences and considers the relationship between lived experience and the interpretation of this experience. At the same time, several limitations should be acknowledged.

The process of reviewing qualitative studies creates what is known as a triple hermeneutic (Weed, 2005) whereby the researcher is interpreting the work of other researchers, who have interpreted the accounts of experiences given by participants, who have in turn offered their interpretations of their experiences. As it is not possible to produce an objective or replicable qualitative review, it is important to increase the trustworthiness of findings through transparency of the processes involved (Bearman & Dawson, 2013). The assessment of methodological quality of the reviewed studies indicated a lack of author discussion of reflexivity (an awareness of the assumptions and biases of the research teams as they collect and analyse data) which indicates overall limitations for the trustworthiness of findings (Lincoln & Guba, 1985). The characteristics of the first author as female, young and UK-based, with limited knowledge about the experience of cancer will have also influenced the synthesis of findings. The first author used a reflective journal to reflect upon personally held

assumptions and values regarding the research and thus mitigate their impact on the review and synthesis.

This review is informed by the application of positive psychology to the lived experience of cancer, with a number of the studies reviewed specifically aiming to explore positive experiences of living with cancer. Research and theory in the field of positive psychology has been subject to criticism on the basis that an exclusive focus on positive experiences may reduce experience to a simplified discussion of the positive alone (Lazarus, 2003). Held (2002) discusses the ‘tyranny of the positive attitude’, questioning whether an assumption that positive experiences are necessary for well-being may place pressure on people to have positive experiences, which may in itself lead to unhappiness. The limitations and potential impact of approaching research from a positive psychology perspective should be remembered, as responses to and experiences of cancer are diverse and for some will not involve a positive narrative (Coyne, Tennen, & Ranchor, 2010). A second, broader wave of thinking in this area considers well-being as the result of a complex interaction between positive and negative experiences and emotions (Lomas & Ivtzan, 2016). This is reflected in the findings of this review, which highlights the experience of both positive changes and challenges for those living with cancer.

As a body of studies, this review is limited by the highly heterogeneous samples included, and offers little information about the experience of any particular group of individuals. The general literature indicates that factors such as gender and living situation may impact on experiences of positive emotions such as gratitude and hope (Kashdan, Mishra, Breen & Froh, 2009; Rustoen & Wiklund, 2000) and factors such as time since diagnosis, treatment received, social support, stage of illness, experiences of surgery, and age may influence the experience of gratitude in cancer. The quality of

demographic information provided by study authors varied, making it difficult to consider the potential impact of these factors and indicating the importance of future research in this area collecting more thorough and comprehensive demographic data to contextualise findings. However, the strength of aggregating findings is that it draws together preliminary evidence of positive experiences across different cancer diagnoses, settings, cultures, stages of illness, and age groups.

### **Implications for Research and Practice**

The findings of this review point to the need for further research in the following areas:

- To directly explore the meaning of the terms gratitude, appreciation and thankfulness for individuals with cancer. Avoiding overreliance on existing conceptualisations of gratitude would render richer information about gratitude for this clinical group and may reveal experiences different to those currently recognised.
- To explore further the different aspects of the lived experience of gratitude in cancer evidenced in this review, for example in the areas of appreciation of life, gratitude in relationships, and religious thankfulness. Within this, future reviews or research could explore spirituality and faith in oncology and the links between these areas and gratitude.
- To explore commonalities and differences between experiences of gratitude in cancer for different illness groups, religious groups, cultural groups, and people at different stages of cancer and different stages in life.
- To consider potential factors which may influence or moderate the experience of gratitude in cancer, whether certain factors increase a person's sense of gratitude, or

whether gratitude occurs across people living with cancer due to the shared experience of living with the diagnosis.

- To explore the relevance of gratitude to the experience of living with other chronic illnesses, as this is likely to vary (see Shields et al., 2015). Within this research the meaning of gratitude for different clinical groups should be considered, as the present review has highlighted that there are many different definitions of this concept and that gratitude can hold different meanings.

Clinically, researchers have begun to conduct studies with cancer patients in which gratitude is measured and the effects of fostering gratitude are evaluated (Ruini & Vescovelli, 2013; Algoe & Stanton, 2012; Otto et al., 2016). This review offers insight into what gratitude means and how it is experienced in cancer, which could affect how intervention studies are designed and evaluated in the future. For example, the finding that people may experience a new appreciation of nature following cancer might mean that increased time outdoors during recovery, rooms with countryside or sea views, or involvement in activities such as growing plants or mindful observation of nature could build on and add to positive changes and experiences relating to gratitude and well-being. Alternatively, highlighting the role played by appreciation and gratitude towards others for care and support could inform the implementation of relationship-focused interventions such as writing gratitude letters to others in the context of living with cancer.

## **Conclusions**

The present review offers new insight into the experience of gratitude for people living with cancer, and explores the way in which these experiences are framed in the



literature. Future research is needed to directly explore the meaning and experience of gratitude in cancer and in other long-term illnesses, to avoid over-reliance on existing conceptualisations of gratitude. Increased knowledge in these areas will inform the future development of gratitude interventions.

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## **Part Two: Empirical Paper**

**What Does Gratitude Mean for People Living with Dementia, and how is it Experienced?**

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This paper is written in the format ready for submission to the journal

*Dementia*

Please see Appendix H for the instructions for contributors

**Word count:** 6,293 (excluding references & tables)

## **Abstract**

Supporting people to live well with dementia is an international government priority. Further research is needed to explore positive experiences and strengths in dementia that can be fostered to support well-being. There is existing empirical evidence of the benefits of gratitude in different clinical groups, but no studies to date have explored how gratitude is experienced by people living with dementia. Eight participants with dementia shared their experiences of gratitude through interviews and diaries, and data were analysed using Interpretative Phenomenological Analysis. The findings indicate that gratitude holds interpersonal and wider meanings for people living with dementia, balanced with the challenges of dementia and ageing. This study offers insight into the existence and relevance of gratitude for people living with dementia, and highlights the importance of using multiple methods in dementia research. Positive psychology interventions informed by these findings may be effective in supporting well-being for this group.

**Keywords:** dementia, diary, gratitude, positive psychology

## Introduction

There is increasing recognition that people living with dementia are individuals who attempt to sustain hope and spirituality (Wolverson, Clarke & Moniz-Cook, 2010; Dalby, Sperlinger & Boddington, 2012) maintain meaningful relationships (Harris, 2013) and draw on their strengths in living with dementia, the experience of which may in itself lead to a sense of personal growth (Wolverson, Clarke & Moniz-Cook, 2016). It is important to further our understanding of positive experiences in dementia in order to continue the development of psychosocial interventions that can help people to live well (Moniz-Cook, Vernooij-Dassen, Woods, Orrell, & Interdem Network, 2011; Department of Health, 2009).

Positive psychology, the science of positive traits and experiences (Seligman & Csikszentmihalyi, 2000) provides one framework through which we might study the strengths that enable people to flourish and lead fulfilling lives. Researchers have begun to investigate the role of positive emotions in living well, exploring the links between specific positive emotions and well-being and the effects of fostering emotions such as gratitude (Sin & Lyubomirsky, 2009). Gratitude is defined in many different ways: as a positive emotion involving a benefactor and a beneficiary, as a trait, a character strength, or as a celebration of any person, activity, event, situation or state that is considered to be free or undeserved (Emmons & McCullough, 2004; Roberts, 2004; Wood, Froh & Geraghty, 2010; Peterson and Seligman, 2004; Steindl-Rast, 2004).

Existing research indicates a link between gratitude and well-being, with gratitude and thankfulness related to lower levels of stress and depression, increased life satisfaction

and improved physical health, among other outcomes (Wood, Froh & Geraghty, 2010). There is also evidence that gratitude has positive effects on relationships for both the benefactor and beneficiary (Lambert, Clark, Durtschi, Fincham & Graham, 2010; Algoe, Haidt & Gable, 2008; Algoe, Gable & Maisel, 2010; Bartlett, Condon, Cruz, Baumann, & Desteno, 2012). Interventions to foster gratitude have been developed, and these involve keeping gratitude diaries and writing letters of thanks (Seligman, Steen, Park & Peterson, 2005). Research with both clinical and non-clinical populations indicates that gratitude interventions increase well-being on a range of measures including happiness, life satisfaction, optimism, perceived stress and depressive symptoms (Chan, 2013; Cheng, Tsui & Lam, 2015; Froh, Sefick & Emmons, 2008; Kerr, O'Donovan & Pepping, 2014; Sergeant & Mongrain, 2011; Watkins, Uher & Pichinevsky, 2015).

Gratitude has been found to correlate with the degree of post-traumatic growth reported (Peterson, Park, Pole, D'Andrea & Seligman, 2008) indicating that gratitude may enhance benefits found in an adverse experience, or that gratitude is a product of the struggle with trauma or adversity. A positive association between gratitude and well-being or quality of life has been found in various illness groups including breast cancer (Ruini & Vescovelli, 2013) arthritis, diabetes and chronic obstructive pulmonary disease (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; Horder, 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; Killen & Macaskill, 2015).



To date, there has been no direct study of gratitude in dementia. However, there is serendipitous evidence that gratitude may be a relevant construct in dementia care. A review of the qualitative literature relating to living well with dementia (Wolverson, Clarke & Moniz-Cook, 2016) reported that gratitude and thankfulness were expressed in the accounts of people living with dementia. A review of the positive aspects of caregiving in dementia also indicates that people living with dementia may express or communicate feelings of gratitude to others (Lloyd, Patterson and Muers, 2016) and that mutual appreciation is part of the process of sustaining couplehood for spouses when one person has dementia (Hellstrom, Nolan & Lundh, 2007).

The primary aim of this study was to explore the subjective meaning and experience of gratitude for people living with dementia. The lived experience of chronic illness is likely to differ depending on the particular illness experienced (Sheilds et al., 2015) and dementia has its own identity as a progressive neurodegenerative illness, which may involve threats to personhood such as disempowerment (Kitwood, 1990). Killen and Macaskill (2015) invited older adults to record their experiences of gratitude in diaries, with entries detailing gratitude for a range of experiences including autonomy and environmental mastery. However, these experiences may be threatened by the malignant social psychology surrounding dementia (Kitwood, 1990) and gratitude in dementia may take on different meanings. A thorough understanding of the meaning and functions of gratitude as a concept has implications for both the measurement of outcomes and the design of interventions in dementia care.

The secondary aim of this study was to explore the use of a gratitude diary as a data collection method. This element of the study was considered important for four reasons:

firstly, to directly access the subjective lived experience of gratitude as it occurs. Secondly, to move beyond the data collection methods commonly used in dementia research, and to explore the lesser-used diary method with this group (see Bartlett, 2012). Thirdly, to offer flexibility in data collection, which is particularly important when participants have been experiencing changes in their cognitive functioning and language abilities and may have difficulty articulating themselves at interview (Hubbard, Downs & Tester, 2003). Fourthly, consideration of the usability of a diary method has implications for the application of positive psychology interventions in dementia, which commonly involve creative methods such as diary or letter writing (Seligman, Steen, Park & Peterson, 2005).

In accordance with these aims, this study sought to answer the following research questions:

- 1. What is the meaning and experience of gratitude for people living with dementia?*
- 2. Is a gratitude diary a usable and acceptable data collection method for people living with dementia?*

## **Methods**

### **Design**

This study took a mixed methods design. Qualitative data were collected using semi-structured interviews and diaries to address the primary research question. Quantitative data were collected to address the secondary research question, using Likert scale

questions that explored the acceptability and usability of a diary method for recording experiences of gratitude. Interview data were transcribed by the first author and combined with the written diary data to form case studies, which were then collectively analysed using Interpretive Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). Quantitative data were summarised using descriptive statistics.

## **Sample**

A purposive sampling strategy was adopted to recruit a relatively homogenous participant group, in line with the requirements of IPA methodology (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 (see Appendix I for a copy of the consent form) and felt comfortable answering questions about their experiences of dementia. Participants were excluded if they reported having received a dementia diagnosis before the age of 65, as young-onset dementia may bring with it different experiences to dementia which develops later in life (Green & Kleissen, 2013). Participants were excluded if they reported any intellectual disability, as individuals living with dementia and a learning disability may have qualitatively different experiences (see Kerr, 2007).

The sample consisted of eight participants who self-reported a diagnosis of dementia, in line with guidelines that recommend a sample size of 4-10 participants for IPA doctoral research (Smith, Flowers & Larkin, 2009). They were recruited through community groups linked to the Dementia Engagement and Empowerment Project 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. There were more men (n=5) than women (n=3). 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 6.

**Table 6.** Details of Sample Characteristics.

| <b>Pseudonym</b> | <b>Gender</b> | <b>Type of Dementia</b> | <b>Returned a Gratitude Diary</b> |
|------------------|---------------|-------------------------|-----------------------------------|
| 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                               |

### **Data Collection**

The study was reviewed and approved by the 'North East – York' branch of the NHS Research Ethics Committee (see Appendix J). A copy of the information sheet given to participants can be seen in Appendix K.

All participants took part in an interview conducted by the first author. Interviews were guided by a semi-structured interview schedule, which used open-ended, exploratory questions (see Appendix L). Questions and prompts were used in the areas of: 1) the meaning and definition of gratitude; 2) personal experiences of gratitude; 3) expression of gratitude; 4) gratitude in relation to dementia; 5) barriers to gratitude. Participants were informed that the interviewer was interested in hearing about their experiences of

living with dementia, with a particular interest in what gratitude meant to them and how they experienced gratitude. The schedule was adapted during the process of each interview to best explore the experiences of each individual, and the interviewer focused on asking open-ended questions. Demographic details were collected to contextualise the data using a brief questionnaire (see Appendix M).

Seven interviews were conducted at the homes of participants, and one interview took place in a community support setting. Interviews were audio-recorded and transcribed by the first author. Four participants chose to have their spouse present during the interview, but speech of spouses was excluded from the analysis due to the research focusing on the meaning and experience of gratitude for people who are living with dementia. The mean length of interviews was 46 minutes (ranging between 19 and 90 minutes in length).

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; see Appendix N). Seven people agreed to this element of the study. After completing the diary participants were invited to complete a short diary evaluation questionnaire (see Appendix O) based on other studies which have assessed usability (Kerssens et al., 2015) and also existing usability questionnaires including the Usefulness, Satisfaction, and Ease of use questionnaire (USE; Lund, 2001) and the System Usability Scale (SUS; Brooke, 1996). 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 by the researcher to prompt diary

completion. None of the participants requested this support. Six diaries were completed; five were returned to the researcher by post and one was collected in person.

### **Data Analysis**

The data were 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 the examination of lived experiences, with a focus on understanding the experiences within their wider context and exploring individual perspectives before considering the meaning of the data set as a whole (Smith et al., 2009). This approach is well-suited to open, exploratory research questions that aim to explore the meaning of a phenomenon for a group of individuals.

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 to increase familiarity with the data.
2. Line by line examination of each case study, commenting on transcripts using three levels of exploratory analytic coding: content-based, linguistic and conceptual.
3. Identification of patterns and themes in the data for each participant.
4. Beginning to look for commonalities and differences across participant accounts. Generating initial codes when reading the transcripts and making a sheet detailing all of the codes with supporting quotes and evidence.
5. Returning to the original data and refining the codes, exploring and testing out how the codes fit together.
6. 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 researcher (see Appendix P for a worked example of data analysis and Appendix Q for additional quotes supporting themes).

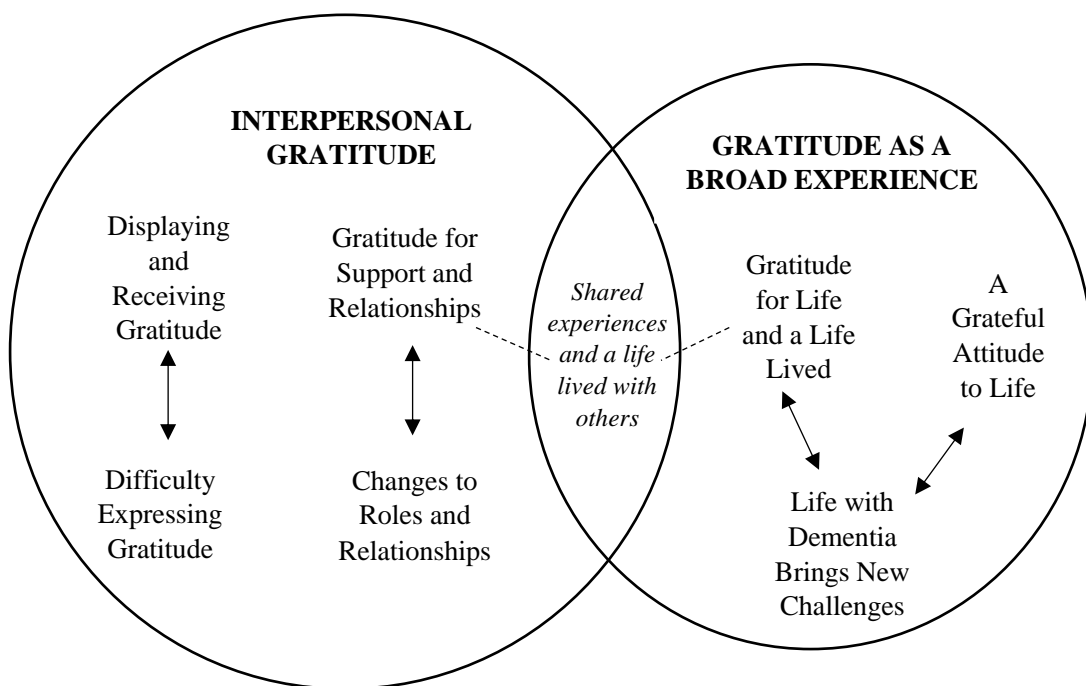
IPA is an interpretative method that involves both participant and researcher in the meaning-making process, with transparency and awareness of one's beliefs as a researcher affecting the understanding of the phenomenon which is reached (Finlay, 2003; Shaw, 2010). During the study, the researcher used a reflective journal to reflect upon personal perceptions of the research (see Appendix R for a reflective statement). The researcher had both family experience of dementia and experience of employment supporting those living with dementia at the end of life. These experiences encompassed both the difficulties of living with dementia and positive moments. As such, the researcher held a belief that dementia brings many changes and challenges for individuals and families, but that it is possible to live well with dementia, enjoying experiences and exhibiting strengths.

## **Results**

### **The Meaning and Experience of Gratitude**

Gratitude was experienced by all participants, with examples of gratitude discussed at interview and recorded in diaries. Two superordinate themes and seven subthemes emerged from accounts and are displayed diagrammatically in Figure 2. The results indicate two overarching aspects of gratitude – gratitude that was experienced and demonstrated interpersonally, and a sense of gratitude linked to the wider experience of life and demonstrated through a grateful attitude. The existence and importance of the two gratitude domains varied in the accounts of participants. Most participants focused

on the interpersonal experience of gratitude, and one explicitly stated that beyond the support of others she had *'nothing to be grateful for'* (Dorothy). The two gratitude domains are presented as overlapping, as discussions of gratitude for life and a life lived included experiences shared with significant others. These experiences of gratitude were balanced with challenges raised by the experience of living with dementia and the process of ageing. Arrows are used in the diagram below to represent this balance.



**Figure 2.** 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 balanced against the difficulties of changed and changing relationships and challenges to the expression of gratitude. Four participants took part in interviews with their spouses present, and some participants spoke in terms of *'we'* or *'us'* when asked about their individual



experiences, supporting the notion that gratitude is primarily experienced in an interpersonal context.

### **Gratitude for Support and Relationships**

Gratitude for support and relationships emerged as the dominant subtheme of the study, discussed at length within interviews and diary entries and assigned explicit importance by participants. Gratitude was defined as being thankful for 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 growth in their experience of gratitude, 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). Lilian and Robert shared their concerns for those living on their own with dementia, and 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' abilities to keep going were 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 an increased sense of dependence on others and a decreased sense of autonomy, which posed challenges for the experience of gratitude and may be perpetuated by a sense that one is 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'* to others. This was also evident in his use of passive language, which conveyed a sense of powerlessness as he spoke of the possibility of 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 threatened 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. In spite of expressing gratitude towards those in the community who offered support, it was difficult for her to draw together her current experience of life and the concept of gratitude.

*'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 balanced their experiences of gratitude for others with the difficulties brought about by decreased independence and autonomy, and the loss of close relationships.

### **Displaying and Receiving Gratitude**

In addition to the felt sense of gratitude experienced internally, many participants communicated and displayed gratitude to others through words and actions. For some, displaying gratitude was straightforward, with Dorothy describing the expression of gratitude through hugs as *'just natural'* and Robert saying he would *'just thank them...that's it. No difficulty about it'*. Thomas identified displaying his gratitude as an important part of 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 also received gratitude 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). Participants discussed ways in which they gave back to others through mentoring, taking part in research, and raising awareness of dementia, 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 their gratitude was displayed 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 which would equal the help offered 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, and for Harry, frontal lobe 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 BROAD 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 triggered by dementia.

## **A Grateful Attitude to Life**

Gratitude was described as a natural and innate part of life and as such, participants often found it difficult to articulate and define:

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

Gratitude was described at times as part of a general attitude to life that would continue 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 their gratitude to be alive and engaging with activities and interests. Harry shared his gratitude for *'treats'* and *'entertainment'*, Lilian expressed gratitude for her ability to continue cooking and singing, and Anne expressed gratitude for walks *'in the fresh air'* and for *'drumming'*. Diary entries of *'waking up'* and *'another day'* indicated that for James, simply being alive from day to day 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 do:

*'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 New Challenges**

Whilst participants shared the importance of carrying on and engaging with life, the experience of living with dementia raised difficulties and challenges. Three participants explicitly 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*' on which she found gratitude more difficult. The use of the language '*have to*' and '*got to*' indicated that participants felt it a necessity to accept their situation and continue.

Though participants spoke of their gratitude for activities and experiences in their daily lives, they were aware that the opportunities and abilities 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 and good fortune helped participants maintain a positive outlook and keep going in the knowledge that things could be worse and were likely to get worse in the future:

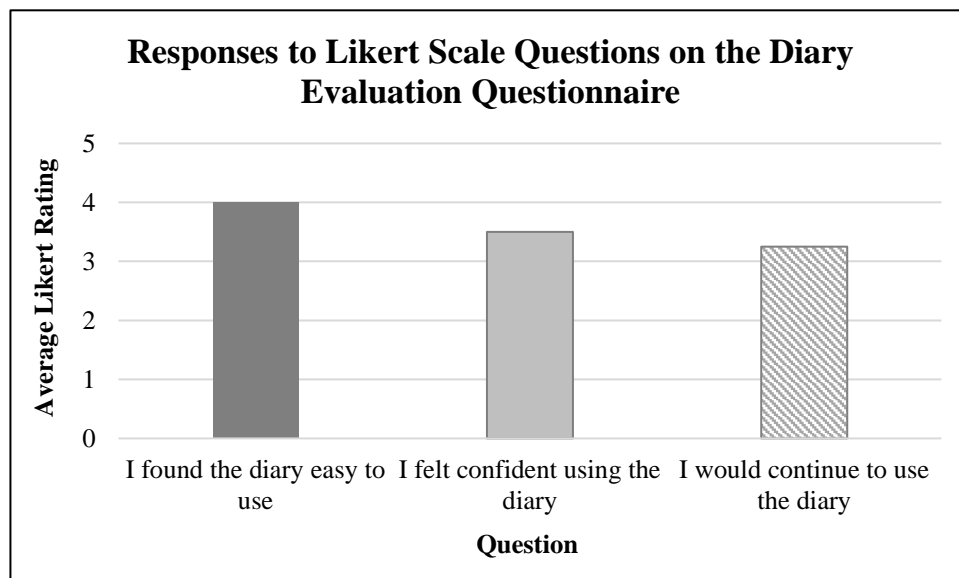
*‘Knowing that there’s other people that’s worse off than me that haven’t got family around them, and you just appreciate what you’ve got’ (Robert)*

### Use and Acceptability of the Gratitude Diary

Table 7 displays details of diary completion. Figure 3 displays the average responses for the four participants who completed the Diary Evaluation Questionnaire.

**Table 7.** Details of Diary Completion

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



**Figure 3.** A graph displaying average responses from the Diary Evaluation Questionnaire.

### ***Qualitative Feedback***

Three participants reported benefits of 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 in the process. One participant shared that on some days he felt pressured to think of things to write in the diary; 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 changes to the diary; 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 findings of this study indicate that gratitude holds subjective meaning and value for people living with dementia in the community, supporting serendipitous findings of gratitude in the lived experience of dementia (Wolverson, Clarke & Moniz-Cook, 2016; Hellstrom, Nolan & Lundh, 2007). Participant experiences of interpersonal and generalised gratitude were balanced with the progression of dementia, in accordance with 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 in



dementia, which mirrors the impact of individual and social factors on the lived experience of dementia more generally (Kitwood, 1990).

Participant use of diaries to communicate the meaning and experience of gratitude indicates 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 (Wood et al., 2010). These findings also evidence the ability of people with dementia to engage with creative methods of data collection, as previously reported by Bartlett (2012) and thus have implications for the trial of specific gratitude diary interventions in dementia, and the involvement of people living with dementia in wider research which uses methods other than interviews. Engagement with the diary method varied 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 this group.

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 involving a benefactor and a beneficiary (Roberts, 2004). 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). Comparison to other findings indicates that interpersonal experiences of gratitude may be more prevalent for those living with dementia than older adults (Killen & Macaskill, 2015). The experience of gratitude in dementia is likely to be influenced by the meaning dementia holds for roles and

relationships, where one increasingly requires support from others and the balance of relationships may change significantly. The findings of this study indicate that for some, changed roles and abilities and 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). This suggests that a relationship between interpersonal gratitude and indebtedness may exist but is likely to be complex.

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 trait (Wood et al., 2010). The experience of gratitude for a life lived echoes psychosocial theory whereby older adults review their lives, processing and integrating conflicts and experiences, and deciding whether they have achieved their 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 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 not be viewed as being bestowed by others.

The experience of gratitude for daily life may be challenged by a decline in one's abilities and the availability of fewer opportunities to engage in. However, changing abilities may also support a sense of gratitude for moment-by-moment experiences by orienting individuals to their present experience. In this sample, an important process that enabled gratitude for a life living and lived was comparison to others, which resulted in a sense of feeling lucky for what one had experienced in life or was still able to do. 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 through the process of describing oneself as feeling both grateful and lucky, 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 present study suggests that the preservation of felt and expressed gratitude may play a role in a continued sense of self, the possibility of which 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 with others. Within the wider literature, Steindl-Rast (2004) proposes a continuum of gratitude ranging from gratitude experienced towards other people to gratitude towards the universe, whilst 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). The

connection between the emotional display of gratitude and the demonstration of gratitude as an approach to life must also be considered. Research suggests that there may be three levels of gratitude (emotions, moods and traits) which interact (McCullough, Tsang & Emmons, 2004). Future research is required to explore potential relationships between the interpersonal and wider aspects of gratitude found in this study, and to begin to build theories of gratitude in 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 support and interventions based on a positive psychology approach more generally.

### **Limitations**

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 further research exploring the meaning of gratitude in different 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 further explore the relational element of gratitude in relationships 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.

Held (2002) questions whether positive psychology research may result in placing pressure on people to have positive experiences. The aim of this study was not to create a single discourse around how things are experienced, or to create an expectation that people living with dementia should feel grateful for their experiences, but instead to consider a possible alternative discourse to that which is more widely known. In spite of its limitations, this study is the first to explore the meaning and experience of gratitude in dementia and offers a good starting point for considering the implications gratitude may have for this group.

### **Implications**

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. It is important to continue exploring the meaning of reciprocity, as further understanding of this concept in the context of 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 – may build upon gratitude by strengthening relationships, and may support a sense of reciprocation and relational balance. Future research should explore the potential costs associated with fostering gratitude, such as the inadvertent fuelling of feelings of indebtedness (see Wood et al., 2010) and consider why some people experience indebtedness and others do not. Supporting individuals to be involved with research, raise awareness of dementia, and engage with groups (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. Within this study people living with dementia were able and willing to engage with diary based data collection methods, indicating that gratitude diaries could be trialled as an intervention in dementia care for fostering and supporting gratitude. The use of mindfulness exercises based on principles such as savouring the moment (close attending to experiences and positive feelings; Bryant & Veroff, 2007) has already been linked to resilience in older adults (Smith & Hollinger-Smith, 2015) and may support the experience of gratitude for daily life experiences 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.

## **Conclusions**

Overall, the findings of this study indicate that gratitude is a meaningful and multidimensional concept for people living with dementia, the complexity of which should be explored more thoroughly through further research. The results 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. It may also be possible to foster a general sense of gratitude using positive psychology interventions informed by the findings of this study.

## **Declaration of Conflicting Interests**

None Declared.

### **Description of authors' roles**

M. Pearson designed the study, carried out the data collection and analysis, and wrote the paper. C. Clarke and E. Wolverson supervised the data collection and analysis, and assisted in preparing the paper.

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## **Part Three: Appendices**



## **Appendix A: Instructions for Contributors to the ‘International Journal of Applied Positive Psychology’**

Aims and Scope: International Journal of Applied Positive Psychology

The International Journal of Applied Positive Psychology is a peer-reviewed journal devoted to promoting and integrating evidence into practice from the scientific field of positive psychology. The knowledge stemming from positive psychology can be applied across the lifespan in contexts such as health care, education, working life, communities and societies. The journal emphasizes the scientific understanding of flourishing, more specifically, the practical conditions that enhance well-being and flourishing.

The journal is an interdisciplinary forum that involves, amongst others, disciplines of psychology, anthropology, sociology, health sciences, educational sciences, management sciences, philosophy, design, biology, medicine and economics.

We welcome studies that are conducted and reported according to well-accepted guidelines in the research community, such as the CONSORT statement (randomized controlled trials), the PRISMA statement (systematic reviews and meta-analyses), STROBE (observational studies), SRQR (qualitative research) and CARE (case reports).

To prevent publication bias, we encourage the authors to preregister their study before execution, for example in <http://www.controlled-trials.com/> or via the Open Science Framework (<https://osf.io/>). At OSF researchers can register their research design and analysis plan (by ‘freezing’ the page, this page cannot be changed)

Example topics for publication in the *International Journal of Applied Positive Psychology* include:

- *Randomized controlled trials* of positive psychological interventions (PPIs) that go beyond common applications for psychology students or in laboratory settings (e.g. for

chronically diseased groups, elderly, disabled youth, various cultural settings et cetera), and look beyond the overall effects of an intervention (dismantling designs, preference-based trials, adherence studies, moderation and mediation effects)

- Development and evaluation of *innovation* within PPIs or their implementation strategies, including the use of technology, social media and social innovation
- *Pilot studies with process evaluation* (using both quantitative as qualitative methods) to evaluate conditions for successful implementation of PPIs
- *Large-scale implementation studies* to evaluate the systematic implementation of a PPI that was already established to be effective
- *N=1 studies* to evaluate in-depth therapeutic processes, in relation to outcomes, and to study personalisation and an individualized approach while offering a PPI
- The competencies, attitudes and mind-set of *professionals* that are needed to work with positive psychological principles and to apply PPIs with certain target groups
- Assessment of *implementation methods*. Scientific study of methods that promote the uptake of research findings from the field of positive psychology into educational, organizational, clinical, community or policy contexts
- How to imbed research findings from positive psychology into *guidelines and clinical protocols*
- To describe and evaluate the (participatory) *process of development* of a positive psychological intervention, implementation instrument or policy paper
- Research that *connects fundamental positive psychological concepts* (such as well-being, flourishing, resilience, strengths, hope, optimism, positive health, et cetera) to certain target / patient groups or settings
- *Theoretical and ethical questions* that arise in the application of positive psychology research
- *Meta-analyses and/or systematic reviews* of the above mentioned types of studies

## **Instructions for Authors**

### **Manuscript Submission**

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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### **Title Page**

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- A concise and informative title

- The affiliation(s) and address(es) of the author(s)
- The e-mail address, and telephone number(s) of the corresponding author
- If available, the 16-digit ORCID of the author(s)

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**Please provide an abstract of 150 to 250 words.** The abstract should not contain any undefined abbreviations or unspecified references.

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[LaTeX macro package \(zip, 182 kB\)](#)

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Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

## **Acknowledgments**

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

## **REFERENCES**

### **Citation**

Cite references in the text by name and year in parentheses. Some examples:

Negotiation research spans many disciplines (Thompson 1990).

This result was later contradicted by Becker and Seligman (1996).

This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).

## **Reference list**

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

Reference list entries should be alphabetized by the last names of the first author of each work.

### **Journal article**

Harris, M., Karper, E., Stacks, G., Hoffman, D., DeNiro, R., Cruz, P., et al. (2001). Writing labs and the Hollywood connection. *Journal of Film Writing*, 44(3), 213–245.

### **Article by DOI**

Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. *Journal of Molecular Medicine*, doi:10.1007/s001090000086

### **Book**

Calfee, R. C., & Valencia, R. R. (1991). *APA guide to preparing manuscripts for journal publication*. Washington, DC: American Psychological Association.

### **Book chapter**

O'Neil, J. M., & Egan, J. (1992). Men's and women's gender role journeys: Metaphor for healing, transition, and transformation. In B. R. Wainrib (Ed.), *Gender issues across the life cycle* (pp. 107–123). New York: Springer.

### **Online document**

Abou-Allaban, Y., Dell, M. L., Greenberg, W., Lomax, J., Peteet, J., Torres, M., & Cowell, V. (2006). Religious/spiritual commitments and psychiatric practice. Resource document.

American Psychiatric Association.

[http://www.psych.org/edu/other\\_res/lib\\_archives/archives/200604.pdf](http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf). Accessed 25 June 2007.

**Journal names and book titles should be italicized.**

For authors using EndNote, Springer provides an output style that supports the formatting of in-text citations and reference list.

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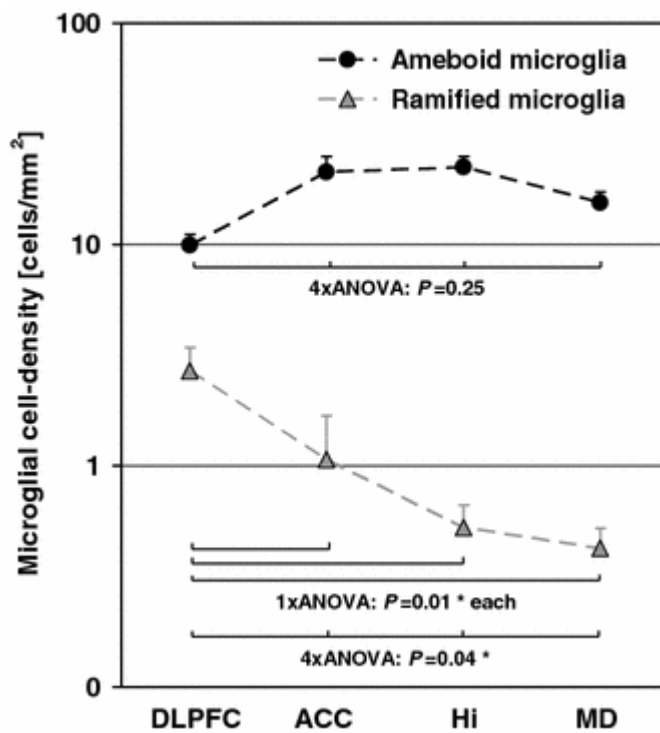
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MOffice files are also acceptable.

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The corresponding author should be prepared to collect documentation of compliance with ethical standards and send if requested during peer review or after publication.

The Editors reserve the right to reject manuscripts that do not comply with the above-mentioned guidelines. The author will be held responsible for false statements or failure to fulfill the above-mentioned guidelines.

## **DISCLOSURE OF POTENTIAL CONFLICTS OF INTEREST**

Authors must disclose all relationships or interests that could influence or bias the work.

Although an author may not feel there are conflicts, disclosure of relationships and interests affords a more transparent process, leading to an accurate and objective assessment of the work.

Awareness of real or perceived conflicts of interests is a perspective to which the readers are entitled and is not meant to imply that a financial relationship with an organization that sponsored the research or compensation for consultancy work is inappropriate. Examples of potential conflicts of interests **that are directly or indirectly related to the research** may include but are not limited to the following:

Research grants from funding agencies (please give the research funder and the grant number)

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- Financial support for attending symposia
- Financial support for educational programs
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- Support from a project sponsor
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In addition, interests that go beyond financial interests and compensation (non-financial interests) that may be important to readers should be disclosed. These may include but are not limited to personal relationships or competing interests directly or indirectly tied to this research, or professional interests or personal beliefs that may influence your research.

The corresponding author collects the conflict of interest disclosure forms from all authors. In author collaborations where formal agreements for representation allow it, it is sufficient for the

corresponding author to sign the disclosure form on behalf of all authors. Examples of forms can be found [here](#):

The corresponding author will include a summary statement **on the title page that is separate from their manuscript**, that reflects what is recorded in the potential conflict of interest disclosure form(s).

See below examples of disclosures:

**Funding:** This study was funded by X (grant number X).

**Conflict of Interest:** Author A has received research grants from Company A. Author B has received a speaker honorarium from Company X and owns stock in Company Y. Author C is a member of committee Z.

If no conflict exists, the authors should state:

Conflict of Interest: The authors declare that they have no conflict of interest.

## **RESEARCH INVOLVING HUMAN PARTICIPANTS AND/OR ANIMALS**

### 1) Statement of human rights

When reporting studies that involve human participants, authors should include a statement that the studies have been approved by the appropriate institutional and/or national research ethics committee and have been performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

If doubt exists whether the research was conducted in accordance with the 1964 Helsinki Declaration or comparable standards, the authors must explain the reasons for their approach, and demonstrate that the independent ethics committee or institutional review board explicitly approved the doubtful aspects of the study.

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**Ethical approval:** “All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.”

For retrospective studies, please add the following sentence:

“For this type of study formal consent is not required.”

## 2) Statement on the welfare of animals

The welfare of animals used for research must be respected. When reporting experiments on animals, authors should indicate whether the international, national, and/or institutional guidelines for the care and use of animals have been followed, and that the studies have been approved by a research ethics committee at the institution or practice at which the studies were conducted (where such a committee exists).

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**Ethical approval:** “All applicable international, national, and/or institutional guidelines for the care and use of animals were followed.”

If applicable (where such a committee exists): “All procedures performed in studies involving animals were in accordance with the ethical standards of the institution or practice at which the studies were conducted.”

If articles do not contain studies with human participants or animals by any of the authors, please select one of the following statements:

“This article does not contain any studies with human participants performed by any of the authors.”

“This article does not contain any studies with animals performed by any of the authors.”

“This article does not contain any studies with human participants or animals performed by any of the authors.”

## **INFORMED CONSENT**

All individuals have individual rights that are not to be infringed. Individual participants in studies have, for example, the right to decide what happens to the (identifiable) personal data gathered, to what they have said during a study or an interview, as well as to any photograph that was taken. Hence it is important that all participants gave their informed consent in writing prior to inclusion in the study. Identifying details (names, dates of birth, identity numbers and other information) of the participants that were studied should not be published in written descriptions, photographs, and genetic profiles unless the information is essential for scientific purposes and the participant (or parent or guardian if the participant is incapable) gave written informed consent for publication. Complete anonymity is difficult to achieve in some cases, and informed consent should be obtained if there is any doubt. For example, masking the eye region in photographs of participants is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic profiles, authors should provide assurance that alterations do not distort scientific meaning.

The following statement should be included:

**Informed consent:** “Informed consent was obtained from all individual participants included in the study.”

If identifying information about participants is available in the article, the following statement should be included:

“Additional informed consent was obtained from all individual participants for whom identifying information is included in this article.”

## **EDITORIAL PROCEDURE**

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This journal follows a double-blind reviewing procedure. Authors are therefore requested to submit:

A blinded manuscript without any author names and affiliations in the text or on the title page. Self-identifying citations and references in the article text should be avoided.

A separate title page, containing title, all author names, affiliations, and the contact information of the corresponding author. Any acknowledgements, disclosures, or funding information should also be included on this page.

### **ENGLISH LANGUAGE SUPPORT**

For editors and reviewers to accurately assess the work presented in your manuscript you need to ensure the English language is of sufficient quality to be understood. If you need help with writing in English you should consider:

Asking a colleague who is a native English speaker to review your manuscript for clarity.

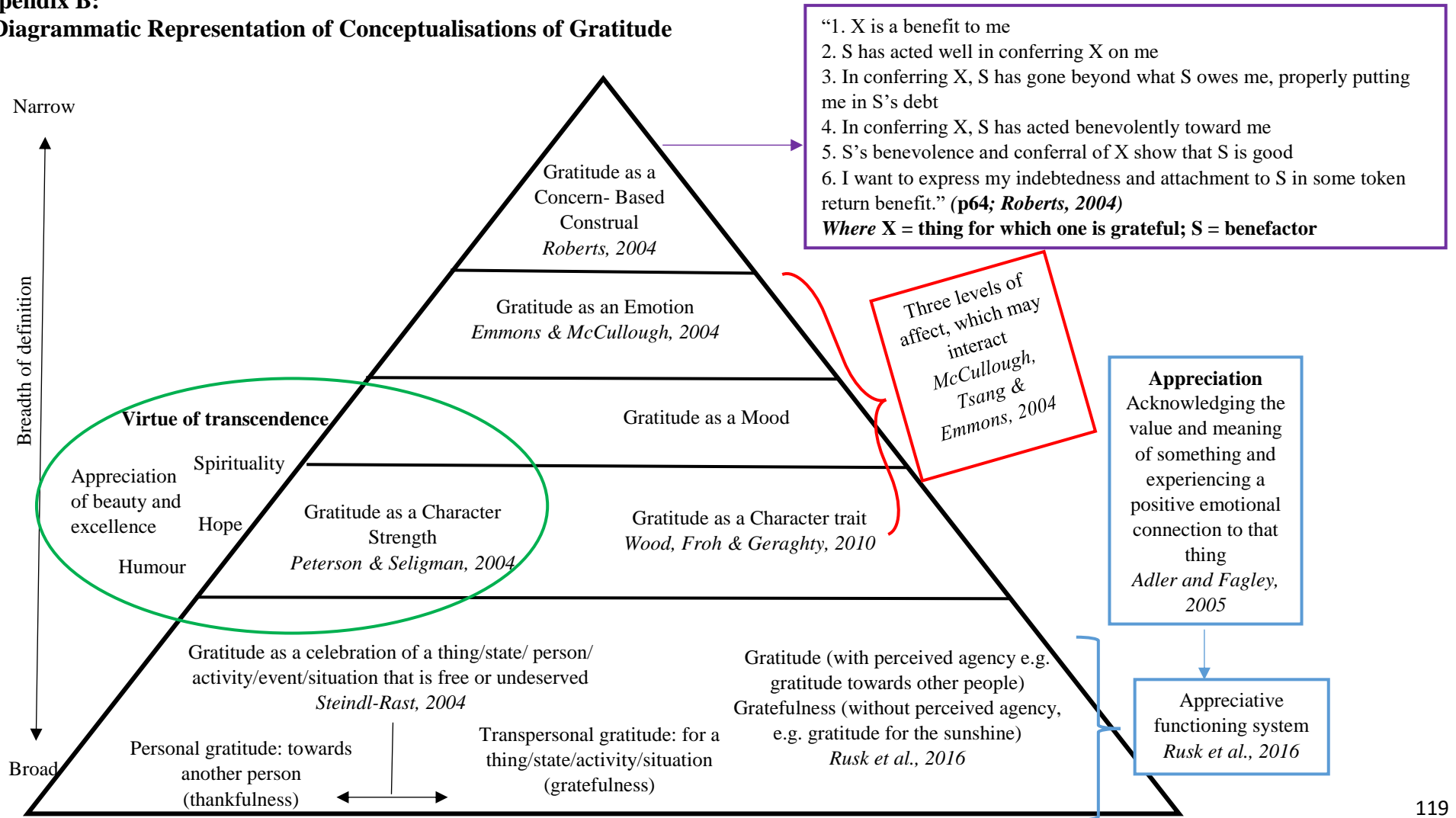
Visiting the English language tutorial which covers the common mistakes when writing in English.

Using a professional language editing service where editors will improve the English to ensure that your meaning is clear and identify problems that require your review. Two such services are provided by our affiliates Nature Research Editing Service and American Journal Experts.

Please note that the use of a language editing service is not a requirement for publication in this journal and does not imply or guarantee that the article will be selected for peer review or accepted.

If your manuscript is accepted it will be checked by our copyeditors for spelling and formal style before publication.

**Appendix B:  
A Diagrammatic Representation of Conceptualisations of Gratitude**





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**Appendix C:**  
**The National Institute for Health and Care Excellence Checklist for Qualitative Studies**

|  |  |                  |
|--|--|------------------|
| <b>Study Identification:</b>   |  |                  |
| <b>Guidance Topic:</b>   | <b>Key Research Question/Aim:</b>  |                  |
| <b>Checklist Completed By:</b> Martha Pearson  |  |                  |
| <b>Section 1: theoretical approach</b>   |  |                  |
| <b>1.1 Is a qualitative approach appropriate?</b><br><i>For example:</i><br>Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings (in healthcare this would apply to how care is organised and patient experiences of care)? Or could a quantitative approach better have addressed the research question? | Appropriate<br><br>Not sure<br><br>Inappropriate                           | <b>Comments:</b> |
| <b>1.2 Is the study clear in what it seeks to do?</b><br><i>For example:</i><br>Is the purpose of the study discussed – aims/objectives/research question(s)? Are the values/assumptions/theory underpinning the purpose of the study discussed?   | Clear<br><br>Mixed<br><br>Unclear  | <b>Comments:</b> |
| <b>Section 2: study design</b>   |  |                  |
| <b>2.1 How defensible/rigorous is the research design/methodology?</b><br><i>For example:</i><br>Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used?  | Defensible<br><br>Not defensible<br><br>Not sure                           | <b>Comments:</b> |
| <b>Section 3: data collection</b>  |  |                  |
| <b>3.1 How well was the data collection carried out?</b><br><i>For example:</i><br>Are the data collection methods clearly described? Were the data collected appropriate to address the research question?  | Appropriate<br><br>Inappropriate<br><br>Not sure/<br>inadequately reported | <b>Comments:</b> |
| <b>Section 4: validity</b>   |  |                  |
| <b>4.1 Is the context clearly described?</b><br><i>For example:</i><br>Are the characteristics of the participants and settings clearly defined? Were observations made in a variety of circumstances and from a range of respondents?   | Clear<br><br>Unclear<br><br>Not sure                                       | <b>Comments:</b> |

|  |   |                  |
|--|---|------------------|
| Was context bias considered (that is, did the authors consider the influence of the setting where the study took place)?   |   |                  |
| <b>4.2 Were the methods reliable?</b><br><i>For example:</i><br>Were data collected by more than one method?<br>Were other studies considered with discussion about similar/different results?   | Reliable<br><br>Unreliable<br><br>Not sure              | <b>Comments:</b> |
| Section 5: analysis  |   |                  |
| <b>5.1 Are the data 'rich'?</b><br><i>For example:</i><br>How well are the contexts of the data described?<br>Has the diversity of perspective and content been explored? Has the detail of the data that were collected been demonstrated? Are responses compared and contrasted across groups/sites?   | Rich<br><br>Poor<br><br>Not sure/not reported           | <b>Comments:</b> |
| <b>5.2 Is the analysis reliable?</b><br><i>For example:</i><br>Did more than one researcher theme and code transcripts/data?<br>If so, how were differences resolved? Were negative/discrepant results addressed or ignored?<br>Is it clear how the themes and concepts were derived from the data?  | Reliable<br><br>Unreliable<br><br>Not sure/not reported | <b>Comments:</b> |
| <b>5.3 Are the findings convincing?</b><br><i>For example:</i><br>Are the findings clearly presented? Are the findings internally coherent (that is, are the results credible in relation to the study question)? Are extracts from the original data included (for example, direct quotes from participants)? Are the data appropriately referenced so that the sources of the extracts can be identified? Is the reporting clear and coherent? | Convincing<br><br>Not convincing<br><br>Not sure        | <b>Comments:</b> |
| <b>5.4 Are the conclusions adequate?</b><br><i>For example:</i><br>How clear are the links between data, interpretation and conclusions? Are the conclusions plausible and coherent? Have alternative explanations been explored and discounted? Are the implications of the research clearly defined? Is there adequate discussion of any limitations encountered?  | Adequate<br><br>Inadequate<br><br>Not sure              | <b>Comments:</b> |
| Section 6: ethics  |   |                  |
| <b>6.1 Was the study approved by an ethics committee?</b>  | Yes<br>No<br>Not sure/not reported                      | <b>Comments:</b> |

|  |  |                         |
|--|--|-------------------------|
| <p><b>6.2 Is the role of the researcher clearly described?</b><br/> <i>For example:</i><br/>         Has the relationship between the researcher and the participants been adequately described?<br/>         Is how the research was explained and presented to the participants described?</p> | <p>Clear</p> <p>Not clear</p> <p>Not sure/not reported</p> | <p><b>Comments:</b></p> |
| <p><b>Section 7: Overall Assessment</b></p>  |  |                         |
| <p>As far as can be ascertained from the paper, how well was the study conducted (see guidance notes)</p>  | <p>++</p> <p>+</p> <p>-</p>                                | <p><b>Comments</b></p>  |

**Appendix D:  
Data Extraction Form**

|   |  |
|---|--|
| <b>Title, Author, Date and Location</b>     |  |
| <b>Relevant Aims</b>                        |  |
| <b>Sample</b>                               |  |
| <b>Design and Methodological Approach</b>   |  |
| <b>Summary of Relevant Findings</b>         |  |
| <b>Author Discussion of Relevant Themes</b> |  |
| <b>Participant Quotes</b>                   |  |

**Appendix E:  
Methodological Quality Summary Table**

| <b>Study</b>          | <b>Theoretical Approach and Aims</b> | <b>Study Design</b>                | <b>Data Collection</b>         | <b>Validity and Reliability</b>   | <b>Richness of Data and Analysis</b>   | <b>Discussion and Conclusions</b>  | <b>Reflexivity</b> | <b>Overall Rating</b> |
|-----------------------|--------------------------------------|------------------------------------|--------------------------------|---|--|--|--------------------|-----------------------|
| Mehrabi et al., 2015  | Appropriate and clear                | Appropriate and defensible         | Appropriate, clearly described | Methods judged to be reliable. Discussion of context bias lacking. Does not explain how researcher differences in analysis were resolved. | Adequate, although researcher discussion of themes could have been more extensive. | Clear and convincing findings, conclusions could have been discussed in more detail. | Lacking            | +                     |
| Cebeci et al., 2012   | Appropriate and clear                | Appropriate, but rationale lacking | Appropriate, clearly described | Clear context description. Methods and analysis judged to be reliable.  | Good, lots of illustrative quotes.   | Clear and convincing findings, good discussion and conclusions.                      | Lacking            | ++                    |
| Tsuchiya et al., 2013 | Appropriate and clear                | Appropriate, but rationale lacking | Appropriate, clearly described | Clear description of participant characteristics, and general setting, but does not discuss where focus                                   | Adequate   | Convincing and clear findings. Lacking in  | Lacking            | +                     |

|                      |   |                                    |                                    |  |   |   |         |    |
|----------------------|---|------------------------------------|------------------------------------|--|---|---|---------|----|
|                      |   |                                    |                                    | groups took place. Methods and analysis judged to be reliable.   |   | discussion of conclusions and practice implications.  |         |    |
| Prince-Paul, 2008    | Appropriate and clear                                     | Appropriate and defensible         | Appropriate and clearly described. | Clear context description. Methods and analysis judged to be reliable.   | Very good, lots of participant quotes and in-depth discussion of these.   | Convincing, clear findings and good discussion of these.  | Good    | ++ |
| Cheng et al., 2013   | Appropriate approach but discussion of aims lacks clarity | Appropriate and defensible         | Appropriate and clearly described  | Clear context description, methods judged to be reliable, and give detail of the processes used to ensure reliability of analysis but don't explain how differences were resolved. | Very Good. Lots of contextual information is provided, participant quotes are used and themes are discussed in depth. | Convincing and clearly presented findings. Plausible conclusions and limitations, and implications are discussed. | Lacking | ++ |
| Davidge et al., 2010 | Appropriate approach but background                       | Appropriate, but rationale lacking | Appropriate and clearly described  | There is some contextual information but this could be discussed in greater  | Adequate. Quotes are provided but author discussion   | Convincing and clear findings.  | Lacking | +  |

|                       |   |   |                                    |  |   |  |         |    |
|-----------------------|---|---|------------------------------------|--|---|--|---------|----|
|                       | literature could be discussed in greater depth. |   |                                    | depth. Methods and analysis judged to be reliable.   | of quotes and themes is limited.  | Discussion of limitations is lacking.  |         |    |
| Semple & McCance 2010 | Appropriate and clear                           | Appropriate and defensible                                | Appropriate and clearly described  | Clear context description. Methods and analysis judged to be reliable.   | Very good   | Convincing and clear findings. A good discussion section with extensive discussion of limitations. | Lacking | ++ |
| Ang et al., 2016      | Appropriate and clear                           | Appropriate, but rationale is lacking                     | Appropriate and clearly described  | Clear context description. Methods and analysis judged to be reliable.   | Good, provision of lengthy quotes, discuss each theme in some depth.                  | Convincing, clear findings.  | Lacking | +  |
| Davies et al 2016     | Appropriate and clear                           | Appropriate, but rationale for analytic method is lacking | Appropriate and clearly described. | Provide sample characteristics but could give further consideration to the influence of the setting. Methods and analysis judged to be reliable. | Adequate, some themes are discussed in limited depth by authors and quotes are brief. | Convincing, clear findings. Discuss limitations and  | Good    | +  |



|                    |                       |  |  |  |  |  |         |    |
|--------------------|-----------------------|--|--|--|--|--|---------|----|
|                    |                       |  |  |  |  | implications for practice.   |         |    |
| Munoz et al., 2016 | Appropriate and clear | Appropriate and defensible although rationale for analysis method could be given in greater depth. | Appropriate and clearly described, although face to face interviews may have elicited richer data than telephone interviews. | Clear context description. Methods and analysis judged to be reliable. | Provide lots of quotes, describe the context and explore diverse perspectives, but researcher discussion of the raw data is limited. | Convincing, clear findings, and discussion section is good.                                      | Lacking | +  |
| Nund et al., 2014  | Appropriate and clear | Appropriate and defensible   | Appropriate and clearly described.   | Clear context description. Methods and analysis judged to be reliable. | Very Good. Provide lots of quotes of varying lengths. Explore differences in perspective within themes.                              | Convincing, clear findings and discuss limitations, implications and complexity of the findings. | Lacking | ++ |

|                      |                       |  |  |  |  |   |         |    |
|----------------------|-----------------------|--|--|--|--|---|---------|----|
| Lin, 2008            | Appropriate and clear | Appropriate, but rationale for sampling and analysis is lacking              | Appropriate and clearly described.                                 | Clear context description. Methods and analysis judged to be reliable.             | Adequate. Although long quotes are provided, some themes are not supported by quotes.    | Convincing, clear findings. Plausible conclusions and discussion is good. | Lacking | +  |
| Lacey, 2002          | Appropriate and clear | Appropriate and defensible, though rationale for sampling method is lacking. | Appropriate and clearly described, including how data were stored. | Clear context description. Methods and analysis judged to be reliable.             | Good, lots of quotes provided.   | Convincing, clear findings. Discussion is good.                           | Lacking | ++ |
| Bulkley et al., 2013 | Appropriate and clear | Appropriate, although the methodology is presented in depth elsewhere.       | Clearly described and appropriate.                                 | Clear context description, methods and analysis judged to be reliable.             | Good, numerous quotes provided, although authors could discuss themes at greater length. | Clear and convincing findings. Comprehensive discussion section.          | Lacking | ++ |
| Clemmens, Knafl,     | Appropriate and clear | Appropriate and defensible   | Clearly described  | Describe participants, and discuss possible limitations of the sample. Methods and | Very Good  | Clear and convincing findings.  | Lacking | ++ |

|                        |                       |                                    |                                    |   |   |  |         |   |
|------------------------|-----------------------|------------------------------------|------------------------------------|---|---|--|---------|---|
| Lev & McCorkle, 2008   |                       |                                    | and appropriate.                   | analysis judged to be reliable.   |   | Good discussion section, though discussion of limitations and implications could be more detailed.   |         |   |
| Kucukaya, 2010         | Appropriate and clear | Defensible, but rationale lacking. | Clearly described and appropriate. | Clear context description. Methods and analysis judged to be reliable.  | Adequate. Contains some illustrative quotes but not for every subtheme. | Clear and convincing findings. Good discussion section.  | Lacking | + |
| Komura & Hegarty, 2006 | Appropriate and clear | Appropriate, but rationale lacking | Clearly described and appropriate  | Context description is lacking. Demographic details are only provided for a subset of the sample. Methods judged to be reliable. The description of the process of analysis is lacking. | Very Good, discuss agreement and disagreement between themes.           | Clear and convincing findings. Good discussion section but lacks clarity concerning the implications | Lacking | + |

|                      |   |  |                                   |   |   |  |         |   |
|----------------------|---|--|-----------------------------------|---|---|--|---------|---|
|                      |   |  |                                   |   |   | of the findings.   |         |   |
| Sinding et al., 2004 | Appropriate approach but discussion of aims lacks clarity | Discuss the rationale for the design, sampling and data collection, but the analytical method used is unclear. | Clearly described and appropriate | The method appears appropriate. The sample is described but context bias is not discussed. Steps taken to increase reliability of analysis are discussed, but the process of analysis is unclear. | Very Good. Provide detailed quotes, give details about context and discuss varied themes. | Convincing findings. Discuss context, limitations and implications, however little consideration is given to the wider literature. | Lacking | + |

**Appendix F:**  
**A summary of the use of gratitude terminology for the themes ‘Experience of Life’ and ‘Relationships and Support’**

| EXPERIENCE OF LIFE: ATTITUDE TO LIFE |   |
|--------------------------------------|---|
| Study                                | Use of Gratitude Terminology in Theme Titles and Quotes   |
| <i>Appreciation</i>                  |   |
| <b>Bulkley et al., 2013</b>          | Appreciate Life More/Second Chance<br>‘Appreciate’ (life)   |
| <b>Cebeci et al., 2012</b>           | Greater Appreciation of Life<br>‘Appreciate’ (the value of being healthy)   |
| <b>Clemmens et al., 2008</b>         | Renewed Appreciation of Life<br>‘Appreciation’ (for life); ‘Appreciate’ (things that didn’t appreciate before); ‘Appreciating’ (everything); ‘Appreciation’ (of life) |
| <b>Komura &amp; Hegarty, 2006</b>    | Greater Appreciation of Health and Life   |
| <b>Kucukkaya, 2010</b>               | Greater Appreciation of Life<br>Increased Appreciation of Personal Worth  |
| <b>Mehrabi et al. 2015</b>           | Appreciation of Life<br>‘Appreciate’ (value of health)  |
| <b>Munoz et al., 2016</b>            | Appreciation for Life   |
| <b>Semple &amp; McCance, 2010</b>    | Appreciation of Life  |
| <b>Tsuchiya et al., 2013</b>         | Increased Appreciation of Life (Appreciation of Family and Friends; Appreciation of Nature)   |
| <b>Lin, 2008</b>                     | ‘Appreciate’ (healthy bodies)   |
| <i>Gratitude</i>                     |   |
| <b>Prince-Paul, 2008</b>             | Gratitude   |

| EXPERIENCE OF LIFE: BEING ALIVE   |  |
|-----------------------------------|--|
| Study                             | Use of Gratitude Terminology in Theme Titles and Quotes                                      |
| <i>Appreciation</i>               |  |
| <b>Bulkley et al., 2013</b>       | Appreciate Life More/Second Chance   |
| <b>Cebeci et al., 2012</b>        | Greater Appreciation of Life   |
| <b>Kucukkaya, 2010</b>            | Greater Appreciation of Life<br>'Appreciate' (every second of being alive) (Kucukkaya, 2010) |
| <b>Mehrabi et al. 2015</b>        | Appreciation of Life   |
| <i>Gratitude</i>                  |  |
| <b>Davidge et al., 2010</b>       | Patients' gratitude to be alive  |
| <b>Davies et al., 2016</b>        | Gratitude  |
| <b>Prince-Paul, 2008</b>          | Gratitude<br>'Grateful' (to survive); 'Grateful' (to be alive)                               |
| <i>Thankfulness</i>               |  |
| <b>Bulkley et al., 2013</b>       | 'Thank' (God to be alive)  |
| <b>Mehrabi et al., 2015</b>       | Spiritual Prosperity (Thanksgiving)<br>'Thank' (God for survival)                            |
| <b>Prince-Paul, 2008</b>          | 'Thankful' (for years on Earth)  |
| RELATIONSHIPS AND SUPPORT         |  |
| Study                             | Use of Gratitude Terminology in Theme Titles and Quotes                                      |
| <i>Appreciation</i>               |  |
| <b>Ang et al., 2016</b>           | Appreciating the Transition Care   |
| <b>Cheng et al., 2013</b>         | Appreciating Support from Family and Friends   |
| <b>Komura &amp; Hegarty, 2006</b> | 'Appreciate' (children more)   |
| <b>Lacey, 2002</b>                | Appreciating the Importance of Support from Family and Friends in Decision Makin             |
| <b>Lin, 2008</b>                  | 'Appreciated/appreciate' (wife, sister in law); 'Appreciate' (friends)                       |
| <b>Prince-Paul, 2008</b>          | Appreciate' (what wife is doing)   |
| <b>Tsuchiya et al., 2013</b>      | Subtheme Appreciation of family and friends (Under theme appreciation of life)               |

|                              |   |
|------------------------------|---|
|                              | 'Appreciate' (daughter); 'Appreciated' (friends and their support)  |
| <i>Gratitude</i>             |   |
| <b>Sinding et al., 2004</b>  | Gratitude for Receiving Equitable Care/Readiness to Fight for Equitable Care (Sinding et al., 2004)                           |
| <b>Prince-Paul, 2008</b>     | Gratitude   |
| <i>Thankfulness</i>          |   |
| <b>Prince-Paul, 2008</b>     | 'Thankful' (God has been good, discussing wife) 'Thankful' (for everyone); 'Thank' (mum); 'Thankful' (for each day with wife) |
| <b>Tsuchiya et al., 2013</b> | 'Thanks' (to the support of those around); 'Thankful' (for support from family and friends)                                   |
| <b>Bulkley et al., 2013</b>  | 'Thank' (the researchers)   |

**Appendix G:**  
**A table illustrating the links between review findings and measures of gratitude**

| <b>Review Theme</b>       | <b>Related Measure(s)</b>  | <b>Example Item</b>   |
|---------------------------|--|---|
| Attitude to Life          | AS – “ <i>Have</i> ” Focus<br><br><i>Awe</i><br><br><i>Present Moment</i><br><br>GRAT – <i>Simple Appreciation</i><br><br>GQ-6<br><br>PTGI – <i>Appreciation of Life</i> | I really notice and acknowledge the good things I get in life.<br><br>When I see natural beauty like Niagara Falls, I feel like a child who is awestruck.<br><br>I recognize and acknowledge the positive value and meaning of events in my life.<br><br>I think that it’s important to “Stop and smell the roses.”<br><br>I have so much in life to be thankful for.<br><br>I changed my priorities about what is important in life. |
| Being Alive               | AS – <i>Awe</i><br><br>GRAT  | I reflect on how lucky I am to be alive.<br><br>Often I think, “What a privilege it is to be alive.”  |
| Relationships with Others | AS – <i>Interpersonal</i><br><br>AS – <i>Gratitude</i><br><br>GRAT – <i>Appreciation for Others</i><br><br>GQ-6  | I reflect on how important my friends are to me.<br><br>I notice the sacrifices that my friends make for me.<br><br>I feel deeply appreciative for the things others have done for me in my life.<br><br>I am grateful to a wide variety of people.   |
| Growth and Challenge      | AS – <i>Loss and Adversity</i>   | Experiences of loss have taught me to value life.   |

**AS = Appreciation Scale (Adler & Fagley, 2005); GRAT = Gratitude Resentment and Appreciation Test (Watkins et al., 2003); GQ-6 = The Gratitude Questionnaire Six-Item Form (McCullough et al., 2002); PTGI = Post Traumatic Growth Inventory (Tedeschi & Calhoun, 1996).**



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## Appendix H:

### Instructions for Contributors to the Journal 'Dementia'

#### Aims and Scope

The aim of the journal is to publish original research, or original scholarship contributions, to the existing literature on social research and dementia. The journal will consider all relevant designs, methods and methodologies that meet this aim. The journal will also consider narrative-based and/or other forms of literature review that seek to answer social research questions in dementia studies; however, such reviews need to have a systematic approach to literature collation and reporting. All original research published in the journal must comply with ethical approval processes.

*Dementia* is hosted on SAGE track; a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Please visit <http://mc.manuscriptcentral.com/dementia> to log in and submit your article online.

All original papers must be submitted to the journal via the online system. The online submission process follows a standard format and contributors will be asked to confirm that all authors have agreed to the submission and that the article is not currently being considered for publication by any other paper-based or electronic journal. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'. We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance [<http://dementivoices.org.uk/resources/deep-guides/>], which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information. Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language [<https://fightdementia.org.au/sites/default/files/NATIONAL/documents/lang...>]. Please

also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Special editions of *Dementia* are commissioned by the journal's Editors and we welcome suggestions for such copy. If you would like to consider being a Guest Editor(s) of *Dementia* and have a topic in mind, please contact prof John Keady ([John.Keady@manchester.ac.uk](mailto:John.Keady@manchester.ac.uk)) and/or prof Penny Harris ([pharris@jcu.edu](mailto:pharris@jcu.edu)) in the first instance.

*Reviews:* Books and educational resources for review / requests to review should be sent to Dr Caroline Swarbrick, School of Nursing, Midwifery and Social Work, Jean McFarlane Building (6<sup>th</sup> floor), The University of Manchester, University Place, Oxford Road, Manchester. M13 9PL, UK (email: [caroline.swarbrick@manchester.ac.uk](mailto:caroline.swarbrick@manchester.ac.uk))

*Innovative Practice:* The journal also welcomes short papers on various aspects of innovative practice in dementia care. Jo Moriarty at King's College London, UK ([jo.moriarty@kcl.ac.uk](mailto:jo.moriarty@kcl.ac.uk)) is the Editor for this section of the journal which is published twice a year. Submissions for Innovative Practice are generally between 750 – 1500 words, but longer papers can be received in exceptional circumstances. Please visit <http://mc.manuscriptcentral.com/dementia> to log in and submit your Innovative Practice article online. This section of the journal is not peer reviewed.

For all other original articles, including literature reviews, *Dementia* operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and the author's name from the reviewer(s). We aim for each manuscript to be reviewed by two reviewers but the Editors reserve the right to return the decision to the author with more, or less, reviews depending upon the context and circumstances of the submitted article. All manuscripts are reviewed as rapidly as possible and correspondence with the main author will be undertaken electronically. All submitting authors should be mindful that their manuscript may be reviewed by a person living with dementia as part of the journal's Editorial Board.

## **Submission Guidelines**

*Dementia* publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

### **1. Peer review policy**

*Dementia* operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

#### **1.1 Authorship**

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

## **2. Article types**

*Dementia* welcomes original research or original contributions to the existing literature on social research and dementia.

*Dementia* also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words.

The journal also publishes book reviews.

## **3. How to submit your manuscript**

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

*Dementia* is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

**IMPORTANT:** If you are a new user, you will first need to create an account. Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the 'Online Help' button at the top right of every screen.

All original papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

**Innovative Practice** papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Jo Moriarty [jo.moriarty@kcl.ac.uk](mailto:jo.moriarty@kcl.ac.uk).

**Books for review** should be sent to: Book Review Editor Dementia, Heather Wilkinson, College of Humanities & Social Science, University of Edinburgh, 55-56 George Square, Edinburgh, EH8 9JU, UK. Email: hwilkins@staffmail.ed.ac.uk

#### **4. Journal contributor's publishing agreement**

Before publication SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. For more information please visit our [Frequently Asked Questions](#) on the SAGE Journal Author Gateway.

*Dementia* and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

##### **4.1 SAGE Choice and Open Access**

If you or your funder wish your article to be freely available online to non subscribers immediately upon publication (gold open access), you can opt for it to be included in *SAGE Choice*, subject to payment of a publication fee. The manuscript submission and peer review procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing *SAGE Choice*. To check journal eligibility and the publication fee, please visit [SAGE Choice](#). For more information on open access options and

compliance at SAGE, including self author archiving deposits (green open access) visit [SAGE Publishing Policies](#) on our Journal Author Gateway.

## **5. Declaration of conflicting interests**

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. It is the policy of *Dementia* to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please include any declaration at the end of your manuscript after any acknowledgements and prior to the references, under a heading 'Declaration of Conflicting Interests'. If no declaration is made the following will be printed under this heading in your article: 'None Declared'.

Alternatively, you may wish to state that 'The Author(s) declare(s) that there is no conflict of interest'.

When making a declaration the disclosure information must be specific and include any financial relationship that all authors of the article has with any sponsoring organization and the for-profit interests the organization represents, and with any for-profit product discussed or implied in the text of the article.

Any commercial or financial involvements that might represent an appearance of a conflict of interest need to be additionally disclosed in the covering letter accompanying your article to assist the Editor in evaluating whether sufficient disclosure has been made within the Declaration of Conflicting Interests provided in the article.

Please acknowledge the name(s) of any medical writers who contributed to your article. With multiple authors, please indicate whether contributions were equal, or indicate who contributed what to the article.

For more information please visit the [SAGE Journal Author Gateway](#).

## **6. Other conventions**

### **6.1 Informed consent**

Submitted manuscripts should be arranged according to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals". The full document is available at <http://icmje.org>. When submitting a paper, the author should always make a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work.

Ethical considerations: All research on human subjects must have been approved by the appropriate research body in accordance with national requirements and must conform to the principles embodied in the Declaration of Helsinki (<http://www.wma.net>) as well as to the International Ethical Guidelines for Biomedical Research Involving Human Subjects and the International Guidelines for Ethical Review for Epidemiological Studies (<http://www.cioms.ch>). An appropriate statement about ethical considerations, if applicable, should be included in the methods section of the paper.

### **6.2 Ethics**

When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) or with the Declaration of Helsinki 1975, revised Hong Kong 1989. Do not use patients' names, initials or hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate which guideline/law on the care and use of laboratory animals was followed.

## **7. Acknowledgements**

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.



All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

### **7.1 Funding Acknowledgement**

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), *Dementia* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit [Funding Acknowledgement](#) on the SAGE Journal Author Gateway for funding acknowledgement guidelines.

## **8. Permissions**

Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our [Frequently Asked Questions](#) on the SAGE Journal Author Gateway.

## **9. Manuscript style**

### **9.1 File types**

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC and DOCX. Please also refer to additional guideline on submitting artwork [and supplemental files] below.

### **9.2 Journal Style**

*Dementia* conforms to the SAGE house style.

Lengthy quotations (over 40 words) should be displayed and indented in the text.

*Language and terminology.* Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used.

*Abbreviations.* As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

### **9.3 Reference Style**

*Dementia* adheres to the APA reference style.

### **9.4. Manuscript Preparation**

The text should be double-spaced throughout with generous left and right-hand margins. Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Innovative practice papers should be between 750-1500 words and should include the words 'Innovative Practice' after the title of their article when submitting to the journal.

#### ***9.4.1 Keywords and Abstracts: Helping readers find your article online***

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#). **The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.**

#### ***9.4.2 Corresponding Author Contact details***

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

#### ***9.4.3 Guidelines for submitting artwork, figures and other graphics***

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

#### ***9.4.4 Guidelines for submitting supplemental files***

This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

#### **9.4.5 English Language Editing services**

Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit [English Language Editing Services](#) for further information.

### **10. After acceptance**

#### **10.1 Proofs**

We will email a PDF of the proofs to the corresponding author.

#### **10.2 E-Prints**

SAGE provides authors with access to a PDF of their final article. For further information please visit <http://www.sagepub.co.uk/authors/journal/reprint.sp>.

### **10.3 SAGE Production**

At SAGE we work to the highest production standards. We attach great importance to our quality service levels in copy-editing, typesetting, printing, and online publication (<http://online.sagepub.com/>). We also seek to uphold excellent author relations throughout the publication process.

We value your feedback to ensure we continue to improve our author service levels. On publication all corresponding authors will receive a brief survey questionnaire on your experience of publishing in *Dementia* with SAGE.

### **10.4 OnlineFirst Publication**

*Dementia* offers OnlineFirst, a feature offered through SAGE's electronic journal platform, SAGE Journals Online. It allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be hosted online prior to their inclusion in a final print and online journal issue which significantly reduces the lead time between submission and publication. For more information please visit our [OnlineFirst Fact Sheet](#).

### **11. Further information**

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office at [dem.pra@sagepub.com](mailto:dem.pra@sagepub.com).

## Appendix I: Consent Form

### Consent Form

#### The Meaning and Experience of Gratitude for People Living with Dementia

Name of Researcher: **Martha Pearson**

IRAS ID: 198865

Please initial all boxes

1. I confirm that I have read and I understand the information sheet dated [\[08.08.16\]](#) [\[Version Number 2\]](#) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to the point of data analysis and transcription, without my medical care or legal rights being affected.
  
3. I confirm that direct quotes from the interview may be used in future publications and understand that they will be anonymised.
  
4. I understand that relevant sections of my medical records and data collected during the study may be looked at by responsible individuals from the NHS Trust or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
  
5. I understand that my data will remain confidential, unless the researcher has serious concerns of risk to me or to somebody else, in which case they will be obliged to share this risk with appropriate professionals.
  
6. I would like to be contacted after the study is complete to receive a summary of my interview and the results of the study.

7. I wish to be invited to any events where the study findings are shared.

8. I agree to take part in the interview part of the study and understand that my interview will be audio taped.

---

| Name of Participant | Date | Signature |
|---------------------|------|-----------|
|---------------------|------|-----------|

---

| Name of Person | Date | Signature |
|----------------|------|-----------|
| Taking Consent |      |           |

9. I agree to take part in the diary part of the study.

---

| Name of Participant | Date | Signature |
|---------------------|------|-----------|
|---------------------|------|-----------|

---

| Name of Person | Date | Signature |
|----------------|------|-----------|
| Taking Consent |      |           |

**Appendix J:  
Documentation of Ethical Approval**

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**Appendix K:  
Participant Information Sheet**

**The Meaning and Experience of Gratitude for People Living with Dementia**

**IRAS ID: 198865**

We would like to invite you to take part in our research study which is looking at the meaning and experience of gratitude for people who are living with dementia. Before you decide if you want to participate we would like you to understand why this research is being done. We would also like you to understand what it will involve for you if you decide to participate. You may want to talk this through with other people before you decide if you want to take part. The researcher will also talk through this information with you, and answer any questions you have about the study.

What is the purpose of the study?

Recently, there has been a lot of interest in the concept of gratitude, what gratitude means to people and whether there are any benefits of gratitude. Gratitude is quite a woolly concept and people define it in different ways, although often it is talked about as giving thanks for things and feeling appreciation. Sometimes people experience gratitude towards others, more widely for the life they live, for the world around them, or for the present moment. At present, we know very little about the meaning and experience of gratitude for people living with dementia. This study is looking to understand more about what gratitude means to people living with dementia and how people living with dementia experience gratitude. We hope that this study will help us to understand more about gratitude for people living with dementia, and hopefully help develop and improve how we support people who are living with dementia.

### Why have I been invited?

We have given you this information if you gave us your contact details after seeing a poster or being told about our study. This may have been on a website, or at a local group for people with dementia.

### Do I have to take part?

No, participation is completely voluntary and there is no pressure to take part. If you decide to take part you will be asked to sign a consent form to indicate that you agree to take part. If you change your mind about taking part you can ask to be withdrawn from the study. However, we will not be able to take your data out of the study after the point where the study results are analysed and written up. You do not have to give a reason for withdrawing from the study. Your decision will not affect your medical care or your legal rights.

### What will happen if I decide to take part?

If you agree to take part please leave your contact details with the researcher. You will then be contacted by the researcher to arrange a meeting at a convenient place and time. You will have to answer some short questions about you, for example your gender and your age. Then you will have a conversation with the researcher about your experiences of living with dementia, which will last around 30-60 minutes. The researcher will audiotape the discussion. There are no right or wrong answers and we are only interested in your opinions, your beliefs and your experience of living with dementia.

If it would help you to feel more comfortable, you could invite a relative or friend to be nearby during the discussion. They would not be expected to take part in the interview as it is your experiences that we are interested in.

Following this discussion, you will be invited to keep a diary over the next week where you would record up to three things you have felt grateful for each day. There is no obligation to take part, and you are welcome to participate in the interview only.

If you do not wish to keep a diary you will not be contacted again unless you would like to hear about the results of the study.

If you do wish to take part in the diary part of the study the researcher will help you to find the best way to keep the diary. It doesn't matter if you forget to keep the diary or if you are not able to record three things you feel grateful for. At the end of the week, you will return the diary to the researcher. The researcher will pay for postage for the diary or will arrange to collect it from you in person. If you wish to keep a copy of your diary this could be arranged.

#### What are the possible disadvantages and risks of taking part?

Meeting and talking with the researcher will involve about 90 minutes of your time and this may be inconvenient or tiring for some. Some people may find it difficult or distressing when they talk about their experience of living with dementia because it may bring to mind difficult issues involved in living with dementia. If this happens to you the researcher will support you during your conversation, and help you to gain access to further help from your GP or support services afterwards if needed.

What are the possible benefits of taking part?

We cannot promise that you will have any direct benefits from taking part in the study. However, we hope that taking part will be enjoyable for you. We also hope that the information you provide will help us to understand more about what it is like to live with dementia and to better support people who are living with dementia.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study before the results are analysed and the study is written-up without giving a reason. This will not affect your legal rights.

What if there is a problem?

If you have a concern about the study you can contact the researcher or either of the research supervisors who will do their best to answer your questions.

Will my taking part in this study be kept confidential?

Yes, all the personal information that you provide will be kept strictly confidential and only seen by the researcher.

Any information that could be used to identify you will not be used in the research. If you decide to participate your information will be stored under a code to protect your anonymity. After the research is completed all of the audio recordings and personal information will be destroyed. All other data will be stored securely, and destroyed after 10 years.

**The only time that information cannot be kept confidential** is if you disclose something that suggests that you or someone else is at risk of serious harm. If this happens during the interview the researcher will need to contact the appropriate authorities to ensure that you and other people are kept safe. It is very unlikely that this will happen and the researcher will talk to you about this before contacting anyone.

#### What will happen to the results of the study?

The results of this study will be written up and submitted to The University of Hull as part of a thesis. They may also be submitted to an academic journal for publication. Some direct quotes from your interview may be used in the report, but this **will not** include your name or any information which could identify you.

If you wish, you will be given written feedback about the study findings when the study is completed.

#### Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull. Some relevant sections of data collected during the study which are relevant to taking part in this research may be looked at by responsible individuals from the University of Hull or from regulatory authorities to ensure that appropriate guidance was followed by the researcher.

#### Who has reviewed the study?

The study is reviewed by an independent organisation which is called a Research Ethics Committee. The Research Ethics Committee protects the interest of people who

participate in research. This study has been reviewed by the North East - York Research Ethics Committee and has received a favourable opinion.

What happens now?

If you wish to take part please leave your contact details with the researcher using the form below. The researcher will telephone you to talk through the information with you. If you are still interested in taking part, the researcher will ask a few questions to see if you might be suitable for the study.

If you would like any further information in the meantime, or have any questions or comments, please don't hesitate to contact **Martha Pearson** using the details listed below.

Thank you for taking the time to read this information.

Yours Sincerely,

**Martha Pearson**

**Trainee Clinical Psychologist**

Supervised by

Dr Emma Wolverson

Clinical Psychologist

Dr Chris Clarke

Clinical Psychologist

## **Further information and contact details**

### **Martha Pearson**

The Department of Psychological Health  
and Wellbeing

Aire Building

The University of Hull

Cottingham Road

Hull

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Tel: 07999544922

E-mail: [M.Pearson@2014.hull.ac.uk](mailto:M.Pearson@2014.hull.ac.uk)

### **Dr Emma Wolverson**

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### **Dr Chris Clarke**

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The University of Hull

Cottingham Road

Hull

HU6 7RX

Tel: 0 1482 464106

Email: [C.Clarke@hull.ac.uk](mailto:C.Clarke@hull.ac.uk)

If you are interested in taking part in the study please leave your contact details on the space provided below. You will be contacted by the researcher to arrange a meeting at a convenient place and time.

Name: .....

Address:.....

.....

.....

.....

Telephone Number:

.....

Mobile Phone Number:

.....

Are there any times of the day that you prefer to be contacted?

.....

Do you have any further comments?

.....

.....

Signature:.....Date:.....

**Thank you very much for your interest!**



## **Appendix L: Semi-Structured Interview Schedule**

### ***Introductory Question and Statement:***

People have different experiences of living with dementia. People can find the experience of being diagnosed with dementia, and the changes that dementia brings very upsetting. Some people will also find benefits or positive experiences even in difficult times, and this is something I wanted to talk more about today.

To start, can you tell me what your experience is like of living with dementia on a day to day basis?

For this study, I'm particularly interested in the idea of gratitude – this is quite a woolly concept and people define it in different ways, although often it is talked about as giving thanks for things and feeling appreciation.

- ***Meaning of Gratitude.*** What does gratitude mean to you/how would you define gratitude?

**Prompt:** Where does your sense of gratitude come from? Have you always been like that? How do you feel when you are grateful for things?

- ***Experience of Gratitude.*** Are there things in your life, large or small, that you feel grateful or thankful about? Do you feel grateful?

- If response is that the person does experience gratitude: What do you feel grateful for? **Prompt:** people experience gratitude for different things.

Sometimes people experience gratitude towards others, more widely for the life they live, for the world around them, or for the present moment. Are there people or situations that make you feel grateful?

- If response is that the person does not experience gratitude: Have you experienced gratitude in the past? How/why has this changed? What hinders or prevents your experience of gratitude now?
- ***Expression of Gratitude.*** How do you show that you are grateful?
- ***Gratitude and Dementia.*** Does gratitude relate to your experience of dementia? Has your experience of gratitude changed since you have been living with dementia?
- ***Barriers to Gratitude.*** Are there things that make it difficult for you to feel or practice gratitude? Do you have any ideas about how these barriers could be overcome?

***Thank you they were all the questions I had, any other comments, anything else?***

**Appendix M:  
Demographic Questionnaire**

**The Meaning and Experience of Gratitude for People Living with Dementia**

Name of Researcher: Martha Pearson

Participant number:

I would like to start by asking you some questions about yourself. Do not worry if you are unsure of the answer, just take your best guess or miss the question out.

Some people may experience these questions as being quite personal. Only answer these questions if you feel comfortable doing so.

**1. What is your age in years?**

.....

**2. What is your gender?** Please circle the one that applies to you.

Male / Female / Other

**3. What is your ethnic background?** Please circle the one that applies to you.

- White British
- Other White Background (please specify) .....
- Multiple Ethnic Background (please specify) .....
- Asian
- Asian British
- African/Caribbean
- African British/Caribbean British
- Other Ethnic Group (please specify) .....

**4. How many years have you spent in education?**

.....

**5. Please describe your current occupation or your previous occupation if retired.**

.....

**6. Roughly when were you diagnosed with dementia?**

.....

**7. Do you know what type of dementia you were diagnosed with?**

.....

**8. Are you taking any medication to help with your dementia?**

.....

**9. Do you identify with a religion? If yes, please specify your religion.**

.....

**10. Do you live with anyone?**

.....

**11. Do you receive any support? If yes, please specify the support you receive. Is this paid support?**

.....

**12. How often do you see family or friends? Please circle the option that applies to you.**

- Daily
- At least once a week
- At least once a month
- Less than once a month

Thank you very much for taking the time to answer these questions!

**Appendix N:  
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. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Appendix O: Diary Evaluation Questionnaire

Version Number: 1 Date: 07/04/16

### End of Diary Questionnaire and Comments Section

For questions a-c, please circle the appropriate answer.

**a) I found the diary easy to use**

|                      |          |                               |       |                   |
|----------------------|----------|-------------------------------|-------|-------------------|
| 1                    | 2        | 3                             | 4     | 5                 |
| Strongly<br>Disagree | Disagree | Neither Agree<br>nor Disagree | Agree | Strongly<br>Agree |

**b) I felt confident using the diary**

|                      |          |                               |       |                   |
|----------------------|----------|-------------------------------|-------|-------------------|
| 1                    | 2        | 3                             | 4     | 5                 |
| Strongly<br>Disagree | Disagree | Neither Agree<br>nor Disagree | Agree | Strongly<br>Agree |

**c) I would continue to use this diary to keep track of things I feel grateful for**

|                      |          |                               |       |                   |
|----------------------|----------|-------------------------------|-------|-------------------|
| 1                    | 2        | 3                             | 4     | 5                 |
| Strongly<br>Disagree | Disagree | Neither Agree<br>nor Disagree | Agree | Strongly<br>Agree |

**d) Has using this diary helped or benefited you in any way? If so, how? Please write a comment:** \_\_\_\_\_

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**e) Was there anything that helped you keep the diary, or anything that made it difficult to keep the diary? Please write a comment:** \_\_\_\_\_

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**f) Would you make any changes to the diary or the method of keeping it? Please write a comment:** \_\_\_\_\_

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**g) Other comments:** \_\_\_\_\_

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**Thank you for taking the time to answer these questions.**

**Appendix P:  
Worked Example of Data Analysis**

Worked example of data extract with descriptive coding and interpretative comments. I= Interviewer, P= Participant, S= Spouse of participant.

| <b>Transcript</b>   | <b>Descriptive Codes</b>   | <b>Interpretative Commentary</b>   |
|---|--|--|
| <p><i>I: For this study I'm particularly interested in the idea of gratitude, which is quite a woolly concept and people define it in different ways, although often it's kind of talked about as giving thanks for things, and feeling appreciation-</i></p>                                       |  |  |
| <p><i>P: -Well I-I just, I just appreciate the help that we get. I mean we first got diagnosed and then a lady from (organisation) came and er told us what we could get and wh-what happened and then she put us in touch with er (name) and (name) and then it-it all just came together,</i></p> | <p>Appreciate help<br/><br/>Third person<br/><br/>Support from groups<br/><br/>and organisations</p> | <p>Changes from first to third person – speaking for self and spouse? For self and others with dementia?<br/><br/>Help has been there since diagnosis – continued help<br/><br/>'Just grateful' implies simplicity</p> |

|   |                                 |  |
|---|---------------------------------|--|
| <i>and the help is there that we need, and we're just grateful for it</i> | Needing help<br>Straightforward | Things others do for you – is there a change in reciprocity, what you do for others and they do for you? |
|---|---------------------------------|--|

*I: Mmm*

|  |  |  |
|--|--|--|
| <i>P: it erm, we know that our welfare's been looked after, and you-you just appreciate what people do for ya.</i> | Third person<br>Appreciate things others do for me | Being 'looked after' by others – implications for roles and reciprocity. What does it mean for others to be looking after one's welfare? |
|--|--|--|

*M: Mmm*

|  |   |   |
|--|---|---|
| <i>P: I mean it's just nice to know that there's people there, er for you. I mean I-it was a bit of a shock to have to give up</i> | People being there<br>Giving up driving is hard | 'nice' – linking gratitude and appreciation in with a general sense of positivity<br>Importance of others being there |
|--|---|---|



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*me driving licence of course, I'd already stopped driving,*

*oh it was ten years wasn't it (spouse's name) before that*

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*S: (Inaudible 00.00.02)*

---

*P: It was ten years when I packed up driving before I got*

*diagnosed, so it didn't bother me – well it didn't, b-I mean*

*I'll be honest, it did bother me, 'cause I like driving, but er,*

*I just sent me licence back and told 'em why, and that was*

*it. So now I just take the mickey out of me daughter when*

*she's driving – you can't do this you can't do that (laughs)*

Giving up driving is

hard

Straightforward

Context of having to give up driving (a difficult experience)

Needing to say it wasn't upsetting when it was?

Sense of things being straightforward

Continuing what is lost through family

Use of humour

---

*I: (Laughs)*

---

|   |  |   |
|---|--|---|
| <p><i>P: And that-that's er, that's it r-really it's, we all just appreciate the things that people do for us.</i></p>  | <p>Straightforward<br/>Appreciate things others do<br/>Third person</p>    | <p>'we all' – third person, sense of being part of, and speaking for, a group<br/>things people do for the group</p>  |
| <p><i>I: Yeah, yeah.</i></p>  |  |   |
| <p><i>P: I mean i-if the people weren't there, we'd be lost. Erm alright I-I-I'd still be alright 'cause I mean I'm only just – it's just started in me but erm anybody else they'd just be lost, they wouldn't know what to do. Erm, I mean y-you get a lo-you see a lot of this charity fundraising what have you for diff-different companies and all that and people, and yet you never see anything on the streets about doing</i></p> | <p>Third person<br/>Lost without others<br/>Comparison<br/>Carrying on</p> | <p>Strong sense of needing others – would be lost without them<br/>Me vs them? Comparisons vs togetherness?<br/>Needing more support over time due to changes dementia brings<br/>'blew up' – explosion. Dementia as an explosion?<br/>Implies dementia has a huge impact. This is contrasted</p> |

---

*collections for dementia or anything like that erm until all  
this suddenly blew up and it's the top one now. But, that's  
life, you just get on with it.*

Straightforward

with the phrase 'that's life'. Getting on with life, sense  
of accepting things and moving forwards.  
Straightforward and simple.

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**Appendix Q:  
Additional Quotes in Support of Themes**

| Theme         | Subtheme                     | Supporting Quotes   |
|---------------|------------------------------|---|
| GRATITUDE AS  | <i>Gratitude for Support</i> | <b>Harry:</b> ‘Thankful that the nurses come each day to check my blood sugar levels  |
| INTERPERSONAL | <i>and Relationships</i>     | <p data-bbox="804 608 1144 633">and administer my insulin’</p> <p data-bbox="804 683 1850 932"><b>Lilian:</b> ‘I feel much gratitude to...another one of our grandchildren today, as she came early today &amp; had a good Hoover &amp; dust for us, &amp; now she has gone to do a big shop for us &amp; pick (grandaughter) up from the nursery and taking her to the Hairdressers &amp; then it will be teatime when they arrive home.’</p> <p data-bbox="804 981 1473 1007"><b>James:</b> ‘as I say you get the backing of your family’</p> <p data-bbox="804 1056 1603 1082"><b>Robert:</b> ‘I’m grateful, because of the people that surround me’</p> <p data-bbox="804 1131 1827 1302"><b>Eric:</b> ‘To me it’s you know for the people who’ve been behind me all this time, you know I’m really thankful for them. I mean I’ve had a lot of help, in the churches and you know even the neighbours’</p> |

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**Thomas:** ‘It means being thankful for er, the help that you receive, and I get loads of that from er all me family, erm, I have a bunch of friends’

**Dorothy:** ‘I’m grateful to the people in ‘ere because they have really helped me a lot, and they still k-keep trying to help me you know wharr I mean, I mean they might not succeed but they do. (Laughs) Er, and I can come in here anytime I like, for, if I’m-if I’m, what can I say if I’m down’

**Anne:** ‘I suppose it’s just enjoyable being with other people who...it might not be exactly the same experiences as-as I’ve had but along that road kind of thing’

---

***Changes to Roles and Relationships***

**Harry:** ‘you know I’ve got to think well this has been done for me obviously you- you know and particularly my daughter, you know wants-wants to er wants to do this (offer care and support)’

**Lilian:** ‘You never think anybody has to do anything like that for you because I- you know I’ve always done me own, and now you know you always cut your toenails that way’

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**Robert:** ‘I mean sometimes I feel as though I’m perfectly alright, er, but then of course my wife and daughter and other people see me differently’

**Thomas:** ‘so every day I-I- in some way, I need some help with something, and if I’m, if I’m by meself, then I’ll ask somebody ‘do you mind just helping me with this?’ No problem, I never come across any-any problems, soon as I say I’ve two forms of dementia and I have trouble with doing this can you just help me, and that’s what they do. I don’t have any pride, that goes, that’s disappeared, and y-you’ve just got to erm accept what help you need. That might not be exactly right about pride, but I’m not far off.’

**Dorothy:** ‘I know one of these days I’ll-I’ll end up in a-a home because er I haven’t got nobody to look after me so, I know that’s what’s going to happen.’

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**Displaying and**

**Receiving Gratitude**

**Harry:** ‘I mean like in my situation, they say (eldest daughter) might say something “oh I’ve got you er, er I’ve got a treat for you” sort of thing, and I say ‘oh, thanks very much’

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**Lilian:** ‘I’d give ‘em, give ‘em lots of love and kisses’

**Robert:** ‘when you’re thanking people for what they’ve done for ya, that’s a showing...of the gratefulness surely’

**Thomas:** ‘I suppose we just do a smile an a, an a peck, if it’s th-if it’s the missus, I can’t do that with me mates’

**Dorothy:** ‘-Oh I’ve always given ‘em hugs, th-I mean, they always give me a hug before-when I come in the door, they always give me a hug when I go back out again. Just natural that’

**Anne:** ‘talking to them...every now and again it might be a hug’

---

**Difficulty Expressing**

**Gratitude**

**Harry:** ‘‘I think, I think I can in my particular case I can come over sometimes as erm - erm depending how-h- how I feel but come over quite erm, quite er either a-a bit hard’

**Lilian:** ‘I let ‘em go away sometimes and I haven’t said thank you for this thank you for that you know and that gets to me’

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**Thomas:** ‘there’s quite a number of steps to er contend with, and I don’t do stairs very well, and the crowd help me up. I can start at the bottom, and there’s one or two of ‘em ‘Come on (name), come on’ and they get hold of me and pull me up and what have you, brilliant. Can’t thank ‘em enough.’

**Dorothy:** ‘in one sense, there’s nothing I feel grateful for or thankful for, only for what these people have done for me in this building that’s, that’s you know you can’t then thank them enough, because I continue to keep comin’ ‘ere.’

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**GRATITUDE AS A** *A Grateful Attitude to*

**BROAD** *Life*

**EXPERIENCE**

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**Lilian:** ‘No. No, nothing is there...nothing I don’t feel grateful for’

**James:** ‘Gratitude and thanks for it would be to just carry on life as normal as possible’

**Eric:** ‘I just carry on as I am now...I just carry on as I am, smile and laugh an-and joke, and you know, that shows gratitude with that. I mean if I were going round sour faced and you know grrrr this is a load of rubbish, no, no no no, that’s not right. Wrong attitude.’

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*Interviewer: 'I was just asking about specific times...when you feel thankful for things?'*

**Thomas:** 'All the time (laughs)...there's no specific time, because it's-it's everyday living'

*Interviewer: 'How do you show that you're grateful'*

**Anne:** 'yeah, that's a good question (laughs)'

*Interviewer (laughs)*

**Anne:** 'I don't know, erm, I s'pose it's partly if I go to these meeting wh-where you know all of us, just about have-have some kind of dementia...not necessarily Alzheimer's but erm, and you know they're just a nice bunch of people and you talk about what you've been doing...and erm, yeah don't dwell on...on the fact that you have Alzheimer's or some other you know, disease.'

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***Gratitude for Life and  
a Life Lived***

**Harry:** 'Music – enjoyed singing along to Songs of Praise. Am thankful that music is so uplifting'

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**Lilian:** ‘I felt gratitude again today, because I achieved making some Muffin for (granddaughter) coming home, (husband) and (granddaughter) really enjoyed them’

**James:** ‘being alive and in this world...that’s another big gratitude...another big thing to be grateful for’

**Robert:** ‘seven and a half years in the RAF, er, been married to my good lady there for fifty years...I’ve never been out of work, always had work. I’m grateful for what I’ve had’

**Thomas:** ‘that (upbringing) prepared me to accept what I’ve got now, but always to accept and be thankful for the help that I get, and erm that set me up for life basically’

**Anne:** ‘Despite my diagnosis of having Alzheimer’s I am grateful that I remain active and that I am able to continue my interests and activities’

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*Life with Dementia*

*Brings New*

*Challenges*

*Harry:* ‘one of the things is with-with something like that, the situ-this p-position I’m in-in here, is er, you get very frustrated.’

*Lilian:* ‘Ohhh, I know, that’s awful, when your bike has to go because we went everywhere on bikes didn’t we’

*James:* ‘the only major thing I’ve found at the moment is giving up driving’

*Robert:* ‘I do get frustrated sometimes when I go places and you know people are still driving around, but, I just have to put up with it. I’m getting morbid now’

*Eric:* ‘Ohh it’s a lot different. I mean er I could, I could laugh at things, I could er you know, set things going, I could even organise things, but I can’t organise things very much anymore, you know I’ve got to either ask somebody, or ask my wife or wh-whatever, but I cannot organise anything on my own now’

*Thomas:* ‘It is a major reason why I get upset, is that I can’t do everyday chores, personal to me, as accurately as I used to do, and without thinking. Now you’ve got to think very hard before you do anything, I do. And so erm, of all the things

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that-that gives me the most angst. Erm, I just er get totally cheesed off from time to time.'

**Dorothy:** 'I've got nothing to be th-thankful for in me life, or, for me dementia, or me diabetes or wharrever me complaints. I've got nothing to be thankful for have I?'

**Anne:** 'quite often I get a bit frustrated...if I you know realise I've forgotten something'

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## **Appendix R:**

### **Reflective Statement**

#### ***Where the Study Came From***

The ideas and motivation for this thesis were influenced by my personal experiences. My grandmother lived with dementia for around ten years, and during this time I can remember changes occurring in our family and in our relationships. There were challenges: it was difficult to come to terms with visiting my grandma as she appeared to be more confused, and we lost opportunities to share conversations and communicate using words. However, I feel as though we were very fortunate as a family. My relationship with my grandma changed in the ways in which we interacted, but the essence and spirit of her, and of our interactions, remained. I learned that words and names were not so important, and that we could continue to share moments of joy and love. On a personal level these experiences challenged both a wider view of dementia as a wholly negative experience, and the ideas that a person living with dementia is entirely lost. I am aware that my research journey has also likely been driven in part by a need to find or see positive experiences within life with dementia. Finding that positive experiences, hope, love, joy and gratitude do not exist for individuals living with dementia would force me to connect with the painful idea that somebody I loved very much lived without positive experiences for many years. Keeping a reflective journal and holding discussions in supervision helped with managing these values and assumptions. Returning to the primary data throughout the processes of analysis and write up ensured that the interpretations of findings were grounded in the words of participants.

The original idea for this study was to trial a gratitude diary intervention. Discussions at peer review indicated that this idea was likely to be too ambitious – how could diaries be used as part of a gratitude intervention when evidence of gratitude in dementia was serendipitous, and when diaries have rarely been trialled as a data collection method in dementia let alone used as a means of intervention? I remember feeling deflated following this realisation, but it has taught me the importance of multiple types of research that involve different methodologies and draw on qualitative and quantitative traditions. Qualitative research is very important for exploring constructs and how things are experienced, which can then form a foundation for the evaluation of interventions.

After this reflection, I felt excited about conducting an exploratory study involving analysis of personal accounts of lived experience. The prospect of engaging with people and hearing their stories appealed to me, and it felt important that my research could offer individuals a place to discuss their experiences. It also felt important to include the use of gratitude diaries to explore how they would be experienced as a method of collecting data, with the hope that future studies may explore their use as an intervention technique in dementia. When gratitude research is being conducted with so many other groups of people, this felt like an important aspect of empowerment, inclusivity and involvement. It challenges common assumptions in research that there is no point exploring a topic or trialling a methodology with people living with dementia as it will not be relevant to their experience or will not be feasible due to changing cognitive abilities. In my view we should not assume something will be unhelpful or irrelevant without exploring this first, and I feel strongly about the importance of inclusion as a human need which is sometimes overlooked for people living with dementia.

### *My Experience of the Research*

My overall experience of conducting this research is a very positive one. I have experienced my own feelings of gratitude and thankfulness towards those who have been part of my research journey. I have learned to more regularly take account of my own experiences of gratitude, to savour these and, where they relate to other people, to express them outwardly. I feel honoured to have been welcomed into people's homes and given an insight into their lives. It is touching to have shared moments of emotion, to have listened as people have opened up and shown vulnerability. During the recruitment period I held a community event with a support group to celebrate the American festival of Thanksgiving. The event involved meeting with people living with dementia, family members and volunteers to share experiences of gratitude and thankfulness, to write a poem together, and to share a meal. I enjoyed this day very much and felt moved by the participation of everybody who attended, witnessing moments where spouses shared their gratitude towards one another for their support and years of marriage. For some, perhaps, this is rarely put into words.

This research has also presented me with challenges and barriers. One of the most difficult elements of my research journey was communicating the ideas and rationale behind the study to others. Time spent discussing my research with my supervisors alone had perhaps placed me in a bubble that was burst when I tried to share these ideas more widely. Although I was aware of the dominant negative discourse and assumptions which still prevail in the area of dementia, I had underestimated the power of these. At times it proved difficult to find a route into speaking with people who were living with dementia because an assumption was made by others that the concept I was discussing would not hold relevance for this group. This led me to doubt my research, and experience a sense of naivety and guilt for imposing a positive view on others. I

also felt angry and oppressed, and I wonder if this feeling was being experienced in parallel by the people with whom I was wanting to speak.

Data analysis also raised challenges for me. I was using qualitative research methods for an extended project for the first time, and felt a pressure to perform. I tried reading around how to conduct a 'good' interview and a 'good' analysis, and at times found myself feeling frustrated that there were no clear answers and a million possibilities. I found myself wondering how I was going to get it 'right' if the data I elicited and the analysis I conducted would be unique and affected by my values and assumptions. After reflecting on this I realised that I was being drawn back to the epistemological assumptions underlying a purely quantitative study. I was searching for a truth and felt a pressure to get things right because I wanted to accurately share people's experiences. Instead, I tried letting this go and focused on throwing myself into analysis, which made the process much more enjoyable. It was a challenge to adjust my mind-set and stop trying to judge my qualitative research by the standards I had been taught for the assessment of quantitative research.

### ***The Impact of Me and My Beliefs***

My relationship with the participants of my study changed during the process of this research. At the beginning of recruitment, I held the view that people were opting to take part entirely as an act of kindness, to do me a favour. However as I conducted the interviews, I began to realise that it was important for people to take part in the study for their own reasons: to give back to others, to further dementia research, to raise awareness, and to share their views. People were at least in part motivated by wanting to help me with my work - but now I felt able to also give something in return. I also realised that I had been thinking about people as individuals, focusing on their singular experiences and the individual benefits of gratitude such as improved health. This was



likely influenced by my choice of IPA as a research methodology, focusing on individual experiences and stories. I had underestimated the importance and involvement of others in these experiences, the interpersonal elements of gratitude, and the impact gratitude can have when it is communicated or displayed to others. Due to the focus of the study it was not possible to analyse the contributions to the interviews made by spouses and family members, but this data was very interesting in itself and it felt difficult to set it to one side.

During the analysis of my data I had the opportunity to think carefully about the impact of my choice of questions, my responses to participants and my non-verbal signals on the experiences participants shared with me. The focus of interviews was on positive experiences, but I realised after collecting data that my carefully constructed schedule with a 'positive' focus was underpinned by implicit negative assumptions which may have limited people's experiences. For example, the focus was on asking how people might show gratitude or things people might feel grateful for, with no prompts around times when people might have been on the receiving end of gratitude. On reflection I think I held the assumption that gratitude would either be experienced as an individual general experience, or as a one-sided relational experience.

During the journey of this research, from the first discussion of the ideas through to the writing of the paper, I have learned more about the views and assumptions I hold.

During the process of interviews I became aware that it felt easier to sit and listen to positive experiences, and can be more difficult to connect with the pain and challenges that people share. This becomes more of an issue the more we reject a dehumanizing view of people with dementia, the more we see people with dementia as people, not 'shells', the more we connect and understand that these are human experiences which

any of us could and may experience in our lives. As a result of conducting this research, I will take forward with me the importance of being open to the experiences of others, in their entirety and diversity. The following quote from Wendy Mitchell, a lady living with dementia, reminds me that the way we speak with others and about others, and the way others speak about us impacts our experience and the narrative by which we live.

*'If someone tells you day after day that you're suffering, you end up believing it. It has a negative impact on your wellbeing. The same would happen if you were told day after day that you are stupid—you end up thinking there might be something in it.'* Wendy Mitchell

## **References**

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## **Appendix S:**

### **Epistemological Statement**

Ontology is defined as the study of being and beliefs about the nature of the social world, whilst epistemology refers to the theory of knowledge and how knowledge can be acquired (Ritchie, Lewis, Nicholls & Ormston, 2013). It is important to consider the assumptions and stance adopted by the researcher in relation to the nature of reality and knowledge, as this affects the way in which research is conducted. Epistemology influences methodology (ideas about how research should proceed) methods (the techniques and tools used to carry out the research and collect data, such as purposive sampling or interviews) and the relationship between researcher and participants (Carter and Little, 2007).

The present study took a mixed methods design, which raises questions and controversies when considering the epistemological stance of the researcher. Within the paradigm of positivism, it is assumed that there is a truth to be discovered. This epistemological stance is in accordance with quantitative research, in which variables are carefully manipulated with the aim of measuring concepts systematically by an objective researcher (Ponterotto, 2005; Lincoln & Guba, 1985). In contrast, qualitative research is often assumed to be underpinned by a more interpretivist or social constructionist stance, which entertains multiple possibilities, and within which knowledge is considered to be influenced by context and the nature of social reality and the researcher is considered to play an active part in meaning making (Ponterotto, 2005). Research which adopts this epistemological stance may explore the meaning of a phenomenon through the collection of data relating to lived experience. It has been argued by some that qualitative and quantitative methods take fundamentally different

stances to knowledge, and thus are incompatible (see Knox, 2004). Following this argument, a researcher would have to adopt one epistemological stance and thus only employ either qualitative *or* quantitative research methods.

Contrary to this argument, there is growing support for the notion that quantitative and qualitative research methods inform each other and can be used in combination (Bryman, 1990). In fact, triangulation of multiple methods has more recently been heralded as important for strengthening a study and improving the quality and trustworthiness of research (Mays and Pope, 2000) and it is recognised that the use of multiple methods can complement one another and compensate for the weaknesses of using one method alone (Ponto, 2006; Yardley, 2001). From an epistemological perspective, these two approaches can be drawn together within a pragmatic stance (Tashakkori & Teddlie, 1998) which takes an eclectic approach to choosing an underlying methodology and accompanying methods. In the present study, the researcher took an eclectic and pragmatic approach (Ponto, 2006) using different methodologies and methods based on the research questions at hand.

The first research question to be addressed considers the meaning and experience of gratitude in dementia. Both the context of research around gratitude and the research around dementia led the researcher to approach this research question from a social constructionist stance, in which there are multiple possibilities for experience, and individual experiences are influenced by the social world. Gratitude is a concept which has been widely researched, but the relevance of which had previously gone unconsidered for the participant group at hand. The wider literature for gratitude explores many conceptualisations of gratitude (Emmons & McCullough, 2004)

suggesting that there is no individual ‘truth’ for the meaning of gratitude. Research indicates that the experience of dementia is likely to be diverse and multifaceted, involving a complex interaction between challenges and strengths, and recent research in dementia challenges common assumptions that the experience of living with dementia is dominated by a single, negative narrative (De Boer et al., 2007; Wolverson, Clarke & Moniz-Cook, 2016). As such, it felt appropriate to approach this aspect of the research with the assumption that there is not one truth about the experience of gratitude in dementia and that there may be many possibilities for experience.

Thus, to address the primary research question, a social constructionist epistemological stance was adopted, leading to the choice of qualitative methodology and methods. The aim was to explore the meaning of a phenomenon for a group of individuals, exploring in-depth experience and considering the impact of social context. Thus, the methodology of Interpretative Phenomenological Analysis (IPA) appeared appropriate, as it is concerned with the examination of human lived experiences, with an idiographic focus on understanding the experiences of individuals within their wider context and exploring individual perspectives before considering the meaning of the data set as a whole (Smith et al., 2009). The most commonly adopted data collection method in an IPA study is the semi-structured interview, as it offers rich data relating to participant experiences. The researcher chose to collect both interview and written diary data in the hope of increasing the richness of data, obtaining data from one occasion but also from day-to-day lived experience. The adoption of this stance and methodology could be seen to position the researcher and participants as co-creators of the meaning of the experience of gratitude, via a double hermeneutic (Smith & Osborn, 2008).

Consideration of different research methods led to the choice of IPA as the most

suitable methodology to address the primary research question. However, alternative methodological approaches were also carefully considered before coming to this conclusion. A general method which researchers use with either qualitative or quantitative data is grounded theory, which enables the development of a theory from the data gathered (Glaser & Strauss, 1967). Grounded theory was discounted in this instance because the aim was not to generate a theory around gratitude. There has been no previous exploration of this phenomenon in dementia and no other data relating to gratitude was available beyond serendipitous qualitative data. Therefore, it was judged inappropriate to try to generate a theory. Another potential choice was thematic analysis, which identifies, analyses and reports patterns across data (Braun & Clarke, 2006). However, this option was discounted due to the aim of analysis to generate a description of data, whereas the present study was interested in an in-depth exploration of experience.

The second research question asked whether diaries could be used within dementia research, and whether they were an acceptable, usable method for people living with dementia. The assumptions underlying this question are perhaps more in line with a positivist stance that methods either are or are not usable and acceptable. The aim was to seek an estimate of overall experience of using a diary on variables which were judged to be important based on previous research. As such, this led to choosing a nomothetic questionnaire approach. The researcher was interested in gaining an overall summary of participant experience of using the diary as a method of data collection to inform whether future research using this method would be appropriate, rather than seeking an in-depth examination of the meaning and experience of using a diary for each individual. It is noted that this research question has different underlying

assumptions to the primary research question, including judgements about what is important – for example, asking whether people feel comfortable using a diary.

Overall, the present study adopted a pragmatic epistemological stance, asking two research questions and using both qualitative and quantitative methodologies to try to answer these questions. The two research questions could be considered separately as taking different epistemological stances and adopting methodological approaches and methods of data collection which fit with these stances. However, overall the researcher took a pragmatic and eclectic epistemological stance, within which the value of drawing from both qualitative and quantitative research traditions can be recognised (Tashakkori & Teddlie, 1998).

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