The meaning of autonomy when living with dementia

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I would like to dedicate this work to my grandparents Beryl and Frank, who first taught me to meet dementia with love. I extend my sincere gratitude to those who participated in this study. Witnessing their stories has been an honour and a privilege. I have been deeply moved and inspired by their warmth and determination. The commitment to this project shown by my supervisors has contained and motivated me, and their passion for human rights will stay with me throughout my future career. Thanks to my parents for their encouragement to aim high despite the challenges of academia. Finally, thanks to my husband Fırat for his unwavering support and for giving me the freedom to be the person I want to be.

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Introductory Chapter: Thesis Overview

Introductory Chapter

The following thesis contains a systematic review and an empirical investigation. The empirical chapter is written in the style required by the journal Dementia to which the author hopes to submit (see Appendix 1 for author guidelines). The appendices are included to lend support to both chapters.

Thesis Overview

Dementia is a cluster of symptoms for which there is no cure and which features in several neurodegenerative illnesses, most commonly Alzheimer ’s disease (Hoang, Crouch, Knifton & Brayne, 2015). In the United Kingdom, the need to improve public awareness of dementia has been highlighted (Alzheimer’s Society, 2009, p.8). Whilst calls have been made for increased funding towards researching a cure, the increasing population of people living with dementia demands that further efforts also be made to enhance quality of life. Not only is this relevant to individuals with a diagnosis of dementia, but also the people providing informal care for their loved ones, who share experiences of distress, exhaustion and stigma (Cuijpers, 2005; Stirling, Andrews, Croft et al., 2010).

As a group made vulnerable by deterioration in memory, comprehension and communication skills over time, people with a diagnosis of dementia have been subjected to stigma and mistreatment which has denied them their human rights (Cooney & Wrigley, 1996; Alzheimer’s Society, 2009; Tronetti, 2014). One of the ways in which services can be shaped to support higher quality of life among people living with dementia is training and service development informed by rights-based approaches to healthcare. Making rights easier to understand and claim involves operationalising the Human Rights Act (Butchard & Greenhill, 2015). Some general agreement about the pillars of human rights based approaches to health is evident in the PANEL (Participation, Accountability, Non-discrimination, Empowerment and Legality) (British Institute of Human Rights,

2013) and FREDA (Fairness, Respect, Equality, Dignity and Autonomy) principles (Curtice & Exworthy, 2010). However, it is recognised that rights and rights based approaches are 'sites of struggle over meaning' (Yamin & Cantor, 2014). How rights are conceptualised will impact upon how well rights based approaches are understood, implemented and measured, and ultimately how effective they are at countering harmful power imbalances.

Not only are clinical psychologists well-placed to influence organisational change through training and consultation (Butchard & Greenhill, 2015), it is increasingly being recognised that protecting and promoting rights is fundamental to mental health care (Kinderman, 2007). The Health and Care Professions Council (HCPC) embed this in the Standards of Proficiency for Practitioner Psychologists calling upon them to 'understand the need to respect and uphold the rights, dignity, values and autonomy of service users including their role in maintaining health and wellbeing' (HCPC, 2015 p.7). The following thesis explores constructions concerning 'autonomy' from the perspective of people living with dementia and their family carers.

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Chapter 1: Systematic Review

Which psychological theories have been applied to research concerning autonomy when living with dementia?: The implications for clinical psychology practice

Abstract

Background and aims: The principle of autonomy currently centres on freedom of choice, self-determination and the ability to make decisions. On the basis of these culturally-bound assumptions and values, people with dementia may be assumed to lack autonomy once their condition advances to the extent that they cannot make independent decisions. Clinical psychologists are often called upon to formally assess capacity, but conceptualising autonomy in different ways may open up alternative means of supporting people with dementia to claim their rights.

Method: This systematic review searched five databases for qualitative research to explore constructions concerning autonomy offered by participants living and working with dementia and the psychological theories used to interpret and inform them. Each article was quality assessed and the use of psychological theory was examined using a published typology.

Results: Nine studies met inclusion criteria. A range of themes emerged from the constructions concerning autonomy offered by participants. The psychological theories utilised were predominantly social or relational in nature. Theories of personhood and identity in dementia were the most commonly cited alongside theories of normal ageing, family adjustment and disability.

Conclusions: People living with dementia have talked about autonomy in a variety of ways, moving beyond traditional assumptions of independence and self-determination. Psychological theories lend credence to the notion that living autonomously with dementia is synonymous with the experience of positive and empowering interactions with others.

Keywords: Autonomy, Dementia, Human Rights, Qualitative, Systematic Review

Introduction

Adjusting to life with dementia demands a great deal from the individuals affected, their family members and friends, and people employed in dementia care services. Whilst dementia undoubtedly has a profound impact upon cognitive functions such as memory, the interaction between the person living with dementia and their relational world is also complex. Dementia challenges commonly-held assumptions about what it means to be a valued member of society, particularly in Western neoliberal society which values individualism, independence, achievement and competition (Gilbert, 2014). Autonomy is a construct commonly associated with these ideals (Mackenzie & Stoljar, 2013). However, the assumption of individual autonomy conflicts with the reality of increasing dependence with advancing dementia.

The European Federation of Professional Psychologists' Association has taken steps to embed human rights and critical ethical thinking within education for psychologists (Hagenaars, 2016). Although the history of the profession does not permit clinical psychology to occupy the moral high ground, promoting human rights, social equity and social inclusion is becoming increasingly recognised as a daily necessity and reality in clinical practice (Kinderman, 2007; British Psychological Society, 2009). Contributing a psychological perspective to complex issues such as dementia and autonomy is one way of supporting health and social care systems to be more person-centred and to help people to claim their rights.

In parallel with the emphasis on recovery and wellbeing in the mental health arena, clinical psychology can support enablement of the positive aspects of living with dementia (O'Neill, 1997). Many people living with dementia and their carers have been considered vulnerable and powerless (Harding, 2012) and it is only within recent years that the voices of people with dementia have been heard in research. Considering how autonomy can be understood in a way that is meaningful and empowering for people with dementia is an important goal. The following systematic review was designed to explore constructions of autonomy as described in the qualitative literature involving people living or working with dementia and the psychological theories or models that have been utilised to inform these understandings.

Human rights and rights-based approaches

The introduction of the Human Rights Act (1998) in the United Kingdom formalised the duty of public bodies and professionals to protect the rights of the people they serve. Not only does the Act aim to prevent human rights abuses, it also contains the idea of positive obligation, which requires employees of statutory organisations, such as the National Health Service, to positively promote the rights of vulnerable groups (Boyle, 2010). Rights-based approaches to healthcare seek to constructively promote human rights by weaving rights principles into policy and practice (Department of Health, 2007). Service leadership, meaningful participation, accountability and attention to vulnerable groups are some of the ways in which rights-based approaches have been operationalised (Department of Health, 2007). The PANEL principles of Participation, Accountability, Non-Discrimination, Empowerment and Legality offer an updated framework for putting human rights into practice within healthcare environments (British Institute of Human Rights, 2013).

Kitwood (1997) argues that the interdependence and interconnectedness of human experience is underplayed in declarations of rights, which instead frame the person as a separate individual reflecting neoliberal values. However, any rights framework can also be construed as a codification of moral demands (Langlois, 2016) or a social code about ‘how we might best live in a world of others’ (O’Byrne, 2012, p1079). The Human Rights Act features qualified rights which necessitate balancing the rights of one person against those of another (Fyson & Cromby, 2013). The key values underlying the HRA are described by the FREDA principles of Fairness, Respect, Equality, Dignity and Autonomy (Curtice & Exworthy, 2010). As an ethical principle, autonomy is usually associated with self-determination and the ability and opportunity to make free choices (Curtice & Exworthy, 2010).

A dichotomy of autonomy: individual versus relational

Dworkin described autonomy as ‘a second-order capacity of persons to reflect critically upon their first-order preferences, desires, wishes, and so forth and the capacity to accept or attempt to change these in light of higher-order preferences and values’ (Dworkin, 1988, p.20). This liberal conceptualisation appears to dominate public, legal and clinical discourse, leading to an emphasis on capacity to make decisions and freedom from coercion. Millian and, to a lesser extent, Kantian philosophy have contributed towards this understanding (McLean, 2010), which implies an awareness of self, prioritising the self and ‘being one’s own person’ (Christman & Anderson, 2005, p.3).

The assumption that autonomy exclusively concerns individual self-determination and individual freedom of choice is problematic when considering the experience of dementia (Harding, 2012). Neoliberalism has been criticised for encouraging people to identify themselves and relate to others as individuals, implying a radical independence and uniqueness that is not a function of relations with others, thus rendering competition a normal model of social interaction and solitary decision-making preferable to group deliberation (Gilbert, 2014). Post (1995) describes modern Western society as ‘hypercognitive’ and over-invested in the notions of individual autonomy and rational capability.

Prioritising an individualised construction of autonomy and rationality arguably promotes economical production at the expense of members of society with disabilities (Kitwood, 1997, p.9; O’Neill, 1997). Gilbert (2014) points out that co-operation and collaboration are essential for human beings to act and exercise their respective capabilities. Post (1995) states that an emphasis on feelings, emotions and the ability to live within relationships would reveal people living with dementia to be highly competent.

Relational autonomy is a construct promoted by some feminists (e.g. MacKenzie & Stoljar, 2013) and philosophers (e.g. Christman, 2004), which places importance on the individual’s existence within ‘relations of social support and community’ (Harding, 2012, p.427). From this point of view, autonomy is dependent upon, created by and exercised via relationships. Relationships and interactions between people become the opportunities in which an individual can experience and express autonomy. However, feminist writing on the subject has described a model of ‘choices within constraints’ and within inequalities that impact upon the experience and expression of autonomy (MacKenzie & Stoljar, 2013). In this sense, relationality in and of itself might not always be beneficial to autonomy and this had led to criticism of the concept of relational autonomy as it has been described (Harding, 2012).

Post (1995) contends that individualism should be replaced with moral solidarity, where the essential unity of all human beings is recognised, regardless of their cognitive abilities. This echoes calls for a capabilities approach to social justice whereby society makes a strong commitment to ‘the good of others’ (Nussbaum, 2006, p.158) and has compassion for those who lack what is needed to live decently and with dignity (Nussbaum, 2006). Under these conditions of social co-operation, securing the rights of citizens is predicated upon them being supported relationally and put in a ‘position of capability’ to function (Nussbaum, 2006, p. 287). This approach has parallels with Vygotsky’s (1978) sociocultural approach to cognitive development which suggested that social interaction involving collaborative or co-operative dialogue with a more knowledgeable other is essential for learning. Being guided in this way, within the zone of proximal development, leads to improved performance when operating independently (Freund, 1990).

Dementia and malignant social psychology

The experience of dementia has been associated with multiple losses (Cheston & Bender, 1999), the impact of which is arguably relevant in the valued quest for continued autonomy. The ability to retain information or planning may impact upon an individual’s ability to make decisions independently, but so may a relative’s over-protection of the individual or society’s inability to adapt to the needs of people with dementia (Gilliard, Means, Beattie & Daker-White, 2005).

Loss of the ability to fulfil social roles, the loss of significant others and decreased motivation are considered likely to increase in line with the progression of dementia (Cheston & Bender, 1999). The greater the contribution of a former valued social role towards a person’s identity, the greater the impact that losing it has. As opportunities for social interaction decrease and routines fade, the person with dementia can become more disorientated and withdrawn (Cheston & Bender, 1999).

Behaviour often attributed to the biological progression of the disease, such as shadowing carers, going missing, searching and ‘fixating’, can all be understood as attachment behaviours – responses to an ever-increasing sense of unsafety (Miesen, 1992, 1993). If attachment needs are not met, the person with dementia may refuse to eat, withdraw, stop speaking or appear to ‘lose the will’ (Cheston & Bender, 1999). According to Kitwood and Bredin (1992a), being a person is about being regarded as having a certain status and being worthy of respect in the eyes of others. Personhood thus emerges in the course of human relating and interaction (Kitwood, 1997b). Failure to treat people in a respectful way results in their personhood being undermined and this is considered to have negative consequences for their wellbeing.

The role of the clinical psychologist in supporting autonomy

The health and social care system, of which clinical psychologists are a part, has been criticised for ‘widespread failure’ in meeting the needs of people with dementia and their families, despite areas of good practice (Knapp, Prince & Albanese et al, 2007, p.xix). Clinical psychologists are well-placed to support the transformational change necessary to embed human rights-based approaches within dementia care at the service level through consultation, training and other forms of clinical governance (Butchard & Greenhill, 2015). Space can be created for reflection about the embodiment and enactment of key values, such as FREDA, through supervision, and formulation offers an opportunity to make sense of behaviour and distress through a biopsychosocial lens (British Psychological Society, 2011, p.20).

In clinical practice, there is an emphasis on assessing and supporting decision-making as the primary means through which autonomy can be promoted. This suggests that an individualistic autonomy is privileged over the emotional and relational aspects of autonomy in the course of day-to-day care. Clinical psychologists are often called upon to undertake capacity assessments to support decision-making in accordance with the Mental Capacity Act (2005). Although the Act was intended to protect the individual's right to decide and be consulted, a capacity assessment may in fact be used to justify surrogate or 'best interest' decision-making. A broader, more relationally sophisticated view of how autonomy can be understood and supported in practice, in a way that is meaningful and empowering for people living with and working with dementia, may be welcome.

The relevance of qualitative research

McLeod (2001) describes the key aim of qualitative research as the development of understanding about how the world is constructed. Meaning is central to this endeavour and places the researcher in the position of inquiry to 'get, grasp, hear, catch and comprehend' (Grant, 2008, p.1) phenomena according to the meanings brought to them by other people (Denzin & Lincoln, 2005). The current review views qualitative research as emphasising personhood by capturing the voices of people living and working with dementia and facilitating enquiry about the meaning of autonomy as a 'complex personal and social issue' (Schwandt, 2007). Furthermore, the intention to listen to the voices of people living with dementia is arguably in keeping the principles of empowerment and participation within a human rights-based approach.

Theory in qualitative research

The current review is interested in qualitative research exploring experiences of dementia and autonomy. Whilst theories of autonomy and the contribution of psychological theory are discussed in academic literature, they are not usually made explicit in the course of clinical practice or day-to-day life with dementia. Qualitative research makes hidden discourses and theories explicit by exploring subjective viewpoints in detail.

Theory-based qualitative research moves away from pure description and facilitates understanding of the social processes that underpin findings (Meyer & Ward, 2014; Reeves, Albert, Kuper & Hodges, 2008). There is a lack of agreement about whether and how theory should be appropriately applied in qualitative studies (Wu & Volker, 2009). However, its inclusion is considered of paramount importance to translate findings into meaningful policy and practice. The following review asks which psychological theories have been applied to constructions of autonomy described by research participants living with dementia.

Review Aims

The aims of the current review are:

1. To identify qualitative research literature exploring constructions concerning autonomy by people living and working with dementia, including people with a diagnosis, relatives and informal carers, and dementia care professionals.
2. To critically assess the quality of the aforementioned research.
3. To summarise the different constructions that are offered in the studies concerning autonomy.
4. To identify and describe the implicit psychological theories or models that are used within the qualitative literature to interpret and inform these constructions.

Method

Search Strategy

A scoping search was undertaken using the EBSCO Discover interface to consider which keywords to include in the main search. A search using the keywords ‘autonomy’ and ‘dementia’ in any field returned 3328 entries. Refining this search by defining the use of the keywords as subject terms returned 627 entries. Changing the search to define the use of the keywords as part of the abstract returned 919 entries, which suggested that relying on subject terms alone might exclude useful entries. Adding the keyword ‘qualitative’ and searching for the additional keyword in any field reduced the number of entries drastically to 73, which may have indicated that few qualitative studies exploring autonomy and dementia were available or that study authors had not explicitly identified their work regarding this topic as qualitative. Many of the citations that emerged in the scoping review focused on concepts that are related and highly relevant to autonomy, such as decision-making and dignity.

The scoping search was also used to identify whether the current review question had already been examined elsewhere. A combined search (autonomy AND dementia AND “systematic review”) for terms used in abstracts returned seven entries that did not address the current review question. Expanding the use of the search terms to any field returned 25 entries. Although some of these reviews and studies explored issues relevant to autonomy, such as decision-making, they did not address the current review question specifically.

A search was undertaken using the PROSPERO register of systematic reviews to ensure that the current review question was not under investigation elsewhere. An initial search using the keyword ‘autonomy’ identified one ongoing review but it was not relevant to dementia. A second search using the keyword ‘dementia’ identified over 100 entries. Each entry title was read to ensure that a review with the same aims was not registered. None of the entries were relevant to the current review. A proposal for the current review was subsequently submitted and registered on the PROSPERO website (ID: CRD42016053083) (see Appendix 2).

Study Selection

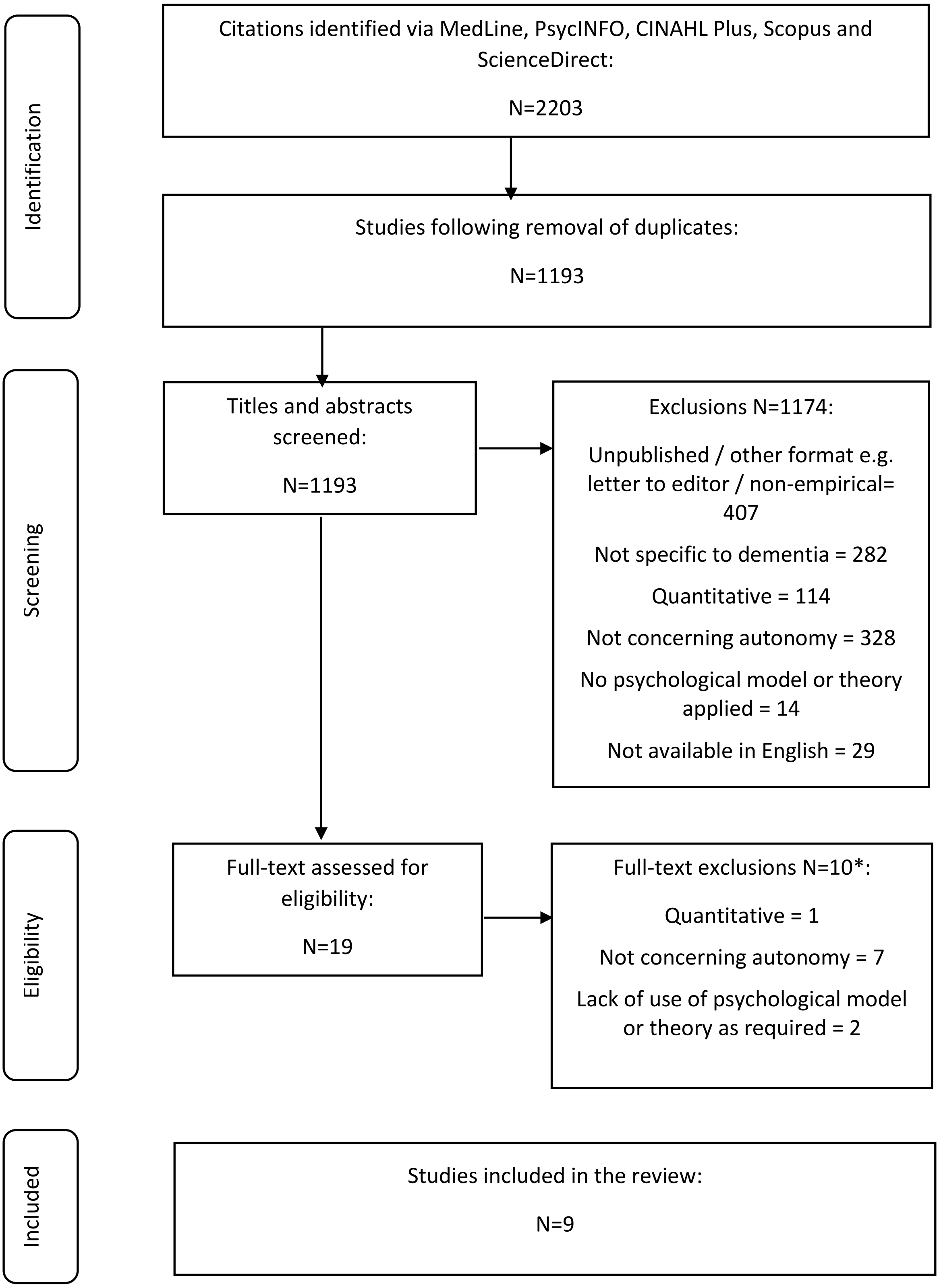
The keywords ‘autonomy’ and ‘dementia’ were combined to form the main search. Proxy terms were considered (e.g. self-determination, decision-making), but it was decided that adding terms might inadvertently exclude papers involving broader conceptualisations of autonomy. Five electronic databases were searched between October 2016 and February 2017: MedLine, PsycINFO, Scopus, CINAHL Plus and ScienceDirect. These databases were selected following consultation with a librarian regarding the review question and appropriate sources of psychologically-informed literature. No exclusion criteria were applied regarding date of publication. Due to resource limitations, only papers available in English were included. All citations were extracted and organised using Mendeley™ reference management software. The main search returned 2203 papers.

Duplicate results were removed electronically using Mendeley™ leaving 1193 papers. These citations were screened and subsequently retained or excluded, based upon the inclusion and exclusion criteria as applied in the order presented (see Table 1). Where suitability was not clear from the abstract, the author referred to the full-text version of the study. Following exclusions, the remaining 19 papers were reviewed in full. The flow diagram below illustrates the review process (see Figure 1). Expert authors were contacted regarding additional works, but no new material was shared (see Appendix 3).

Table 1. Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
The study was published in a peer-reviewed journal	Unpublished dissertations, conference presentations, letters to journal editors and non-empirical (theory only) studies
The study focused on any type of dementia	Studies without a focus on dementia
The study used qualitative methodology	Quantitative studies
The study report featured constructions of autonomy and/or related and highly relevant concepts (e.g. decision-making, dignity), as expressed by participants	The study did not feature reported constructions of autonomy and/or related and highly relevant concepts, as captured within the empirical material and outlined in the results section of the study
Assumptions about the meaning of autonomy were related to a psychological theory or model, or an existing psychological theory or model was used as a framework for data interpretation	Constructions of autonomy were not related to a psychological theory or model, and an existing psychological theory or model was not used as a framework for data interpretation
The paper was available in English	Papers only available in languages other than English

Figure 1. Flow diagram of the review search process[1]



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[1] *See Appendix 4 regarding final excluded papers

Data extraction and quality assessment

The key features and findings of each study were extracted using a simple data collection form designed specifically for the current review (see Appendix 5). Each study was quality assessed using the Evaluation Tool for Qualitative Studies (Long & Godfrey, 2004). The tool was chosen due to its focus on making explicit both the basis for judgements about quality and identification of the theoretical framework in which the concerned studies are located, in line with the focus of the review (see Appendix 6).

During development, Long and Godfrey (2004) realised that within an area of interest a range of competing models can underpin the research base, calling for a delineation of the theoretical frameworks underpinning studies as part of evaluation. The tool was developed to allow for sufficient flexibility to evaluate a range of qualitative studies without compromising on utility and value. This was important since a range of qualitative designs were likely to emerge from the literature search. Finally, one section of the tool focuses on policy and practice implications which is pertinent to the clinical relevance of the review question and recognises the importance of evidence based practice.

The four subsections of the evaluation tool allow comments to be recorded regarding: the phenomenon of interest and context (including theoretical) issues; ethics; data collection and analysis processes; and policy and practice implications. The main author (S.W.) completed this stage of the review and a random sample of three papers was assessed by an independent researcher with the same training. Judgements regarding quality assessment were consistent in 100% of cases.

The outcome of the quality assessment of each study was used to describe quality indicators and to screen out any studies of very low quality. The results were not intended to be used to weight the findings of the various studies cited.

Constructions concerning autonomy and use of theory

Constructions concerning autonomy were extracted by reading the results sections of each paper sentence by sentence and recording keywords or phrases pertinent to or explicitly describing constructions concerning autonomy and closely related concepts (e.g. decision-making), paying close attention to any data extracts used to support findings. The resulting lists of keywords and phrases were re-read and summarised.

The introduction, results and discussion sections of each paper were read to identify whether a psychological theory or model had been used to frame the study or explain findings relating to autonomy. Whether a theory was psychological or not was determined by the review author's (S.W.) prior knowledge, explicit references to this made in the study report, by looking up the credentials of the authors cited (including their qualifications and previous publications) and referring to the journal in which the study was published.

The use of psychological theory in each study was considered using the 'Levels of Theoretical Visiblity Typology' (Bradbury-Jones, Taylor & Herber, 2014) to complement the quality assessment (see Appendix 7). This allowed for reflection on the varying extents to which the different studies made use of theory, in recognition of the fact that such application is not always reported clearly in qualitative research (Wu & Volker, 2009). Each theory identified by the reviewer was assigned to a category to indicate the level to which it was applied in the relevant study (implied, partially applied, retrospectively applied, consistently applied).

Results

Summary of included studies

In accordance with its first aim, this review identified nine qualitative studies offering constructions concerning autonomy and other highly relevant concepts (see Table 2). All of the studies were published between 2005 and 2016, indicating that research into dementia and autonomy-related issues have been of relatively recent interest. The studies were written by researchers and clinicians from a range of disciplines including sociology, nursing, occupational therapy and gerontology. One study (Berry, Apesoa-Varano and Gomez, 2015) was conducted by researchers with expertise in social psychology.

The studies were carried out in a limited number of countries with predominantly white populations (United States, Canada, United Kingdom, Norway, Sweden and Australia). However, Berry, Apesoa-Varano and Gomez (2015) studied the views of Latina caregivers exclusively. The two studies conducted in Australia were undertaken by research teams with the same primary author (Fetherstonhaugh, Rayner & Tarzia, 2016; Fetherstonhaugh, Tarzia, Bauer, Nay & Beattie, 2016).

The studies sought the views of a range of stakeholders. On a positive note, people living with dementia participated in six of the nine studies. Five studies included family caregivers or spouses and two sought the perspectives of dementia care professionals. Whilst the majority of studies (6/9) took place in community settings, usually participants' homes, two were undertaken in residential or inpatient settings (Heggestad, Nortvedt & Slettebø , 2013; Fetherstonhaugh, Tarzia, Bauer, Nay & Beattie, 2016). One study involved participants living at home in the community and in residential care (Smebye, Kirkevold & Engedal, 2012).

Six of the studies provided demographic information about gender of participants. Two of these studies involved a balanced gender split with equal numbers of males and females living with dementia (Öhman & Nygård, 2005; Phinney, Chaudhury & O'Connor, 2007). Of the remaining four, three involved more females than males living with dementia. Studies involving family carers which provided gender data tended to have a higher number of females than males. Seven out of nine studies provided data regarding age of participants. Overall, participants with dementia ranged from 56 to 94 years of age. Family carers ranged from 30 to 88 years of age and encompassed spousal relationships, siblings, adult children and extended family members.

Dementia is a broad category encompassing various conditions with varying symptomatology. Of the studies reviewed, three focused on people living with Alzheimer's in particular. Three involved people living with different types of dementia, including Lewy Body dementia, Parkinson's Disease and vascular dementia, and a further three did not report on these characteristics.

The reviewed studies explored a range of topics relevant to autonomy, although decision-making was a common focus. How everyday decisions are made and how they are supported was investigated in four of the studies. The meanings behind activities from the perspective of people living with dementia were also explored. One paper looked explicitly at how strategies to support autonomy and manage risk changed as functional decline increased (Berry, Apesoa-Varano & Gomez, 2015). One study examined the experiences of dignity among people living with dementia in nursing homes (Heggestad, Nortvedt & Slettebø, 2013). One study considered the importance of mealtimes for promoting and sustaining identity (Genoe, Dupuis, Keller, Schindel Martin, Cassolato & Gayle Edward, 2010).

Triangulating data collection methods is one way of enhancing credibility in qualitative studies. The majority of studies used interviews to collate data, three of which combined this with participant observation. One study involved interviews and focus groups (Fetherstonhaugh, Tarzia, Bauer, Nay & Beattie, 2016). One study involved focus groups only (Chung, 2013). Four of the studies used grounded theory, four used phenomenological approaches to analysis, and one used qualitative comparison analysis (Öhman & Nygård, 2005).

Table 2. Summary of included studies

Author(s)	Year	Study Title	Participants, Sampling and Context	Method of Data Collection	Method of Analysis	General Findings
Berry, Apesoa-Varano & Gomez	2015	How family members manage risk around functional decline: The autonomy management process in households facing dementia	15 Latina caregivers of people living with Alzheimer's in the community in the United States	Three semi-structured interviews with each participant every six months	Modified grounded theory	Family members managed their relative's involvement in daily activities through three stages of support: collaborative, transition, and unilateral.
Chung	2013	Professionals partnering with family carers in home-based activity for those with dementia	21 co-resident carers (relatives) in the United Kingdom	Two focus groups	Constant comparison method (grounded theory)	Purposeful activities within the home served three key functions: To enhance autonomy and independence, to keep active, and to trigger improvement in mood.
Fetherstonhaugh, Rayner & Tarzia	2016	Hanging on to some autonomy in decision-making: How do spouse carers support this?	16 dyads (spouses and people living with dementia) and two spouse carers in Australia	Semi-structured interviews	Interpretive phenomenological analysis	Three broad themes emerged: the importance of decision-making to the humanity of people with dementia, the importance of knowing the person and working together, and the paradox of care –being risk averse or over-riding decisions made by the person living with dementia.
Fetherstonhaugh, Tarzia, Bauer, Nay & Beattie	2016	"The red dress or the blue?" How do staff perceive that they support decision-making for people living with dementia living in residential aged care facilities?	80 direct care staff from 14 different facilities in Australia	Semi-structured interviews and focus groups	Grounded theory	'A little effort goes a long way' emerged as a core category. Three sub-categories identified details of the strategies employed: keeping it simple, knowing the person and negotiating a compromise.
Genoe, Dupuis, Keller, Schindel Martin, Cassolato & Gayle Edward	2010	Honouring identity through mealtimes in families living with dementia	26 dyads (care partners and people living with dementia) and one triad in Canada	Semi-structured interviews	Grounded theory	Personal and social identities were honoured through mealtimes and their associated roles in several ways: protecting dignity while struggling for autonomy, having meaningful roles, and reaffirming a sense self in the world.
Heggestad, Nortvedt & Slettebø	2013	'Like a prison without bars': Dementia and experiences of dignity	Five people with dementia in two nursing homes in Norway	Semi-structured interviews and observation	Interpretative hermeneutic approach	Three themes emerged: to be seen and heard, captivity and homesickness.

Öhman & Nygård	2005	Meanings and motives for engagement in self-chosen daily life occupations among individuals with Alzheimer's disease	Six people living with Alzheimer's in the community in Sweden	Repeated semi-structured interviews and observation	Qualitative comparative method of analysis	Eight categories emerged from the analysis: maintaining an ordinary pattern of everyday life, the importance of a feeling of autonomy, communicating certain identity characteristics, finding and creating a private sphere, staying active, double-edged 'keys' crucial to occupation, two modes of making sense of the cessation of occupation.
Phinney, Chaudhury & O'Connor	2007	Doing as much as I can do: The meaning of activity for people with dementia	Eight people living with Alzheimer's in the community in Canada	Semi-structured interviews	Interpretive phenomenological analysis	Participants were involved in four types of activity: leisure and recreation, household chores, social involvements, and work-related activities. Three themes were identified regarding their significance: enjoyment and pleasure, connection and belonging, autonomy and identity.
Smebye, Kirkevold & Engedal	2012	How do persons with dementia participate in decision making related to health and daily care? A multi-case study	30 triads (people living with dementia, family members and professionals) in Norway	Semi-structured interviews and observations	Hermeneutic interpretive approach	Participation in decision-making varied between participants. Variations of decision-making were identified as: autonomous, pseudo-autonomous, shared, delegated and non-involvement.

Quality assessment summary

In accordance with the second aim, the selected studies were critically assessed using Long and Godfrey's (2004) evaluation tool (see Table 3). All of the studies included in the review were retained. One paper (Chung, 2013) was considered of lower quality in contrast to the other papers. However, it was not considered so poor as to exclude it from the analysis because the use of theory and constructions of autonomy described in the paper were deemed important and worthwhile contributions in response to the questions posed by this review.

Phenomenon studied and context. All nine studies described the aforementioned phenomena of interest in sufficient detail. All studies drew upon other research to locate the work within the existing knowledge base. Social psychological theories relevant to dementia were used to inform all of the studies to varying degrees. Other guiding theories included dignity theory (1/9), the Family Adjustment and Adaption Response model (Patterson, 1988) (1/9) and activity theory (1/9). It was not always explicit how the theories presented in the introduction to the studies influenced the way the studies were subsequently undertaken. One study used Thompson's (2007) taxonomy of participation levels as a frame of reference which guided the interpretive approach to the analysis (Smebye, Kirkevold & Engedal, 2012). One study emphasised the importance of the perspective of people with dementia and described the influence of interpretive phenomenology on their study of the meaning of activity (Phinney, Chaudhury & O'Connor, 2007).

Three studies took place within urban areas and the remaining six did not provide clear geographical information. Six of the studies took place within the community and family home setting, two were specific to residential and nursing care settings and one study included both (Smebye, Kirkevold & Engedal, 2012). Most (8/9) of the studies justified their choice of care setting with many (4/9) citing the care in the community agenda and the increasing numbers of people with dementia living at home. Two studies cited informal caregiver burden as a key rationale for choosing the family home setting. One study did not make the rationale for the choice of care setting explicit in their report (Phinney, Chaudhury & O’Connor, 2007). Two studies described ethical issues relevant to the chosen care setting as motivators. Two cited gaps in the literature that dictated the choice of care setting. One study described sample diversity as the reason for undertaking the study in both community and institutional care settings (Smebye, Kirkevold & Engedal, 2012). The choice of care setting appeared appropriate to the research question and aims in most cases. However, details of the chosen settings were insufficient in five of the studies. The time period over which the studies were conducted was omitted in four of the reports but otherwise ranged from six months to two years.

Eight studies used purposive non-probability sampling which is appropriate but can lead to low reliability and high levels of bias, although representativeness and generalisability are not of primary concern in qualitative research. One study explicitly described using theoretical sampling as part of grounded theory (Genoe et al., 2010). One study was not explicit about the sampling method utilised (Chung, 2013). Four studies described their samples as self-selecting. All samples appeared appropriate to the aims of the studies. The samples captured a range of perspectives including those of people with dementia exclusively (2/9), family carers (2/9), dementia care professionals (1/9), service users and carers combined (2/9), and service users and staff combined (1/9). Only one study captured the perspectives of all three groups (Smebye, Kirkevold & Engedal, 2012). Six studies involved contact with participants at more than one time point offering depth and breadth of perspectives.

Ethics. Seven out of nine studies recorded that ethical approval had been obtained. Five of the studies did not include detailed descriptions of consent processes, although it was sometimes referred to briefly under inclusion criteria. Three studies were particularly sensitive to the research context and described how the consent process was adapted for participants with dementia. One study highlighted the importance of participation in research by people living with dementia as part of the rationale for the study (Phinney, Chaudhury & O’Connor, 2007). One study discussed the ethical implications of the research findings as part of the discussion (Berry, Apesoa-Varano & Gomez, 2015).

Data collection, analysis and potential researcher bias. Five of the studies combined data collection methods to improve depth, breadth and validity. However, one of the studies involved analysis of secondary data which means that the findings are based on material originally gathered in response to a different research question (Phinney et al., 2007). Three studies used interviews only where triangulating methods might otherwise have enhanced credibility. One study used focus groups alone and provided insufficient detail regarding the process of fieldwork thus preventing replication (Chung, 2013). Eight studies provided enough information for replication but none of the studies included detailed topic, interview or observation guides in the reports. All recordings were transcribed which may allow for independent analysis, although this was not confirmed in the articles. The involvement of members of the research teams in data collection was made explicit in four studies, one of which used third party trained interviewers (Genoe et al., 2010). Evidence of researcher reflexivity was lacking in a large proportion of the studies (7/9).

The studies used either grounded theory (or constant comparison) (4/9), phenomenological approaches (such as interpretive phenomenological analysis or interpretive hermeneutic analysis) (3/9), or qualitative comparison analysis (1/9). The process of analysis was adequately described for replication by all studies except one (Chung, 2013). One grounded theory study provided a particularly clear account of the process of data collection and analysis, and was consistent with the principles of the chosen methodology (Genoe et al., 2010).

Raw data extracts were used to support findings in all reports. Other efforts to support analysis included checking findings with participants (1/9), more than one team member undertaking independent analysis, discussing interpretations with expert colleagues, using multiple sources, and searching for negative evidence. All studies interpreted findings in the context of other studies and theory. Researcher bias was addressed explicitly in one study where the author concerned found her pre-understanding of nursing led her to focus on interventions and drew her away from interpreting the text (Smebye, Kirkevold & Engedal, 2012). Otherwise explorations of possible researcher bias were not evident.

Policy and practice implications. Five studies described small samples sizes limiting the possibility of generalising findings to setting or population, although generalisability is not an aim of qualitative studies. The settings in which all studies took place were typical environments of care for people with dementia, including the family home and nursing homes. Three studies explored experiences of Alzheimer's, therefore their findings may not be relevant to experiences of other forms of dementia.

The majority of studies (6/9) called for a culture shift in society and within services towards person-centred attitudes that value the individual's history and identity and that avoid making assumptions about preferences and needs. Three studies emphasised the need for services to work in partnership with carers and wider family members. Four studies recommended training for family carers and residential staff to support them in identifying unhelpful strategies and techniques to promote involvement in decision-making, family routines and personally meaningful activity. Several studies identified the need for change in practice to support autonomy through opportunities to participate in decision-making (Smebye, Kirkevold & Engedal, 2012; Fetherstonhaugh, Rayner & Tarzia, 2016), tailored routines and meaningful traditions (Öhman & Nygård , 2005; Genoe, et al., 2010), a flexible environment that promotes spontaneous activity (Phinney, Chaudhury & O'Connor, 2007) and meaningful opportunities for activity beyond simple leisure past-times (Öhman & Nygård , 2005; Phinney, Chaudhury & O'Connor, 2007; Chung, 2013). Two studies recommended clinical assessment to include coping during mealtimes and identifying facilitators to promote autonomy (Öhman & Nygård , 2005; Genoe, et al., 2010).

Table 3. Quality assessment of included studies (Long & Godfrey,2004)

Study	**Phenomenon Studied & Context**	**Ethics**	**Data Collection, Analysis & Potential Researcher Bias**	**Policy & Practice Implications**	**Evaluative Summary**
Berry, Apesoa-Varano & Gomez (2015)	The study explores how family members manage functional decline and the associated risks. Functional decline is framed as a social problem and the study is situated within existing knowledge regarding the role of social psychological factors in the expression of dementia. Caregiver stress and long-term prognosis are cited as the rationale for the study setting. Sample limited to Latina caregivers (*n*=15), most of whom were adult children. Few additional demographics provided. No other perspectives or evidence gathered. Interviews repeated three times over two years providing depth.	Refers to institutional review board approval. Informed consent process not explicitly described. Ethical issues pertinent to the findings discussed in the paper (e.g. duplicity).	Telephone (29) and face-to-face (16) interviews conducted, digitally recorded and transcribed. Interview guide not supplied but question topics described. Consideration given to the importance of building rapport for eliciting disclosure. Third author conducted each interview. Little evidence of reflexivity provided. All authors participated in the analysis using line-by-line coding, summary timelines and discussion. Interpretive discrepancies were reportedly resolved through consensus building but further detail is not provided. Limited use of quotes to support the emerging model.	Non-probability sampling method limits the findings to Latina families with adult children caregivers of people living with Alzheimer's specifically. Findings support theories about the constraining nature of social context on people with dementia. Highlights the importance of caregiver perceptions of declining awareness or anosognosia for autonomy management in the home and caregiver burden.	This study offers important insights into the social context of declining functional ability by exploring how family members manage risk. An exclusively Latina sample gives voice to the experiences of this group, but also introduces bias due to the lack of involvement of other ethnic and cultural groups. Further contextual detail such as socioeconomic status is absent. The nature and the impact of the relationship between adult-children and parents living with dementia with regards to approaches to support and risk management, as opposed to spousal relationships, is not explored but acknowledged. The process of analysis is described sufficiently. The three stages of support are richly described and supported to a limited extent with data extracts. Researcher bias was not explored in the published article. The findings are considered in relation to research about deficit awareness and highlight the role of denial, stigma and resistance.
Chung (2013)	This study explores how carers enhance their relative's autonomy and sense of self through engaging them in activities, despite progressive decline in their cognitive function. Supporting person-centred care is the rationale for the study, which draws on the social psychological literature regarding personhood and the impact of quality of care on the	Research approval obtained from a local ethics committee and Research and Development Unit. Consent process not described.	Five focus groups conducted on the premise of generating rich data cost effectively. All were audiotaped and transcribed verbatim. Process of fieldwork not adequately described. Questions posed not outlined in the paper. No evidence of reflexivity. The researcher's role in the data collection and analysis is not clear. Rich quotations were used to	Whilst the home setting may be typical for many families living with dementia, it is difficult to determine population generalisability in the absence of demographic information. However, the conclusions are rooted in the findings.	This study informs person-centred care and promotes support for family carers. Details regarding participant characteristics and the setting in which data collection took place are not provided. Whilst the focus groups may have prompted discussion and provided rich data, some participants may have felt inhibited by the group format. Although the process of analysis is not described, the description of the findings is rich and supported by data extracts that are consistent with the author's interpretations. A lack of

	socially presented self. Sample of 21 co-resident family caregivers recruited via gatekeepers. No demographic information provided. No other perspectives gathered.		support the findings.	Activity engagement identified as a complex and demanding task for carers and the need for support to identify effective and unhelpful strategies. The study calls for a culture shift towards dementia-friendly communities. Recommendations are made regarding the development of outcomes measures.	references to study limitations indicates a lack of critical analysis. The impact of the researcher's clinical role is not explored. The study concludes that a sense of control can be maintained for the person with dementia. The author highlights the need to appreciate the carers role and the importance of regular breaks and training about what to do when the general approach to activity engagement is no longer effective.
Fetherstonhaugh, Rayner & Tarzia (2016)	This study explores the role of spouse carers in facilitating decision-making for people living with dementia in the community, and the strategies they employ to achieve this. Decision-making is linked with well-being and quality of life through reference to relevant literature, including a previous paper by the same research team. The concept of couplehood is used to frame the focus of the study on the spouse carer role and experience. Purposive sampling is described involving self-selection through third sector organisations (*n*=16). The sample involves heterosexual spouse and person with dementia dyads of varying ages. A demographics table is	The need for consideration of the ability to consent is described. The consent process is clearly outlined. A university research ethics committee approval number is provided.	The study draws upon van Manen's (1990) approach to phenomenology and empathic engagement with participants . Single face-to-face interviews were conducted by two of the research team, audio-recorded and transcribed. Five dyads opted to be interviewed together. This method offers depth as well as contrast of perspectives. The questions posed are briefly described. The method section eludes to challenges in interviewing people with dementia but this is not referred to in the discussion. Despite a high level of detail in the method section, there is little evidence of reflexivity. The process of interpretative phenomenological analysis is	The findings may be generalisable to white, co-resident, heterosexual couples living with dementia in their own homes, but the sample is not representative of the broader community. The sample was also self-selecting which limits generalisability further. The conclusions of the study acknowledge these limitations and offer a fair summary of the findings. The study highlights the importance of being consulted for people with dementia, the impact of a loving and	The authors clearly articulate where the study is located within the existing knowledge base and the theory underlying the methodological approach is described. The recruitment and consent process is clearly outlined and the authors acknowledge the possibility of a selection and positive response bias. Undertaking interviews in optional dyads provided rich perspectives and opportunities to identify contrasting views, although it may also have led to self-censorship. The questions posed and the process of analysis is sufficiently explained. Unusually for an IPA study the authors' background influences are not explored. The authors highlight the spouse carers unique position in being able to facilitate meaningful decisions based on preferences and personal values due to their knowledge of the person and the basis of love and respect that forms the foundation of those relationships.

	provided.		described to a replicable extent. Two of the authors participated in the analysis separately providing rigour.	trusting relationship on motivation to involve people with dementia in decision-making, and the need for carers to respect all perspectives when considering risk.	
Fetherstonhaugh, Tarzia, Bauer et al. (2016)	This study explores how staff in residential care for older people perceive that they support everyday decision making for residents living with dementia. The phenomenon under study and the rationale for the research is well described. The residential setting of the study is justified as a gap in the literature. The study is located alongside existing knowledge regarding decision-making in dementia but the theoretical framework guiding the study is not clear. The sample appear to be self-selecting and additional demographic information is lacking, but the sample is appropriate for the research question. Professional perspectives (*n*=80) are the focus and some breadth and depth is achieved via interviews and focus groups.	A university ethics approval number is provided. The consent process is not outlined.	41 interviews and eight focus groups were conducted, audio-recorded and transcribed. Duration of interviews varied considerably. No observations were conducted alongside, although the rationale for the method chosen is clear. The main question posed is outlined, although no further detail is provided. The report describes steps taken to avoid influencing participant responses by defining dementia or delineating on the basis of severity. The researcher's role during data collection is not described explicitly and there is little evidence of researcher reflexivity. Analysis was undertaken using specialist software and there is evidence of cross-checking and consultation until data saturation was reached. Original data extracts are used to support findings. The discussion draws upon other studies to interpret findings and	The study generated a high volume of qualitative data but the report acknowledges that the views offered cannot be generalised, in part due to the person-centred nature of existing practice in the sample residential homes. Since participants were self-selecting they may have been more engaged or aware of issues regarding decision-making. The conclusions offer a justified summary of the findings and considers the need for further research in light of the limitations. The study highlights the importance of compromise, choice, language, environment and knowing the person, as well as	This study addresses a gap in the research due to its focus on the residential care context and staff views. The theoretical background is described and includes references to levels of decision-making and empowering communication which are considered in the light of the study's findings. The recruitment process and sampling method are adequately described. Certain participant characteristics, such as ethnicity, are absent. Different dynamics may be evident in findings from a similar study involving participants from different backgrounds or who are supporting people with different cultural needs. The process of fieldwork is described sufficiently and the process of analysis is described in brief. Further detail about this would ensure replicability, for example is it unclear how emerging themes influenced the questions posed during subsequent interviews and focus groups. Although researcher biographies are provided, little evidence of reflexivity is offered. The authors caution against decision-making that is pseudo-autonomous i.e. which uses knowledge of the person to manipulate their decision-making rather than support it

			considers relevant ethical issues.	awareness of issues such as the power imbalance between the residential routine and residents.	
Genoe, Dupuis, Keller et al. (2010)	This study explores the experience and meaning of mealtimes for people living with dementia and their families, and the role that mealtimes play in honouring identity. The study richly describes the theoretical background regarding identity, mealtimes and family adjustment. Selective and theoretical sampling were used to recruit person with dementia and partner in care dyads (*n*=26) and one triad. Researchers worked with third sector agencies to recruit participants reflecting a diversity of experiences of dementia. Detailed demographics are provided. Service user and carer perspectives were gathered over one month offering contrasting views.	Ethical approval is not reported. Informed consent was part of inclusion criteria but not described in detail.	Shared and individual interviews were undertaken, gathering collective and personal meanings. Data collection and analysis occurred in parallel so that emerging themes informed subsequent data collection. Interview questions are not provided although general themes are described. The coding and decision-making process are described in some detail, alluding to common and divergent perspectives and observations. Participants were also invited to discuss and help refine initial findings. Raw data is used to support the findings described in the report. The theoretical implications are described at length. The researcher's own position is not explored.	The findings are not generalizable to populations who are not white or who enjoy different cultural practices. The findings do not generalise into the wider family unit since the focus of the data collection was the person with dementia and partner in care dyad. The experiences of people in long-term care settings are also not represented. Several practice implications are offered, including assessing mealtime experience as a barometer of coping, routine questions about mealtimes, education regarding management strategies for families to support involvement, and raising awareness of the importance of mealtimes for identity.	This study provides valuable insight into the importance of mealtimes for supporting, honouring and reaffirming identity. The article outlines the theoretical framework that guides the study in depth, offers a summary of the relevant literature and both are considered again in the discussion section in light of the study findings. Although the interview questions are not provided, the process of data collection is described informatively. The inclusion of individual and dyad interviews with the same participants allows for contrast and depth of analysis. The process of analysis is sufficiently outlined for replicability. The description of the findings is rich and detailed with evidence from data extracts. Evidence of reflexivity is lacking, although findings were discussed with participants to ensure they were refined to better reflect their experiences. The findings are not generalizable to families who are from non-White backgrounds or who are living with advanced dementia. The study calls for relationship-centred care.

Heggestad, Nortvedt & Slettebø (2013)	This study explores how life in nursing homes affects experiences of dignity among residents living with dementia. Theories of dignity are explained alongside a summary of the empirical research. The study is framed in a phenomenological and hermeneutic approach which is explained and evident through the approach to data collection and researcher reflexivity. The settings and sample are described, however it is not clear how the nursing homes were selected and further demographic information is absent. Service user perspectives were elicited formally from a limited number of residents in depth (*n*=5). Other service user and staff perspectives were also captured informally offering some breadth.	The consent process is clearly described and considerate of the participant groups. The use of proxy consent is explicit but not discussed. Regional ethics committee approval is documented.	Interviews and participant observation were undertaken providing opportunities to generate verbal and non-verbal data, as well as contrasting and validating perspectives. The role of the researcher is clear and embedded in the data collection process. The observation and interview processes are described, including note-taking, length and timings. The observation and interview guides are reportedly rooted in relevant research, but this is not referenced and the guides are not included in the report. There is evidence of reflexivity appropriate for the methodological approach, but this insight is not expanded upon in detail. The analysis was undertaken primarily by one researcher. Consistency of interpretation when findings were discussed by the whole research team is not commented upon. The process of induction and abduction is described and referenced but arguably insufficient for replication. The findings are supported by use of the raw data and interpreted in the context of other key studies.	The findings may generalise to other nursing homes in the same country, but not to other residential settings in other locations. From the report it is not possible to generalise to a population as there is insufficient demographic information about participants. The conclusions offer recommendations based upon the findings and the authors subjective views based on their professional experiences. Person-centred care and a focus on a person's strengths rather than their limitations is encouraged. Further research that includes participants with dementia is encouraged.	This study usefully outlines the theory regarding dignity, identity and personhood, which frames the work and is considered in light of the findings. The research context is well described and reflected upon in the discussion. The author's preconceptions are alluded in to in accordance with an hermeneutic approach. An interview guide was developed for the study but is not included in the article, otherwise the data collection process is well described. Undertaking observations as well as interviews and informal conversations in context generated data that could be contrasted and triangulated. The process of analysis is framed theoretically and described using examples to support replicability. Findings are reported succinctly and supported by extracts from the data. The authors suggest attention be paid to the built environment, the role of the family beyond that of visitors, and confirming the person's current and past identity as part of person-centred care.

Öhman & Nygård (2005)	This study explores motives for engagement in chosen daily activities among people living with Alzheimer's. The evidence base for therapeutic activities is outlined and the meaning of activity is described in brief. The choice of setting in the community is justified as addressing a gap in the literature. The sample was purposive and the inclusion criteria are clear. Basic demographics, symptomatology and memory test scores are provided. All participants (*n*=6) were older adults (aged 65 years and above) with Alzheimer's Disease. Individual service user perspectives are addressed in detail.	Local ethical committee approval is referred to. Written and verbal informed consent was reportedly obtained.	Interviews (at least two per participant) and observations (generating 110 pages of notes) were undertaken offering depth and validity. The interview guide is referenced. Both participant and non-participant observations were made to further understand participant engagement in self-chosen everyday occupations. The comparative method of analysis is described sufficiently for replication. There is little evidence of researcher reflexivity and possible bias is not explored. Some reference to the raw data is made in the findings, which are then linked clearly to previous studies and relevant theory.	Although many people live with Alzheimer's disease at home, the small sample size limits generalisability of the study's findings. The conclusion to the study is a fair summary of the findings and the implications for developing supportive interventions. The study calls for support to maintain preferred activities and experience autonomy.	This study promotes the importance of nonpharmacological interventions to support wellbeing in older people living with Alzheimer's in the community. Although the authors acknowledge the lack of theoretical clarity underlying assumptions about occupation, they provide references to relevant work to frame the study. The characteristics of the small sample are provided and the interview guide is adequately described. Interviews were undertaken at least twice and complemented by observations. The process of analysis is well described and the authors allude to their efforts to scrutinise their interpretations throughout each step. The findings are considered within the context of relevant theory. The study suggests identifying facilitators or 'keys' to maintain self-selected occupation and consideration for the importance of the private sphere as a sanctuary.
Phinney, Chaudhury & O'Connor (2007)	This study explores how people living with dementia define meaningful activity and its significance using secondary data. The article draws upon activity theory to introduce the key constructs. The importance of giving voice to the perspectives of people living with dementia is also highlighted. The community setting is justified by gaps in the literature. The sample was recruited via a research centre and a diagnostic support group.	The ethical issue of opportunities to participate in research for people with dementia is discussed as part of the rationale for the study. The necessity of repeated consent processes is	Recorded interviews lasting 45-100 minutes took place three times with each participant. The general nature of the questions posed is described but a topic guide is not provided. Efforts were made to capture lived examples of experiences rather than abstract generalisations. Four to six hours of observations were also conducted and written in field notes so as not to rely solely on recall during interview. The approach to	The study emphasises the importance of providing opportunities for personally meaningful activity as part of dementia care, beyond just leisure past-times. Activity biographies are one suggested mechanism for identifying previously valued activities. The authors encourage social and physical	This study highlights the importance of the person living with dementia remaining engaged with the world around them. The concept of 'meaningful activity' is defined and the study is located within existing knowledge about activity theory. The process of analysis is well described and appropriate for an IPA study. Efforts to enhance credibility are well-described and linked explicitly to the methodology. Evidence for the findings is provided through data extracts which are consistent with the interpretations outlined. The small sample arguably lacks diversity and so the findings are limited to people living with dementia who are white and living at home in

	Inclusion criteria are made clear. Participant characteristics (*n*=8) are described and the homogenous nature of the sample is acknowledged. The study achieves depth of perspective about a variety of experiences through repeated interviews.	described in brief. Ethical approval is not recorded.	interpretive analysis is well described and referenced. Transcripts were checked against audio data. Researcher reflexivity and steps taken to tackle researcher bias are described, such as rigorous discussion and consulting experts in the subject area about emerging interpretations. The findings appear rooted in case examples and supporting quotes.	environments that foster spontaneous activity. Since the study involves analysis of data collected with a different research question in mind from a small sample, it cannot claim to offer a comprehensive picture.	the community. The study concludes that opportunities for meaningful activity should be provided for people living with dementia with a view to helping them feel part of their family and community. Specific strategies are suggested, such as activity biographies and privileging familiarity over structure.
Smebye, Kirkevold & Engedal (2012)	This study explores how people living with dementia participate in decision-making regarding their health and how family carers and professional carers influence such decisions. The introduction explores the importance of autonomy, the construct of competence, and theory about levels of involvement. The latter provided a frame of reference for the analysis, which is evident in the findings. The multi-case design included person with dementia, family member and professional caregiver dyads (total *n*=30). Purposive sampling is cited as an effort to promote diversity. Inclusion criteria and reasons for non-participation are provided. Participant characteristics are made	Informed consent processes are described in detail, taking into account the needs of participants. Ethical issues regarding consent and the solutions found are described. Regional ethical committee approval is provided.	Audio-recorded interviews and observations were undertaken by the same researcher. An interview guide was used and sample questions are provided. How observational data was recorded and organised is unclear. Supplementary data such as memory test scores were also collated. All data for each participant was collected over one to two days. The complex analysis using framework analysis alongside a hermeneutic interpretive approach is described in detail. Efforts to build trustworthiness are also made explicit, such as triangulation of data and discussion between researchers about the influence of pre-understandings. Raw case material and quotes are used to support findings, which are	Whilst the study achieved its aim of an in-depth understanding of patterns of involvement, the findings cannot be generalised due to the small sample size. The settings in which participants lived also varied. The study calls for a shift towards empowering people with dementia to participate in decision-making irrespective of cognitive functioning. This right reportedly needs to be adapted to 'the realism of interdependency in dementia care' (p.10). Health professionals	This study sheds light on how the right to participate in decision-making is exercised in dementia care. A summary of the relevant literature is provided and the article describes the theoretical framework that was used to guide the analysis, which is consistent with the presentation of the findings. People living with dementia in a range of living situations were included as well as family members and formal carers. The authors describe how they adapted their approach to recruitment and consent in consideration of the needs of the client group. Views provided by members of each triad were compared with one another and between groups. Combining interviews with observations provided more comprehensive descriptions of the process of decision-making. Selected quotes and references to observations are used to support the findings described. Pre-understandings were considered and discussed by the authors in light of experiences of clinical practice. The study calls for empowerment for decision-making regardless of cognitive functioning and

	explicit.	linked back to the theoretical framework and other existing studies.	are encouraged to balance needs and facilitate decision-making through participation.	added emphasis to the importance of understanding relationships.

Constructions concerning autonomy

In accordance with the third aim of the current review, a number of themes emerged from the study findings with respect to constructions concerning autonomy (see Table 4). Those focused on decision making identified how support evolved from collaborative to restrictive efforts, where an increasing aversion to risk often resulted in acting contrary to the desire to support decision-making. Where people with dementia were involved in decisions, those decisions could be made autonomously (i.e. independently), pseudo-autonomously (often with a degree of input from others that might become manipulative), shared (joint between two or more people) or delegated. Decision-making was linked with humanity and supported through knowing the person concerned and people working together, simplifying information where helpful and negotiating compromise when necessary.

Activity emerged as important for autonomy, as well as pleasure and a sense of connection. The exploration of mealtime experiences provided a useful example of having meaningful roles both for the purposes of autonomy and reaffirming one's identity. The role of the family member in this, particularly the spouse, was highlighted. People living with dementia talked about being seen and heard, following the ordinary patterns of everyday life and needing a private space. These opportunities relied upon 'keys' or facilitators that could be provided by others in how they related to the person with dementia, supported them to access resources and contributed to an enabling environment.

Despite the slight variation in the focus of the studies, several keywords and phrases which are highly relevant to conceptualisations of autonomy repeated across the findings of the studies reviewed. Independence was one theme which was linked with being in charge of oneself, being in control and being free. For some people this included the right to make unwise decisions. For others, knowing one's own limits, keeping safe and getting help when needed was part of autonomy. Self-expression was an important theme which included expression of desires, wishes, feelings, values, beliefs and creativity. Protesting against one’s situation was perceived as a valid aspect of asserting independence. Creating space for oneself reflected a need for privacy.

Doing purposeful and meaningful activity was another important theme. This activity could be done alone or with others and provided a sense of accomplishment and confidence. One important aspect of doing meaningful tasks with others was making a contribution within the family or community. When alongside others, people sought trust and respect, a sense of being valued, loved and accepted. Other people supported autonomy by recognising the person’s sense of self and knowing their history. Participants also highlighted the importance of having opportunities for personal change both before and after their diagnosis of dementia.

When decisions needed to be made, participants wished to be consulted about both small and big issues. Autonomy involved having options and choice as well as negotiating or compromising when necessary. Autonomy required other people to listen, give their time and provide clear information and, in doing so, enable people with dementia to live the life they wanted to live.

Use of psychological theory

In response to the final aim of the current review, the psychological theories which the studies drew upon in order to frame the research or explain findings were social or relational in nature (see Table 4). Kitwood’s (1997) theory of personhood emerged in seven of the studies. Sabat’s (1994, 1998, 2001, 2005, 2006, 2008; Sabat & Harré, 1992) theories of personal and social identity in dementia were also popular, emerging in seven of the studies, although one also drew upon Hewitt’s (1991) theory of social identity. Clare’s (2002, 2003) work regarding psychosocial factors of awareness (anosognosia) was cited by three of the studies.

Other psychological theories and models utilised in the studies related to couplehood (Kaplan, 2001) and family adjustment (Patterson, 1988). Others referred to later life, the social environment and the importance of activity, including continuity theory (Atchley, 1989), activity theory (Havighurst & Albrecht, 1953) and theory of place and personal identity (Rowles, 1983). General theories of dependency in later life (Baltes, 1996) and challenges involved with living with dementia specifically, such as the loss of social roles (Cheston & Bender, 1999) and the social model of disability (Gilliard, Means & Beattie, et al., 2005), were included. Schwartz's (2000) theory regarding the tyranny of freedom was referred to in direct challenge to the value of individualistic constructions autonomy.

There was a great deal of variation in the extent to which the psychological theories and models were used in the studies. Kitwood's theory of personhood was the most consistently applied overall. Fetherstonhaugh, Rayner and Tarzia's (2016) study made the least use of psychological theory. However, all studies made use of psychological theory to at least a partial extent.

Table 4. Constructions concerning autonomy and associated use of theory for included studies

Study	**Constructions**	**Psychological Theories Utilised**	**Use of Theory Typology*:**			
			Implied	**Partially Applied**	**Retrospectively Applied**	**Consistently Applied**
Berry, Apesoa-Varano & Gomez (2015)	Being independent and a self-directed agent, being aware of your limitations/declining abilities, avoiding risk, expressing a desire to do things, others having confidence in your ability, asking for support and working with others, articulating how you feel	The role of psychosocial factors in awareness during early stage dementia (Clare, 2002; 2003, Clare, Roth & Pratt, 2005)				●
		Personhood and the ability to live within relationships (Kitwood, 1997)	●			
		Personal identity in dementia (Sabat, 2001)				●
Chung (2013)	Independence, initiating and doing purposeful or meaningful activity, making a contribution, taking part in everyday activities, being enabled and stimulated, being trusted and respected with decisions, being kept active, exercising a sense of control, negotiating and taking risks, continuity in interests, relationships and sense of self, having your sense of self recognised by carers	Personhood and the ability to live within relationships (Kitwood, 1990; 1995; 1998; Kitwood & Bredin, 2002)				●
		Personal identity in dementia (Sabat, 2001; 2006; 2008)		●		
Fetherstonhaugh, Rayner & Tarzia (2016)	Being independent, deciding for yourself, being trusted and respected, being involved and consulted regarding decisions about small things and complex things, having options and exercising choice, making decisions/choices that support your identity, having a sense of self, having some control, being listened to, having things explained, being given time, others knowing and being sensitive to your likes/dislikes/abilities/needs, saying no, being encouraged, supported and empowered, working together, participating, feeling valued and needed, negotiating and resolving disagreement, loving and being loved, having opportunities for personal change and the development of new likes/dislikes	The role of psychosocial factors in awareness during early stage dementia (Clare, 2002)		●		
		Couplehood (Kaplan, 2001)	●			
		Personhood and the ability to live within relationships (Kitwood, 1997)		●		
		The survival of sense of self into later stages of dementia (Sabat & Harré, 1992)		●		
Fetherstonhaugh, Tarzia, Bauer et al. (2016)	Having clear options, knowing what you want, choosing what you want, being able to express choices and preferences, carers respecting your decisions, other people knowing your history and your likes/dislikes, being given time to decide, having things explained clearly and effectively, being made to feel relaxed and comfortable, trust, compromise and working around problems	Self-determination: the tyranny of freedom (Schwartz, 2000)			●	
Genoe, Dupuis, Keller et al. (2010)	Independence and freedom, making and expressing your own decisions, having control, other people respecting your choices, emphasising and using your strengths, drawing on your values and preferred routines/traditions, beliefs and spirituality, having meaningful roles and not letting go of them until you have to, making a contribution, being involved and part of things, keeping informed, accomplishment, feeling capable, purposefulness, learning new things, expressing creativity, knowing what you're doing and when to get help, negotiating, being acknowledged, accepted and enabled, being valued and respected, honouring and reaffirming your identity, give and take, others having respect for your uniqueness, giving your view, shared decision-making	Loss of social role and threats to identity (Cheston & Bender, 1999)		●		
		Social identity (Hewitt, 1991)		●		
		Personhood and the ability to live within relationships (Kitwood, 1997)				●
		Family adjustment and adaptation response model (Patterson, 1988)				●
		Personal identity in dementia (Sabat, 1998; 2001; 2002)		●		

Heggestad, Nortvedt & Slettebø (2013)	Making your own decisions in your everyday life, having choice, having freedom, thinking for yourself, knowing what you're saying, expressing your wishes, doing what you like, having choice, being listened and responded to, being known by others, being taken seriously as an individual, being given time	Personhood and the ability to live within relationships (Kitwood, 1997)				●
Öhman & Nygård (2005)	Feeling free, being in command of your life, showing what you can do, showing who you are, doing what you wish (with limitations), being physically active, doing valued activities, accomplishing things, seeking pleasure, making a contribution, maintaining your preferred way of living, being able to go out when you want, creating space for yourself, knowing your own limits, keeping yourself safe, being able to do things with others, being encouraged and supported to do what is meaningful to you	Continuity theory of normal ageing (Atchley, 1989)			●	
		The role of psychosocial factors in awareness during early stage dementia (Clare, 2002)			●	
		Personal identity in dementia (Sabat, 2001)			●	
Phinney, Chaudhury & O'Connor (2007)	Independence, doing things that you enjoy, being in a community that permits or solicits your involvement, being an active participant in the world, contributing in meaningful ways, having a worthwhile life, fulfilling valued roles, doing everything you can for as long as you can, having privacy, being reminded what you can still do	Activity theory (Havighurst & Albrecht, 1953)		●		
		Personhood and the ability to live within relationships (Kitwood, 1997)	●			
		Place and personal identity (Rowles, 1983)			●	
		Personal identity in dementia (Sabat, 1998)	●			
Smebye, Kirkevold & Engedal (2012)	Expressing your values, being free to make 'unwise' decisions, having and discussing options, others knowing you and your life history, being consulted, making decisions on your own terms, others helping you to carry out a decision, authorising others to act on your behalf, protesting	Theory of dependency (Baltes, 1996)			●	
		Social model of disability and dementia (Gilliard, Means, Beattie & Daker-White, 2005)				●
		Personhood and the ability to live within relationships (Kitwood, 1997)				●
		Personal identity in dementia (Sabat, 1994; 2005)				●
		Self-esteem in dementia (Sabat, 1999)	●			

*Typology categories adapted from Bradbury-Jones, Taylor & Herber's (2014) Levels of Theoretical Visiblity Typology: First category (none applied) removed due to inclusion criteria

Discussion

This review systematically examined the qualitative literature to explore constructions concerning autonomy by people living and working with dementia and the use of psychological theory to interpret and inform these constructions. A basic search of five databases produced nine studies from a range of disciplines, following the application of inclusion and exclusion criteria. This suggests that autonomy and dementia is a meaningful concern for various academic and applied disciplines which also draw upon psychological concepts and theories in their work. Interestingly, none of the identified studies involved clinical psychology researchers. All of the studies were published since 2005, despite a number of older non-empirical studies emerging from the literature search. This may have been influenced, at least in part, by the impact on clinical practice of the introduction of the Human Rights Act in 2000 and the Mental Capacity Act in 2005.

The studies investigated the perspectives of a range of stakeholders including people with a diagnosis of dementia, family carers or close relatives and dementia care professionals, in community, residential and inpatient settings. This may reflect an increasing appreciation of the voices of people with dementia, for which qualitative study is arguably appropriate, as well as broad support for person-centred approaches. The popularity of community-based studies may reflect the increasing number of people living with dementia at home (Alzheimer’s Society, 2014b).

Constructions of autonomy when living with dementia

The studies indicated that being free, independent and making decisions for oneself are important aspects of autonomy for some people living with dementia, as promoted in traditional liberal definitions (e.g. Dworkin, 1988). Autonomy was associated with being able to make unwise decisions, as outlined in the MCA, and the right to protest, but also compromising when necessary. Alongside that, however, was the need for options, choice, clear information, and opportunities to be listened to and consulted, which arguably often rely on the social co-operation of other people, as asserted by Nussbaum's (2006) capabilities approach.

Holding a sense of self and identity was described as part of exercising autonomy, which is also evident in the emphasis on self-awareness and being one's own person in Millian and Kantian philosophy (Christman & Anderson, 2005). However, the constructions offered in the studies extended these ideas about autonomy and associated it with retaining valued roles, a sense of personal history, and having opportunities for personal change. The studies described how relationships with other people provided these opportunities and in doing so appeared crucial for experiencing and expressing autonomy when living with dementia, as proposed by proponents of relational autonomy (e.g. MacKenzie & Stoljar, 2013). Doing meaningful activity was considered part of exercising autonomy, which not only required other people but also flexibility in the immediate environment. The right to privacy was also considered important for autonomy.

Autonomy was associated with a number of values including respect and dignity, which are also FREDA principles (Curtice & Exworthy, 2010). The importance of humanity for autonomy was also described, alongside being valued, accepted, trusted and loved. The emotional quality of these ways of being within relationships echoes Post's (1995) insistence that meeting people with dementia on an emotional as opposed to cognitive level may be more enabling. It also relates closely to Sabat and Harre's (1992) theory of self-identity where the positions others take in relation to the person with dementia determine whether the self is brought into being or lost.

Use of psychological theory in constructions of autonomy

Where complex constructs such as autonomy are not outlined explicitly in research studies, reliance upon 'taken for granted' assumptions may serve to privilege an individualistic conceptualisation of autonomy. All of the studies utilised psychological theories and models to inform the constructions concerning autonomy as described by the research participants. The theories utilised were social or relational in nature, with theories of personhood and identity in dementia cited most frequently (Kitwood, 1997; Sabat, 2001). This implies that an individualistic conceptualisation of autonomy might be limited in its utility, applicability and scope. Instead, these theories lend support to constructions of autonomy that promote person-centred care in a relational context.

Theories with a focus away from dementia in particular were used to lend support to a broader conceptualisation of autonomy. Schwartz's (2000) theory regarding self-determination suggests that cultural bias towards freedom of choice leads to dissatisfaction with life and increased risk of depression. Self-determination is considered desirable but within constraints in order to experience optimal functioning. Indeed, Baltes' (1996) theory of dependence considers how productive and creative use of dependence may in fact be necessary to adjust to the losses encountered in old age. Making use of support is considered to free up resources for use in other domains of daily life where personal efficacy and growth can be experienced. Even in the absence of dementia, the cultural ideal of individual autonomy and independence may be misplaced.

Other theories of normal ageing were also utilised by the studies reviewed, with emphasis on the importance of social support. Havighurst and Albrecht (1953) highlight the importance of the community in helping older people to access socially approved roles. Over time, in addition to personal capabilities, family and community are considered increasingly valuable resources. Similarly, Atchley (1989) describes how drawing upon internal experience as well as external structures, such as the social environment, relationships and activities, are important adaptive strategies during later life. Rowles (1983) highlights the importance of place, social connection and personal narrative for sustaining personal identity in older age. The experience of dementia may put additional emphasis on the need for external structures and social connections in order to experience autonomy and well-being.

Patterson (1988) describes cycles of adjustment, crisis and adaptation which families experience while seeking to maintain function by balancing resources with stressors. Kaplan's (2001) typology of couplehood describes the impact of institutionalisation upon perceptions of marriage status among spouses whose loved ones have dementia, describing a range of degrees of affiliation. Gilliard and colleagues (2005) attempt to explore the applicability of the social model of disability to the experience of dementia. These theories highlight the importance of the family unit and social context in minimising or exacerbating the challenges faced by people living with dementia, thereby increasing or denying opportunities to experience autonomy.

Strengths of the studies reviewed

Multiple voices were captured in the studies reviewed, including people with a diagnosis of dementia (*n*=70), their family members (*n*=83) and dementia care professionals (*n*=80). All of the studies went beyond the question of whether people with dementia can make decisions and explored their relational and emotional worlds. Some good examples of efforts to strengthen the studies through triangulation were evident. There were also some good examples of clear approaches to qualitative data analysis, which can be difficult to articulate within word count limits. All of the studies offered interpretations and practical implications that appeared consisted with their respective findings.

Limitations of the studies reviewed

Most of the studies referred to limitations resulting from small sample sizes and a lack of diversity within the samples. Some authors claimed that findings may generalise within the settings in which the studies were undertaken, but qualitative research does not seek to produce a representative sample or make statistical inference. Instead, transferability refers to the applicability of a study’s findings to similar situations. Detailed description of participants and the study context are ways in which transferability might be demonstrated. Where such information is provided, it is possible to consider the clinical implications of study findings.

The samples recruited during most of the studies were from white backgrounds, apart from one which focused on the views of Latina caregivers. Socioeconomic data about the samples was not always provided, but might provide important insight into the impact of poverty and other challenging social contexts. In some cases participants were self-selecting and may have been more engaged with the topic of interest, which may have limited the variety of perspectives encountered. Although a range of types of dementia were represented in the studies, it was not clear from the reports what impact different symptoms and presentations might have had on participant views and experiences.

Ethical considerations were not commonly outlined despite the complexity of consent given the needs of the research population. Not all studies were replicable based on the information provided in the journal articles and in many cases authors would need to be contacted regarding the specific questions that were posed to research participants. Although the importance of researcher reflexivity is emphasised in qualitative methodology there was a clear lack of explicit reports about this, which may have been due to limited word counts, other journal requirements and emphasis on other pertinent information.

Implications for dementia policy and practice

The constructions of autonomy offered in the studies reviewed and the psychological theories used to further inform those views lend support to several policy and community initiatives. All of the studies alluded to the importance of relationships and social context, leading to calls for relationship-centred care for those living with dementia. The Dementia Friends initiative to improve awareness of dementia among the general public and may go some way towards developing dementia-friendly communities. If dementia is considered a disability, investment in community-level interventions like this could have a significant impact upon the ability to live well and autonomously with dementia.

This review has highlighted the particular value of close family and spousal relationships in supporting the autonomy of the person with dementia. The involvement of people with dementia and family carers in decision-making is emphasised in the British Psychological Society's (2016) advisory document 'Psychological Dimensions of Care: Putting the Person at the Centre of Care'. Working alongside family members as care partners and supporting the relationship between the person with dementia and their closest relative should be considered paramount. Where such relationships are absent, efforts need to be made to support the person living with dementia to connect with peers and the wider community.

Meaningful activity is also promoted in the aforementioned advisory document and is reiterated by the findings of this review. Dementia care services would ideally offer information about keeping active and support people with dementia in daily activity that supports social connections. Enabling environments should offer opportunities to be spontaneous and creative, and space for privacy when needed. Whilst occupational therapists have expertise to offer in this regard, facilitating meaningful activity should not be seen as solely their responsibility.

It was noted during the review that attachment theory was not explicitly utilised by the included studies. Whilst informative theories of normal ageing were used, they infer a focus upon older people. Not every person living with dementia would identify themselves as an older person. There may be opportunities to make further use of psychological theory, particular theory employed regularly in the course of clinical psychology practice, to inform the evolving understanding of autonomy and how to effectively support people with dementia to claim their rights.

Implications for clinical psychology practice

Clinical psychologists are often called upon to undertake capacity assessment. The findings of this review imply that this individualistic and cognitive process is likely to be disadvantageous for people living with dementia, despite the intention of the Mental Capacity Act to empower and protect vulnerable people. Not only should assumptions about lack of capacity be avoided, but other people in the system around the person with dementia should be challenged with offering resources to support the person’s autonomy, rather than relying on tests of an individual’s ability to make use of information.

In cases where decisions need to be made according to best interests, the involvement of close and willing members of the person’s family or community network should be an important consideration. This could serve as an important check and balance against the misuse of power by professionals who would otherwise dominate best interest decision-making proceedings. However, it is also important for best interest proceedings to draw upon a range of sources of information in order to safeguard the individual at the centre, particularly in cases where there are concerns regarding familial conflict or malevolent intent on the part of a family member. Additional forms of assessment could incorporate family and personal routines and traditions and assess family coping, with the explicit purpose of considering the impact on the person’s autonomy.

Cognitive analytic formulation can help bring unhelpful patterns of relating into awareness and may be useful to help service users, family members and clinicians to consider how these patterns might play out when considering issues about risk or the need to make decisions (Brown & Lloyd, 2012). Supervision and training to broaden thinking about autonomy, particularly for dementia care staff, would promote more effective ways of supporting people with dementia and their family members. Oakes, Wolverson and Cowell (2017) recently highlighted the need to develop the notion of professional love to allow supportive and transformational relationships to flourish in healthcare settings. Supervision and therapeutic family support may facilitate conversations about the emotional impact of living and working with dementia and identify when concerns about relational risk might be impeding efforts to support autonomy.

Through the current review it became clear that a range of disciplines can contribute towards research and practice to support people living with dementia to claim their rights in the context of their interaction with health and social care services. Interdisciplinarity involves integrating the expertise of different professionals from different disciplines to create new combined knowledge and novel practice (Choi & Pak, 2006). Approaching human rights in an interdisciplinary way may help to bring about a broader vision of ‘how we might best live in a world of others’ (O’Byrne, 2012, p1079). Clinical psychologists arguably have the skills to influence research and clinical practice to rise to this challenge (Butchard & Greenhill, 2015).

Limitations of the review

The high number of duplicates returned by the literature search suggests a great deal of overlap between the databases accessed. Considering the variety of disciplines whose research met the criteria for the review, a wider variety of databases may have yielded additional citations not captured by the original search. Although each study made explicit reference to the relationship between the research and autonomy, the specific focus of each study varied and it is not clear whether the research participants necessarily had the construct of autonomy in mind when taking part. The views of people living with dementia about the construct of autonomy could be sought more explicitly through further research.

The review included published empirical studies but did not include grey literature. Additional sources relevant to constructions of autonomy by people living and working with dementia may be available through grey literature. Only studies available in English were included in the review. The original search returned some studies in other languages where database filters did not screen them out, but resources were not available for interpreting. Non-English language studies may offer a broader range of perspectives.

It was challenging to identify whether theories utilised by the included studies were exclusively psychological. For example, theories that identified themselves as concerned with social psychology were sometimes written by sociologists. As such, there may be some disagreement with the review's inference that the theories identified are psychological.

Conclusion

This review sought to identify the psychological theories used by qualitative research studies to interpret and inform constructions concerning autonomy as offered by participants living and working with dementia. The findings illustrate the importance of social and relational thinking, as well as theories of ageing, family adjustment and disability, in making sense of the experience of dementia and contributing to developing ideas about how to support people with dementia to live autonomously. The review also highlighted the value of interdisciplinary research and practice in making use of existing knowledge and contributing to rights-based approaches. Within limitations, the review calls into question a traditional individualistic conceptualisation of autonomy and indicates an opportunity to further explore the meaning of autonomy according to people living with dementia and subsequently build upon existing rights-based frameworks.

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Chapter 2: Empirical Investigation

The meaning of autonomy when living with dementia: A Q-method investigation[2]

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[2] To be submitted to: *Dementia* (6000 word limit excluding references)

Abstract

Background and aims: Autonomy is considered a core problem for people living with dementia. The liberal tradition of individual sovereignty dominates ideas about autonomy, even though the person-as-individual is not a cross-culturally universal concept. Some critics question whether rights-based approaches embody loose and ill-defined ideas incapable of bringing about meaningful change. This study explored the viewpoints of people with dementia and family carers regarding the meaning of autonomy.

Methods: Twenty participants conducted a Q-sort of statements regarding the meaning of autonomy. A by-person factor analysis was used to identify patterns in how statements were ranked.

Results: Three factors emerged: retaining independence and self-expression, accepting dependence but being included, and opportunity for connection.

Conclusions: The findings suggest a variety of ways of construing autonomy and possibilities for developing rights-based approaches further to better support autonomy in dementia care.

Keywords: Dementia, autonomy, rights-based approaches, Q-method, clinical psychology

Introduction

There are approximately 850,000 people living with dementia in the United Kingdom and a 40 per cent increase by 2025 has been predicted (Alzheimer's Society, 2014a; 2017). Sixty-one per cent of people aged over 65 and living with dementia reside in their own home, with the remainder living in residential or nursing care (Alzheimer's Society, 2014b).

Applying psychological science to rights issues has been actively encouraged within clinical psychology and dementia care (Kinderman, 2007; British Psychological Society, 2009; 2016; Hagenaars, 2016). Human rights can be understood psychologically as codifications of how relationships can be understood and the social obligations we hold as human beings (Kinderman, 2004). Psychological research can be used to inform social policy and clinical practice since it contributes to societal understanding of how personal needs and desires are negotiated and met in social relationships (Kinderman, 2007; Kinderman & Butler, 2006).

The loss of autonomy associated with the experience of having dementia is considered to be a core problem for those living with the condition (DeWaal, 2014). Autonomy is viewed as a fundamental right (Doyal & Gough, 1991) which is protected and promoted in the UK by the Human Rights Act (1998) and in particular in health care settings by Article eight, which incorporates rights to family life, private life, home and correspondence.

The importance of social context and respectful and responsive relationships for people with dementia has been highlighted (Cheston & Bender, 1999; Kitwood, 1997; Sabat & Harré, 1992). Rights declarations have been criticised for underplaying the interdependence and interconnectedness of human experience and framing the person as a separate autonomous individual (Baldwin & Capstick, 2007). An emphasis on the role of social connection may become particularly important as dementia progresses and participation in decision-making becomes more problematic.

Clinical psychologists are well placed to question the assumptions underlying rights language and to collaborate with people affected by dementia to make rights-based approaches more meaningful. The following study explores what autonomy means to people living with dementia, including service users and family carers.

Rights-based approaches

The FREDA principles of Fairness, Respect, Equality, Dignity and Autonomy (Curtice & Exworthy, 2010) are highly valued by the public, particularly when it comes to use of public services (Ministry of Justice, 2008). The National Health Service, the Universal Declaration of Human Rights and the profession of clinical psychology have these principles in common (Butchard & Greenhill, 2015; Department of Health, 2008). A rights-based approach describes the process through which public services can apply these valued principles in practice (Department of Health, 2008). Notably, a rights-based approach should be considered a way of bringing about meaningful change for service users, carers and staff and their inter-relationships, not an end in and of itself (Donald, 2012).

Dementia, autonomy and social context

There is a vast literature regarding autonomy encompassing a range of perspectives with no universally accepted definition. Autonomy is frequently referred to in healthcare and political discourse, but traditionally centres on the liberal notion of self-determination and is reinforced through neoliberal ideology based on independence and consumerism (Fyson & Cromby, 2013; Harding, 2012). These ideals may be unrealistic and at odds with the interdependent nature of care relationships when living with dementia (Holstein, Parks & Waymack, 2011).

Christman and Anderson (2005) describe the core meaning of autonomy as ‘the idea of being one’s own person, directed by considerations, desires and conditions, and characteristics that...are part of what can somehow be considered one's authentic self'(p.3). Kitwood's (1997) theory of dementia recognises personhood as the human being in relation to others, being seen by others to hold a certain status and being worthy of respect. Rather than a result of maturation, personhood is thought to emerge out of interaction with and attachment to others (Agich, 2003; Holstein et al, 2011; Kitwood & Bredin, 1992). Therefore, the key task in dementia care is a way of meeting and creating intersubjectivity, effectively scaffolding and keeping the individual's personhood in being (Kitwood & Bredin, 1992). Studies exploring 'couplehood' and the relational self in assisted living settings support the idea that social interaction, valued social roles and supportive others contribute to the maintenance of autonomy and selfhood (Perkins, Ball, Whittington & Hollingsworth, 2012; Wadham, Simpson, Rust & Murray, 2015).

Supporting autonomy in clinical practice

Psychologists are encouraged to deliver training and to provide the necessary support to the health and social care workforce to deliver excellence in dementia care, including upholding and asserting the rights of people affected by dementia (British Psychological Society, 2016). Clinical psychologists in particular have expertise in consultation and organisational change to support rights-based approaches (Butchard & Greenhill, 2015).

The MCA was introduced to protect vulnerable people who are not able to make their own decisions (Brown & Lloyd, 2012). The test for capacity stipulated by the Act is a codification of common law understandings of the right to autonomy and how it might operate (Coggon & Miola, 2011; Harding, 2012). In practice, the individual and highly cognitive focus of the MCA is arguably reductionist and risks making autonomy redundant once a person's capacity is questioned (Peel & Harding, 2015). This has led to calls to recognise the importance of relationality when it comes to exercising autonomy and attending to the background social, political and economic conditions against which choices are made (Sherwin & Winsby, 2010; Brown & Lloyd, 2012).

Social constructionism

Human rights can be considered part of a context-dependent and socially constructed discourse (Miller, 2010), providing a framework about ‘how we might best live in a world of others’ (O’Byrne, 2012, p1079). According to social constructionism, traditions of meaning are ‘taken-for-granted’ assumptions that are historically and culturally situated (Gergen, 2009).

When people make a claim to truth, social constructionism posits that they are not claiming their description offers a true picture of the world. Instead, they are offering the words that have come to function as truth-telling according to the shared conventions and interactions of particular groups (Gergen, 2009). These claims to truth are ‘legitimate in the traditions in which they were created’ (Gergen, 2009, p.4). However, when a construct moves away from its grounding in a specific tradition, undesirable possibilities such as constriction, conflict, and oppression can result (Gergen, 2009).

The goal of research, according to social constructionism, is to explore ‘taken for granted’ constructions and a variety of alternative understandings. From this, an integration of perspectives can emerge (Galbin, 2014). The researcher’s task is to participate in generative discourse to challenge existing understandings and develop new pathways for action (Gergen, 2009). The current investigation is based upon this premise and seeks to explore as yet unheard viewpoints about the meaning of autonomy when living with dementia.

Q-methodology offers a systematic means to examine human subjectivity (McKeown & Thomas, 2013). Simply establishing a viewpoint can powerfully impact upon practice if it contradicts or undermines established preconceptions (Watts & Stenner, 2012). Therefore, Q-methodology was selected for the current project to answer the following question: what does autonomy mean to people living with dementia?

Use with people living with dementia. Q-methodology has been used in previous research to elicit the views of people with dementia. It has been used to assess chronic pain using a 30-card Q set with 13 people with Alzheimer's disease (Forrest, 2010). A recent study included the views of people with dementia regarding the factors that contribute to high quality end of life care (Hill, Mason, Poole, Vale & Robinson, 2016). Q-method has also been used to evaluate the acceptability of adapted dementia care mapping with patients with a range of neurological conditions (Westbrook, McIntosh, Sheldrick, Slurr & Hare, 2013).

Study Aims

The aims of the study were:

1. To further understand the range of subjective viewpoints that people living with dementia, including people with a diagnosis of dementia and family carers, might hold regarding the meaning of autonomy.
2. To consider how these viewpoints might open up new possibilities for action to support autonomy in dementia care services, particularly in relation to the role of the clinical psychologist.

Method

Q-methodology

Q-methodology consists of two stages. Firstly, a variety of methods are used to generate as full a range of statements as possible about a particular topic, known as the ‘concourse’. Statements about the topic of interest are extracted, collated and grouped into themes to produce a manageable number of representative items called a ‘Q-set’.

Secondly, participants are asked to rank the statements in a Q-set according to the extent to which they agree or disagree, using a grid featuring a ‘forced choice distribution’ (from agree to disagree with neutral at the centre). Groups of participants who rank the statements in a similar way can then be identified.

Sampling

Q-methodology participants are selected due to their special relevance to the goals of a study (McKeown & Thomas, 2013). Purposive sampling was used to recruit participants with experience of dementia through an older adult community team within a local National Health Service Trust. A briefing session was held during a team meeting to support recruitment. Short presentations were held at a service user forum and at a memory group. The majority of participants self-selected in response to the advertisements at these meetings. Additional participants were sought through team clinicians in an effort to increase diversity within the sample.

Participants

Watts and Stenner (2012) recommended that the number of participants in the Q-sort stage of the research should not exceed the number of statements they are asked to rank. Balance and coverage of viewpoints is important, but participants with cognitive difficulties benefit from a less complex research process. Phrasing the statements in short and clear sentences and reducing the number of statements is advised (Watts & Stenner, 2005a; Westbrook et al, 2013).

The inclusion and exclusion criteria utilised are outlined below (see Table 5):

Table 5. Inclusion and exclusion criteria

	Inclusion Criteria	**Exclusion Criteria**
Stage 1: Interviews	• A family carer of a person with dementia • A person with a diagnosis of dementia • A dementia care professional • Fluent and literate in English • Capacity to consent to and complete an interview	• A person with dementia who lacks capacity and cannot provide consent • A person with dementia who is not able to understand interview questions • Inability to read or speak fluently in English
Stage 2: Q-sorts	• A family carer of a person with dementia • A person with a diagnosis of dementia • Fluent and literate in English • Capacity to consent to and complete reading and sorting tasks	• A person with dementia who lacks capacity and cannot provide consent • A person with dementia who is not able to understand and sort statements • Inability to read or speak fluently in English

Ten participants were sought for the interview stage including people with dementia, family carers, and dementia care professionals (see Table 6). Twenty participants, including people with dementia and family carers, were recruited to complete the Q-sort stage (see Table 7). People with dementia and carers who participated in the first stage were invited to opt in to the second stage.

Table 6. Participant characteristics (interview stage)

Role	**Gender**	**Marital Status**	**Age Range**	**Ethnicity**	**Years of experience of dementia**	**Education History**	**Employment History**	**Religion***

Person with dementia	Male	Widowed	61-70	White British	4 years	Diploma	Nurse	CofE
Daughter carer	Female	Single	51-60	White British	10 years	Secondary school	Business owner	Catholic
Person with dementia	Male	Divorced	71-80	White British	18 months	Apprenticeship	Electrician	CofE
Person with dementia	Male	Married	71-80	White British	2 years	Degree	Civil servant	None
Spouse carer	Female		61-70	White European		Degree	Lecturer	Buddhist
Person with dementia	Male	Married	61-70	White British	2 years	Apprenticeship	Manager	None
Spouse carer	Female		61-70	White British		Degree	Teacher	Catholic
Professional	Female	Married	41-50	White British	8 years	Degree	Speech and language therapist	None
Professional	Female	Married	41-50	White British	22 years	Degree	Nurse	None
Professional	Female	Married	41-50	White British	17 years	Degree	Occupational Therapist	None

*CofE – Church of England

Table 7. Participant characteristics (Q-sorts)

Role	**Gender**	**Marital Status**	**Age**	**Ethnicity**	**Years of experience of dementia**	**Education History**	**Employment History**	**Religion***
Person with dementia	Male	Widowed	61-70	White British	4 years	Diploma	Nurse	CofE
Daughter carer	Female	Married	41-50	White British	10 years	Diploma	Administrator	Catholic
Person with dementia	Female	Divorced	71-80	White British	18 months	Secondary school	Pub manager	Catholic
Daughter carer	Female	Single	51-60	White British	10 years	Secondary school	Business owner	Catholic
Spouse carer	Female	Married	71-80	White	3 years	Secondary	Homemaker	None

				British		school		
Person with dementia	Female	Married	81-90	White British	3 years	Degree	Teacher	CofE
Spouse carer	Male		81-90	White British		Degree	Manager	CofE
Person with dementia	Male	Divorced	71-80	White British	18 months	Apprenticeship	Electrician	CofE
Person with dementia	Male	Married	71-80	White British	2 years	Apprenticeship	Joiner	None
Spouse carer	Female		71-80	White British		Secondary school	Homemaker	None
Person with dementia	Male	Married	81-90	White British	2 years	Degree	Civil servant	None
Spouse carer	Female		61-70	White European		Degree	Lecturer	Buddhist
Person with dementia	Male	Married	61-70	White British	2 years	Apprenticeship	Manager	None
Spouse carer	Female		61-70	White British		Degree	Teacher	Catholic
Person with dementia	Male	Co-habiting	61-70	White British	3 years	Secondary school	Business owner	None
Person with dementia	Female	Married	61-70	White British	4 years	Diploma	Nurse	None
Spouse carer	Male		61-70	White British		Diploma	Support worker	None
Person with dementia	Male	Married	61-70	White British	6 years	Diploma	Train driver	Catholic
Person with dementia	Male	Married	71-80	White British	10 years	Degree	Accountant	None
Spouse carer	Female		61-69	White British		Secondary school	Teacher	None

*CofE – Church of England

Ethical considerations

Ethical approval. Ethical approval for this study was granted by the NRES Committee North West and Health Research Authority on 9th August 2016 (REC reference 16/NW/0528) (see Appendices 8 to 11).

Consent. Participants expressed their interest via telephone or email and were given copies of the participant information sheet to consider (see Appendix 12). The information sheet made explicit reference to the need for all participants to be able to provide consent to participate at the research appointment and how their capacity to do so might vary over time. Care co-ordinators were informed of expressions of interest made by people under their care who were living with dementia, which provided an opportunity for clinicians to monitor potential participants and to raise concerns regarding capacity prior to the research appointment. At the research appointment the participant information sheet was provided again by the researcher (S.W.). If participants agreed to take part, written informed consent was obtained at the point of participation immediately prior to completing the research tasks (see Appendix 13). In the event that a participant was deemed to lack the capacity to consent at that point, contingency plans were in place to offer alternative means of making a contribution, if appropriate, and to inform their care co-ordinator.

Step 1: Generating the Q-set

The Q-set was developed via a literature review and interviews involving dementia care professionals, people living with dementia and family carers.

Generating Statements from the Literature. An electronic search was undertaken using the keywords ‘autonomy’ and ‘dementia’. A selection of 35 empirical and non-empirical academic papers focusing on autonomy or closely related concepts were read in full (see Appendix 14). Statements pertaining to the meaning of autonomy were extracted and collated in a database.

Interview topic guide. A topic guide was developed through consultation between the research team members and was designed to explore the participants’ understanding of the term ‘human rights’, experience of dementia, roles and responsibilities, experience of decision-making and types of support (see Appendix 15). During the interview, participants were asked for reflections in response to a quote providing a definition of autonomy adapted from Curtice and Exworthy (2010):

> ‘Autonomy is being allowed to make free choices about what happens to you, deciding this based on information and acting upon your decision’

The definition was provided since the term autonomy might not be familiar to all participants. The research team discussed whether this might prejudice the participants’ statements during interviews. The interview guide was developed to prompt discussion about the relevance and limitations of the definition according to participants' experiences of dementia.

Procedure. Interviews were conducted at a local community hospital or at the participant's home according to their preference and convenience. Couples who both wished to participate were interviewed jointly. All interviews were audio-recorded as per written consent. Interviews were transcribed by an external agency under a confidentiality agreement.

Development of final statements. Interview transcripts were read and statements pertaining to the meaning of autonomy were extracted. Two members of the research team (S.W. and J.D.) met to review the statements by printing out each one and organising them into themes (see Appendix 16).

Once the full range of possible themes was identified, the statements under each theme were reviewed by the team and a single sentence or phrase chosen to capture the essence of each theme. Effort was made to retain original wording and to choose statements that were clear and concise. This was a dynamic and time consuming process which involved constant discussion between researchers and several iterations, resulting in a Q-set of 24 statements (see Table 8).

Pilot. In order to ensure that the Q-set was suitable, the Q-sort procedure was piloted by a volunteer living with dementia. Subsequently, four statements were edited and four statements were removed. The final Q-set was printed on yellow cards for better visibility, with a number representing each statement printed on the front.

Table 8. The final Q-set

Statements
Other people taking decisions for you
Being helped to see things from different perspectives
Being free to make unwise decisions and take risks
Having a use and giving back
Being able to say no
Being given the time to think and weigh things up before making decisions
Being included in decision-making that concerns you
Needing help from professionals in order to do things
Using technology to have freedom and keep safe
Being given the chance to be listened to
Making decisions based on your values
Being given the opportunity to understand what's happening to you
Making decisions about the small things that matter to you
Someone being with you who can make you feel good - then you can make good decisions
Having user-friendly systems
Other people knowing you and your history very well
Other people listening to what you want now
Being kept active
Being in charge of yourself, what you think and what you want
Being given resources to make free choices
Being recognised by other people as an individual with memories
Being able to express who you really are
Being able to cope with your feelings about what is happening to you
Doing the things that you did before, just with limitations

Step 2: Administering the Q-sort

Procedure. Q-sorts were undertaken at a local community hospital or at the participant's home. Where couples were taking part, Q-sorts were completed individually starting with the carer to reduce response bias where the person being cared for wished for their partner to be present during their own Q-sort. Observing carers were asked to refrain from interjecting. The researcher supported participants with dementia by reiterating instructions and highlighting any ranking of the statements which appeared incongruous with verbal utterances.

Participants were given a sheet with the stimulus question 'what does autonomy mean to people living with dementia?' and three boxes marked 'agree', 'neutral' and 'disagree' (see Figure 2). They were asked to read through the Q-set and form three piles according to whether they agreed, disagreed or felt neutral about each statement, drawing on their personal views and experiences. Any reflections or comments were recorded as notes.

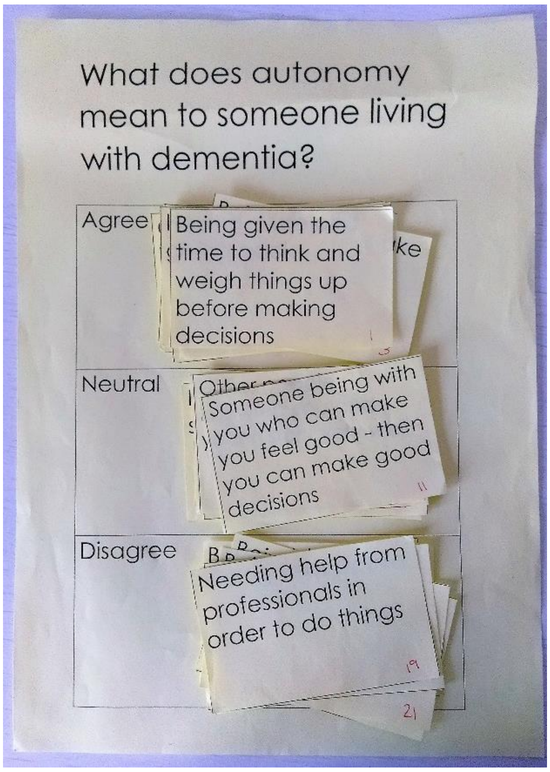
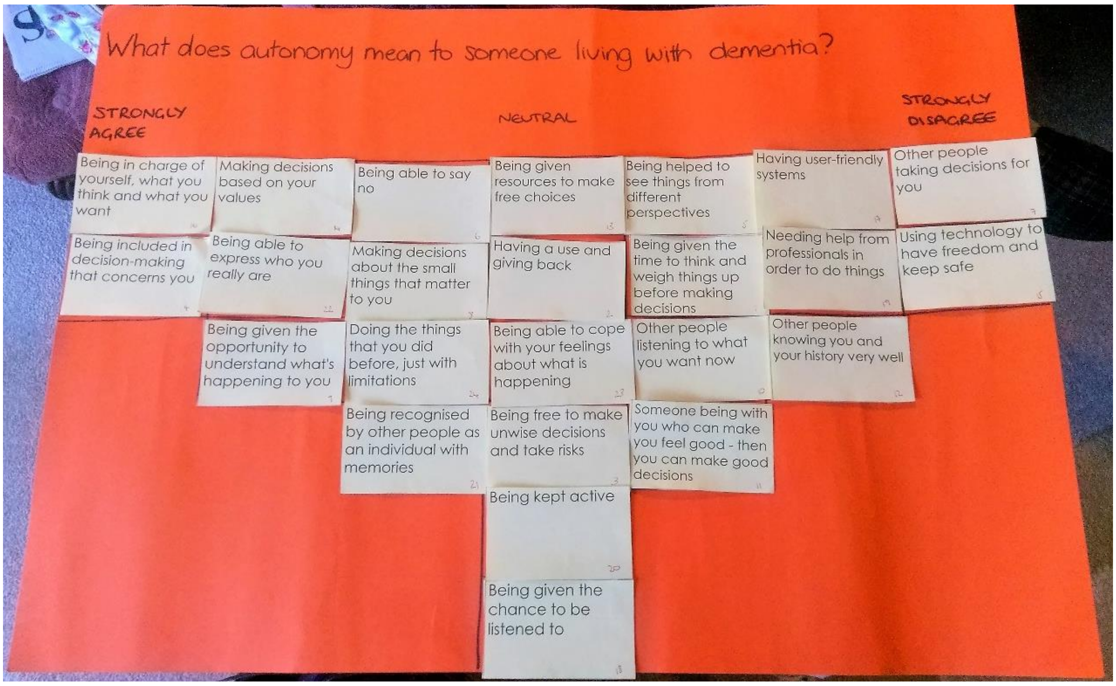


Figure 2. Q-sort initial task

The participants were then introduced to the Q-sort grid and invited to organise the statements in response to the same question indicating their level of agreement (see Figure 3). Participants started with the statements they agreed with, chose two they agreed with most strongly and placed them at the +3 position on the grid. They then placed statements across the grid along the agree continuum until all agree statements were placed. They considered the statements they disagreed with, chose two they most disagreed with most strongly and placed them at the -3 position. Finally they placed the neutral statements around the 0 position. Participants were informed that they could move statements around until they were happy with the completed grid. Comments offered during the task were recorded as notes.

Figure 3. Example of a completed Q-sort grid



Step 3: Data analysis

In a Q study, by-person factor analysis is used to illuminate groups of people who have ranked the different statements in a Q-set in a similar way (Watts & Stenner, 2012). The covariation of the rankings made by the people within these groups is thought to indicate that their individual Q-sorts are manifestations of latent factors (Watts & Stenner, 2012). By interpreting these emergent factors using the statistical output from factor analysis alongside field notes, it is possible to understand the nature of the opinions expressed about a given topic. In the current study, by-person factor analysis was undertaken using a free software programme called PQMethod (Schmolck, 2014).

Factors were extracted using Brown's (1980) centroid factor analysis method. An attempt was made to extract four factors in accordance with Watt & Stenner's principle of one factor for every six Q-sorts (Watts & Stenner, 2012, p.197). Factors with eigenvalues over 1.00 were deemed significant in line with the Kaiser-Guttman criterion (Guttman, 1954; Kaiser, 1960, 1970). However, factor loadings indicated that only three factors reached significance levels. Minimum loadings were identified via the automatic flagging feature in PQMethod.

Results

Three factors were identified: retaining independence and self-expression, accepting dependence but being included, and opportunity for connection. The emergent factors accounted for 42% of the variance, which is 'the proportion of the meaning and variability in a Q study that is held in common' by the participant group (Watts & Stenner, 2012, p.98).

The extent to which a participant's individual Q-sort overlaps each emerging factor is represented by the factor loading, ranging between zero (no match) and one (perfect match) (see Table 9). Overall, twelve out of twenty participants loaded significantly on a factor and no participants loaded on more than one .

Table 9. Factor matrix of all participants' loadings on each factor

Participants	Factor 1	Factor 2	Factor 3
1	0.5865	-0.2770	-0.5437
2	0.4668	-0.2981	0.4453
3	0.5154	-0.4159	0.4403
4	0.6967*	0.1242	-0.1723
5	0.3401	-0.1910	-0.2731
6	0.3401	0.2558	0.4553*
7	0.8275*	-0.4566	0.0808
8	0.2458	-0.4578*	0.3048
9	0.5353*	0.3406	0.3829
10	0.3942	0.1441	-0.1504
11	0.6552*	-0.2639	-0.3289
12	0.2815	-0.0035	0.1616
13	0.1701	0.5357*	0.0494
14	0.4811*	0.1614	-0.0164
15	-0.1418	0.3554	0.2495
16	0.3262	0.3672	-0.2657
17	0.5590*	0.1299	-0.0306
18	0.8907*	0.0326	0.1399
19	0.2850	0.4026*	-0.1702
20	0.4224*	0.2067	-0.1373
% Variance	25	9	8

*Significant loading determined by automatic flagging

Eight participants loaded on factor one, three loaded on factor two and one participant loaded on factor three (see Tables 10-12). Of the three who loaded on factor two, participant eight loaded negatively, which indicates that they expressed the opposite opinion.

Table 10. Demographic information for participants who significantly loaded on Factor One

Participants	Experience of dementia (years)	Gender	Age Range	Marital Status	Employment History	Religion
People with dementia 3	2-6 Average 3.7	Male 3	60-79	Married 3	Joiner Manager Train Driver	None 2 Catholic 1
Relatives/Carers 5	2-10 Average 5.8	Male 2 Female 3	60-89	Married 4 Single 1	Business owner Manager Lecturer/Teacher Support worker	None 2 Catholic 1 CofE 1 Buddhist 1

Table 11. Demographic information for participants who significantly loaded on Factor Two

Participants	Experience of dementia (years)	Gender	Age Range	Marital Status	Employment History	Religion
Participants with dementia 2	1.5-10 Average 5.75	Male 2	71-80	Divorced 1 Married 1	Electrician Accountant	CofE 1 None 1
Relatives/Carers 1	2	Female 1	61-70	Married 1	Teacher	Catholic 1

Table 12. Demographic information for the participant who significantly loaded on Factor Three

Participants	Experience of dementia (years)	Gender	Age Range	Marital Status	Employment History	Religion
Participants with dementia 1	3	Female 1	81-90	Married	Teacher	CofE
Relatives/Carers 0	N/A	N/A	N/A	N/A	N/A	N/A

Factor One – Retaining independence and self-expression

Out of the eight participants who endorsed this viewpoint, five were carers (two males and three females) and three were men living with dementia of the Alzheimer's type. The majority (7/8) were married or co-habiting and all had previously been in paid employment. There was a wider range of ages among the carers in this group compared to the other factors.

Table 13. Distinguishing statements for Factor One

Statement	**Q-sort Value**
Being included in decision-making that concerns you	+3
Being able to express who you really are*	+1
Being able to cope with your feelings about what is happening to you*	0
Needing help from professionals in order to do things*	-3

*Significance at p<0.01

The most important thing for this group is being involved in decision-making that concerns them (+3) or, ideally, exercising their own judgements and choices (see Table 13 and Appendix 17). They seek to make sense of their condition and situation (+2) and draw upon their values (+3) and sense of self-identity (+1) to manage independently day-to-day. Deciding about the small things for oneself (0) and being able to adapt emotionally to one's situation (0) were also rated more positively in this factor compared to Factors 2 and 3.

This group prefer not to rely upon technology (-2) and although they feel a sense of connection was important in general, they do not value being with others who can make them feel good above self-determination (-1) when it comes to exercising autonomy. They are particularly averse to the over-involvement of health and social care professionals (-3) or other people taking decisions on their behalf unless necessary (-3). This group value person-centred care and seek the involvement of close family members when necessary.

Factor Two – Accepting dependence but being included

One female carer and one male living with vascular dementia positively loaded on this factor. A man living with Alzheimer's loaded negatively on this factor, which means he endorsed the opposite opinion. The latter lived alone and the other two were cohabiting with their spouses.

Table 14. Distinguishing statements for Factor Two

Statement	**Q-sort Value**
Someone being with you who can make you feel good – then you can make good decisions*	+3
Doing the things that you did before just with limitations	+3
Being included in decision-making that concerns you	+2
Other people taking decisions for you*	+2
Having user-friendly systems	+1
Using technology and having freedom to keep safe	0
Being in charge of yourself, what you think and what you want*	-3
Having a use and giving back*	-3

*Significance at $p<0.01$

For this group continuing with routines is important, as well as maintaining interests and roles post-diagnosis, by working around the limitations that they confront (+3) (see Table 14 and Appendix 18). A key aspect of this is being in the company of others day-to-day who have the skills and ability to make them feel good, particularly their life partners (+3). The group value user-friendly systems (+1) and willing listeners (+1) in helping them to achieve their goals, but accept that other people taking decisions on their behalf (+2) might be necessary. They prefer these people to be friends or family members who they trust.

This group are not concerned with other people being interested in their memories in particular (-1) and they do not consider having a use and giving back as important for autonomy (-3). In contrast to the viewpoint expressed in factor one, this group do not seek to be in charge of themselves (-3). They feel neutral about having the resources to make free choices (0), having access to technology (0) and being able to take risks (0), and they do not place as much emphasis on being able to say no (0) and making decisions based upon personal values (0), compared with the other two groups.

The participant with a negative loading on this factor expressed a strong a wish to decide his own destiny. In the here and now he associated autonomy with complete independence and making informed decisions for himself alone, which he regarded as necessary for a person living alone and lacking reliable support. The participant described difficulty with the idea of other people, including close family or partners, influencing or taking decisions for him. He described dependence on others as an inevitable but dreaded consequence of advancing dementia. The views of this participant contrasted with those expressed by participants loading on Factor One, who preferred independence but were willing and open to seeking support from trusted family or friends as and when it was needed.

Factor Three – Opportunity for connection

The participant who loaded on this factor was an older female living with Alzheimer's co-habiting in a deprived area. Although other participants described religious upbringings, this participant expressed a deeper commitment to her faith, which appeared to influence her attitude to her condition and her views about autonomy. She expressed a real interest in meeting and new people, which she described as an opportunity for stimulation, sharing stories and being of service to others.

Table 15. Distinguishing statements for Factor Three

Statement	**Q-sort Value**
Being helped to see things from different perspectives*	+3
Being kept active	+3
Being recognised by other people as an individual with memories	+2
Being included in decision-making that concerns you	0

*Significance at p<0.01

This group place importance on being kept active (+3) and being supported to see things from different perspectives (+3) (see Table 15 and Appendix 19). Compared to the other two factors, this group emphasise the importance of being seen as individuals with memories (+2), retaining the right and ability to say no (+2) and having a use and giving back (+1). They do not seek to be included in decision-making (0) to the same extent and prefer not to take risks (-2). Adapting emotionally to what is happening (-3) and expressing sense of self (-3) were also not considered important.

Discussion

Summary of the findings

This study has given voice to people affected by dementia and has helped to facilitate integration of new perspectives (Galbin, 2014) regarding autonomy as a human rights principle and social obligation (Kinderman, 2004). There has been some debate regarding whether autonomy should be conceptualised as individual or relational (e.g. Harding, 2012). However, the factors that emerged in this study challenge neoliberal influences on the language of human rights (Fyson & Cromby, 2013) and suggest a range of perspectives indicating a more complex relationship than this binary distinction.

Factor One emphasised independence, individuality and self-expression akin to Christman and Anderson's (2005) conceptualisation of autonomy. A lack of desire for professional involvement was clear. However, the importance of having opportunities for self-expression and valued social roles was evident and is supported by theories of normal ageing and loss in dementia (Cheston & Bender, 1999; Havighurst & Albrecht, 1953). The intention to remain at the forefront of decision-making and to maintain independence in spite of dementia may indicate a powerful desire to resist the effects of the condition.

Factor Two described adapting to life with dementia with the support of spouses and close relatives, echoing research about the role of couplehood in dementia (Perkins, Ball, Whittington & Hollingsworth, 2012; Wadham, Simpson, Rust & Murray, 2015) and theories of intersubjectivity (Kitwood & Bredin, 1992). Adapting to limitations and a willingness to entrust other people with decision-making may suggest greater acceptance of the realities of living with dementia and an emphasis on getting needs met wholly through relationships (Kinderman, 2007; Kinderman & Butler, 2006). In contrast, the opposite viewpoint suggested anxiety about relying upon others to such an extent. This raises the question of whether prior experiences within relationships or attachment styles might influence views of autonomy and ways of coping.

Factor Three emphasised the importance of people taking a position of curiosity towards one another and not interacting as strangers, emphasising the importance of personal interconnections for autonomy (Kitwood & Bredin, 1992; Kitwood, 1997). It was also suggested by the participant concerned that valuable and empowering connections might be experienced through spirituality, not just through interactions with other people, which is supported by previous research (Agli, Bailly & Ferrand, 2015).

Limitations

This study has value in helping to establish previously unheard viewpoints (Watts & Stenner, 2012). The factors that emerged in this study have been generated through responses to the statements used in the Q-set and it is possible that different factors would be extracted if other statements had been included. Additional sources could have been used to generate the concourse, including social media.

Diversity within the sample was discussed among the research team in recognition of the variety of meanings that the concept of autonomy might hold for people with different life experiences, which might be influenced by education, socioeconomic status or ethnicity. All participants were White European and most had prior employment in professional roles. Many participants were engaged in service user participation initiatives, which suggests that they were a relatively empowered and motivated group. These shortcomings may have limited the breadth of perspectives captured by the study.

However, not all participants in the sample were familiar with the term autonomy at the outset of the study. The use of a definition of autonomy during the interview stage may have unduly influenced the perspectives expressed by participants. The lack of familiarity with the term autonomy is noteworthy when considering the extent to which human rights language is meaningful for people in receipt of public services (Donald, Watson & McClean et al., 2009).

Clinical Implications

In accordance with a social constructionist approach, the findings of this study allow for consideration of new pathways for action (Gergen, 2009) to develop rights-based practice. The findings indicate that a 'one size fits all approach' to thinking about and supporting autonomy is of limited utility for people with dementia. Training about different viewpoints among people living with dementia would assist staff in providing more meaningful rights-based care. Early assessment of attitudes and preferences may help counter assumptions about values, priorities and what is expected from professionals.

When making use of the Mental Capacity Act and supporting autonomy in general, clinicians would be advised to incorporate action that facilitates the continuation of valued social roles and which harnesses the empowering potential of valued relationships. Rather than focusing upon the abilities of the person with dementia in an atomistic fashion (Peel & Harding, 2015), assessments should take the person's immediate social context into account and consider where action may be taken within the system of care to better support a person's autonomy (Sherwin & Winsby; Brown & Lloyd, 2012). Where best interest decision-making is necessary, the clinician would be advised to collaborate in partnership with the person, the family unit and the system of care around them in a person-centred and pro-active fashion. By taking steps to foster greater co-operation, people with dementia may be supported into a position of capability to exist and function as they wish (Nussbaum, 2006). Arguably clinical psychologists are well placed to model and promote this stance and to influence organisational change (Butchard & Greenhill, 2015).

Future Research

The views of people with learning disabilities who also have dementia were not explored in this study, which is a limitation and important for future investigation. There is a higher prevalence of dementia among people with learning disabilities, but greater disparity in the availability of timely diagnosis and effective care (Voluntary Organisations Disability Group, 2016). The vulnerabilities of older people with dementia and people with learning disabilities have also been highlighted previously (Department of Health, 2012).

Dementia care professionals were not included in the Q-sort stage. Contrasting the views of staff working within different settings and comparing perspectives of service users, carers and professionals could make a worthwhile contribution to practice. The findings of this study indicate that technology is not helpful or of interest for some people with dementia, but this may reflect cohort effects and could be investigated again in future.

It remains unclear what influence views of autonomy and personal values have upon how people living with dementia wish their care to be organised. Future research could seek to elicit predictors of where, how and what care people go on to receive post-diagnosis.

Conclusions

Autonomy means more than independence and self-determination for some people living with dementia. Service user preferences and the role of relationships should be considered paramount when supporting people with dementia to live autonomously. In light of the findings, clinical psychologists are positioned to offer more meaningful rights-based training, contribute to the evolution of capacity assessment, and model effective person-centred practice.

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Appendices

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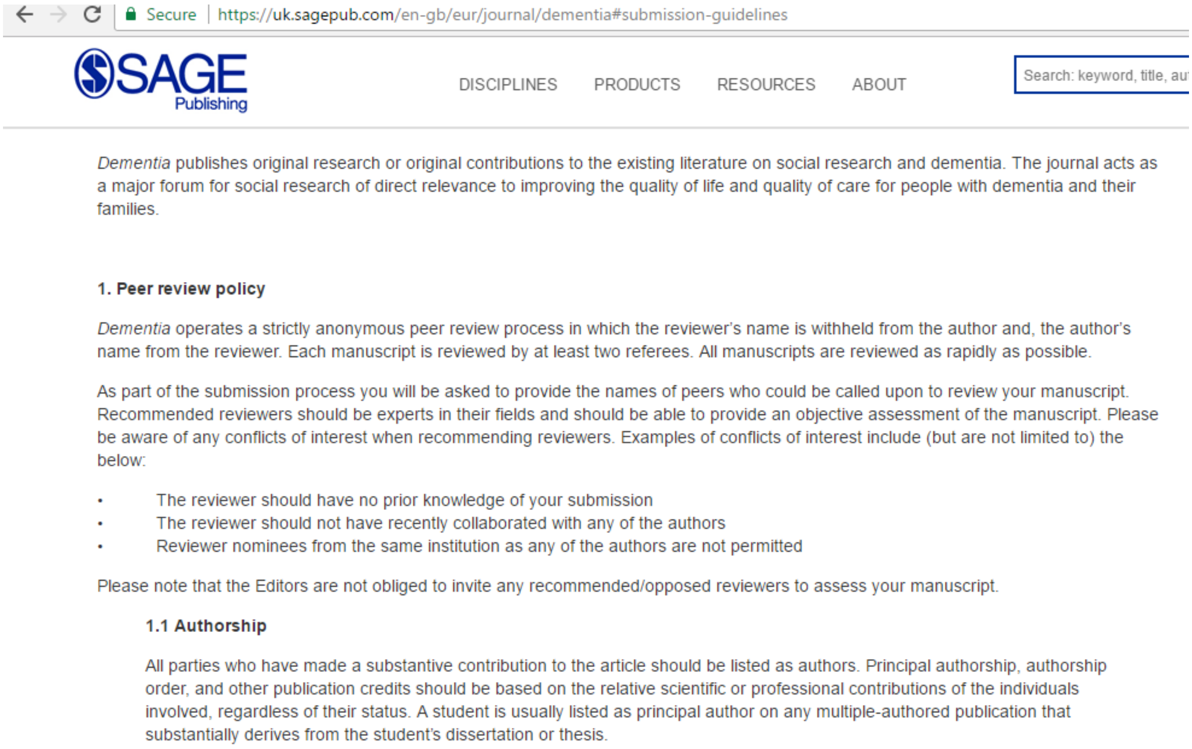

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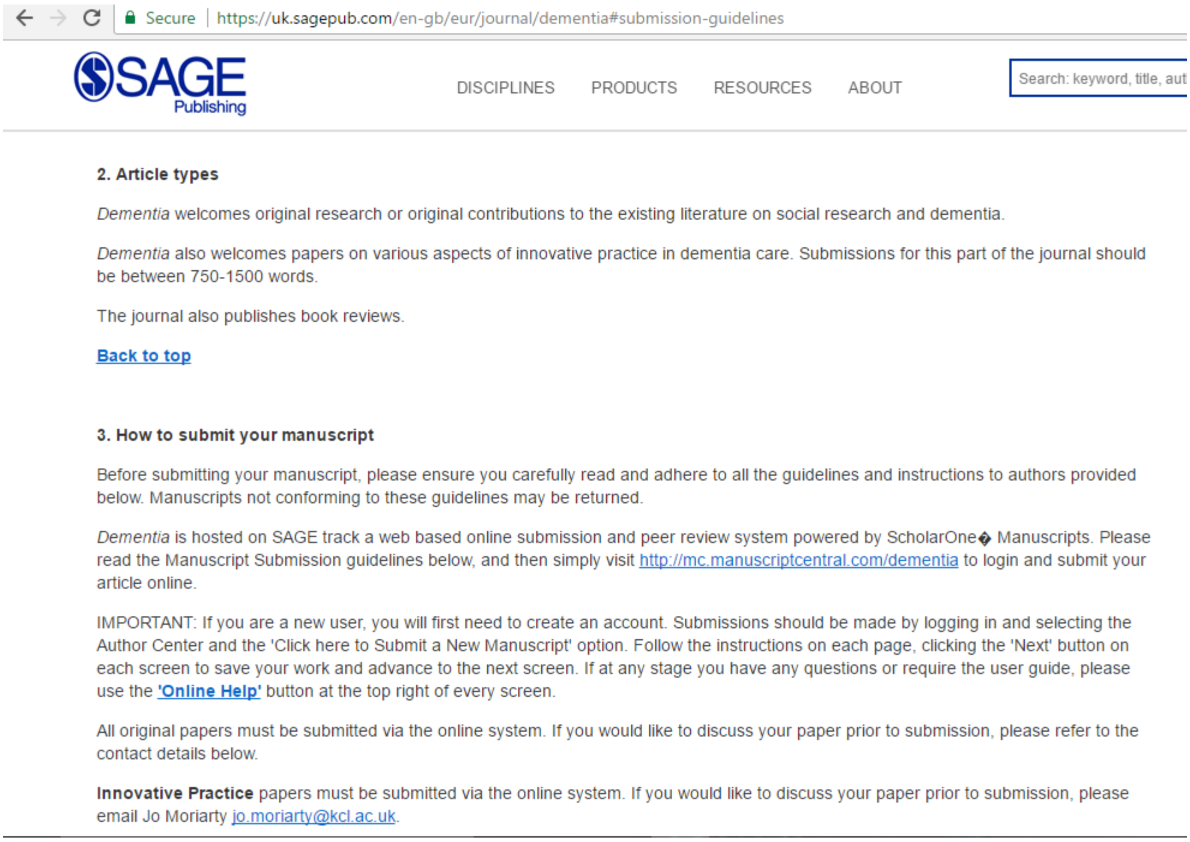

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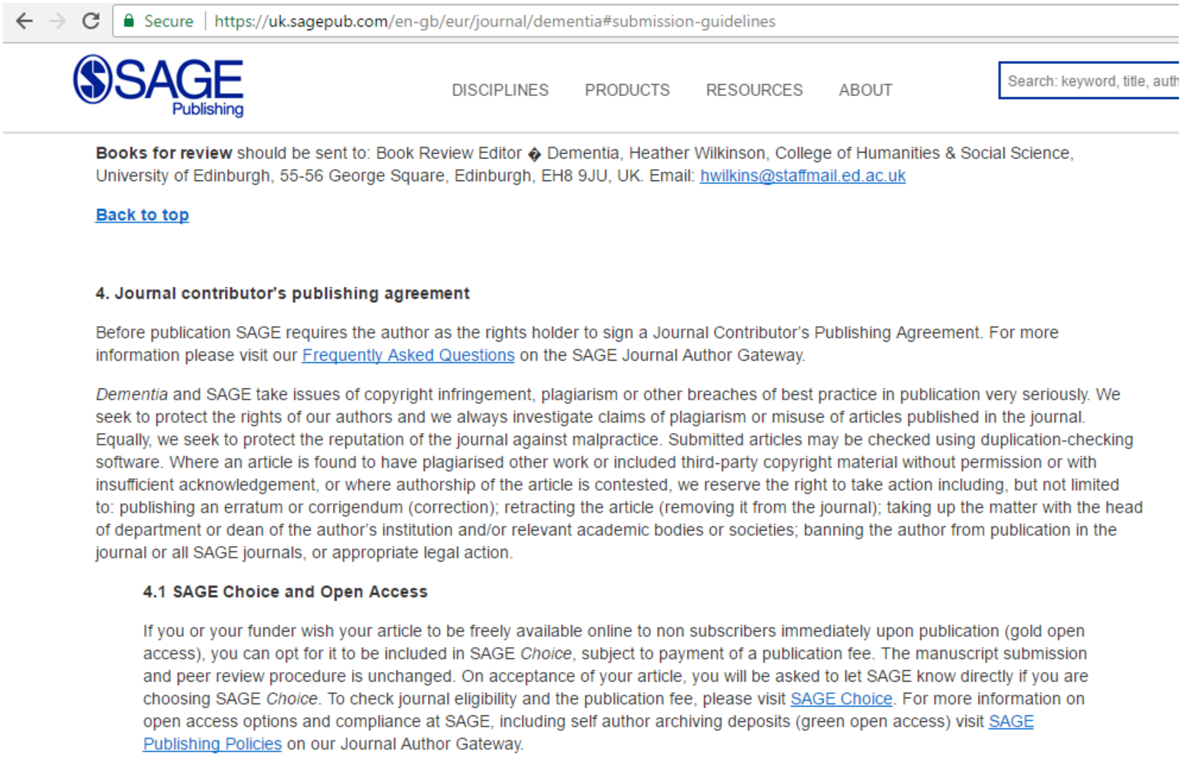

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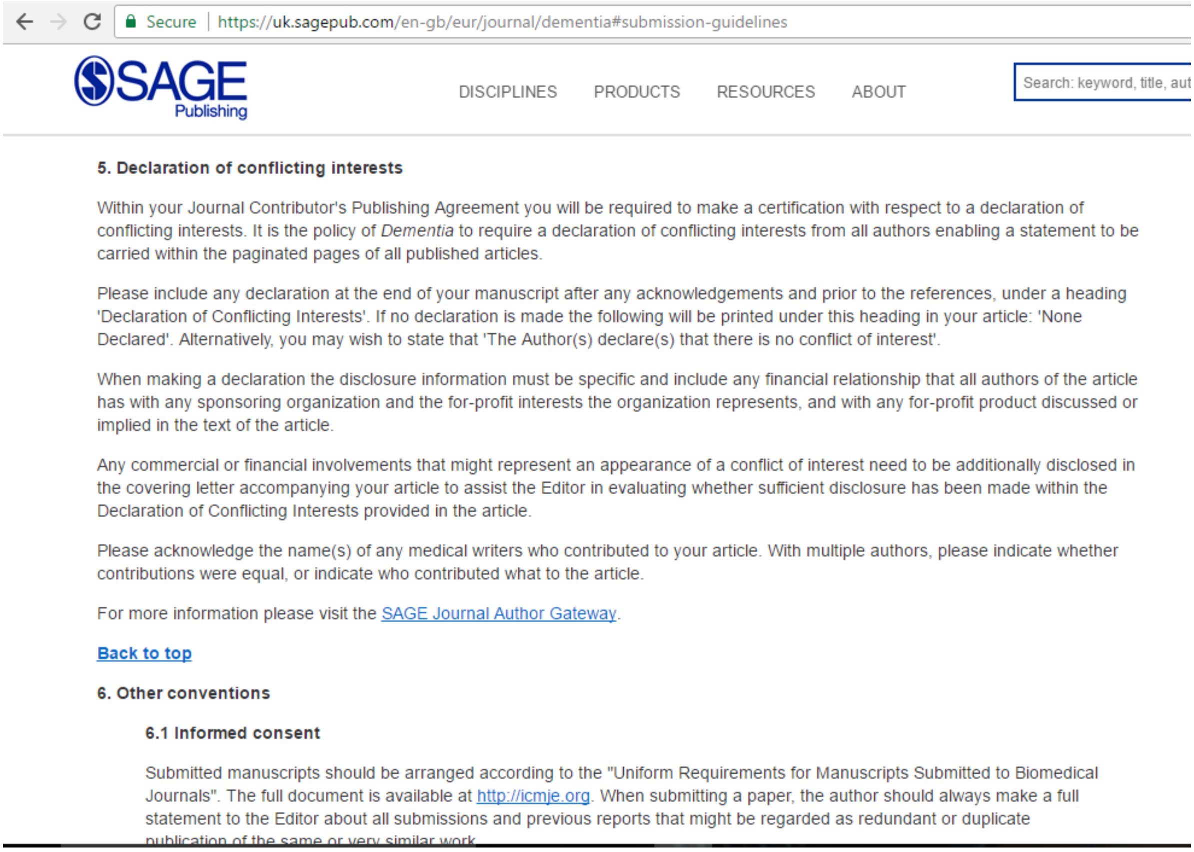

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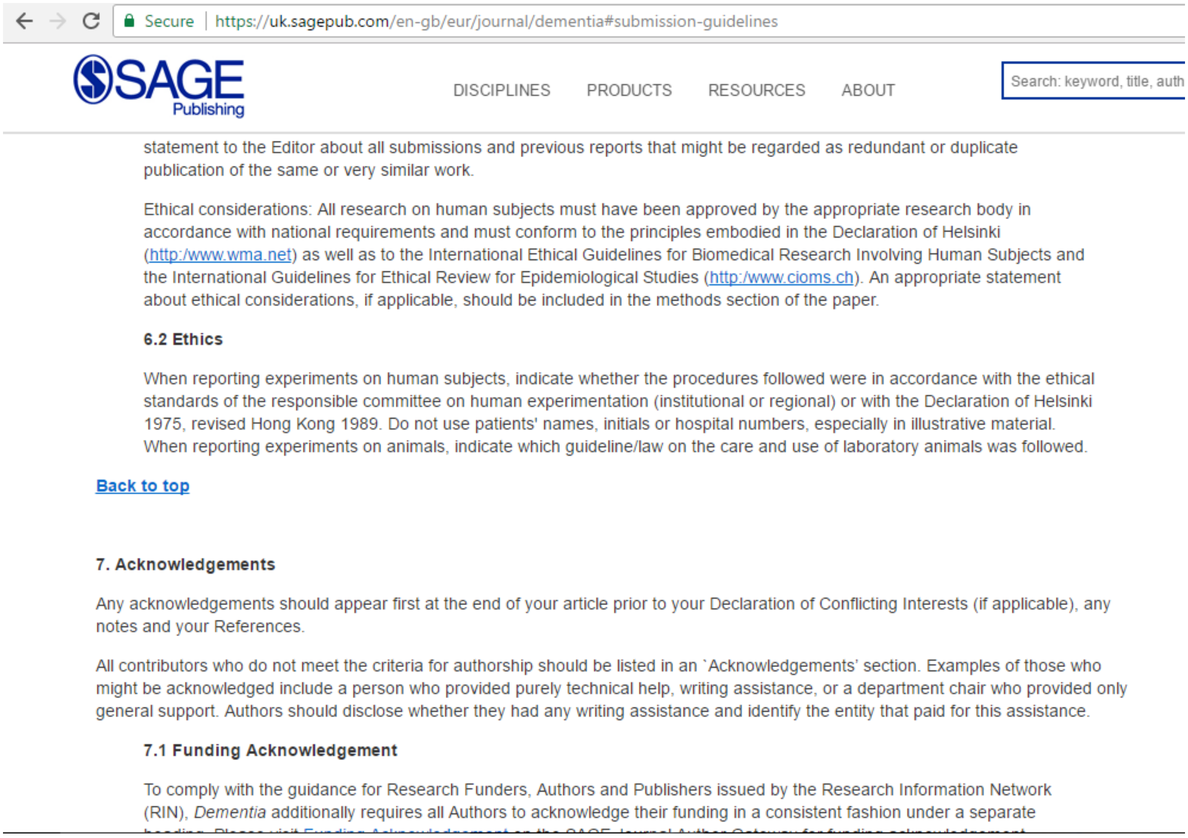

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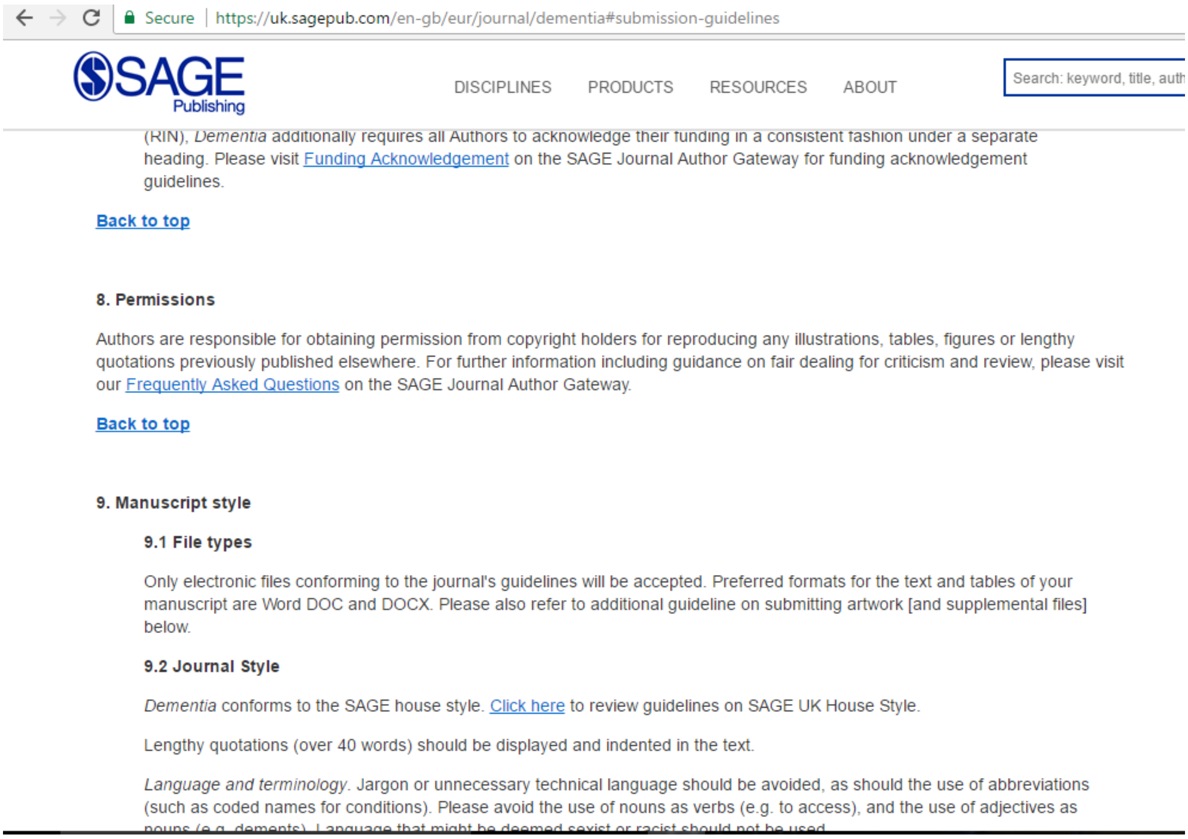

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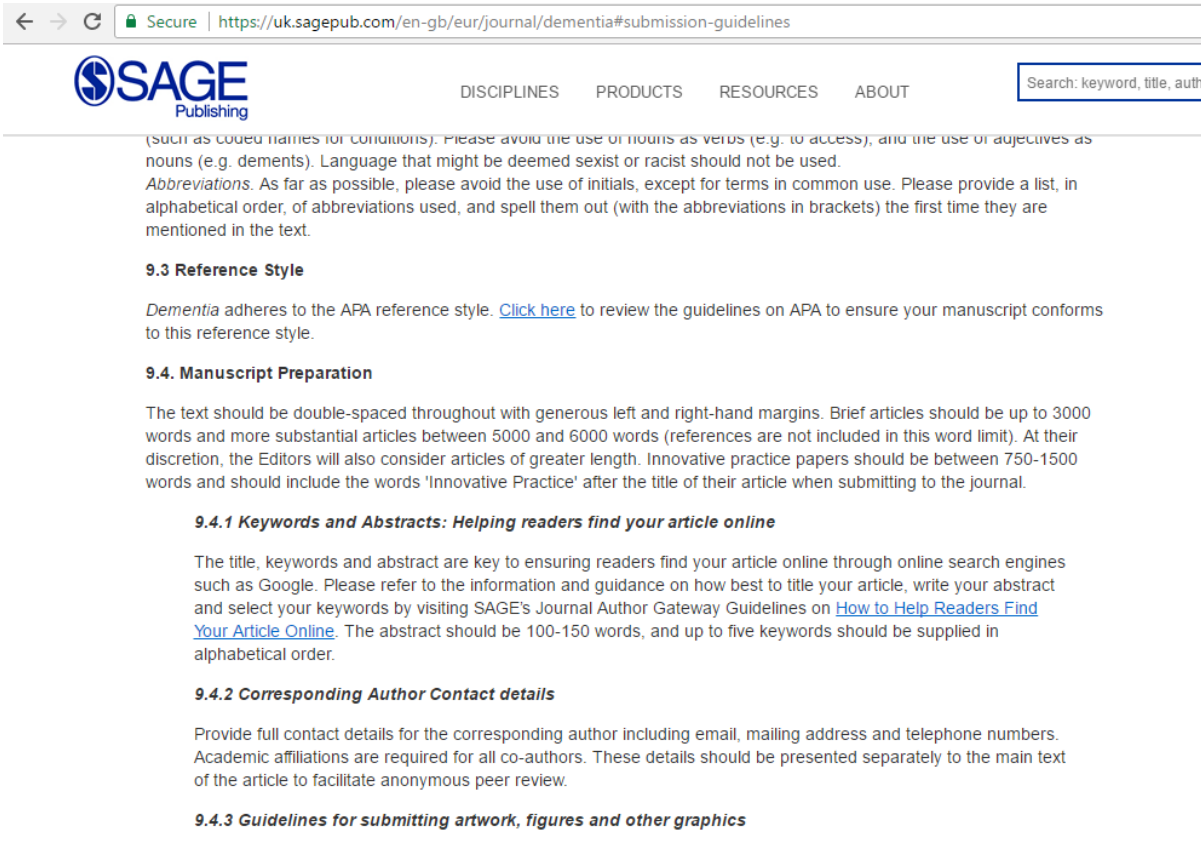

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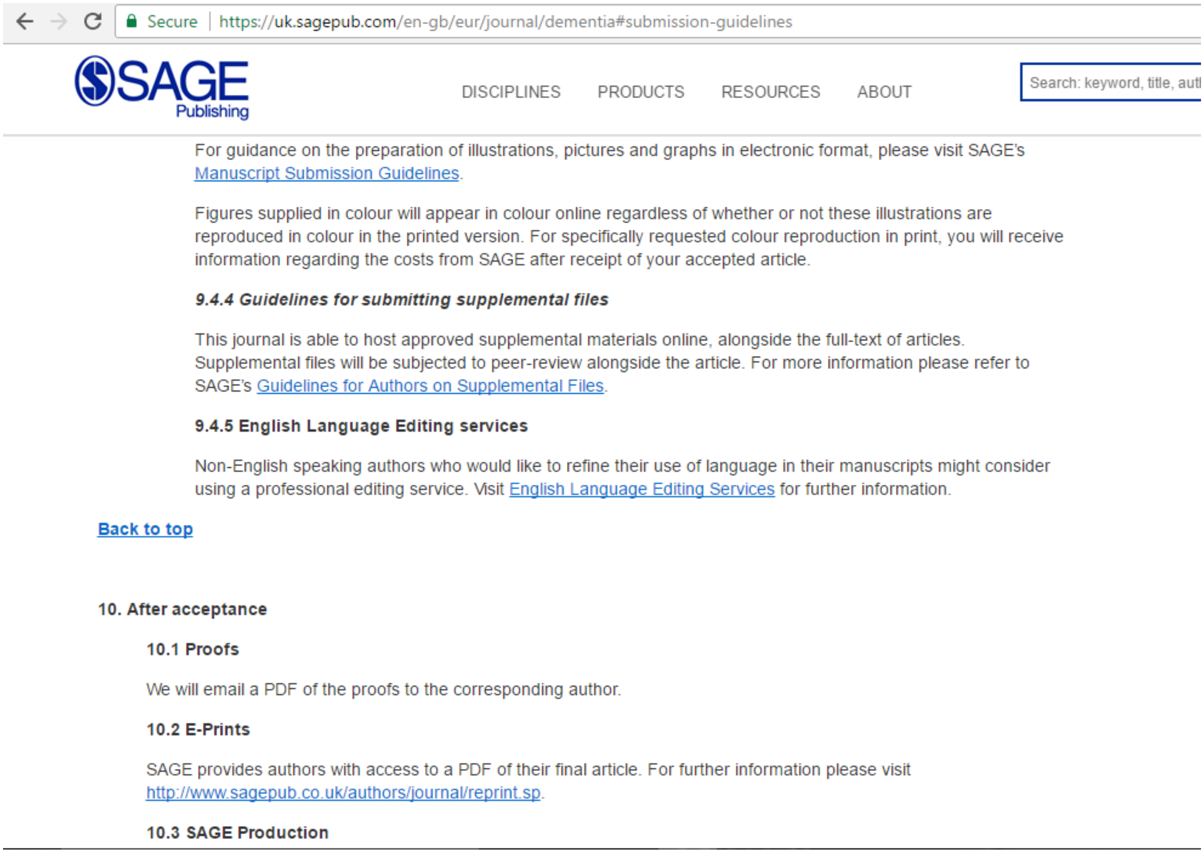

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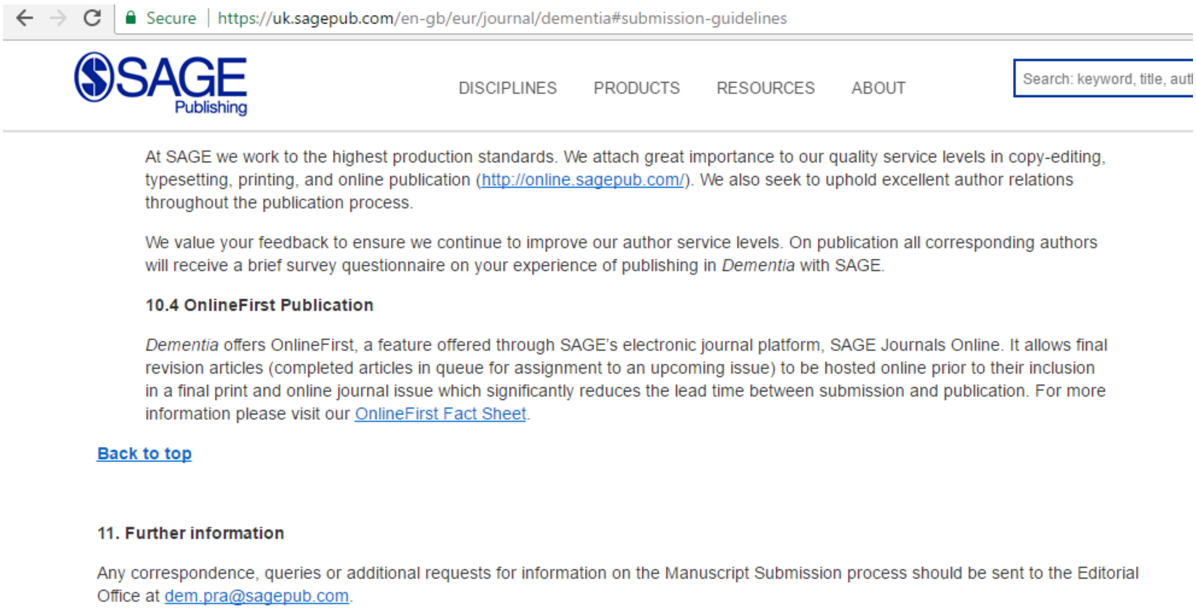

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We value your feedback to ensure we continue to improve our author service levels. On publication all corresponding authors will receive a brief survey questionnaire on your experience of publishing in *Dementia* with SAGE.

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.

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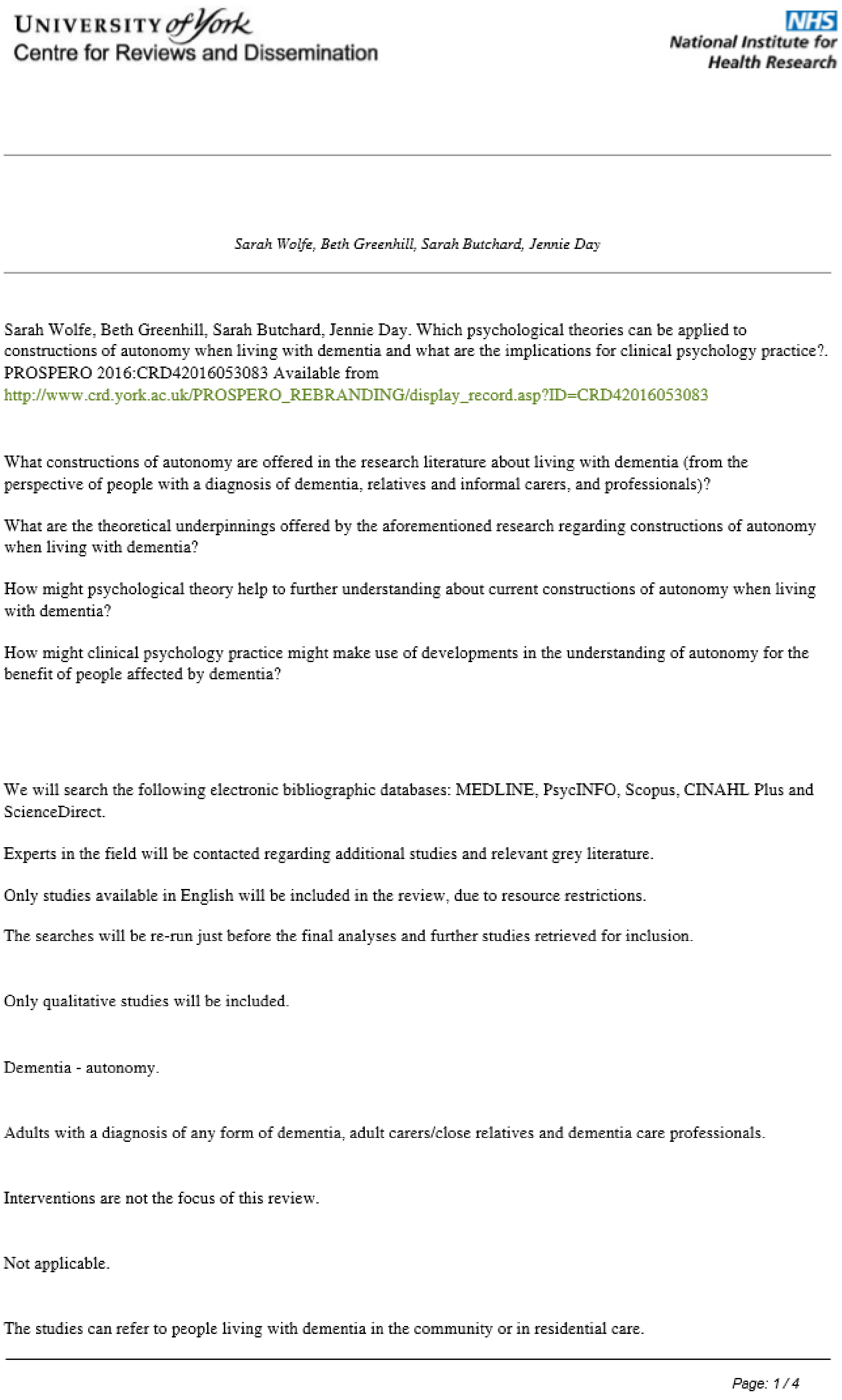
11. Further information

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.

Appendix 2: Prospero Review Protocol



UNIVERSITY of York
Centre for Reviews and Dissemination

NHS
National Institute for
Health Research

Sarah Wolfe, Beth Greenhill, Sarah Butchard, Jennie Day

Sarah Wolfe, Beth Greenhill, Sarah Butchard, Jennie Day. Which psychological theories can be applied to constructions of autonomy when living with dementia and what are the implications for clinical psychology practice?. PROSPERO 2016:CRD42016053083 Available from http://www.crd.york.ac.uk/PROSPERO_REBRANDING/display_record.asp?ID=CRD42016053083

What constructions of autonomy are offered in the research literature about living with dementia (from the perspective of people with a diagnosis of dementia, relatives and informal carers, and professionals)?

What are the theoretical underpinnings offered by the aforementioned research regarding constructions of autonomy when living with dementia?

How might psychological theory help to further understanding about current constructions of autonomy when living with dementia?

How might clinical psychology practice might make use of developments in the understanding of autonomy for the benefit of people affected by dementia?

We will search the following electronic bibliographic databases: MEDLINE, PsycINFO, Scopus, CINAHL Plus and ScienceDirect.

Experts in the field will be contacted regarding additional studies and relevant grey literature.

Only studies available in English will be included in the review, due to resource restrictions.

The searches will be re-run just before the final analyses and further studies retrieved for inclusion.

Only qualitative studies will be included.

Dementia - autonomy.

Adults with a diagnosis of any form of dementia, adult carers/close relatives and dementia care professionals.

Interventions are not the focus of this review.

Not applicable.

The studies can refer to people living with dementia in the community or in residential care.

The review aims to achieve an understanding of the range of constructions offered about autonomy when living with dementia. The review will explore the theoretical underpinnings of those constructions and will consider what psychological theory might also apply. The purpose of this will be to inform human rights-based approaches to dementia care.

None.

Studies retrieved using the search strategy and any additional sources will be stored in Mendeley. The results will be sorted alphabetically and duplicates will be removed. Two reviewers will independently complete an initial screening using titles and abstracts to identify studies that potentially meet the inclusion criteria. The reviewers will then assess the full text versions of the remaining, potentially eligible, studies. Any disagreement between them over the eligibility of particular studies will be resolved through discussion with a third reviewer.

A standardised, pre-piloted form will be used to extract data from the included studies for assessment of study quality and evidence synthesis. Extracted information will include: Author, title, year of publication and source, type of study, setting and population, sample size and participant characteristics, theoretical assumptions, method, results, theoretical links, implications, limitations. Two review authors will extract data independently, discrepancies will be identified and resolved through discussion (with a third author where necessary).

The Evaluation Tool for Qualitative Studies (Long & Godfrey, 2004) will be used as the appraisal instrument. The tool explores key features of qualitative research, including the applied theoretical framework and implications, which are pertinent to the review question. Disagreements between the two reviewers regarding judgements of quality can be discussed or resolved through the involvement of the third reviewer.

A paper will be submitted to a leading journal in this field. A presentation will be made to Mersey Care NHS Trust and a local service user forum.

Sarah Wolfe

Doctorate in Clinical Psychology Programme

University of Liverpool

Whelan Building

Brownlow Hill

Liverpool

L69 3GB

Appendix 3: Letter to Authors

Miss S. E. Wolfe

Clinical Psychologist in-Training

Doctorate Programme in Clinical Psychology

University of Liverpool

wolfes14@liverpool.ac.uk

Dear Dr

Re: Literature review regarding autonomy in dementia

Please forgive my unsolicited enquiry. I am contacting you as I am aware of your expertise in the field of dementia and human rights.

I am undertaking a literature review to explore constructions concerning autonomy that have been captured in qualitative research involving people with dementia and family carers. As part of this review I am investigating the extent to which psychological theory has been utilised to interpret and inform such constructions.

I would be grateful if you could inform me of any sources of literature which may not have been highlighted through my database search. For your information I have used the following databases: Medline, Scopus, PsycINFO, CINAHL Plus and ScienceDirect.

My email address can be found at the top of this letter. I look forward to hearing from you.

Yours Sincerely

Appendix 4: Final Excluded Papers

Author	Year	Reason for exclusion		
		Quantitative methodology utilised	Participant constructions of autonomy absent	Autonomy not related to psychological theory/model or no theoretical framework applied to results
Godwin & Poland	2015		✓	
Groen-van de Ven, Smits, Span, Jukema, Coppoolse, de Lange, Eefsting, Verbooij-Dassen	2016		✓	
Hellstrom, Eriksson & Sandberg	2015			✓
Horton-Deutsch, Twigg & Evans	2007		✓	
Jakobsen & Sørlie	2010		✓	
Robinson, Hutchings, Corner, Finch, Hughes, Brittain & Bond	2007		✓	
Samsi & Manthorpe	2013			✓
Smebye	2016		✓	
Tyrrell, Genin & Myslinski	2006	✓		
Van Gennip, Pasman, Oosterveld-Vlug, Willems & Onwuteaka-Philipsen	2016		✓	

Appendix 5: Data Collection Form

Author(s) and year of publication	
Journal	
Study aims	
Research context	
Participants	
Data collection method	
Psychological theory/model applied	
Themes/Constructs	
Clinical implications	
Limitations	

Appendix 6: Evaluation Tool for Qualitative Studies (Long & Godfrey, 2004)

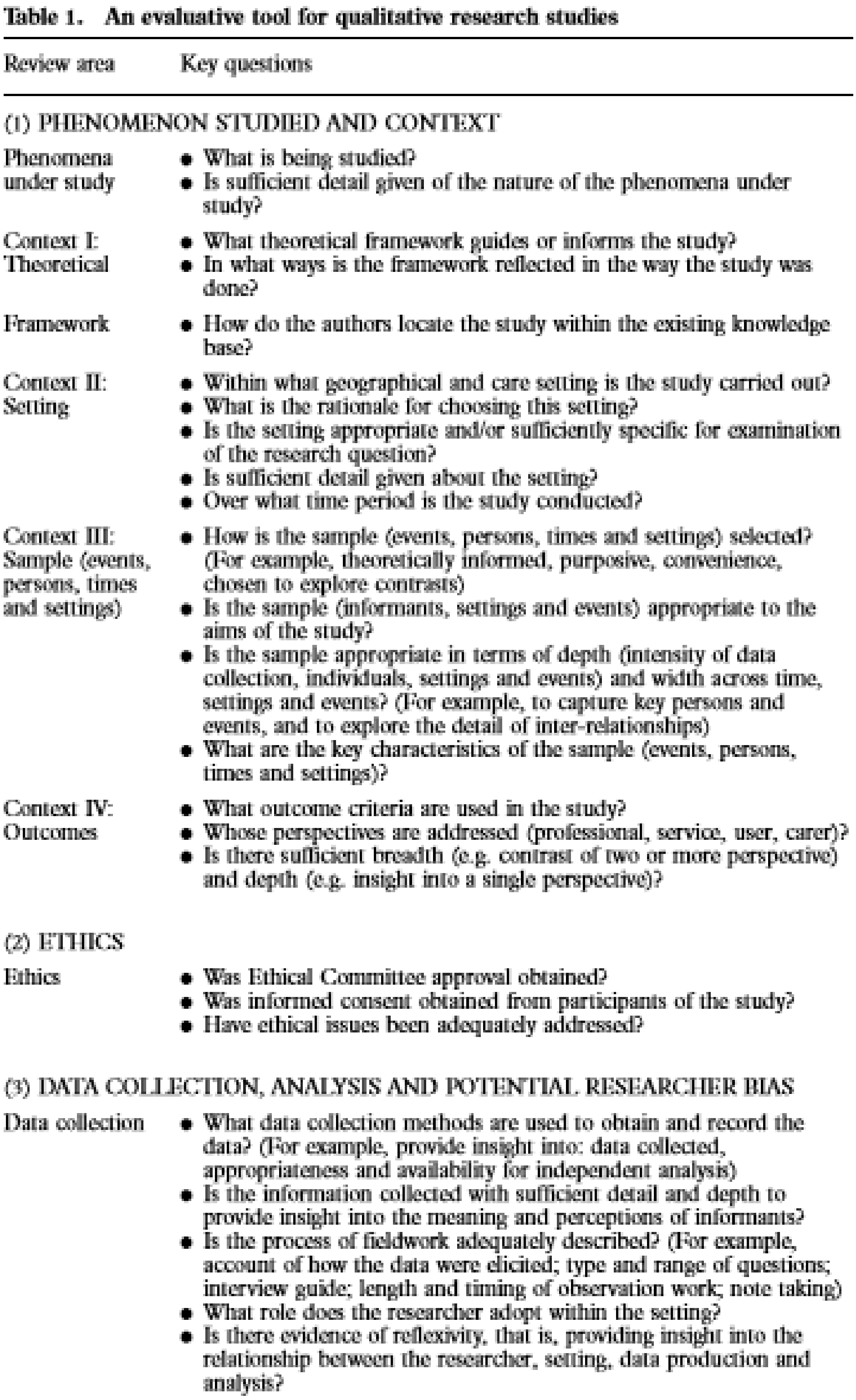


Table 1. An evaluative tool for qualitative research studies

Review area	Key questions
(1) PHENOMENON STUDIED AND CONTEXT	
Phenomena under study	• What is being studied? • Is sufficient detail given of the nature of the phenomena under study?
Context I: Theoretical	• What theoretical framework guides or informs the study? • In what ways is the framework reflected in the way the study was done?
Framework	• How do the authors locate the study within the existing knowledge base?
Context II: Setting	• Within what geographical and care setting is the study carried out? • What is the rationale for choosing this setting? • Is the setting appropriate and/or sufficiently specific for examination of the research question? • Is sufficient detail given about the setting? • Over what time period is the study conducted?
Context III: Sample (events, persons, times and settings)	• How is the sample (events, persons, times and settings) selected? (For example, theoretically informed, purposive, convenience, chosen to explore contrasts) • Is the sample (informants, settings and events) appropriate to the aims of the study? • Is the sample appropriate in terms of depth (intensity of data collection, individuals, settings and events) and width across time, settings and events? (For example, to capture key persons and events, and to explore the detail of inter-relationships) • What are the key characteristics of the sample (events, persons, times and settings)?
Context IV: Outcomes	• What outcome criteria are used in the study? • Whose perspectives are addressed (professional, service, user, carer)? • Is there sufficient breadth (e.g. contrast of two or more perspective) and depth (e.g. insight into a single perspective)?
(2) ETHICS	
Ethics	• Was Ethical Committee approval obtained? • Was informed consent obtained from participants of the study? • Have ethical issues been adequately addressed?
(3) DATA COLLECTION, ANALYSIS AND POTENTIAL RESEARCHER BIAS	
Data collection	• What data collection methods are used to obtain and record the data? (For example, provide insight into: data collected, appropriateness and availability for independent analysis) • Is the information collected with sufficient detail and depth to provide insight into the meaning and perceptions of informants? • Is the process of fieldwork adequately described? (For example, account of how the data were elicited; type and range of questions; interview guide; length and timing of observation work; note taking) • What role does the researcher adopt within the setting? • Is there evidence of reflexivity, that is, providing insight into the relationship between the researcher, setting, data production and analysis?

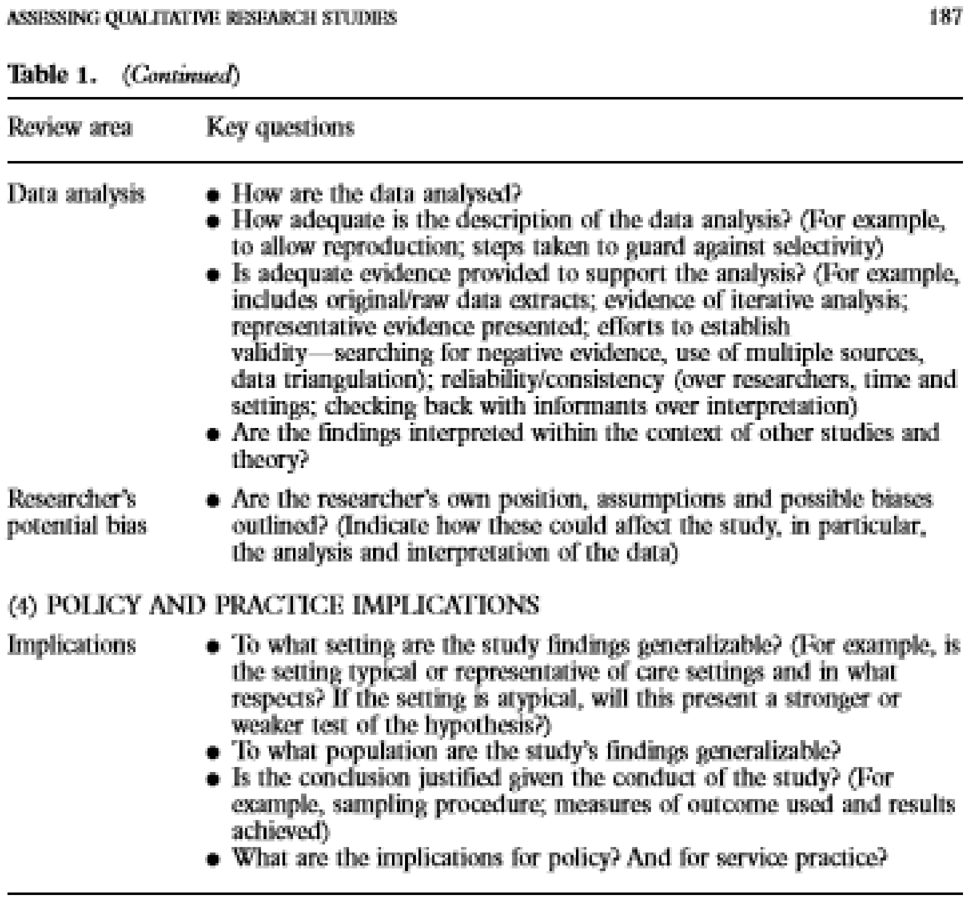


Table 1. *(Continued)*

Review area	Key questions
Data analysis	• How are the data analysed? • How adequate is the description of the data analysis? (For example, to allow reproduction; steps taken to guard against selectivity) • Is adequate evidence provided to support the analysis? (For example, includes original/raw data extracts; evidence of iterative analysis; representative evidence presented; efforts to establish validity—searching for negative evidence, use of multiple sources, data triangulation); reliability/consistency (over researchers, time and settings; checking back with informants over interpretation) • Are the findings interpreted within the context of other studies and theory?
Researcher's potential bias	• Are the researcher's own position, assumptions and possible biases outlined? (Indicate how these could affect the study, in particular, the analysis and interpretation of the data)
(4) POLICY AND PRACTICE IMPLICATIONS	
Implications	• To what setting are the study findings generalizable? (For example, is the setting typical or representative of care settings and in what respects? If the setting is atypical, will this present a stronger or weaker test of the hypothesis?) • To what population are the study's findings generalizable? • Is the conclusion justified given the conduct of the study? (For example, sampling procedure; measures of outcome used and results achieved) • What are the implications for policy? And for service practice?

Appendix 7: Levels of Theoretical Visibility Typology

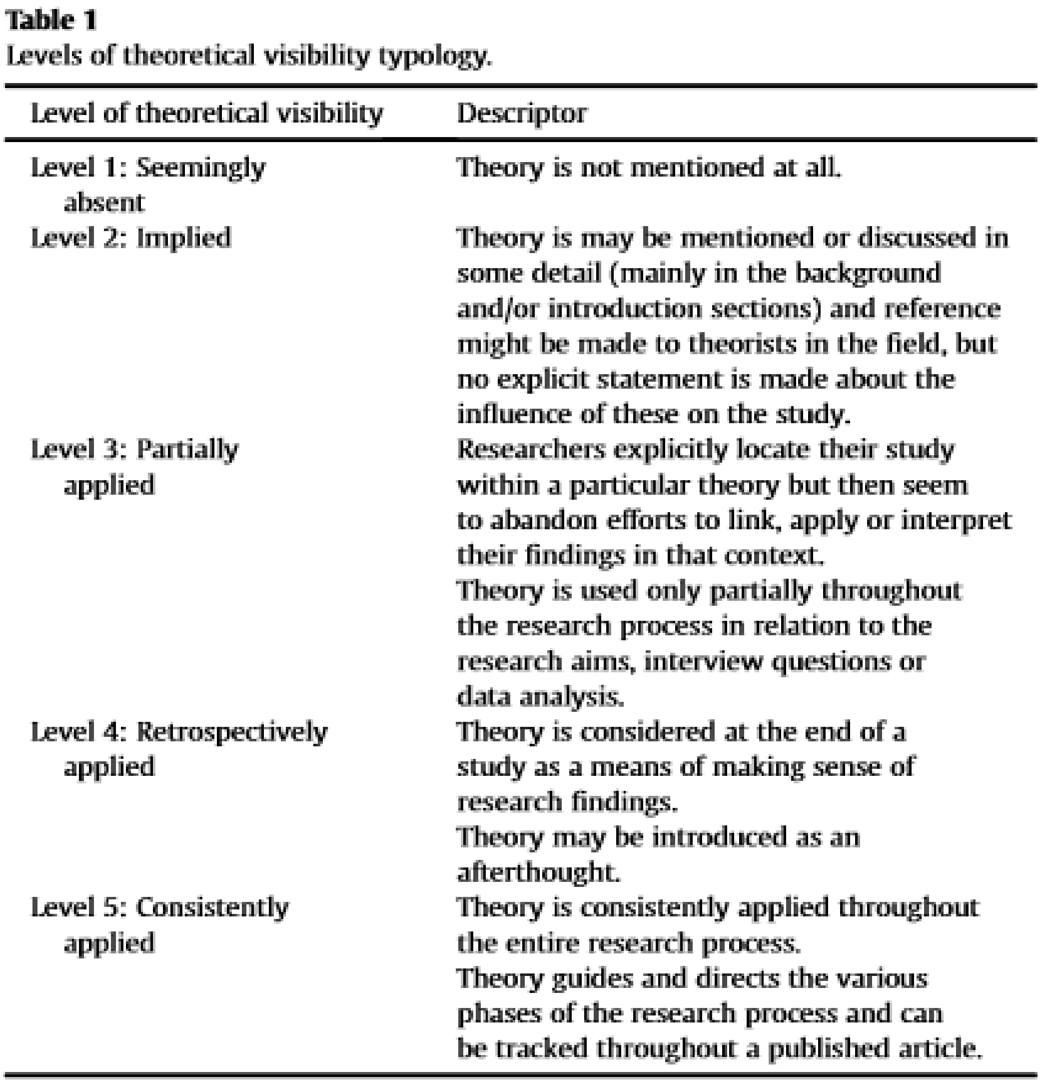


Table 1
Levels of theoretical visibility typology.

Level of theoretical visibility	Descriptor
Level 1: Seemingly absent	Theory is not mentioned at all.
Level 2: Implied	Theory is may be mentioned or discussed in some detail (mainly in the background and/or introduction sections) and reference might be made to theorists in the field, but no explicit statement is made about the influence of these on the study.
Level 3: Partially applied	Researchers explicitly locate their study within a particular theory but then seem to abandon efforts to link, apply or interpret their findings in that context. Theory is used only partially throughout the research process in relation to the research aims, interview questions or data analysis.
Level 4: Retrospectively applied	Theory is considered at the end of a study as a means of making sense of research findings. Theory may be introduced as an afterthought.
Level 5: Consistently applied	Theory is consistently applied throughout the entire research process. Theory guides and directs the various phases of the research process and can be tracked throughout a published article.

Appendix 8: Doctorate in Clinical Psychology Research Review Committee Approval

UNIVERSITY OF
LIVERPOOL

D.Clin.Psychology Programme
Division of Clinical Psychology
Whelan Building, Quadrangle
Brownlow Hill
LIVERPOOL
L69 3GB

Tel: 0151 794 5530/5534/5877
Fax: 0151 794 5537
www.liv.ac.uk/dclinpsychol

07/04/2016

Sarah Wolfe
Trainee Clinical Psychologist
Doctorate of Clinical Psychology Programme
University of Liverpool
L69 3GB

RE: The nature of autonomy when living with dementia: A Q-method investigation

Dear *Sarah*,

Thank you for our response to the reviewers' comments of your research proposal submitted to the Chair of the D.Clin.Psychol. Research Review Committee (version 2, ***dated 6/04/2016***).

I can now confirm that your amended proposal (version 2, ***dated 6/04/2016***) meet the requirements of the committee and have been approved by the Committee Chair.

Please take this Chairs Action decision as ***final*** approval from the committee.

You may now progress to the next stages of your research.

I wish you well with your research project.

Dr Peter Taylor
Vice-Chair, DClinPsychol Research Committee

A member of the
Russell Group

Professor John Read
Programme Director
readj@liv.ac.uk

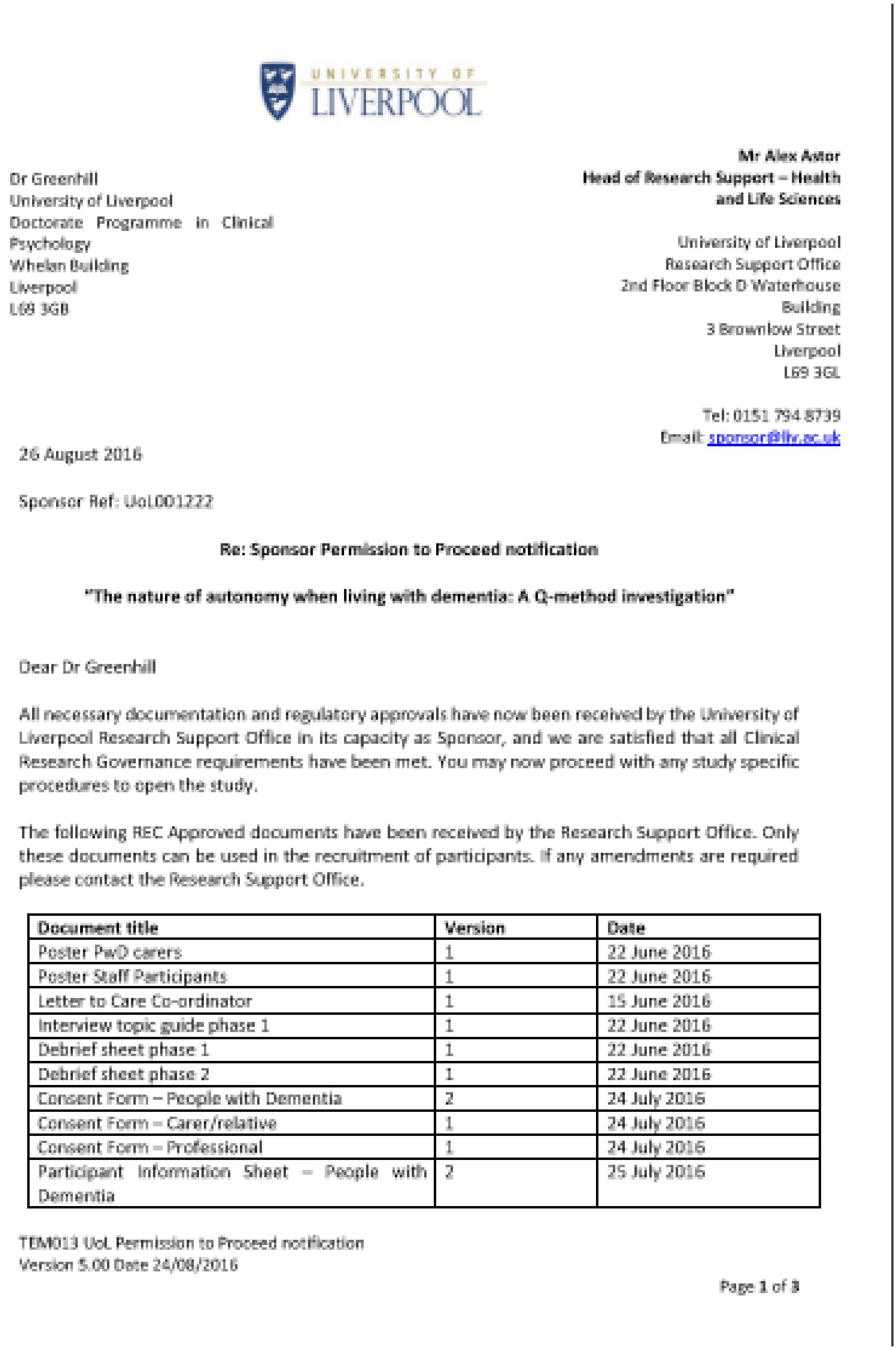
Dr Jim Williams
Clinical Director
[illegible]

Dr Joanne Dickson
Research Director
jdickson@liv.ac.uk

Dr Laura Golding
Academic Director
l.golding@liv.ac.uk

Mrs Sue Knight
Programme Co-ordinator
sknight@liv.ac.uk

Appendix 9: University of Liverpool Sponsorship Approval



UNIVERSITY OF LIVERPOOL

Mr Alex Astor
Head of Research Support – Health and Life Sciences

University of Liverpool
Research Support Office
2nd Floor Block D Waterhouse Building
3 Brownlow Street
Liverpool
L69 3GL

Tel: 0151 794 8739
Email: sponsor@liv.ac.uk

Dr Greenhill
University of Liverpool
Doctorate Programme in Clinical Psychology
Whelan Building
Liverpool
L69 3GB

26 August 2016

Sponsor Ref: UoL001222

Re: Sponsor Permission to Proceed notification

"The nature of autonomy when living with dementia: A Q-method investigation"

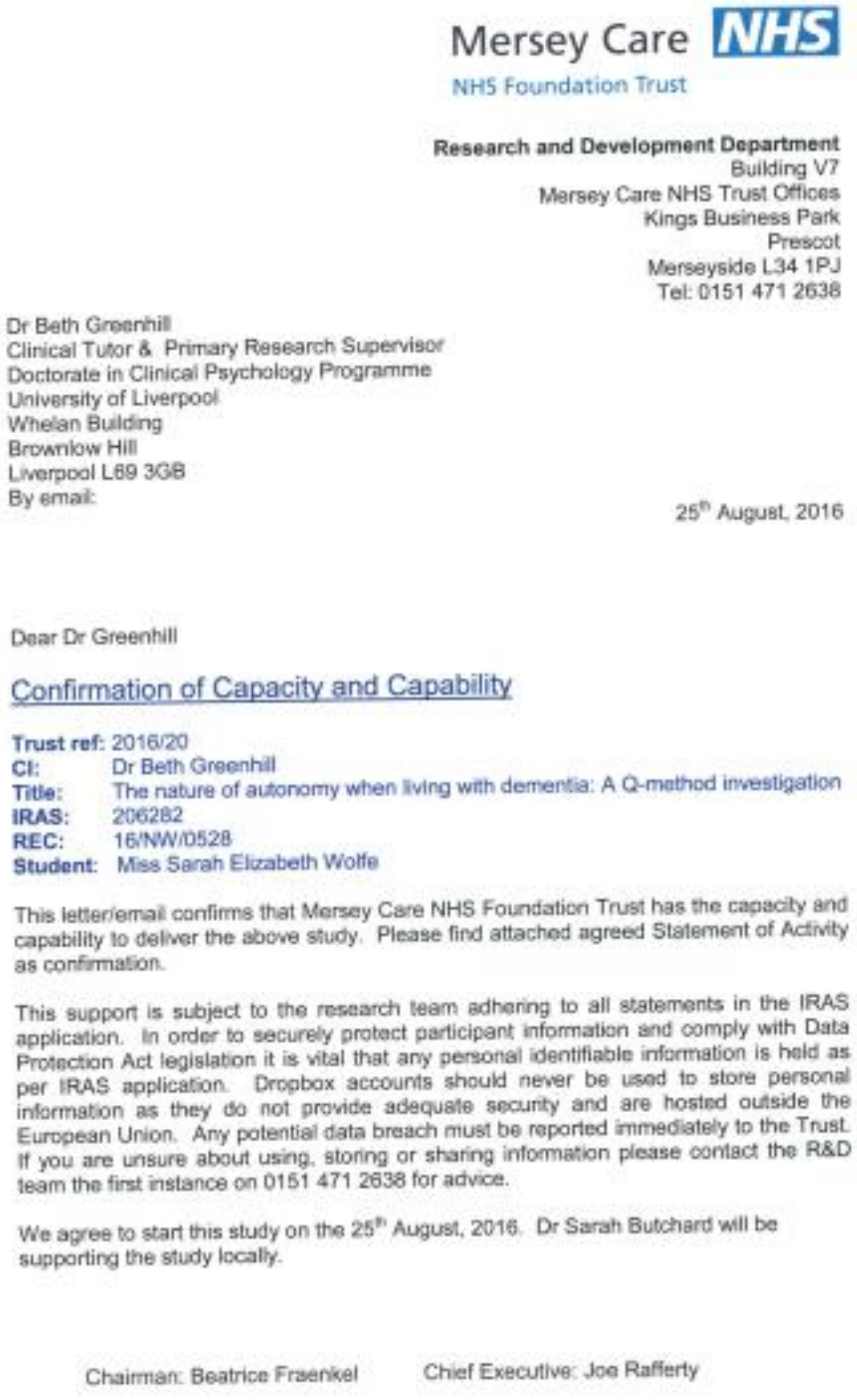
Dear Dr Greenhill

All necessary documentation and regulatory approvals have now been received by the University of Liverpool Research Support Office in its capacity as Sponsor, and we are satisfied that all Clinical Research Governance requirements have been met. You may now proceed with any study specific procedures to open the study.

The following REC Approved documents have been received by the Research Support Office. Only these documents can be used in the recruitment of participants. If any amendments are required please contact the Research Support Office.

Document title	**Version**	**Date**
Poster PwD carers	1	22 June 2016
Poster Staff Participants	1	22 June 2016
Letter to Care Co-ordinator	1	15 June 2016
Interview topic guide phase 1	1	22 June 2016
Debrief sheet phase 1	1	22 June 2016
Debrief sheet phase 2	1	22 June 2016
Consent Form – People with Dementia	2	24 July 2016
Consent Form – Carer/relative	1	24 July 2016
Consent Form – Professional	1	24 July 2016
Participant Information Sheet – People with Dementia	2	25 July 2016

Appendix 10: Research and Development Approval



Mersey Care NHS
NHS Foundation Trust

Research and Development Department
Building V7
Mersey Care NHS Trust Offices
Kings Business Park
Prescot
Merseyside L34 1PJ
Tel: 0151 471 2638

Dr Beth Greenhill
Clinical Tutor & Primary Research Supervisor
Doctorate in Clinical Psychology Programme
University of Liverpool
Whelan Building
Brownlow Hill
Liverpool L69 3GB
By email:

25th August, 2016

Dear Dr Greenhill

Confirmation of Capacity and Capability

Trust ref: 2016/20
CI: Dr Beth Greenhill
Title: The nature of autonomy when living with dementia: A Q-method investigation
IRAS: 206282
REC: 16/NW/0528
Student: Miss Sarah Elizabeth Wolfe

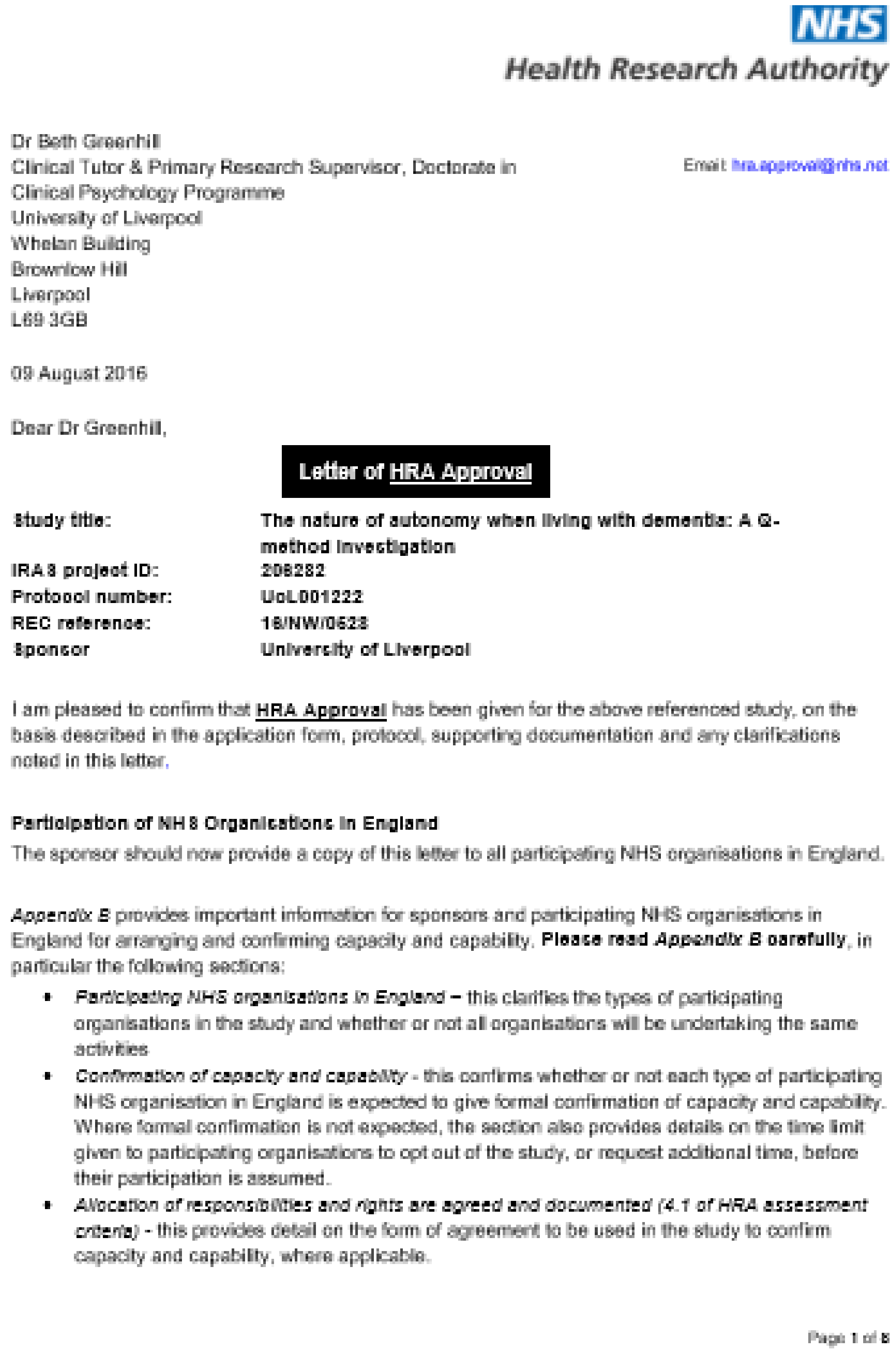
This letter/email confirms that Mersey Care NHS Foundation Trust has the capacity and capability to deliver the above study. Please find attached agreed Statement of Activity as confirmation.

This support is subject to the research team adhering to all statements in the IRAS application. In order to securely protect participant information and comply with Data Protection Act legislation it is vital that any personal identifiable information is held as per IRAS application. Dropbox accounts should never be used to store personal information as they do not provide adequate security and are hosted outside the European Union. Any potential data breach must be reported immediately to the Trust. If you are unsure about using, storing or sharing information please contact the R&D team the first instance on 0151 471 2638 for advice.

We agree to start this study on the 25th August, 2016. Dr Sarah Butchard will be supporting the study locally.

Chairman: Beatrice Fraenkel   Chief Executive: Joe Rafferty

Appendix 11: HRA Approval



NHS
Health Research Authority

Dr Beth Greenhill
Clinical Tutor & Primary Research Supervisor, Doctorate in Clinical Psychology Programme
University of Liverpool
Whelan Building
Brownlow Hill
Liverpool
L69 3GB

Email: hra.approval@nhs.net

09 August 2016

Dear Dr Greenhill,

Letter of HRA Approval

Study title:	**The nature of autonomy when living with dementia: A Q-method investigation**
IRAS project ID:	**206282**
Protocol number:	**UoL001222**
REC reference:	**16/NW/0528**
Sponsor	**University of Liverpool**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Appendix 12: Participant Information Sheet

Participant Information Sheet:

We would like to invite you to take part in the following study:

'The nature of autonomy when living with dementia: A Q-method investigation'

Please read the following information carefully. Take time to decide whether or not to take part. You are able to change your mind at any time.

What is Q-Method?

Q-methodology is a technique used to study people's viewpoints. Firstly it involves finding out the range of views available about a topic by carrying out interviews and looking at media sources. A set of statements are then created from this information, which a sample of people are asked to rank according to whether they agree or disagree.

What is the purpose of the study?

Human rights-based approaches to healthcare talk about principles which, usually, have not been defined by service users or carers. These principles include fairness, respect, equality, dignity and autonomy (FREDA).

Researchers at the University of Liverpool would like to find out what people living with dementia think about the idea of 'autonomy' – what it means to them and what is important about it.

Who is sponsoring the research?

The research is being undertaken by a full-time postgraduate student as part of their clinical psychology training. It is sponsored by the University of Liverpool.

Do I have to take part?

No - participation is always voluntary. You can change your mind at any time. If you withdraw, any information held about you by the research team will be destroyed. This will not impact upon the service you receive from the older adult community mental health team.

Who can I contact about the study?

For further information or to arrange an appointment, please call the Student Researcher:

Sarah Wolfe (Trainee Clinical Psychologist)

Doctorate Programme in Clinical Psychology

Office Tel: 0151 794 5530.

What will I have to do?

The study involves two phases – you can take part in Phase 1, Phase 2 or both.

	Phase 1	**Phase 2**
How long will it take?	Approximately 30 minutes	Approximately 60-90 minutes
Where will the research appointment take place?	At your home or the community mental health team clinic.	
Who will be involved?	You and the Researcher. A carer can be present.	
What will I have to do?	The Researcher will talk with you about the term 'autonomy' and what it means to you. The conversation will be audio-recorded.	You will complete a sorting task during which you will be asked to sort approximately 25 statements to show how strongly you agree or disagree.

Phase 1: Interview

Phase 2: Sorting task

Will my taking part in the study be kept confidential?

Your Care Co-ordinator will be informed that you have decided to take part in the study. Otherwise, all information about you will be kept confidential.

- Your name and address will be removed from any information about you which leaves the university .
- Individual information will be anonymised and given a code known only to the research team.
- All data will be held on a password-protected computer on a secure and encrypted server.
- All data will be held for up to 5 years and then destroyed.

What will happen to the results of the study?

The views expressed in the Phase 1 interviews will contribute to the sorting task that people living with dementia will complete in Phase 2.

All participants will receive a feedback letter giving a summary of the research findings. The results will be included in a thesis report that will be submitted to the University of Liverpool as part of the researcher's clinical training.

The thesis report will also be submitted for publication in a journal to share the findings with other psychologists. The research team hope to be able to present the results at a national conference and a local service user forum.

All data used in reports, publications and presentations will be anonymised.

How will I be compensated for my time?

If you travel to participate in the research, you will be able to claim mileage or public transport costs.

All participants will be automatically entered into a prize draw giving them a chance to win one of three £40 vouchers. Participants who take part in both phases will be entered twice.

What are the possible benefits of taking part?

Although taking part in the study may not help you directly, some people find that sharing their experiences can feel worthwhile and rewarding.

It is hoped that the findings will contribute to understanding about human rights when living with dementia and how best to support them.

What are the possible drawbacks or risks of taking part?

It may be upsetting for you

Discussing experiences of living with dementia can be emotional. This is understandable, but you may wish to consider carefully whether this is the right time to be taking part in the research.

The Student Researcher is a Trainee Clinical Psychologist employed by Mersey Care NHS Trust who is trained to support people in distress. If needed, appropriate additional support can be made available through your older adult community mental health team. Details of support organisations will also be offered to all participants.

There may be concerns about your safety or someone else's

Talking about exercising or supporting autonomy might raise concerns about your safety or someone else's. The Student Researcher has a duty of care to report safeguarding concerns, which will mean breaking confidentiality even if you decide to withdraw. The Student Researcher will try to tell you if they need to do this, unless doing so might place you or someone else at further risk.

Your ability to take part might change over time

If you wish to take part, you will need to be able to complete an interview, a sorting task or both. If you are a person with a diagnosis of dementia, your ability to do this may change over time. This means that you might agree to take part but be unable to do so at the research appointment.

The Student Researcher will ask some questions at your research appointment to assess your ability to agree and undertake the research tasks. If you take part in Phase 1 of the study but you are unable to take part in Phase 2, the data collected during Phase 1 will still be used for the research analysis. No new data will be collected.

What if I have a concern or a problem with the research?

If you have a concern, please contact the Student Researcher or the Research Supervisor. They will do their best to help:

Sarah Wolfe (Student Researcher) or Dr Beth Greenhill (Research Supervisor)

Doctorate Programme in Clinical Psychology

University of Liverpool

Whelan Building

Brownlow Hill

Liverpool

L69 3GB

Telephone: 0151 794 5530

The older adult community mental health team clinician supporting this research is Dr Sarah Butchard (Clinical Psychologist).

If you feel that your concern has not been resolved and you wish to make a formal complaint, please contact Mersey Care NHS Trust Complaints Department:

Complaints Department

Mersey Care NHS Trust

V7 Building

Kings Business Park

Prescot

L34 1PJ

Telephone: 0151 472 4002

Email: complaints@merseycare.nhs.uk

Thank you for taking the time to consider participating in and supporting this research.

Appendix 13: Consent Form

Informed Consent Form

I, the undersigned, confirm that (please tick the box as appropriate):

I have read and understood the Participant Information Sheet.	
I have been given the opportunity to ask questions.	
I voluntarily agree to participate in the study.	
I understand I can withdraw at any time without giving reasons or facing repercussions.	
I give permission for the researcher to access my clinical casenotes (if applicable).	
I give permission for the researcher to contact the older adult community mental health team to make them aware that I have agreed to participate (if applicable).	
The procedures regarding confidentiality have been clearly explained to me.	
I agree to my interview being audio recorded and recordings being sent to a professional transcription service (Phase 1 only).	
If my ability to consent changes following completion of my part in the study, I agree to the research data previously generated to be used in any analysis.	
The use of the data in research, including publications, sharing and archiving, has been explained to me.	
I understand that other researchers will have access to the data, only if they agree to preserve confidentiality and to the terms specified here.	
I, along with the Researcher, agree to sign and date this informed consent form.	

Participant:

Name of Participant	Signature	Date

Researcher:

Name of Researcher	Signature	Date

Appendix 14: Concourse Literature References

Berry, B., Apesoa-Varano, E. C., & Gomez, Y. (2015). How family members manage risk around functional decline: the autonomy management process in households facing dementia. *Social Science & Medicine, 130*, 107-114.

Birchley, G., Jones, K., Huxtable, R., Dixon, J., Kitzinger, J., & Clare, L. (2016). Dying well with reduced agency: a scoping review and thematic synthesis of the decision-making process in dementia, traumatic brain injury and frailty. *BMC Medical Ethics, 17*, 46-60.

Bollig, G., Gjengedal, E., & Rosland, J. H. (2016). Nothing to complain about? Residents' and relatives' views on a ''good life'' and ethical challenges in nursing homes. *Nursing Ethics, 23*(2), 142–153.

Burmeister, O. K. (2016). The development of assistive dementia technology that accounts for the values of those affected by its use. *Ethics and Information Technology, 18*., 185-198.

DeWaal, H. (2014). Rethinking dementia: How autonomy and control can be fostered through the development of person-centred services. *Working with Older People, 18*(2), 82-89.

Dresser, R. (2001). Advance Directives in Dementia Research. *Ethics & Human Research, 23*(1), 1-6.

Fetherstonhaugh, D,. Tarzia, L., & Nay, R. (2013). Being central to decision making means I'm still here!: the essence of decision-making for people with dementia. *Journal of Aging Studies, 27*, 143-150.

Fetherstonhaugh, D., Tarzia, L., Bauer, M., Nay, R., & Beattie, E. (2014). "The red dress or the blue?" How do staff perceive that they support decision making for people with dementia living in residential aged care facilities?. *Journal of Applied Gerontology, 35*(2), 209-226.

Gather, J. & Vollman, J. (2013). Physician-assisted suicide of patients with dementia. A medical ethical analysis with a special focus on patient autonomy. *International Journal of Law and Psychiatry, 36*, 444-453.

Glos, A. (2016). Solidarity in healthcare: the challenge of dementia. *Diametros, 49*, 1-26.

Graneheim, U., Norberg, A., & Jansson, L. (2001). An observational study focusing on a woman with dementia and `behavioural disturbances', and on her care providers. *Journal of Advanced Nursing, 36*(2), 256-265.

Haberstroh, J. (2015). Autonomy and capacity to consent in dementia. *GeroPsych, 28*(1), 5–6.

Harding, R. (2012). Legal constructions of dementia: discourses of autonomy at the margins of capacity. *Journal of Social Welfare and Family Law, 34*(4), 425-442.

Heggestad , A. K. T., Nortvedt , P., Slettebø, A. (2013). ‘Like a prison without bars’: Dementia and experiences of dignity. *Nursing Ethics, 20*(8), 881–892.

Hill, S. R., Mason, H., Poole, M., Vale, L., & Robinson, L. (2016). What is important at the end of life for people with dementia? The views of people with dementia and their carers. *International Journal of Geriatric Psychiatry.*

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Appendix 15: Interview schedule

Topic Guide

Thank you for taking part in this interview. I'd like to ask you some questions about your experience of living/working with dementia. There are no right or wrong answers. Please ask if you need me to repeat any questions. Are you happy to carry on?

Introductory information to be sought:

People with dementia:

- How long have you been living with dementia?
- Who supports you with day-to-day activities, if anyone?
- What do they do to support you? (if applicable)
- How do you find this?
- What does human rights mean to you?

Relative/carer only:

- How long have you been supporting *the person living with dementia*?
- In what ways do you support them currently?
- What changes have they noticed in *the person living with dementia* over time?
- What does human rights mean to you?

Dementia care professionals only:

- How long have you been working in dementia care?
- What are your main responsibilities?
- What does human rights mean to you?

What does autonomy mean to you?

Provide the following definition:

'Autonomy is being allowed to make free choices about what happens to you, deciding this based on information and acting upon your decision'

What do you understand this to mean?

What would you expect to be able to do on this basis?

What would you expect from others on this basis?

How does this definition fit with your experience of living/working with dementia?

What's the most important bit about it for you?

What might you change or add to this definition, if anything?

How helpful is this definition for people who are living /working with dementia?

What other ideas do you have about what autonomy might mean to you?

Is there anything you would like to add?

Appendix 16: Example of Theme and Final Statement Development

Theme	Corresponding statements
Authentic self	They are fighting for the fact that they're still a person…there's still somebody in there who is a person Autonomy is being thought of and treated as an individual The right to be one's self We have this idea of an individual being able to be themselves and…and function in a manner which is independent of other people We're looking at it through a filter of thoughts when sometimes we need to be coming back to that expression of self Perhaps it links back in to that thing of being able to express your authentic self The ability to express your authentic self Recognising that although I had Alzheimer's I was still an individual, that I still had somewhere tucked away, no matter how far away it was tucked, I had memories, I had things that would enable me to make choices or make the decision To make, to judge and control my own destiny This person has the right to autonomy and autonomy being allowed to make the free choices and making the decision about what happens to them as individual - to treat them as individual, not as a person or as a thing or as a patient That right not to be sedated where I could sit and reminisce with people…being able to recount the past and go over the past, to allow me to reminisce and to keep alive the past memories Retaining my own individuality, me influencing decisions which would affect me To realise I'm still me but I'm just perhaps act in a different way It's all about what you but at the same time it's not about selfishness either you know it's not about you always getting your own way erm but you make the decisions based on your values and all that sort of thing The key note speaker was talking about freedom within a relationship and I think that, I've never spoken to XXXX about this but I think that sums us up that we in our relationship I know I have the freedom to be the person I like to be and I think you feel the same way Living life as your own person, not your living life according to someone else's values and interests Considering what someone wants and desires at that point in time, not based on who they were before We're all human beings and we're all unique Me being me and being unique

Example of final statements under a theme

Theme	Final statements
Authentic self	Making decisions based on your values Other people listening to what you want now Being recognised by other people as an individual with memories Being able to express who you really are

Appendix 17: Composite Q-sort for Factor One

-3	-2	-1	0	+1	+2	+3
Other people taking decisions for you	Being helped to see things from different perspectives	Being free to make unwise decisions and take risks	Having a use and giving back	Being able to say no	Being given the time to think and weigh things up before making decisions	Being included in decision-making that concerns you
Needing help from professionals in order to do things	Using technology to have freedom and keep safe	Someone being with you who can make you feel good - then you can make good decisions	Making decisions about the small things that matter to you	Being given the chance to be listened to	Being given the opportunity to understand what's happening to you	Making decisions based on your values
	Having user-friendly systems	Other people knowing you and your history very well	Other people listening to what you want now	Being kept active	Being in charge of yourself, what you think and what you want	
		Being given resources to make free choices	Being recognised by other people as an individual with memories	Being able to express who you really are		
			Being able to cope with your feelings about what is happening to you			
			Doing the things that you did before, just with limitations			

Appendix 18: Composite Q-sort for Factor Two

-3	-2	-1	0	+1	+2	+3
Having a use and giving back	Being helped to see things from different perspectives	Making decisions about the small things that matter to you	Being free to make unwise decisions and take risks	Other people listening to what you want now	Being given the time to think and weigh things up before making decisions	Someone being with you who can make you feel good - then you can make good decisions
Being in charge of yourself, what you think and what you want	Being able to express who you really are	Other people knowing you and your history very well	Being able to say no	Having user-friendly systems	Being included in decision-making that concerns you	Doing the things that you did before, just with limitations
	Being able to cope with your feelings about what is happening to you	Being recognised by other people as an individual with memories	Being given the opportunity to understand what's happening to you	Being given the chance to be listened to	Other people taking decisions for you	
		Needing help from professionals in order to do things	Being given resources to make free choices	Being kept active		
			Making decisions based on your values			
			Using technology to have freedom and keep safe			

Appendix 19: Composite Q-sort for Factor Three

-3	-2	-1	0	+1	+2	+3
Being able to express who you really are	Being free to make unwise decisions and take risks	Making decisions about the small things that matter to you	Being included in decision-making that concerns you	Having a use and giving back	Being given the time to think and weigh things up before making decisions	Being helped to see things from different perspectives
Being able to cope with your feelings about what is happening to you	Other people taking decisions for you	Being given resources to make free choices	Being given the opportunity to understand what's happening to you	Other people listening to what you want now	Being able to say no	Being kept active
	Using technology to have freedom and keep safe	Having user-friendly systems	Someone being with you who can make you feel good - then you can make good decisions	Making decisions based on your values	Being recognised by other people as an individual with memories	
		Needing help from professionals in order to do things	Other people knowing you and your history very well	Doing the things that you did before, just with limitations		
			Being in charge of yourself, what you think and what you want			
			Being given the chance to be listened to			