

Interviewing people living with dementia in social care research

METHODS REVIEW



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Disclaimer

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ABSTRACT

This review focuses on qualitative research approaches used in interviews with people living with dementia. Semi-structured and unstructured interviews are a popular method of qualitative data collection, potentially unearthing rich data in quantity and quality, and helping to build practice evidence.

Interviewing people living with dementia poses several ethical, methodological and practical challenges – including gaining consent, taking account of the symptoms of the dementia syndrome, negotiations with gatekeepers, proxies or informants, and analysing data. These are discussed along with strategies to address them. As with other users of adult social care services, there is also the need to avoid any impression that the interview may affect service entitlements. Aids such as Talking Mats and field notes are also discussed. Sampling as an iterative aid to qualitative interviewing is briefly outlined.

Although most of these approaches are shared with health services and other research, those particularly relevant to social care research are drawn upon and the implications of using qualitative interviewing to improve practice with people living with dementia are highlighted.

Contents

| | |
|---|-----------|
| INTRODUCTION | 1 |
| WHY INTERVIEW PEOPLE LIVING WITH DEMENTIA? | 1 |
| Ethical and practical challenges | 3 |
| Potential challenges of interviewing | 7 |
| Language and speech matter in interviews | 7 |
| Peer Research | 8 |
| Access and recruitment | 9 |
| Whose “voice”? – can people living with dementia take part in an interview? | 10 |
| Undertaking interviews with people living with dementia | 12 |
| Use of counselling principles | 13 |
| Iterative approaches | 13 |
| Structure of qualitative interviews | 14 |
| Question types | 15 |
| Interview topic guides | 15 |
| How many participants to interview? | 16 |
| Repeat interviews | 17 |
| INTERVIEW PROCESS | 17 |
| Setting the context and mentioning the content | 17 |
| Dealing with anxieties about interviews | 17 |
| Building rapport | 18 |
| Communicating effectively | 18 |
| WHAT MIGHT HELP DURING INTERVIEWS? | 20 |
| Joint interviews with carers | 20 |
| Interview aids | 20 |
| OTHER METHODOLOGICAL CONSIDERATIONS | 23 |
| People living with dementia as co-researchers or leading research | 23 |
| Analysis and writing up | 23 |
| CONCLUSION | 25 |
| REFERENCES | 26 |

INTRODUCTION

An interview is ‘*a conversation with a purpose*’ (Webb and Webb 1932, p 30). It is one way of gathering information; this methods review considers the use of interviews in social care research with people living with dementia. Research on the delivery and use of social care for people living with dementia has changed over the past decades.

While professionals, followed by carers (family and friends) were initially the primary participants in many studies, people living with dementia are increasingly included and their insights into social care can make a valued contribution to training, commissioning, quality assurance, and service improvement. There is growing appreciation of the importance of understanding the perspectives of people living with dementia in all types of research, including randomized controlled trials, service evaluations, and the development of services and interventions.

We need to make the most of this rich set of data and not burden people living with dementia by repeatedly asking them the same questions. Indeed, some researchers feel it is important to avoid topics that have been over-researched or saturated in order to reduce duplication and the waste of resources, which includes the time given by people living with dementia to be involved in research (Van der Steen and Goodman 2015).

The first and perhaps the most important point of this methods review is to establish whether research is needed and, if so, are interviews with people living with dementia the best way to answer the research question?

That answered, this review explores studies that have used the method of qualitative interviews

with people living with dementia in social care research to guide the novice researcher in social care or experienced researchers newly embarking on interviews with people living with dementia. Five broad topics are covered in this review:

1. why conducting qualitative interviews with people living with dementia may be helpful to researchers in addressing their research questions, focusing on some of the insights this method can provide;
2. practical challenges, drawing on specific examples of social care studies with people living with dementia;
3. the interview process and how to communicate effectively in order to elicit rich data;
4. consideration of what might help produce high quality data from interviews, and
5. other considerations.

Other guides are available, including one written by and for people living with dementia undertaking research (Dementia Enquirers 2019) that contains a great deal of useful information in an accessible format. Recent textbooks, such as Keady et al. (2017) also cover a variety of research methods including interviews in greater detail.

In addition to discussing the specific sensitivities of interviewing in the context of living with dementia, this review also discusses some general points about interview techniques that are thought necessary to cover here to provide as full an understanding of the method as possible. Where other texts cover key aspects of the method in more detail, these are referenced in this review.

WHY INTERVIEW PEOPLE LIVING WITH DEMENTIA?

The impact of dementia on everyday life is increasingly apparent (Alzheimer’s Society undated). This will be particularly evident to social care practitioners who work with people living with dementia in the community or in care homes. Professionals and service funders (commissioners) need to know what works in social care, for whom and in what circumstances, or indeed what people living with

dementia think about social care and how it contributes to their well-being.

Over 25 years ago, the traditional biomedical model of dementia was challenged as simplistic and inadequate (Kitwood 1989). Kitwood argued that this prioritised neuropathological symptoms, disregarded the social environment of the person presenting with dementia-like

symptoms, and failed to acknowledge the consequences of a diagnostic label on the individual. The biomedical model was criticised for seeing people living with dementia primarily as 'patients' and for neglecting the social and psychological context of individual experiences. As dementia progresses, an individual's ability to communicate is likely to become compromised and there may be a corresponding decline in social activities or social functioning (Sommerlad et al. 2017). This may mean that a person living with dementia is more likely to stay inside the home in generally familiar surroundings, but then may become isolated, and progressively more reliant on the person who supports them, be they family members, friends or social care staff.

A biopsychosocial model offers a holistic framework within which to consider the impact of dementia as it relates to social care. Admittedly 'biopsychosocial' is a very awkward term and one that most people do not use, but the biopsychosocial model of dementia encourages researchers to focus on the personal characteristics, the lived experiences of the person living with dementia, their attitudes to any care and support that they may be receiving, unmet needs, and their relationships with others including social care practitioners. Qualitative research methodologies, including in-depth interviews, can help explore these individual perspectives in some detail, and at the pace of the person living with dementia.

Collecting the subjective views of people living with dementia in research has been increasingly common since the turn of the millennium, when it started to become more generally accepted that people living with dementia should be more than a 'silent presence' in studies with their views represented by others (McColgan et al. 2000). Research with people living with dementia highlights the ability of many people, despite their cognitive impairment, to state consistent preferences (not everyone is consistent of course), make self-assessments about their well-being, and describe their feelings and concerns. For example, as we discuss below, by using techniques such as asking simply phrased questions and limiting response options, some people living with dementia can respond to questions. While this is helpful to researchers, it is also potentially transferable into care and assessment practice and to quality assurance more broadly.

Engaging people living with dementia to offer their perspectives and experiences in a face-to-face interview is one way of capturing their perceptions, measuring change, and detecting the effectiveness of support and what elements are impactful. Interviews can cover the experiences of seeking help from social care, receiving care, and desired improvements. Although researchers have tended to include people with early or mild dementia when seeking to learn more about views and experiences, more people living with moderate to severe dementia are being encouraged to lend their voice to research in different ways (Pickett and Murray 2018, Wang et al. 2019) and others are taking the lead themselves (Scottish Dementia Working Group on Research 2014, DEEP 2013).

The numbers of people living with dementia documenting their own experiences are steadily on the increase; from early accounts such as those from McKillop and Wilkinson (2004) to current and ongoing reports such as Wendy Mitchell's (ongoing) and her book (Mitchell 2018). There is also the roundup of regular blogs written by people living with dementia published in each issue of the *Journal of Dementia Care*, although these tend to depict everyday experiences of living with and managing their dementia, rather than their experiences of accessing or receiving social care.

Qualitative research methods, such as in-depth interviews but also observations or ethnographic work using the arts, provide channels through which subjective experiences can be explored, and are a popular mode of enquiry in social care research (see Phillipson and Hammond's 2018 review of innovative methods). They are reported to lessen some of the challenges related to research in dementia, such as communication problems, difficulty in selecting response options in a survey, and compensating for some participants' limited concentration spans.

Some researchers have suggested that interviews can offer time to respond to questions in a 'safe context' (Hellström et al. 2007). Relatively unexplored topics can also be highlighted through interviews, such as what life is like for people living with dementia who live on their own (Duane et al. 2013), how people living with dementia self-manage medication (While et al. 2013), or how people living with dementia experience and manage incontinence (Cole and Drennan 2017).

However, interviews are not the only method; for example, observational studies of home care for older people living with dementia (Leverson et al. 2019) can offer valuable insights into practice and the experience of care services. Brooker et al. (2011) developed a rigorous observational method of measuring engagement in care homes that provided detailed evidence of residents' often limited contact with staff.

As with all studies undergoing peer review, researchers are likely to encounter greater insistence on the quality of reporting in current times and should prepare for this. In many cases the qualitative version of the Critical Appraisal Skill Programme (CASP) (Critical Appraisal Skills Programme 2018) is used to assess the methodological quality of a qualitative study in any later synthesis – for example, to inform quality guidelines or evidence collections.

This growth of interest in quality means that care is needed not to interview people living with dementia where we already have substantial information about the subject being researched. In planning any research, as noted, there needs to be background work to consider if the research question has already been addressed. If there is substantial work already on the subject it may be worth undertaking a summary of the qualitative studies reported instead. One example of making effective use of previously collected data was a secondary analysis of a set of transcripts of 81 unstructured conversations with care home residents living with moderate to severe dementia (Clare et al. 2008) about their feelings of life in a care home.

In other circumstances, primary data collection may be needed which may benefit from early engagement with people living with dementia (see Scottish Dementia Working Group 2014). For researchers who are not familiar with local groups of people living with dementia in their area, the DEEP website (www.dementiavoices.org.uk) provides details as well as a valuable series of guides. Most relevant to this present review is their guide on 'Collecting the Views of People with Dementia' (DEEP 2013). Other guides cover involving people living with dementia on advisory groups and choosing a dementia-friendly meeting place. Many of these would also be useful in social care practice when undertaking consultations. Such guides can help with addressing the challenges of interviews, as described next.

Ethical and practical challenges

The Mental Capacity Act 2005 (England and Wales) (MCA) states that adults have the right to make their own decisions unless proved otherwise incapable, and this includes taking part or refusing to take part in research. Dementia symptoms can affect decision-making because weighing up options is likely to be challenging and communication may be affected. People living with dementia should not be assumed to lack mental capacity. Every attempt should be made to help the person living with dementia as far as is practicable to make their own decision about taking part in research.

As researchers, safeguarding the rights of people living with dementia when conducting interviews is important (these include rights to anonymity and data protection) and other relevant matters need to be considered such as permissions round data sharing. However, this can result in over-protectiveness by family or professionals (see DEEP 2013). Thorogood et al. (2018) recently produced a document seeking international consensus on research with people living with dementia that covers many of these considerations in detail.

The MCA's Code of Practice (Department for Constitutional Affairs 2007) on research should be familiar to researchers; social care practitioners will likely be very familiar with the main body of the Act and Code and its terminology and processes. Those unfamiliar with the Act are advised to remedy this whatever type of research they intend to undertake on dementia practice. Separate sections of the Act relate to practice and research. At the time of writing (end 2019) the Code is under review and a consultation is anticipated.

The MCA Code of Practice (Department for Constitutional Affairs 2007) (specifically section 11) when covering research outlines what is meant by capacity to consent to take part in research and the circumstances in which research can take place without such consent. Few studies that involve qualitative interviewing involve people who are not able to consent, as inability to consent is likely to mean that the person will struggle to contribute to an interview. Research in these circumstances may involve other methods such as observation. However, some people may not be able to consent but might be able to take part in an

interview as the Code sets out in section 11.5 when talking of the requirement for a study that has not been able to obtain consent from the person concerned to establish that it might be of benefit to the person:

Benefits may be direct or indirect (for example, the person might benefit at a later date if policies or care packages affecting them are changed because of the research). It might be that participation in the research itself will be of benefit to the person in particular circumstances. For example, if the research involves interviews and the person has the opportunity to express their views, this could be considered of real benefit to a particular individual. (Department for Constitutional Affairs 2007).

Several ethical concerns need to be addressed when conducting research with people living with dementia and many of these general areas (such as safeguarding) are covered in the methods review by Woolham (2011)¹ and are not repeated here. Instead, we focus on specific matters related to dementia and social care research.

Few research studies describe and publish the ethical principles and processes they intend to follow prior to starting their data collection but this may be needed in social care research where care settings or professionals have duties of care. There is some evidence about how people living with dementia would like the process of obtaining consent to be undertaken (DEEP (2019) and the work currently being undertaken by Dementia Enquirers (2019) will add to our knowledge.

Currently, it is also helpful to learn from others about the process of seeking ethical permissions, which in social care research might be needed from a University Ethics Committee, the Health Research Authority (HRA) which has authorised Committees specialising in social care research and in the MCA, and in some cases from social care providers or local authorities and NHS bodies. The HRA Social Care Research Ethics Committee (SCREC) is recognised by the Secretary of State as an Appropriate Body for giving permission to research that involves people lacking capacity in England and Wales and that requires approval under the MCA 2005 (see www.hra.nhs.uk/planning-and-improving-

[research/policies-standards-legislation/social-care-research](http://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/social-care-research)). This Committee is easily contactable and those unfamiliar with the HRA processes should seek advice from colleagues and/or their local National Institute for Health Research (NIHR) Research Design Service (RDS) (www.nihr.ac.uk/explore-nihr/support/research-design-service.htm).

A recent social care example of the steps that were being taken to obtain consent from people living with severe dementia that was approved by an Ethics Committee was reported by Chester et al. (2017):

Informed consent will be sought from participants before starting the research. Staff working within agencies will: introduce the study to participants; provide them with an information sheet; and gain their consent to be contacted by a member of the research team. Before conducting the interview, the researcher will explain the study to participants and obtain their formal consent. Researchers will decide upon the capacity of people with dementia to consent in accordance with the Mental Capacity Act 2005 (House of Commons, 2005). It will be assumed that people with dementia can consent to participate unless there is evidence to the contrary. This decision will be made in conjunction with the carer who will be asked for their opinion on whether or not the person with dementia would want to be involved. If they decide the person with dementia would have no objection to taking part the carer will provide written consent on their behalf.

Obtaining consent is not a one-off matter and the 'Ethics as a process' model or the process consent framework developed by Dewing (2007) encouraged researchers to view consent as running through the course of a whole study, during preparation, when obtaining consent to take part in an interview, and when using information.

Process consent complements the consent process of the MCA and is widely used in research (McKeown et al. 2010). It prompts researchers to be mindful during the interview of possible expressions of verbal, non-verbal and behavioural displeasure, disengagement and discomfort. At any sign of these, the participant

1, www.sscr.nihr.ac.uk/publication/mr004

should be asked what they wish to do and offers to postpone or stop the interview should be extended.

Table 1 summarises the process consent framework and what is involved at each stage as modified for social care research and Table 2 presents a general checklist.

Table 1: Dewing’s (2007) process consent framework modified

| Stage | What is involved? |
|----------------------------|---|
| Preparation and background | <ul style="list-style-type: none"> • Gaining ‘permission’ from gatekeepers to access the person if they are in a location where this is necessary. • Finding out about the person’s biography and indicators of wellbeing • Establishing basis for consent • Understanding the person’s capacity or ability to consent and facilitating this • Establishing usual ways of expressing consent and signs of well-being and ill-being |
| Initial consent | <ul style="list-style-type: none"> • Considering consent and assent • Using a range of written and visual prompts/information to enhance understanding • Maintaining extensive notes as evidence to account for methods/decision |
| Ongoing consent | <ul style="list-style-type: none"> • Monitoring • Revisiting consent on each research encounter with the person and responding accordingly |
| Feedback and support | <ul style="list-style-type: none"> • Providing feedback to participant, care staff/ family carers following research encounter (while respecting confidentiality of person living with dementia). • Assisting the person’s transition from research encounter back into care environment. Identifying any concerns to take to lead investigator or research supervisor. |

Table 2: Summary of approaches before, during and after qualitative interviews with people living with dementia that will help build an ethically sound study

| Stage | What is involved? |
|---|---|
| Before data collection | <ul style="list-style-type: none"> • Involve people with dementia in developing the research and social care practitioners • Be clear why interviews will help clarify or address the research question • Consider the right to be heard and safeguards • Obtain approval from relevant Ethics Committee • Take account of setting and social care usage • Check and double check equipment • Reflect on piloting • Offer feedback from the study |
| During the interview | <ul style="list-style-type: none"> • Check that hearing aids are working (if relevant), and that the space to talk is as quiet and not interrupted as possible. • Be prepared for interruptions and offer breaks • Consider how to manage distress • Have a safeguarding protocol in place • Check that all details relevant to the research have been collected, e.g. about social care usage or funding sources or can be collected later |
| After the interview | <ul style="list-style-type: none"> • Check that the person is not distressed and get support from a member of staff or carer if so or stay with the person • Manage farewells or 'exits' sensitively • Keep promises made about feedback • Secure the data and check transcriptions as soon as possible • Anonymise the transcripts • Keep fieldnotes and consent forms |
| Over-arching approaches during the research | <ul style="list-style-type: none"> • Remain vigilant for non-verbal cues that the person wishes to stop or is distressed • See consent as an on-going process through the course of research interview, rather than a one-off procedure • Reassure person (and others) about confidentiality and anonymity when using information from interview as far as safeguarding protocol permits • Offer support to researchers about possible stress and distress of interviewing |

Potential challenges of interviewing

Interviews are not the only option for social care researchers and this next section presents a brief overview of the potential challenges of interviewing when collecting data from people living with dementia. Challenges can be portrayed as disadvantages but, however they are framed, they do need to be considered.

Interviewing takes time and expense, including recruiting and briefing interviewers, travel to and from participants' homes or the research setting, sometimes long hours of interviewing, broken interviews, cancelled interviews, transcribing and analysing. In addition, there may be field notes to write up, and interview schedules to refine. There may be additional time and expense if interview topic guides and data need to be translated, or if an interpreter is needed (a good example of a study that considered interpreting is Mazaheri et al. 2014). Such costs need to be factored into any application to funders.

As with other research in social care the likelihood of people not being well enough to take part in an agreed interview needs consideration, as well as possible fatigue, meaning that interviews might need to be cut short and possibly resumed later. Interviews over the telephone or computer may sometimes be very difficult to arrange and conduct and need careful planning and piloting.

It is also important to consider the impact of people conducting interviews. Cridland et al. (2016) talked about 'dementia friendly' interviewing and also applied this to researcher well-being. They argued both can be supported by the maintenance of healthy boundaries (between the researcher and participants) and through debriefing sessions with supervisors; keeping a reflective journal, taking time for reflection, and being part of a research team or network.

While this is good practice for any social care research, interviewing someone with dementia can be distressing and researchers may feel powerless about what they see and hear. This may apply to practitioners who are undertaking research as much as to researchers. Care of researchers is something that managers should foster, colleagues support, and funders acknowledge.

Language and speech matter in interviews

Some of the challenges encountered by people living with dementia may be due to changes to verbal expression that are part of their dementia. These have been summarised as follows:

Common changes in language production include word-finding difficulties, idiosyncratic word uses, semantic (i.e. replacement of one word for another in which the meaning of the latter is related to that of the intended word) and phonemic (i.e. the substitution of a word with a non-existing word that preserves some of the segments or syllables of the intended word) paraphasias, the use of semantically empty words (e.g. unrecoverable referents), reduced phrase length, diminished grammatical complexity in sentence production, and the flattening of pitch. (Swinnen and de Medeiros 2018 p 763). (For an explanation of paraphasia see <https://en.wikipedia.org/wiki/Paraphasia>)

These changes mean that interviews with people living with moderate to severe dementia may need modification according to the research questions. Clare et al. (2008) reported on the use of 81 audio-recorded 'unstructured conversations' between two researchers and residents over time who were living with moderate to severe dementia to find out more about the subjective experience of living with dementia in a care home and to understand its psychological impact. They noted that, of the residents recruited, just eight had little or no verbal communication and they excluded just three transcripts from one resident's interviews from analysis 'because we could not distinguish any intelligible words in the participant's communication' (p712). This small number may help others in calculating recruitment targets and provides some reassurance that, despite the presence of moderate to severe dementia-related symptoms, useful data can be collected.

Cahill and Diaz-Ponce (2011) described how they supplemented semi-structured interviews with other details when interviewing nursing home residents with severe cognitive impairment (CI) about their quality of life. They made decisions about excluding some data from their analysis by considering responses they obtained to qualitative open-ended questions, non-verbal communication during the

A short note on terminology

Both Clare et al. (2008) and Cahill and Diaz-Ponce (2011) used the Mini-Mental State Examination (MMSE) in their research (other measures are available and free of charge). This enabled them to classify residents as having a probable dementia and to give some approximation of the severity by using categories that are familiar in health services research. Social care researchers need to consider how they will identify people living with dementia, whether they see value in asking about symptom severity and using well-established categories from service records (if they exist) or if they plan to collect such data themselves and how, and if they wish to use categories such as Alzheimer's disease or vascular dementia, mild cognitive impairment, or young onset dementia. Some researchers choose not to use the term dementia and use 'people with memory problems' instead, however this may raise many questions in the reader about the cause of such problems or if the person has had a diagnosis. As some of the studies mentioned in this review illustrate, other researchers use the term cognitive impairment. Some use the term 'people affected by dementia' as an umbrella term that may include people living with dementia but also their carers, family, friends and/or paid staff. Clarity is needed when using such terms. In addition, some social care researchers refer to people with complex needs, often reflecting the language of publicly funded social care entitlements and thresholds. For example, Gridley et al. (2014) explored what people with severe or complex needs and carers thought constituted good social care. One of the groups they focussed on was older people living with dementia (all 15 care users were interviewed individually or in a focus group, but most carers by phone).

In UK social care research, the term dementia is generally used, not least because of its use in policy making and government documents which often directly affect social care provision, but that still leaves open the question of whether to include more diagnostic information (type of dementia or stage or severity of symptoms) that might be relevant to the research question. There are arguments both ways; one that is often encountered in research reporting is the tendency to interview people living in the early stages of dementia rather than severe. Wang et al. (2019) recently reported that this seems to be changing and their review found studies were increasingly mentioning the 'stage' of a person's dementia. Finding out the 'stage' of someone's dementia is not straightforward and needs careful thought and preparation: will a person living with dementia be asked directly about the stage of their dementia or will other people be asked, or records consulted? It is also worth considering how a cognitive score on a standardised test relates to other categories used in social care. In the next section we consider another element of interviewing, that is, who will be doing the interview?

interviews (tone of voice, gestures, and so on) and weighing this up against professionally assessed scores of cognitive impairment on standardised tests.

Their study revealed that people living with more severe CI felt far lonelier in the care home than other residents with milder symptoms, with consequent implications for practice about the need for care homes to encourage visits and community engagement.

Peer Research

Interviews are generally conducted by a researcher or practitioner but there is interest in the potential for peer research whereby people living with dementia are engaged in interviewing. Di Lorito et al. (2018) reviewed the literature on the benefits, risks and practical

challenges of peer research generally, and used this information to develop a model of good practice in peer research with people living with dementia together with the European Working Group of People with Dementia. Overall, they found that the potential benefits of peer research included enriched data but also empowerment of people living with dementia, while potential risks included awkwardness of the power differentials between researchers and difficulty of achieving representativeness. 'The practical issues for good practice included the training of peer researchers, defining involvement and roles, working with cognitive impairment and considering resource implications' (Di Lorito et al. p504). In their contribution to this paper, the European Working Group of People with Dementia also emphasised the importance of addressing equality issues.

More broadly, as mentioned above, the Dementia Enquirers' projects are underway (2018-22). These are developing new approaches to research or 'enquiry' that are led and controlled by people living with dementia. DEEP groups across the UK are conducting their own research projects (see www.dementiavoices.org.uk/dementia-enquirers). As also noted, the DEEP research guide (DEEP 2013) could be a useful document for all.

Recently, McConnell et al. (2019) have defined 'empowerment' with people living with dementia since this term can be used in many different and confusing ways. Their definition of empowerment is 'A confidence building process whereby PWD (people with dementia) are respected, have a voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources'. This may help to make sense of the general claims made about research involvement by setting out some more concrete and measurable outcomes.

Access and recruitment

There may be added complications in that those who are deemed 'hard to reach' by services could be similarly experienced by researchers. Some researchers have addressed such challenges by using creative methods of accessing participants and devising recruitment strategies (see DEEP 2013). Dementia researchers also have the advantage of access to a very large number of people with dementia and carers who have registered their interest in taking part in research (see www.joindementia.research.nihr.ac.uk). In social care research there is also the potential to use the services of NIHR Clinical Research Networks and the initiative Enabling Research in Care Homes (ENRICH) to help with recruitment and obtaining informed consent from people (contact the local NIHR RDS for this and other research enquiries – many funders, not just the NIHR, will expect that the RDS will have already advised on an application for funding).

The use of gatekeepers, either service providers or community contacts, can help researchers get in touch with people living with dementia, along with the use of snowball sampling techniques where one participant introduces the research to another potential participant in a similar situation, such as mentioning the study to another service user. However, there are problems in accessing people who do not use

social care services, for obvious reasons, if the research wants to explore why they are not using services, for example. Fletcher (2019) was unable to get ethical permission for an informal recruitment strategy that intended to strike up conversations with people living with dementia in public places. Instead permission was only given to contact through intermediary organisations such as churches and community organisations.

The use of gatekeepers can be worrying, particularly if they seem to be making decisions on behalf of people without consulting them or seem to be perpetuating social inequalities. However, they are often necessary in contacting social care users, such as people living in care homes, by introducing a study, helping the researchers to talk to possibly reticent individuals and generally encouraging people to participate. They have an important role in advising that some people should not be contacted (for a variety of reasons) in their professional opinion (for example, death is imminent or there is a risk of harm) and they may point out that people are already taking part in one or more research studies. In social care research these situations may be more commonly encountered than others, since social care research can include, for example, studies of adult safeguarding where there may be a risk of re-traumatisation, and some well-known providers of social care are frequently asked to take part in research and may want a break. General strategies to improve recruitment to studies have recently been discussed in detail by Bartlett et al. (2019). While this is written with nurse researchers in mind it is very transferable to social care research.

In some studies, the study population may only be accessible by gatekeepers. For example, the Optimal Time study (Samsi et al. 2019) relied on care home managers to ask residents if they might like to talk to researchers about their decision to move to a care home. In this study, it emerged that the only residents who were able to consent to an interview were those who were self-funders (paying the care homes' fees themselves, rather than paid by local councils or the NHS). The research team concluded that local authority funded residents probably were not well enough to take part as they had made the move so much later in the course of their dementia than the self-funders and were consequently less able to communicate. This view was confirmed by residents' relatives and social workers.

Nothing can beat the anonymity of postal survey questionnaires where the researcher has very little background knowledge of participants save for their response sheets or electronic survey forms but for people living with dementia surveys may go unanswered or be completed by someone else. Nonetheless, they are used in research and should not be discounted. Some studies undertake a mix of interviews and survey questions.

Qualitative interviews can involve loss of anonymity which might deter potential participants. For in-depth studies with a small sample, this anonymity may be even harder to maintain. Moreover, if the study is a service evaluation, staff who know care users well or have simply seen the researcher talking to someone may recognise them and care users may feel inhibited in their responses. In such instances the researcher needs to provide extra reassurance to participants about anonymity and retaining their confidentiality or to be honest that it may not be possible to protect their identities. For example, a study of day care involved interviews in a day centre – this had the advantage of people being interviewed in a familiar place but the potential disadvantage of staff knowing who contributed (Mausdal Strandenaes et al. 2016). Similarly, a rare sub-type of dementia may also identify the few people diagnosed with it.

How such challenges get addressed needs discussion and preparation. A related point is that qualitative interviews that might seem like detailed explorations of individuals' lives tend to recruit people who are willing to share such details in conversations. Those more shy or reticent about discussing feelings and personal stories may not want to participate, even with encouragement, time and patience.

Interviewing people living with dementia often means hearing personal stories, and some research uses a biographical approach in which this is the focus, using life story or reminiscence approaches, for example. However, research with people living with dementia sometimes fails to collect or present other personal and/or services data that might set the individual in their socio-demographic and care system contexts, which are often relevant to social care. While gender is generally reported, other characteristics may be missing in reports. For social care practice, this means that readers may not be clear about their links with local authorities or service contacts, or funding

arrangements; other important considerations may be missed, such as accompanying disabilities or illnesses, and the different options that are open to people living with dementia and their families by the nature of their social contacts, social capital and biography. Establishing a person's socio-economic status is not easy and other approximations are sometimes used, such as date of leaving full-time education or home ownership. While black and ethnic minority status may be recorded, migration experience is often not noted. Until recently sexual identity was overlooked, although there have been recent increases in studies of social care experiences among people living with dementia from gay and lesbian communities (e.g. McParland and Camic 2018).

The next section considers a question which is sometimes raised of whether people living with dementia have enough insight into their own condition in order to be able to take part in research and, by extension, their insight into adult social care services.

Whose “voice”? – can people living with dementia take part in an interview?

The question of whether people living with dementia are aware of or have insight into their dementia, and so can comment on their wishes for support or care experiences, has been addressed in several research studies (although in many studies the views of carers predominate). The adult social care sector is increasingly careful not to simply accept the views of a carer or assume that these will represent the views of the person with dementia (or any user of social care services). A recent case taken to the Health and Care Professions Council (HCPC); now Social Work England) has confirmed that this is not ethical social work practice (see www.communitycare.co.uk/2015/08/26/social-worker-struck-mental-capacity-assessment-cover).

Proxy accounts also used to be justified as ‘protecting’ a person with dementia from potential emotional distress and asking a relative or social worker used to be thought sufficient in probably reflecting what the person with dementia might think. A combination of these attitudes, along with seeing carers of people living with dementia as the ‘hidden victim’ of the syndrome, led to an initial over-reliance in research on carers being asked to respond on behalf of their relatives with dementia.

Undoubtedly there are often challenges when interviewing a person with dementia (as discussed later), including difficulties with communication, poor health, acknowledging the impact of their symptoms, and in making value judgements. However, relying on a carer, or a relative who may not necessarily know the person with dementia well, to speak on behalf of someone with dementia is not generally acceptable nowadays. This is because people living with dementia and carers may have very different needs and wishes, and how carers feel about their role is very likely to affect their perspectives and responses. Studies have shown that people living with dementia tend to report a more positive outlook on their lives, while carers tend to overestimate depression and negative feelings in their relatives living with dementia. Carers are thought to give more weight to negative rather than positive information and to make evaluations based on information given to them. However, many studies acknowledge that interviewing people with severe dementia – often the user group using social care services such as care homes – is not easy because they may find it hard to think in the abstract and address complexity (Train et al. 2005) or because they are physically

unwell. In these circumstances, interviews may not be the best option, even if interview aids are used (see below) and other methods could be considered.

Charlesworth (2018) acknowledged that 'Carer's proxy responses are an approximation of the person with dementia's views and feelings, influenced by the carers' own experience' (p1065), and is one way of accepting that sometimes hearing from a carer may be the only option, when seeking to hear of the person living with dementia's perspectives. As with any interviews with carers, asking about their relationship with the service user may help throw light on how well they know the individual and the insights they bring. In adult safeguarding research and other areas of practice, care needs to be taken about the risk of distressing anyone who is being asked to recall specific incidents and their aftermath. Other subjects may also be potentially distressing to carers; in the Optimal Time study (Samsi et al. 2019) several of the carers interviewed were in tears when talking about the move of their relative to a care home. It is important that interviewers are trained and prepared to deal with these emotions during the interview and are provided with support afterwards if needed.

A short note on terminology

Lack of insight is associated with the development of dementia and a symptom that increases in severity as the dementia progresses (see Sommerlad et al. 2017). However, perceiving loss of insight as a natural consequence of dementia may be presumptuous; not everyone with dementia experiences it or in the same way, and it may not matter to a specific study. Furthermore, the practice, social and legal consequences of assigning an individual living with dementia the additional label of 'lacking in insight' can be disempowering and stigmatising, leading to exclusion from discussions (Adams and Gardiner 2005). Such a stereotype may limit researchers from exploring ways in which people living with dementia experience everyday life and care services.

A biopsychosocial model of dementia sees awareness as influenced by both changes in the brain as well as an individual's psychosocial circumstances. For the purposes of qualitative interviewing, Macquarrie (2005) highlighted the inappropriateness of perceiving people living with dementia as being 'in denial' (different from lacking insight) as this inhibits researchers from exploring how people living with dementia are managing. She described participants with dementia in her study as keen to show they had a strong sense of agency, while struggling against 'objectification' (Macquarrie 2005). Furthermore, awareness of deterioration may be independent of awareness of one's own feelings. The implications of this for social care researchers are that they can have greater confidence in seeking to conduct research with people living with dementia, and that asking them for their views directly may work. Assuming everyone with dementia is unable to respond to questions is no longer acceptable and this may need to be argued in applications to ethics committees and funders. While some people living with dementia may not be able or willing to take part in interviews this needs to be assessed on a case by case basis.

In addition to the argument that people living with dementia can take part in research, is the principle that

it is important to include them (see DEEP 2013 and Dementia Enquirers 2019). Participation can fulfil a need to be helpful and productive and give a sense of purpose and usefulness, it can emphasise a person's value and honour their personhood and enhance their autonomy (Cridland et al. 2016). These points are useful in making the case for a person's right to participate in research and in meeting the requirements of Ethics Committees and the Mental Capacity Act 2005.

There is evidence that participating in an interview can be potentially enriching because of therapeutic emotions of feeling valued, increased self-esteem and having experiences and feelings validated. James McKillop, a person living with dementia who has actively engaged with research, said he found the experience empowering and welcomed the chance to benefit future generations of people living with dementia (McKillop and Wilkinson 2004). McKillop's work is included in good practice guidance from Social Work Education (www.iriss.org.uk/sites/all/files/SCLD-Effective-Engagement.pdf), in England's National Dementia Strategy, of which he was a member of the Implementation and Monitoring Group, and NHS Scotland's Education Resources (www.nes.scot.nhs.uk/media/350872/acute_dementia_interactive_2011.pdf). Some of James McKillop's advice points are summarised in Box 1.

Box 1: Advice on including people living with dementia in research from a person with dementia (James McKillop)

The person with dementia can make a choice, be it an oral answer, a nod or shake of the head, or perhaps moving a part of their body such as a finger. The trick is to get to know how they best communicate and go down that line.

Face the person and speak clearly. The tone and volume of your voice is important. Many people who are older have hearing difficulties. Do not talk too quietly, screech at them or flap your arms about. Find the level at which the person can hear you clearly and maintain that level.

Undertaking interviews with people living with dementia

In-depth qualitative interviews may be an effective way of eliciting responses to questions although they are not the only approach. Principally, their potential strengths are the naturalness of the setting and spontaneity of the context; the flexibility they afford and the control a researcher can have over the environment (to some extent). A setting may not be 'natural' in some social care contexts (such as an office); but rapport and empathy can be established. For social care practitioners this may be easier than for others and researchers have much to learn from practitioners about how to approach people using social care services and engage them.

Grinnell and Unrau (2010) described the spontaneity and naturalness that qualitative interviews can evoke, particularly because oral communication and face-to-face conversations come naturally to many people. By encouraging a relaxed atmosphere for participants, the research interview can become like a friendly conversation in which the skilled researcher can discuss sensitive matters and get to the nub of the research question.

Grinnell and Unrau (2010) also noted that qualitative interviews command a higher 'response rate' compared to other types of studies, such as surveys and participation in clinical trials (see Vernooij-Dassen et al. 2005). In conversation with participants, researchers can answer any questions about the research study and address any concerns. Moreover, there is less scope for missing data as researchers can rephrase any questions on the interview topic guide that participants may not understand. A well-trained or experienced interviewer is likely to be skilled in rephrasing questions so that participants find it easier to respond to them; indicating the need for novice researchers to learn from others by listening to recordings, reading transcripts or talking with them.

Flexibility is one advantage of qualitative interviews as it enables researchers and participants to help the research narrative to unfold and potentially unearth new and greater insights into the subject. A skilled interviewer who is using effective probes (see later) that are part of the study design in the interview topic guide can facilitate this. This means the interviewer may have to deviate from a structured or semi-structured interview

schedule, questions may have to be rephrased, their sequence may need to be adapted, and some can be eliminated if the researcher feels they are inappropriate or unnecessary for a specific participant. With the help of probes, more detail can be derived, and field notes may help the analysis by contextualising the responses. For example, Duane and colleagues (2013) made field notes over multiple interviews to record “points of discussion and strategies used to assist them [participants] in living alone” (p. 126). On subsequent visits, they then used these field notes to confirm previous ideas that had been raised and to record change of any kind. Other researchers have used visual aids to prompt contributions that may be more attractive to and less taxing for people living with dementia (see <https://designingfordementia.eu>).

Using nonverbal or contextual material is another option for qualitative interviews. By being face-to-face with participants, researchers can take in more detail and nonverbal cues than would be possible in a postal or on-line survey or telephone interviews. These can include change in attitude or demeanour to certain questions, such as hesitation or enthusiasm; break in eye contact; or smiles or frowns at certain times in the interview.

Furthermore, if the research is being conducted in participants’ own homes, contextual information can be incorporated to add to the richness of the data collected and should be noted in the research protocol and ethical applications. In the case of dementia research, this can include seeing if certain items give clues about a person’s biography or interests (pictures, photos, and so on) to prompt conversation.

Non-verbal cues about the relationship between the person with dementia and a carer or care worker can throw light on the topic under study. In relation to this, Grinnell and Unrau (2010) also highlighted the value of being in the research environment and cited the problem of not knowing who is filling in a questionnaire in a postal survey (the same could apply to on-line surveys). In interviews, the researcher can gain some understanding of the context and will be aware of who is responding to questions, or not. This information is particularly useful in joint interviews of people living with dementia and carers, or in care settings.

Although qualitative interviews might be valued for their flexibility and spontaneity, people living

with dementia may have short attention spans and be affected by poor recall which can hamper discussions. The routine of a care setting or family may interrupt a conversation, such as mealtimes or activities. Similarly, carers may have competing demands on their time or need a break. Interviews may have to be undertaken in several ‘chunks’ or the key questions prioritised. Some parts of the day may be better than others and some days may not work at all.

Use of counselling principles

Some authors have likened the process of qualitative interviewing to counselling (Coyle and Wright 1996, Payne 1999) which for social care researchers may be familiar territory. Payne (1999) has commented on the helpful use of some counselling techniques in qualitative interviewing, such as:

1. requesting self-disclosure of feelings by asking “How did you feel about that?”
2. acknowledging feelings raised by participants by reflecting them back with a summary statement
3. engaging with the participant by actively using empathy, genuineness and unconditional positive regard
4. providing linkages between various elements of the interview so that participants can also get a sense of the bigger picture of their lives and can clarify their positions.

One example from Payne (1999) was of a researcher mentioning to the participant that they seemed to have experience of feelings of loneliness in other parts of their life. This may have given the participant a chance to clarify the different types of loneliness they had experienced, thereby producing richer qualitative data.

Iterative approaches

An iterative approach is a powerful tool in qualitative research, most commonly used in Grounded Theory analysis (Charmaz 2003). It advocates a cyclical research process, that is, beginning analysis before data collection is complete. This gives the researcher or team the chance to see whether the right questions are being asked, if responses are getting to the heart of the matter, and if any revisions to the topic guide are needed (see Livingston et al. 2010). A pilot interview and consultation about

the interview schedule may also do likewise. An iterative approach can also indicate whether a change in sampling or choice of participants is required, or if further data collection from under-represented groups is needed. In one study, for example, it emerged that the sample was lacking female participants (there were sufficient men), participants living in urban and rural settings (as opposed to suburban), and participants with a recent diagnosis of mild dementia (compared to those with mild cognitive impairment). There was time to make up for this by targeted recruitment (Manthorpe et al. 2010).

Structure of qualitative interviews

The structure of an interview topic guide needs to be considered at the outset as this can determine the outcome and the value of the data. Semi-structured and unstructured are the most popular types of qualitative interviews. Structured interviews are less common but are discussed briefly, as is the use of conversations in research settings that are not formal interviews.

Structured interviews have a clear format, include specific wording of questions and the researcher needs to ask everyone the same question. Not much training is generally required for a researcher to carry out these interviews, but when interviewing people living with dementia it is important to brief interviewers well about the possible challenges arising from symptoms such as anxiety, depression, agitation or memory loss as well as possible distress, tiredness and limited concentration spans. Limited probing is used, and researchers should not seek clarification of ambiguous answers, or draw on their own knowledge of the participant's context. Not surprisingly, these are rarely used in social care research or dementia studies.

Semi-structured or focused interviews include specific topic areas that need to be covered, but the way in which the researcher does this or phrases these questions is not prescriptive. A good level of researcher skill and training is helpful, as well as knowledge of and commitment to the research question for the appropriate level of probing to be achieved. The value of qualitative interviews lies in potentially unanticipated responses from participants and semi-structured topic guides are generally best suited to following up such comments.

However, focus needs to be maintained throughout a series of open-ended questions in the interview topic guide as it will enable the researcher to probe effectively but still maintain control of the interview and on the research question; generally open-ended questions seem to be more appropriate for people living with dementia. Within the framework of the research question, participants are encouraged to talk freely. A risk of semi-structured interviews is that due to the high level of involvement of the researcher with phrasing the questions and subsequent probing of responses, their assumptions and what they expect from the data can create bias. This needs to be minimised, through a process known as reflexivity (how one's own beliefs and attitudes play a part in a research study). Many social care practitioners are familiar with this approach to considering the impact of their subjective position in supervision and reflection.

Interviews such as these may accompany other data collection. For example, van Wijngaarden et al. (2019) asked people living with dementia to keep diary recordings and 16 of them provided 322 recorded messages in their diaries. The research team then interviewed 37 other people living with dementia and combined their data. Their interviews took the form of firstly asking participants to tell their story, this was followed by semi-structured interviews to enquire about topics that had not emerged or been covered in depth.

In **unstructured interviews**, only the problem or question area is determined in advance. The researcher needs to be fully aware of the reason and parameters of the research question with freedom to ask whichever questions they feel will best answer the research question and to probe appropriately. This type of interview is considered most appropriate to unearthing psychological phenomena such as questions about deep-seated beliefs, attitudes and feelings. As a result, researchers should have good skills and experience, self-awareness, knowledge of the research question, and sensitivity. Like semi-structured interviews, researchers conducting unstructured interviews should also be aware of the potential for bias. Reflecting on their own preconceptions and expectations of the data can help minimise this risk. Generally, most interviews are audio-recorded but there is increasing use of video. For example, in a hospital setting, people living with dementia were interviewed by video recording two or three times by a researcher

(Hung et al. 2018). The researcher filmed the environment with a handheld camera, following the patient participant's lead. She asked each patient what he or she liked and disliked about the hospital environment. The interviews took place in the corridors and activity room of the ward and were shown to staff to enable them to see the environment through patients' 'eyes'.

Again, in an unstructured way, conversations that had been audio-recorded apart from the interviews themselves were analysed in one study (Abendstern et al. 2019): 'The findings demonstrate how unsolicited comments during structured interviews may appear incidental but can reveal important aspects of living with dementia'.

Question types

Four main types of questions can be included in qualitative interviews, all of which may be included in the types of qualitative interviews discussed above:

1. **Open-ended questions** invite detailed responses following the description of a situation or encourage reflection on a participant's feelings, attitudes or belief systems. A narrative is generally the outcome of an open-ended question. Data generated tend to be harder to code and thematise and individual and team researcher skills are an important part of analysis.
2. **Closed questions** evoke structured, discrete, factual responses, such as yes/no, with no room for discussion. Coding and analysing data generated from closed questions are generally straightforward but do not often lead to great insights and may not be consistent.
3. **Double questions** are when two questions are asked in tandem and the participant generally struggles to respond to this by answering just one of them and leaving the other question unanswered. Double questions should be avoided.
4. **Multiple choice questions** are asked of participants who are then presented with different response options. The danger of this is that none of these may accurately reflect participants' views and the response may be inappropriate. Again, caution is needed in such an approach for people living with dementia who may find it difficult to recall the options or understand hypothetical options.

Interview topic guides

Developing a topic guide

Developing an interview topic guide is essential. This will determine the questions asked, the prompts used, and reduce the extent to which the researcher can potentially lead the participant and bias the data. A well-developed interview topic guide will ensure that all topics are covered and represent a range of participant views. Many more journals are asking for the topic guide (at least in summary) to be contained in a research article or to be available as supplementary material online.

Interview topic guides are dictated by the research question which may link to a study for which a great deal of preparatory work has been done prior to the interviewing (see, for example, Abendstern et al. 2019). The most common way to develop topic guides is through reviewing the literature although identification of relevant gaps in knowledge should have been included in the overall study design. For example, by conducting a systematic review highlighting key studies in dementia diagnosis, Robinson et al. (2011) were able to identify gaps and questions, such as: reasons for and against diagnostic disclosure, information provision, and the impact of disclosure that they thought could be addressed by interviews. These question areas were incorporated in the interview study which followed (Samsi et al. 2014), exploring the assessments experienced by individuals and the impact they had on their lives. Previous qualitative work on this topic was referred to in order to highlight the outstanding areas needing to be covered.

A further strategy to develop questions is to use a bottom-up technique such as a focus group, discussion groups or consultations to explore the topic under investigation. These seek input from people with some experience of the subject. The group discusses the subject and suggests ideas which can be developed for the topic guide. For instance, in a study exploring transitions experienced by people living with dementia (Tanner 2012), a consensus group discussion contributed to the development of a framework with six dimensions: first noticing that something was wrong, doing something about it, first contact with services, receiving help and support, living with dementia, hopes and fears for the future. The final topic guide included questions that related to each dimension in the framework.

Funnelling using prompts

The degree of structure used in an interview topic guide varies, with some guides having detailed questions while others may just list topics to cover. Individual or team preference may dictate the format of topic guides.

Generally, these is a list of questions, starting with a general open-ended question as an 'ice-breaker', followed by more specific questions. This technique of narrowing down questions, known as funnelling, enables rapport to be established, and the participant may be able to get comfortable before more personal and possibly sensitive questions are asked (see Box 2 for an example).

Box 2: Use of prompts in interviews with people living with dementia and multi-morbidity (Bunn et al. 2016, Appendix 2 of their report)

"Participant background/bio (conversational to find out about the person)

Probe for:

- Have they always lived in current area or are they from another area?
- Previous employment.
- Education level.
- Family – married/widowed, children/grandchildren.
- What carers there are? Who else lives with them?

Ask about family support – how often do they see/speak to family and friends?

Any help from social services/day centres/carers coming to house/community nurses?

Health problems and comorbidities"

How many participants to interview?

A criticism routinely levelled at qualitative research is the small size of study samples, compared to quantitative studies, where the larger sample size is likely to yield generalizable findings. This makes the synthesis of existing studies attractive. For example, in a recent synthesis of interview studies that had included three groups (people living with dementia, their carers and professionals), Tujit et al. (2020) drew on studies that together had interviewed 252 people living with dementia. Across the studies, the number of people living with dementia interviewed ranged from 1 to 51 per study, with an average of 6.5 participants.

The ethos of qualitative research is to value individual perspectives, so the size of the sample is less important than the depth and richness and diversity of data. Qualitative studies have varying sample sizes. Some seeking specific groups to interview may recruit only small numbers, for example, a study of people with young-onset dementia recruited 14 people aged between 57 and 67 years (Rabanal et al. 2018). Of these, five interviews were paired (person with dementia and their carer) and they lasted 30-120 minutes. In some cases, multiple interviews may be necessary to establish rapport and obtain the data required. Below are a few concepts that qualitative researchers use to indicate when recruitment and data collection can stop.

Some methodologies, such as Grounded Theory (Charmaz 2003), suggest that data should be collected iteratively, alongside data analysis, in order to indicate to researchers whether the theory being developed is reaching saturation (sufficiency). Recruitment and data collection should stop when theoretical saturation has been reached, which generally means when no new themes are being identified in the data. This will also mean that the researcher has gained a near-complete understanding of the field or phenomenon they were aiming to understand, and that further interviews will reveal nothing particularly new. Of course, this is easier said than done, but many qualitative researchers now aspire for theoretical saturation, by defining it as "when no new themes emerge". Identifying when theoretical saturation has been reached can be done when data analysis is being conducted in tandem with recruitment and data collection.

The iterative approach to recruiting and conducting interviews, alongside data analysis, is a strong guiding principle of qualitative research and seen as ethically acceptable. This ensures that each voice is given its due share in the study, that no extra interview is being conducted which may later prove unnecessary, and that each interview adds depth to understanding the area of enquiry. For this reason, knowing which themes are in the data and if theoretical saturation has been reached, is crucial. Sim et al. (2018) have argued that it is very difficult to know how many interviews are enough in advance of fieldwork, but this may not be easy to convey to research commissioners or funders and so general estimates are given.

Case studies

There is limited, but growing, recognition of the value of case studies in qualitative research. Research case studies of people living with dementia are not very common (for examples relevant to social care see Sabat 2002; Normann et al. 2005; Ritchie et al. 2015; Brent Council 2015); but there is a growing body of evidence of people living with dementia writing about their own experiences of living with the condition (Mitchell 2018; Friedell 2002). This highly personalised account of an individual's life can be argued as moving away from research; however, the light it sheds on matters that otherwise may not be addressed means that the insight gained may be valuable. Alternatively approaches such as Interpretative Phenomenological Analysis² and others encourage the use of small sample sizes in order to explore the detailed richness of an individual's life; sometimes this approach is adopted in case studies but others can be used.

The specifics of recruitment and sampling in qualitative research methodologies are covered in the Qualitative Overview Methods Review (Moriarty 2011) and so are not discussed here.

Repeat interviews

A point relevant to interviewing people living with dementia is the value of conducting more than one interview with participants, if time and resources allow. Killick (1999) declared that people living with dementia need: 'time and space to decide what to say and how to articulate it... you cannot rush into a relationship and expect intimacies to unfold... With some people, that can take a few minutes, with some a few hours, with others a number of visits'. Duane et al. (2013) interviewed people living with dementia several times. The number of interviews varied and depended on 'the varying time required to build rapport with the participant and saturation of themes to be achieved'; they were then subject to conversational analysis. In another study exploring living alone with dementia with a manifest care need, the data set consisted of field notes from 32 visits and transcriptions from 11 audio-recorded conversations with six participants (Svanström and Sundler 2015), indicating some difference in the number of visits made by the researcher and the number of recordable or relevant conversations.

INTERVIEW PROCESS

Setting the context and mentioning the content

One of the advantages of qualitative interviews is that they offer people living with dementia the opportunity to be themselves, as comfortable as possible, in a safe and familiar context (though they can take place in more formal settings). It becomes the responsibility of the researcher to create this context as far as possible. Offering the opportunity to be interviewed at home is generally thought to work best, followed by another place of their choosing. If a participant chooses a noisy, busy public space, such as a day centre or a café or out of doors, it may be sensible to try to find a quiet spot. Some researchers try to ensure that the venue is as free of distractions as possible, which can also help with hearing problems which are common

among older people (not all people living with dementia are older people, of course). Being in one's own home is generally advantageous to the participant living with dementia for the sake of familiarity, which can trigger feelings of security and control. However, walking interviews take a different view (see, for example, Gibson et al. 2018), although such studies often seem to use a variety of methods.

Dealing with anxieties about interviews

We should not underestimate possible worries about interviews, particularly if they are about social care, as people may be, for example, generally apprehensive or even fearful that their support will be negatively affected. Abendstern et al. (2019) recently reported someone's

2. Interpretative Phenomenological Analysis is a methodological approach that aims to understand the lived experience of participants and how they make sense of their experiences.

feelings of anxiety about the content of an interview (I=interviewer; P1= participant):

- I: So in the last week, have you been worried about how you're feeling or...?
- P1: I've been worried about this.
- I: About coming?
- P1: Yeah [laughs]
- I: So would you say it was a little, quite a bit?
- P1: A little
- I: A little
- P1: Because I didn't know what to expect [laugh]

Upon closer examination, these researchers recognised the potential for studying incidental conversation during structured interviews, as noted in the transcript above. When doing this, they found that people living with early stage dementia contributed very few conversational comments during interviews. This led them to realise that people even with early stage dementia found it difficult to manage conversation exchanges with the interviewer, respond to direct questions, sometimes on quite sensitive topics, and express their views about day-to-day-feelings and experiences. They also recognised that many people living with early stage dementia may find structured interviews linguistically and cognitively demanding; and it is something researchers should remain mindful of when beginning and throughout the interview. Taking more time, having breaks and being flexible in approach may help.

Building rapport

Researchers should devote time to establishing a good relationship or rapport with participants living with dementia and explain the benefits of this in their proposals when estimating the time needed for interview preparations. This should

help reduce any power inequalities a participant might feel, which can be minimised by fostering trust, warmth, and empathy (Hellström et al. 2007). Hochgraeber and Riesner (2013) advised not using questions regarding 'date or similar facts, in order to prevent an embarrassing feeling of disability'; and instead, use a person-centred attitude (see examples of this in the following discussion) and focus on questions about their experience and 'being here'. Reid et al. (2001) found that 'being here' may be easier to understand for people living with dementia to use when talking about a service (such as a day centre or care home). McKillop and Wilkinson (2004) strongly recommended that an interview should finish with the person with dementia feeling a sense of achievement or happiness, making it important to complete the interview on a positive note. The need for positive completion is even more important if repeated interviews are planned. As with any interview, a researcher should show interest and empathy with the person with dementia during and after the interview and a 'hit and run' approach should be avoided (Hellström et al. 2007). Some social care researchers find it helpful to get to be a familiar face in the care setting before embarking on recruitment of individuals, as adopted by Orellana et al. (2020) who visited her case study day centres several times before approaching individuals.

Communicating effectively

In qualitative interviews an attentive listener is necessary, as well as using a calm voice, and maintaining eye contact. It is also important that the researcher should not talk down to participants, contradict them, or probe repeatedly for details – more examples of being person-centred. Understanding and preparing for these and other potential challenges will help a researcher think about what to do should these occur. Beuscher and Grando (2009) proposed (see Table 1) a set of strategies to aid effective communication during an interview with a person living with dementia.

Table 1: Strategies to aid effective communication during qualitative interviews with a person living with dementia (adapted from Beuscher and Grando 2009)

| Effects of dementia (possible) | Strategy |
|--|---|
| Attention and concentration lapses | <ul style="list-style-type: none"> • Conduct interview in familiar place, or place that is not likely to be distracting • Redirect conversation if possible |
| Decreased abstract reasoning | <ul style="list-style-type: none"> • Restructure questions to concrete topics • Use participant's wording that is familiar and comfortable to them |
| Difficulty with word finding | <ul style="list-style-type: none"> • Give ample time to respond • If participant seems uncomfortable, offer reassurance and help |
| Memory loss | <ul style="list-style-type: none"> • Use reminiscence • Provide cues |
| Repeating phrases or dwelling on a topic | <ul style="list-style-type: none"> • Validate meaning • Redirect conversation, if appropriate |
| Fatigue or anxiety or distress | <ul style="list-style-type: none"> • Monitor for signs • Offer to stop interview |

An acronym cited by Beuscher and Grando (2009) was designed by Ripich et al. (1995) for a training programme; and may also serve as a helpful aide memoire for researchers:

FOCUSED

F = **face to face** – including facing the person and maintaining eye contact

O = **orientation** – including repeating key words – perhaps for several times, repeat sentences verbatim and give the participant time to understand

C = **continuity** – continue the same topic but highlight and prepare the person when switching to another topic

U = **unsticking** – helping participants become “unstuck” by suggesting words they are looking for, corroborate what participant may mean

S = **structure** – provide clear, concise, structured questions and limit response options

E = **exchange** – make the conversation an informal exchange to relax participant, beginning with easy, everyday questions

D = **direct** – ensure sentences are simple, short, direct and specific; use hand signals and expressive facial expressions, where relevant.

WHAT MIGHT HELP DURING INTERVIEWS?

A few strategies may help engage people living with dementia to help them to participate as fully as they would like to in interviews. For example, a researcher may initially talk with their carer or care worker or someone who knows them well. Other approaches can be useful, such as using vignettes to help start sensitive discussions, or Talking Mats (Murphy et al. 2007) that encourage people living with dementia to express themselves in non-verbal ways. In this section we discuss these possibilities.

Joint interviews with carers

When we talk of qualitative interviews with a person living with dementia, the assumption is of a face-to-face interview. Given that researchers are likely to be keen for participants to be in as familiar place to avoid stress and feel as comfortable as possible, in some circumstances the person living with dementia may be with another person, such as a carer, relative or friend, or a care worker. The person living with dementia may want that other person to remain. As a result, the one to one interview may turn into a dyadic (with two people) interview, in which both parties respond to questions. This may be intentional and by prior arrangement or it may occur without notice or planning. The possibility of it occurring and the strategies to adopt should be considered in the research plan.

The most important aspect to note in dyadic interviews, compared to individual ones, seems to be the relationship between the two participants and what responses their interaction is likely to bring forth. These can be either an advantage or disadvantage or a mixture of both, depending on the research question, and whether the resulting co-construction of a shared research narrative is valuable to the research study. Designing a dyadic interview study with people living with dementia is most likely thought about in the context of including their carers (generally a co-habiting partner or another trusted family member or friend) but possibly also a care worker or advocate – these distinctions should be reported (the term ‘carer’ gets erroneously used for both relatives or workers). If the research aim is to elicit the perspectives of the person with dementia on their general care experiences, a dyadic interview can potentially be helpful and not too difficult. Indeed, if the

research aim is to ascertain the person with dementia’s and carer’s ‘pathway’ into care (Manthorpe et al. 2013), a dyadic interview can be enlightening, with both participants supporting and corroborating one another’s shared narrative (McCleary et al. 2013). As far as possible, if the aim of the research study is to collect data from both the person with dementia and the carer, the researcher should be prepared for either participant to suggest a dyadic interview, and have a response ready regarding why they do or do not think that would be appropriate, which may run the risk that the interview does not go forward.

There is some evidence that group interviews with people living with dementia and their carers may not enable either party to express themselves fully, but it is not easy to weigh the advantages and disadvantages. A detailed study of group dynamics (Wiersma et al. 2016) over a two-year period in Canada, when groups were assembled to consider a dementia self-management programme, concluded that the choice for the research team of single or mixed groups had no obvious right or wrong answer. These researchers advised others to consider the variety of factors influencing the research question and to keep questioning and revisiting the options. The findings of Kindell et al. (2017), who referred to family members as conversation partners, seem relevant here:

Conducting a conversation can pose challenges to people with dementia and their everyday conversation partners. At the same time, conversation can also reveal unique skills and competences that people with dementia have retained or have spontaneously developed in response to the cognitive changes associated with dementia, as well as skills employed by conversation partners to scaffold such abilities (p406).

Interview aids

Conducting qualitative interviews with people living with dementia can be challenging, as mentioned, and if we are to communicate effectively, some aids to interviewing may be helpful. These could include creating accessible information in clear, large font information sheets and consent documents, visual cues and prompts indicating what the interview is about, and routine verbal reminders to determine that the participant is still happy to participate

(Bamford and Bruce 2000). DEEP guidance on written documents could be helpful here (Dementia Enquirers 2019) and this contains some examples of documents that were co-produced with people living with dementia. Two examples of aids are discussed in more detail next.

Vignettes

A vignette in dementia research generally consists of a short story or description about a fictitious person with dementia, possibly discussing symptoms and subjects that the researcher wishes the participant to discuss in their interview. Sensitive topics can generally be addressed in this way, as it enables participants

to retain some distance from the fictitious characters being described and may be less threatening than direct questioning (Torres 2009). However, self-references are sometimes spontaneously made.

Vignettes have been used in dementia research to ascertain understanding amongst the general population and professionals. Although they are not commonly used with people living with dementia, studies that have used them (Lawrence et al. 2011, Clare et al. 2012), have identified the benefits of using them as an ice-breaker, helping to encourage people to discuss matters they may have otherwise not thought to address. The researcher can also benefit from raising discussion points that they may have hesitated to introduce (see Box 3).

Box 3: Vignette Example from Lawrence et al. (2011)

We constructed a vignette which described a man, Mr G, displaying symptoms of moderate dementia. We deliberately provided a “culturally unbiased situation to which everyone could respond”. We asked colleagues from different ethnic backgrounds whether they could relate to the scenario, and tweaked elements, as necessary. The vignette was used to elicit participants’ reactions to Mr G, responses to their own condition, as well as more general ones about dementia, “Alzheimer’s disease”, Mr G’s future and their own future.

‘Mr G is 75 years old. He has become very forgetful. He confuses people’s names, even his own family, and often seems unable to remember things from one moment to the next. Yesterday when he went to the market to buy food, he came back with nothing, having forgotten what he went out for. He repeats himself in conversation. Sometimes when he goes out, he gets lost and has to be brought back by neighbours’.

Lawrence and colleagues deliberately included mention of some of the common symptoms of moderate dementia so that participants might be able to relate to them and perhaps talk about themselves in relation to Mr G.

Another valuable use of vignettes is to elicit participants’ opinions when they may lack awareness of their own condition. The general question of awareness is one that many dementia researchers struggle with and seek to address in different ways. Clare et al. (2012) found using three vignettes – depicting healthy ageing, early stage dementia, and established dementia – a useful means to elicit participants’ responses and to explore the utility of vignettes to assess awareness (see Box 4) which in this case related to some social care decisions.

Talking Mats

Talking Mats are a low-technology, accessible, inexpensive communication tool that helps

people with communication difficulties to continue to express their views about topics. It can be used with groups and individuals. Developed by researchers and clinical practitioners at the University of Stirling, a social enterprise now provides this support ‘whose vision is to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about things that matter to them’ (www.talkingmats.com). It uses the following three sets of picture symbols:

1. **Topics** – whatever the participant wants to talk about, including activities, environment, relationships, self-care.
2. **Options** – relating specifically to each topic, e.g. listening to music, playing card games, visiting friends.
3. **Visual scale** – for participants to express their overall feeling about each topic and option, e.g. happy, unhappy, unsure.

Box 4: Vignette Example from Clare et al. (2012)*Vignette 1: Established dementia*

Mrs Hughes is a 65-year-old lady who lives alone. Her friend has become concerned about her as she often forgets to do things, such as switching off the oven. She tells the same stories over and over again, without seeming to realise that she has already told her friend. She also tends to miss appointments, for example, at the doctors and hairdressers. Her next door neighbour is also worried as Mrs Hughes knocked on her door late at night saying that she wanted to go to the local shop but could not remember the way.

Vignette 2: Early-stage dementia

Mrs Owen is a 72-year-old lady who lives with her husband. Mr Owen tends to the garden, whilst Mrs Owen has always taken care of the household chores. However, lately she has been finding it difficult to organise and look after the house. She has also noticed that she sometimes struggles to find her words and does not feel able to complete the daily crossword in the newspaper anymore. She is worried that there is a problem with her memory and her husband has suggested that she should go and speak to her GP.

Vignette 3: Healthy ageing

Mrs Roberts is a 90-year-old lady who lives alone. She cooks and cleans for herself and enjoys her hobbies of listening to music, reading and keeping up with current affairs. Her neighbours often visit for a chat and help with shopping. She speaks to her son on the telephone most days; however, her son is worried about his mother living on her own and would like her to move to a local residential home for older people. Mrs Roberts has told her son that she is happy at home and does not want to move.

Talking Mats can also be used in group discussions, as illustrated in a study of people living with dementia's changing food preferences (Murphy and McKillop 2015). This short report is a good example of the use of the tool relevant to social care practice where it enabled people attending a dementia resource centre to:

- have a shared framework for thinking about the subject (food and drink) in a visual way making it easy for them to understand and engage with;
- consider issues one at a time and communicate their thoughts to others;
- use the visual and tangible images;
- listen to each other and then express their thoughts without forgetting the specific subject under discussion.

Talking Mats is a way of gaining the views of and engaging a person with dementia that may be more effective than both structured and unstructured interviews (see Box 5). This is because it helps engage the person with dementia, reduces distractibility and perseverative (repetitive) behaviour.

Researchers found that it potentially gave family members and care workers a way to find out more about the views and preferences of the person with dementia they are supporting. They cautioned that although the Talking Mats framework could be used successfully with many people living with dementia, it may not be appropriate for everyone. Moreover, it should not be used as a substitute for speech, but mainly as an aid to face-to-face conversations and interviews.

Box 5: Example of how Talking Mats helped a person with dementia communicate her experience of living in a care home (Murphy et al. 2010)

“The following example shows how an older woman felt about the environment of the care home where she was living. She indicated she was happy with the comfort of the furniture, the food, the area surrounding the care home and the temperature of the building. She was unsure about living in the care home in general and the safety. She was not happy with the noise level.”

A short note about transcribing

There are professional transcribers to whom a researcher can send their audio recorded interview. Most transcribers simply type out discussions, unless specifically instructed to do otherwise. For interviews with people living with dementia, a transcriber can be asked to pick out more subtle nuances within speech, such as pauses, interruptions, intonation, volume of speech, incomplete sentences, false starts, laughter and word repetition. This will highlight whether the interview flowed uninterruptedly from start to finish, whether there were pauses brought on by symptoms of dementia (word finding difficulty, concentration lapses), or whether by other interview characteristics, such as poor rapport, uncomfortable questions, and so on. It will of course be essential if an analytic method, such as conversational analysis, is being used (see Kindell et al. 2017). Briefing the transcriber is important and the longer the transcription the higher the cost, of course.

OTHER METHODOLOGICAL CONSIDERATIONS

People living with dementia as co-researchers or leading research

There is a small but growing trend to include people living with dementia as co-researchers but also in them taking the lead in research (see above, section 4 on peer researchers). This is seen as being valuable for two reasons. First, it enhances the personhood and status of people living with dementia through active recognition of their self-worth. This can further challenge the marginalisation and stigmatising perception of people living with dementia as unable to participate in or contribute to society (Ward et al. 2008, Wilkinson 2002).

Second, people living with dementia may feel closer to and establish rapport with co-researchers, as they may feel that their “voice” will be heard and respected more by someone with similar experiences. Studies of older people as co-researchers have found warmth, ability to communicate and empathise based on shared experiences as strong features (Miller et al. 2006). It is also possible that participants are likely to feel more relaxed with a peer interviewer, who can elicit richer perspectives (Leamy and Clough 2006, Frankham 2009). Ellins and colleagues (2012), however, highlighted that recruitment of co-researchers can be challenging as the characteristics and representativeness of the co-researcher are debatable. They adopted a participatory approach as an integral part of their research with older people, including a sub-sample of people living with dementia. Training was provided to co-researchers who helped with data collection through interviews. The

university researchers felt these co-researchers were able to build rapport, probe personal experiences by having a shared experience, and empathised appropriately during the interview. The richness of the data collected was highlighted. However, they recommended future studies should involve co-researchers at more than just the interview stage in order that their views become fully incorporated into the study. While in their study participants with and without dementia appeared to be more at ease with co-researchers as interviewers, especially if there was shared language or cultural heritage, the researchers felt that this may have impacted on quality of data. Co-researchers often struggled to balance being a third-party interviewer rather than a helpful person who was able to give advice. Of course, these tensions always need to be balanced in participatory approaches, in dementia research or otherwise.

Analysis and writing up

We have mentioned analysis several times in the course of this review, emphasising that analysis is not just the ‘next stage’ but needs to be kept in mind from the start. Many journals now want researchers to report more on their analytic processes than previously. Researchers generally explain their theoretical framework, and then give some details of their approach. The examples below relate to broad social care research and more detail of analytical frameworks relevant to dementia related studies can be found in textbooks such as those by Keady et al. (2017) and Bowling (2018).

One example of analysis of interviews with people living with dementia is from a Norwegian study that interviewed 12 people who were aged between 69 to 89 years old, and who were living at home. The team analysed each interview as a single text, then as parts of a set of texts, and lastly as a whole single text. The authors suggested that the implications for practice were that advanced care planning should ask people in the early stages of dementia about the 'rhythms' of their life at home to find out what was important to maintain (see Fæø et al. 2019).

In a study that was complicated by interviewing (in Persian and English) Iranian older people living in Sweden who had dementia, Mazaheri et al. (2014) described their process of content analysis:

The transcribed interviews were first read through to acquire an overall understanding of the content related to the research aim. Then, the data were read word-for-word to derive meaning units. To achieve immersion and obtain a sense of the whole, all data were read repeatedly and discussed among the authors. The process continued to distill (sic) condensed meaning units and construct sub-themes and themes.

The implications for services from this study, among others, were to avoid stereotyping of migrants; many for example, reported feeling very safe outside their home in Sweden and were confident that if needed the police would assist them to get back home.

Other options include narrative analysis, as undertaken in Manthorpe et al.'s (2011) study of dementia transitions that helped to identify a process of internal meaning-making as people started to seek help with their problems. The team held several data workshops to discuss the transcripts with the researchers who had undertaken the interviews to make sure that their fieldnotes and other recollections helped inform the analysis.

Conversational analysis, augmented with video, was used to consider life story work (another development based in part on interviews) that is increasingly familiar in social care practice. Kindell et al. (2019) considered that life story

work had the potential to help people with 'semantic dementia' (people with symptoms that affect memory and include difficulty finding words or understanding words and concepts) to express their views. Based on this evidence and others they suggested that life story work could help build new connections or relationships particularly in care settings.

The leap from analytical themes and codes to writing up for a report or practice materials can seem daunting. One way to start is having separate sections according to the over-arching themes identified. Describe what the theme stands for and what people talked about in this theme. A direct quote from a participant's interview transcript is a good way to illustrate the theme. Most researchers try to find a spread of supportive and contradictory quotes (and explain why a contradiction may exist). It is important that the same participant is not the source of quotes all the time.

With research with people living with dementia, matters to be mindful of in analysis and writing up include:

- Due to natural pauses in conversation, or a loss of attention in conversation, a quote from an interview with a person living with dementia may need to include an extract of the conversation, with the interviewer's comments included;
- Avoid over-using an eloquent yet atypical participant's quotes to typify too many themes in the study. This might make the findings appear relevant simply to that one participant rather than the sample.
- Make efforts to acknowledge comments from participants who may have been less verbal or expressive than others.
- Consider how to address the uses of metaphor, allusion and figures of speech – both in helping readers understand why you think this is the meaning but also so that readers are clear about this being imagery.

The choice of analysis method is very much left to researchers; perhaps greater attention to this by funders, journal and report reviewers, and the research community may encourage more reporting of not only what approach was taken but what worked or did not work well.

CONCLUSION

Qualitative interviewing of people living with dementia in social care research is popular but needs to be justified. While there are advantages and disadvantages to interviews, this methods review has tried to highlight how the advantages may be maximised, and the methodological challenges managed. The insights offered by qualitative interviews with people living with dementia remain the essence of this approach and we have drawn on several studies to highlight effective methods of

communication and relevance to adult social care practice. Although there are ethical challenges with in-depth interviewing about topics of sensitivity to some people living with dementia (and others), we have described how some of these challenges may be addressed in order to gain insights that will improve social care practice. For adult social care improvement, striving to keep the perspectives and the words of people living with dementia at the heart of research remains a valuable endeavour.

REFERENCES

- Aalten P, de Vugt ME, Jaspers N, Jolles J, Verhey FR (2005) The course of neuropsychiatric symptoms in dementia. Part 1: Findings from the two-year longitudinal Maasbed study, *International Journal of Geriatric Psychiatry*, 20, 6, 523–530.
- Abendstern M, Davies K, Chester H, Clarkson P, Hughes J, Sutcliffe C, Poland F, Challis D (2019) Applying a new concept of embedding qualitative research: an example from a quantitative study of carers of people in later stage dementia, *BMC Geriatrics*, 19, 1, 227.
- Adams T, Gardiner P (2005) Communication and interaction within dementia care triads: Developing a theory for relationship-centred care, *Dementia*, 4, 2, 185–205.
- Alzheimer's Society (undated) *The Psychological and Emotional Impact of Dementia*, Alzheimer's Society, London. www.alzheimers.org.uk/get-support/help-dementia-care/understanding-supporting-person-dementia-psychological-emotional-impact
- Bamford C, Bruce E (2000). Defining the outcomes of community care: The perspectives of older people living with dementia and their carers, *Ageing and Society*, 20, 5, 543–570.
- Bartlett R, Milne R, Croucher R (2019) Strategies to improve recruitment of people with dementia to research studies, *Dementia*, 18, 7–8, 2494–2504.
- Beuscher L, Grando V (2009) Challenges in conducting qualitative research with person with dementia, *Research in Gerontological Nursing*, 2, 1, 6–11.
- Bowling A (2018) *Research Methods in Health: Investigating Health and Health Services*, Open University Press, Milton Keynes.
- Brent Council (2015) *Living with Dementia in Today's Community: Brent*, London Borough of Brent, London. www.brent.gov.uk/media/16403194/living-with-dementia-report.pdf
- Brooker D, La Fontaine J, De Vries K, Porter T, Surr C (2011) *How can I tell you what's going on here? The Development of PIECE-dem: An observational framework focussing on the perspective of residents with advanced dementia living in care homes*. Association for Dementia Studies, University of Worcester, Worcester. https://pdfs.semanticscholar.org/9ab3/6f2a6c47ecf7c7c0a1e2cc6cac3dfdbeee29.pdf?_ga=2.50446697.1747180562.1566661633-1117738201.1565537913
- Bunn F, Burn AM, Goodman C, Robinson L, Rait G, Norton S, Bennett H, Poole M, Schoeman J, Brayne C (2016) *Comorbidity and dementia: a mixed-method study on improving health care for people living with dementia (CoDem)*, Health Services and Delivery Research, 4, 8. NIHR Journals Library, Southampton. www.ncbi.nlm.nih.gov/books/NBK344388
- Cahill S, Diaz-Ponce AM (2011) 'I hate having nobody here. I'd like to know where they all are': can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment? *Aging and Mental Health*, 15, 5, 562–572.
- Charlesworth G (2018) Patient and public involvement in dementia research: time to reflect, *Dementia*, 17, 8, 1064–1067.
- Charmaz K (2003) Grounded theory: Objectivist and constructivist methods, in Denzin K, Lincoln YA (eds) *Strategies of Qualitative Inquiry (2nd ed)*, Sage Publications Limited, London, pp.249–291.
- Chester H, Clarkson P, Hughes J, Russell I, Beresford J, Davies L, Jolley D, Peconi J, Poland F, Roberts C, Sutcliffe C, Challis D, Members of the HoSt-D (Home Support in Dementia) Programme Management Group (2017) Evaluating the effectiveness of different approaches to home support for people in later stage dementia: a protocol for an observational study, *International Psychogeriatrics*, 29, 7, 1213–1221.
- Clare L, Rowlands J, Bruce E, Surr C, Downs M (2008) The experience of living with dementia in residential care: An interpretative phenomenological analysis, *The Gerontologist*, 48, 6, 711–720.

- Cole L, Drennan V (2017) Living with incontinence: the experience of people with dementia, *Dementia*, 18, 5, 1826–1839.
- Coyle A, Wright C (1996) Using the counselling interview to collect research data on sensitive topics, *Journal of Health Psychology*, 4, 431–440.
- Cridland E, Phillipson L, Brennan-Horley C, Swaffer K (2016) Reflections and recommendations for conducting in-depth interviews with people living with dementia, *Qualitative Health Research*, 26, 13, 1774–1786.
- Critical Appraisal Skills Programme (2018) In CASP Qualitative Checklist. <https://casp-uk.net/casp-tools-checklists/>
- Dementia Enquirers (2019) *Dementia Enquirers Research Pack: Carrying out your research project, Simple guidance and ideas for DEEP groups*, www.dementiavoices.org.uk/wp-content/uploads/2019/06/Dementia-Enquirers-Research-Pack.pdf
- DEEP (2013) *Collecting the Views of People with Dementia*, DEEP, www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf
- Department for Constitutional Affairs (2007) *Mental Capacity Act Code of Practice*, London, Department for Constitutional Affairs, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf
- Dewing J (2002) From ritual to relationship: A person-centred approach to consent in qualitative research with older people who have a dementia, *Dementia*, 1, 2, 157–171.
- Dewing J (2007) Participatory research. A method for process consent with persons who have dementia, *Dementia*, 6, 1, 11–25.
- Di Lorito C, Birt L, Poland F, Csipke E, Gove D, Diaz-Ponce A, Orrell M (2017) A synthesis of the evidence on peer research with potentially vulnerable adults: how this relates to dementia, *International Journal of Geriatric Psychiatry*, 32, 1, 58–67.
- Downs M (2005) Awareness in dementia: In the eye of the beholder, *Aging & Mental Health*, 9, 5, 381–383.
- Duane F, Brasher K, Koch S (2013) Living alone with dementia, *Dementia*, 12, 1, 23–136.
- Ellins J, Glasby J, Tanner D, Mclver S, Davidson D, Littlechild R, Snelling I, Miller R, Hall K, Spence K, the Care Transitions Project co-researchers (2012) *Understanding and Improving Transitions of Older People: A User and Carer Centred Approach. Final Report*. NIHR Service Delivery and Organisation programme, Southampton.
- Fæø SE, Husebo BS, Bruvik FK, Tranvåg O (2019) “We live as good a life as we can, in the situation we’re in” – the significance of the home as perceived by persons with dementia, *BMC Geriatrics*, 19, 158.
- Feinberg LF, Whitlatch CJ (2001) Are persons with cognitive impairment able to state consistent choices? *The Gerontologist*, 41, 374–382.
- Fletcher JR (2019) Negotiating tensions between methodology and procedural ethics, *Journal of Gerontological Social Work*, 64, 4, 384–391.
- Fletcher JR, Lee K, Snowden S (2019) Uncertainties when applying the Mental Capacity Act in dementia research: a call for researcher experiences, *Ethics and Social Welfare*, 13, 2, 183–197.
- Frankham J (2009) *Partnership Research: A Review of Approaches and Challenges in Conducting Research in Partnership with Service Users*, ESRC National Centre for Research Methods, Swindon.
- Friedell M (2002) Awareness: a personal memoir on the declining quality of life in Alzheimer’s, *Dementia*, 1, 359–366.

- Gibson G, Robertson J, Pemble C, Harrison R, Strachan K, Thorburn S (2018) *A Qualitative Evaluation of Paths for All's Dementia Friendly Walking Groups*, University of Stirling, Stirling. https://dementia.stir.ac.uk/system/files/filedepot/72/04_paths_for_all.pdf
- Gridley K, Brooks J, Glendinning C (2014) Good practice in social care: the views of people with severe and complex needs and those who support them, *Health and Social Care in the Community*, 22, 6, 588–597.
- Grinnell RM, Unrau YA (2011) *Social Work Research and Evaluation: Foundations of Evidence-Based Practice*, Oxford University Press, Oxford.
- Hellström I, Nolan M, Nordenfelt L, Lundh U (2007) Ethical and methodological issues in interviewing persons with dementia, *Nursing Ethics*, 14, 608–619.
- Hochgraeber I, Riesner C (2013) The experience of people living with dementia in a social care group: case study, *Dementia*, 12, 6, 751–768.
- Hung L, Phinney A, Chaudhury H, Rodney P (2018) Using video-reflexive ethnography to engage hospital staff to improve dementia care, *Global Qualitative Nursing Research*.
- Keady J, Hydén LC, Johnson A, Swarbrick C (eds.) (2017) *Social Research Methods in Dementia Studies: Inclusion and Innovation*, Routledge, London.
- Killick J (1999) 'What are we like here?' Eliciting experiences of people living with dementia, *Generations*, 23, 3, 46–49.
- Kindell J, Keady J, Sage K, Wilkinson R (2017) Everyday conversation in dementia: a review of the literature to inform research and practice, *International Journal of Language and Communication Disorders*, 52, 4, 392–406.
- Kindell J, Wilkinson R, Keady J (2019) From conversation to connection: a cross case analysis of life story work with five couples where one partner has semantic dementia, *Ageing & Society*, 39, 10, 2322–2345.
- Kitwood T (1989) Brain, mind and dementia: With particular reference to Alzheimer's Disease, *Ageing & Society*, 9, 1–15.
- Lawrence V, Samsi K, Banerjee S, Morgan C, Murray J (2011) Threats to valued elements of life: The experience of dementia across three ethnic groups, *The Gerontologist*, 51, 1, 39–50.
- Leamy M, Clough R (2006) *How Older People Became Researchers: Training, Guidance and Practice in Action*, Joseph Rowntree Foundation, York.
- Leverton M, Burton A, Rees J, Rapaport P, Manthorpe J, Downs M, Beresford-Dent J, Cooper C (2019) A systematic review of observational studies of home care for older people, *Health & Social Care in the Community*, 27, 6, 133–140.
- Livingston G, Leavey G, Manela M, Livingston D, Rait G, Sampson E, Bavishi S, Shahriyarmolki K, Cooper C (2010) Making decisions for people living with dementia who lack capacity: qualitative study of family carers in UK, *British Medical Journal*, 341, c4184.
- McConnell T, Sturm T, Stevenson M, McCorry N, Donnelly M, Taylor BJ, Best P (2019) Co-producing a shared understanding and definition of empowerment with people with dementia, *Research Involvement and Engagement*, 5, 19. www.ncbi.nlm.nih.gov/pubmed/31205750
- McParland J, Camic PM (2018) How do lesbian and gay people experience dementia? *Dementia*, 17, 4, 452–477.
- Macquarrie CR (2005) Experiences in early stage Alzheimer's disease: Understanding the paradox of acceptance and denial, *Ageing & Mental Health*, 9, 430–441.

Manthorpe J, Samsi K, Campbell S, Abley C, Keady J, Bond J, Watts S, Robinson L, Gemski A, Warner J, Goodman C, Drennan V, Iliffe S (2010) *The Transition from Cognitive Impairment to Dementia: Older People's Experiences: Final Report*, NIHR Service Delivery and Organisation programme, Southampton.

Manthorpe J, Samsi K, Campbell S, Keady J, Abley C, Bond J, Robinson L, Watts S, Warner J, Iliffe S (2013) From forgetfulness to dementia: Clinical and commissioning implications of diagnostic experiences, *British Journal of General Practice*, 63, 606, e69–e75.

Manthorpe J, Moriarty J (2014) Examining day centre provision for older people in the UK using the Equality Act 2010: findings of a scoping review, *Health and Social Care in the Community*, 22, 4, 352–360.

Mausdal Strandenaes M, Lund A, Mork Rokstad AM (2016) Experiences of attending day care services designed for people with dementia- a qualitative study with individual interviews, *Aging and Mental Health*, 22, 6, 764–772.

Mazaheri M, Eriksson, LE, Nasrabadi, AN, Sunvisson H, Heikkilä K (2014) Experiences of dementia in a foreign country: qualitative content analysis of interviews with people with dementia, *BMC Public Health*, 14, 794.

McCleary L, Persaud M, Hum S, Pimlott NJG, Cohen CA, Koehn S, Leung KK, Dalziel WB, Kozak J, Emerson VF, Silvius JL, Garcia L, Drummond N (2013) Pathways to dementia diagnosis among South Asian Canadians, *Dementia*, 12, 769–789.

McColgan G, Valentine J, Downs M (2000) Concluding narratives of a career with dementia: accounts of Iris Murdoch at her death, *Ageing & Society*, 20, 1, 97–109.

McKeown J, Clarke A, Ingleton C, Repper J (2010) Actively involving people living with dementia in qualitative research, *Journal of Clinical Nursing*, 19, 1935–1943.

McKillop J, Wilkinson H (2004) Make it easy on yourself!: Advice to researchers from someone with dementia on being interviewed, *Dementia*, 3, 1, 117–125.

Miller E, Cook A, Alexander H, Cooper S-A, Hubbard G, Morrison J, Petch A (2006) Challenges and strategies in collaborative working with service user researchers: reflections from the academic researcher, *Research Policy and Planning*, 24, 3, 198–208.

Mitchell W (ongoing) <https://whichmeamitoday.wordpress.com>

Mitchell W (2018) *Somebody I Used to Know*, Bloomsbury, London.

Moriarty J (2011) Qualitative Methods Overview, Methods Review 1, NIHR School for Social Care Research, London.

Murphy J, Gray CM, Cox S (2007) *Communication and Dementia: How Talking Mats Can Help People Living with Dementia to Express Themselves*, Joseph Rowntree Foundation, York.

Murphy J, Gray CM, van Achterberg T, Wyke S, Cox S (2010) The effectiveness of the Talking Mats framework in helping people living with dementia to express their views on well-being, *Dementia*, 9, 4, 454–472.

Murphy J, McKillop J (2015) *'I don't enjoy food like I used to': the views of people living with dementia about mealtimes*, Talking Mats, www.talkingmats.com/wp-content/uploads/2016/01/Dementia-and-Mealtimes-final-report-2015.pdf

Normann HK, Henriksen N, Norberg A, Asplund K (2005) Lucidity in a woman with severe dementia related to conversation: A case study, *Journal of Clinical Nursing*, 14, 7, 891–896.

Orellana K, Manthorpe J, Tinker A (2020) Day centres for older people: attender characteristics, access routes and outcomes of regular attendance. Finding of exploratory mixed methods case study research, *BMC Geriatrics*, forthcoming.

Parrao T, Brockman S, Bucks RS, Bruce DG, Davis WA, Hatch KK, Leavy TL, Axten CAP, Starkstein SE (2017) The structured interview for insight and judgment in dementia: development and validation of a new instrument to assess awareness in patients with dementia, *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 7, 24–32.

Payne S (1999) Interview in qualitative research, in Memon A, Bull R (eds) *Handbook of the Psychology of Interviewing*, John Wiley, Chichester, pp89–102.

Phillipson, L, Hammond A (2018) More than talking: a scoping review of innovative approaches to qualitative research involving people with dementia, *International Journal of Qualitative Methods*, 17.

Pickett J, Murray M (2018) Editorial: patient and public involvement in dementia research: setting new standards, *Dementia*, 17, 8, 939–943.

Rabanal LI, Chatwin J, Walker A, O'Sullivan M, Williamson T (2018) Understanding the needs and experiences of people with young onset dementia: a qualitative study, *BMJ Open*, 8, 10, e021166.

Reid D, Ryan T, Enderby P (2001) What does it mean to listen to people living with dementia? *Disability & Society*, 16, 3, 377–392.

Ripich DN, Wykle M, Niles S (1995) Alzheimer's disease caregivers: The FOCUSED program: A communication skills training program helps nursing assistants to give better care to patients with Alzheimer's disease, *Geriatric Nursing*, 16, 1, 15–19.

Ritchie L, Tolson D, Danson M (2015) Dementia in the workplace case study research: Understanding the experiences of individuals, colleagues and managers, *Ageing and Society*, 38, 10, 2146–2175.

Robinson L, Gemski A, Abley C, Bond J, Keady J, Campbell S, Samsi K, Manthorpe J (2011) The transition to dementia – individual and family experiences of receiving a diagnosis: a review, *International Psychogeriatrics*, 23, 7, 1026–1043.

Sabat SR (2002) Surviving manifestations of selfhood in Alzheimer's disease: A case study, *Dementia*, 1, 25–36.

Samsi K, Abley C, Campbell S, Keady J, Manthorpe J, Robinson L, Watts S, Bond J (2014) Negotiating a Labyrinth: Experiences of assessment and diagnostic journey in cognitive impairment and dementia, *International Journal of Geriatric Psychiatry*, 29, 1, 58–67.

Samsi K, Cole L, Manthorpe J (2019) *Investigating 'Optimal Time': Perspectives on the Timing of People Living with Dementia Moving into Care Homes*, Research Findings 88, NIHR School for Social Care Research, NIHR School for Social Care Research, London.

Scottish Dementia Working Group Research Sub-Group, UK (2014) Core principles for involving people with dementia in research: innovative practice, *Dementia*, 13, 5, 680–685

Sim J, Saunders B, Waterfield J, Kingstone T (2018) Can sample size in qualitative research be determined *a priori*? *International Journal of Social Research Methodology*, March.

Sommerlad A, Singleton D, Jones R, Banerjee S, Livingston G (2017) Development of an instrument to assess social functioning in dementia: The Social Functioning in Dementia scale (SF-DEM), *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 7, 88–98.

Svanström R, Sundler, AJ (2015) Gradually losing one's foothold – A fragmented existence when living alone with dementia, *Dementia*, 14, 2, 145–163.

Tanner D (2012) Co-research with older people living with dementia: Experience and reflections, *Journal of Mental Health*, 21, 3, 296–306.

Thorogood A, Petäjä-Leinonen AM, Brodaty H, Dalpéa G, Gastmans C, Gauthiere S, Gove D, Harding R, Knoppers BM, Rossor M, Bobrow M behalf of the Global Alliance for Genomics and Health, Ageing and Dementia Task Team (2018) Consent recommendations for research and international data sharing involving persons with dementia, *Alzheimer's & Dementia*, 14, 10, 1334–1343.

- Torres S (2009) Vignette methodology and culture relevance: Lessons learned through a project on successful aging with Iranian immigrants to Sweden, *Journal of Cross-Cultural Gerontology*, 24, 1, 93–114.
- Train G, Nurock S, Kitchen G, Manela M, Livingston G (2005) A qualitative study of the views of residents with dementia, their relatives and staff about work practice in long-term care settings, *International Psychogeriatrics*, 17, 2, 237–251.
- Tujit R, Rees J, Frost R, Wilcock J, Manthorpe J, Rait G, Walters K (2020) Comparing health care experiences of people living with dementia, carers and health care professionals: a systematic review and thematic synthesis, *Dementia*, forthcoming
- Van der Steen J, Goodman C (2015) What research we no longer need in neurodegenerative disease at the end of life: The case of research in dementia, *Palliative Medicine*, 29, 3, 189–192.
- van Wijngaarden E, Alma M, The A-M (2019) 'The eyes of others' are what really matters: The experience of living with dementia from an insider perspective, *PLoS ONE*, 14, 4, e0214724.
- Vernooij-Dassen M, Moniz-Cook E, Woods R, De Lepeleire J, Leuschner A, Zanetti O, De Rotrou J, Kenny G, Franco M, Peters V, Iliffe S (2005) Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma, *International Journal of Geriatric Psychiatry*, 20, 377–386.
- Wang G, Marradi C, Albayrak A, van der Cammen T (2019) Co-designing with people with dementia: A scoping review of involving people with dementia in design research, *Maturitas* 127, 55–63.
- Ward R, Vass A, Aggarwal N, Garfield C, Cybyk B (2008) A different story: Exploring patterns of communication in residential dementia care, *Ageing and Society*, 28, 629–651.
- Webb S, Webb B. (1932) *Methods of Social Study*, Longmans Green, London.
- While C, Duane F, Beanland C, Koch S (2013) Medication management: The perspectives of people living with dementia and family carers, *Dementia*, 12, 734–750.
- Wiersma, EC, O'Connor DL, Loïselle L, Hickman K, Heibein B, Hounam B, Mann J (2016) Creating space for citizenship: The impact of group structure on validating the voices of people living with dementia, *Dementia*, 15, 3, 414–433.
- Wilkinson H (2002) Including people living with dementia in research: Methods and motivations, in Wilkinson H (ed) *The Perspectives of People Living with Dementia: Research Methods and Motivations*, Jessica Kingsley, London, pp.9–24.
- Woods RT, Pratt R (2005) Awareness in dementia: Ethical and legal issues in relation to people living with dementia, *Ageing & Mental Health*, 9, 423–429.
- Woolham J (2011) *Research Governance and Ethics for Adult Social Care Research: Procedures, Practices and Challenges*, Methods Review 4, NIHR School for Social Care Research, London.



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