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Methodological reflections on conducting online research with people with dementia: The Good, The Bad and the Ugly

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Abstract

Conducting qualitative research with people with dementia (PwD) is inherently challenging due to their fluctuating mental capacity and symptom of forgetfulness. These challenges were compounded during the early phase of the COVID-19 pandemic when social distancing and lock down were enforced. This article critically discusses the researchers' experiences on conducting online research with PwD on a sensitive topic based on an empirical study that aimed to explore the changing needs of PwD and how that affects their expectations of future. The focus is on: i) moving qualitative research to an online space, ii) the impact of joining online research on participants and iii) the impact on researcher (s). Participants were recruited via the Join Dementia Research platform. Narrative online interviews were conducted with 13 PwD and 4 dyads of PwD and carers.

Moving to online interviews removed geographical barriers from researcher and participants thus making the study more accessible. The virtual elements of online interviews created a unique interaction since the researcher was simultaneously co-occupying the space virtually but not physically with participants. Disadvantages included internet connection instability and flexible informed consent procedures were required.

The primary researcher’s expressed identities positioned him variously as an ‘in-betweener’ which challenged the dualistic concept of researcher insiderness-outsiderness. PwD’s familiar environment -their homes- appeared to enable them to take more control in the interview and potentially reduced their forgetfulness. The impact on researchers involved vicarious trauma that occurred during and after the interviews; the distress protocol was revised to include supports for the interviewer.

Keywords

Qualitative; COVID-19; Online interviews; Dementia; Reflection; Internet methods
1. Introduction
The COVID-19 pandemic has caused several disruptions and changes in society (Lowe et al., 2022). These disruptions and changes affected how qualitative researchers generated research data and interacted with participants (Karl et al., 2022; Teti et al., 2020; Thunberg & Arnell, 2022). That is, the global lockdown restrictions and enduring social distancing measures during the early phase of the COVID-19 pandemic forced researchers to rethink, reconfigure and re-design qualitative research to ensure that newly designed projects were safe, ethical and legally compliant (Authors' publication, 2021a; Thunberg & Arnell, 2022). This shift often involved conducting online data generation which saw an exponential growth during the COVID-19 pandemic and has an increasing, persisting trend afterwards (Kristiansen, 2022; Lowe et al., 2022).

However, there are several inherent challenges with online research methods – namely, the researchers’ limited support for participants due to the lack of physical proximity, technical difficulties with the chosen platform and internet instability that might affect the data generation (Davies et al., 2020). These inherent challenges are further complicated when researching specific topics or certain populations such as conducting research about potentially sensitive topics (such as health issues or victimisations) (Thunberg & Arnell, 2022) or conducting research with people with dementia (PwD). For instance, there exist inherent challenges around conducting qualitative research with PwD due to their fluctuating mental capacity, symptoms of anxiety and forgetfulness (Webb et al., 2020). Consequently, qualitative researchers need to be mindful of these challenges and provide appropriate support for participants to safeguard their well-being whilst ensuring that participants can meaningfully and ethically participate with research via online methods (Authors' publication, 2021b).

Using online methods, with different practical, technical and ethical challenges, requires critical reflection about their advantages and disadvantages and their impacts on participants and researchers. As such, this article aims to critically discusses the researchers’ experience on conducting online research with PwD. We reflect on and discuss our experiences of and the thought process around: i) moving qualitative research to an online space, ii) the impact on participants and iii) the impact on researcher.
2. Study background

The critical reflection presented in this article is based on an empirical study in which a narrative approach was used to generate data from PwD, their family carers and the researchers via online semi-structured interviews and telephone interviews. The focus was on the experiences of the initiation and revision process of Advance Care Planning (ACP) with and for PwD. The aim of the empirical study was to: i) examine the changing needs of PwD as the disease progress and how they influence the ACP process ii) examine the social contexts around PwD that affect the initiation and revision of ACP and iii) identify if the optimal time to initiate and revise an ACP with and for PwD exists. In the empirical study, the term ACP is defined as ‘a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care’ (Sudore et al., 2017, p 286).

2.1. Research paradigm and research approach considerations

The study utilised a social constructionist paradigm with relativist ontology and subjectivist epistemology. We acknowledge that multiple realities exist (Scotland, 2012); consequently, truths are fluid and can be co-constructed from several factors such as from the researchers and the researched (Denzin & Lincoln, 2017). The social constructionist paradigm relates to the initiation and revision of ACP with and for PwD since the ACP process:

- is subjective and contextualised given that the multiple contexts of PwD’s lives influence their understanding of the process
- involves several stakeholders - PwD, family carers and healthcare professionals (HCPs)
- is socially constructed in relation to each PwD’s circumstances

An integrated narrative approach was used (Wong & Breheny, 2018) to capture participants’ multiple social contexts and interactions over time. This approach was chosen since the process of ACP with and for PwD involves meaning making of their disease, subjective experience of key events that occurred over the disease trajectory (and may have triggered the need for an ACP) and negotiations about the initiation and revision of ACPs with a range of involved stakeholders. Moreover, using a narrative approach enabled the capture, and sense-making of qualitative data on the social and structural as well as disease
related barriers and facilitators associated with the ACP process over time. Stephen and Breheny’s (2018) integrated narrative approach utilises three levels of narrative:

- personal stories
- interpersonal co-creation of accounts
- social narratives

These three levels of narrative provided a comprehensive perspective to understand multiple narrators’ stories—PwD and family carers—from different levels at the same time.

Given that the COVID-19 pandemic was a complex phenomenon that affected individuals differently, the social constructionist paradigm appeared to be beneficial within the context of the study. That is, the pandemic acted as an ACP facilitator (Bender et al., 2021; Gupta et al., 2021) yet ACPs created this way tended to be predominantly medicalised due to the health impacts of COVID-19 as well as lifestyle restrictions at the time. The current study helped to generate more insight regarding how the pandemic influenced participants’ understanding of and reasoning around ACP discussion amidst the pandemic.

2.2. Participant recruitment process

The study was initially conceived to utilise the face-to-face interview technique with PwD and their family who live at home in Scotland. The research protocol was submitted to the ethical committee in February 2020. However, due to the impact of COVID-19 and lockdown restrictions in the UK at that time (Ghosh et al., 2020), the research team had to drastically change the study design to ensure that the researchers and potential participants were safe from potential exposure to COVID-19 infection and that the study was legally compliant. The study was redesigned to employ online data generation methods instead. The revised research protocol was created after a rapid scoping review, conducted by the team in April 2020, that investigated the practical, technical and ethical considerations of conducting online research with PwD and how to mitigate them (Authors’ publication, 2021a).

A Public and Patient Involvement process was implemented with PwD, family carers and HCPs as stakeholders before the study design was finalised to ensure their voices influenced the design and that the study and research objectives were relevant to their needs and experiences. The purposive sampling technique was utilised (Palinkas et al., 2015) to recruit
participants through an existing non-clinical network, Join Dementia Research (JDR) (Karagiannidou et al., 2022). JDR is a General Data Protection Regulation (GDPR) compliant UK-based national service, the Health Research Authority (HRA) endorsed and an online self-registration service which enables volunteers who have been living with dementia, carers of PwD, and healthy volunteers to register their interest in taking part in dementia research. After scrutiny of the study designs by relevant ethical committees and the team from JDR, researchers can then contact volunteers, in line with each volunteer’s preferred method of contact, to discuss potential inclusion in a study.

To make the study more inclusive and uphold the human rights of PwD, there was no age limit for PwD who could join the study meaning that both people living with young onset dementia (age less than 65) and older PwD participated. Moreover, PwD were not excluded from the study based on their clinical stage; participation of the study was based on their capacity to consent at the time of the study (Dewing, 2008; Murphy et al., 2014). This decision is also in line with the Adult with Incapacity Act (2000) in Scotland; that is, PwD must be presumed to have capacity to consent unless established otherwise (Adult with Incapacity (Scotland) Act, 2000); excluding PwD from full participation could be considered discriminatory (Fletcher, 2020; A. Thorogood et al., 2018).

2.2.1. Participants characteristics

Between October 2020–March 2021, 145 PwD and 71 family carers were contacted to take part in the study. Of these, 13 PwD joined the study; all were white British. The age range was from 51 to 87 years old with the mean of 68.7. In terms of PwD registered on the JDR database, PwD’s clinical staging ranged from mild to severe dementia. The majority of PwD (n=8) were male. The most common diagnosis was Alzheimer’s disease (n=8), followed by vascular dementia (n=3). Six PwD were living with young onset dementia. Pseudonyms were used throughout to safeguard participants’ anonymity.

Twenty-three family carers joined the study; all except one (Lebanese-British) were white British. The age range was from 41 to 78 years old with the mean of 59.4. Most family carers (n=17) were female, most of whom were daughters (n=11); the remaining were wives/partners (n=6). Participants were distributed across Scotland; that is, there were participants from urban areas (n=17), small towns (n=5), rural areas and islands (n=14). Thirty-one narrative interviews were conducted across Scotland. Of these, there were 19
online interviews (6 with PwD, 13 with family carers), 8 telephone interviews (2 with PwD, 6 with family carers) and 4 dyadic interviews (each with a PwD and a family carer).

2.3. Data generation process

Narrative data was generated with PwD and family carers, along with the primary researcher via semi-structured online and telephone interviews. The study offered two options for participation in the research to offer participants more flexibility with the interview process and, thereby, prevented premature exclusion of potential participants. Telephone interviews were used as an alternative interview method in the event of poor internet signals making online interviews difficult.

Semi-structured interviews were chosen to strike a balance between the predesignated question list of the structured interviews and the flexible conversations of the unstructured interviews (Salmons, 2016). This was considered beneficial for PwD who might have fluctuating mental capacity thus would need more structures during the interviews.

Interview schedules for this study were informed by a narrative review conducted prior (Authors’ publication, 2020). Four individual pilot interviews were conducted with two PwD and two family carers via Microsoft Teams to determine the practicality of the interview schedules and the support and distress protocol. The interview schedules and the support and distress protocol were revised after the pilot sessions.

Prior to the interviews, the primary researcher contacted participants on JDR platform via email and/or telephone to inquire if they would be interested in joining the study. After the first contact, for those opting for an online interview, instructions about how to download, and install Microsoft Teams as well as how to join the virtual meeting room were provided to participants via their emails. A reminder email was sent to participants one day before the interview date to ensure that participants, especially PwD, would not forget about the interview due to the symptom of forgetfulness. Written or verbal informed consent was obtained from participants before the interviews were undertaken.

PwD who lived with family carers could choose to join the interviews individually or as a dyad. In instances when participants opted for dyad interviews, informed consent was sought from both the PwD and the family carer. For PwD who lived with family carers and chose to
participate in an individual interview, an agreement (either be email or telephone communications) was sought before the interview that family carers would assist with the informed consent process and prepared the device to join Microsoft Teams for PwD. They were not involved during the interview process. This was to safeguard PwD’s confidentiality during the interviews.

Another consideration was that the mental capacity of PwD who joined or intended to join the study could fluctuate over time. We deduced that PwD had sufficient mental capacity to make decisions at the time that they registered with JDR. Additionally, the primary researcher reassessed PwD’s mental capacity using the Mini-Cog instrument (Seitz et al., 2021) during the informed consent process. For this study, the Mini-Cog instrument was not used to assess PwD’s clinical status; it was used as a proxy tool to ensure that PwD had the cognitive abilities to take part in the interview - in the moment of interview - and had a capability to converse and understand what they were consenting to. This included the purpose of the study, how they would be involved during the interview and what would happen with their data. This approach was utilised since there is no gold standard capacity assessment tool for PwD and most tools available are based on clinical and professional judgements which can be subjective (Adrian Thorogood et al., 2018).

For the online interviews, participants were encouraged to keep their cameras on but were free to turn them off, if preferred. This flexibility provided more control to participants so that they could participate to the degree to which they were comfortable with.

For the telephone interviews, the primary researcher called the participants with a predesignated phone and activated speakerphone. The interviews were recorded on Microsoft Teams to ensure that the data was securely stored and to prevent the risk of data breach. The primary researcher notified the participants when he activated speakerphone, and when the recording had started and stopped to ensure that they were being fully informed during the whole process. Participants were advised to find a quiet place in their home to join the interview and to use headphones, if possible, to protect their confidentiality.

All interviews were recorded in Microsoft Teams and were automatically uploaded and stored in Microsoft Stream once the recordings were processed to comply with the GDPR
and data security. Fieldnotes were created during and after the interviews as a part of the data generation process.

Immediately following each interview, the primary research gave a verbal debrief with participants and answered questions they had. The debrief form was sent to participants via emails once the interviews had concluded. This process was to ensure that participants recalled the purpose of the study and mitigated the risk of deception, especially with PwD who could have fluctuating mental capacity and might forget the purpose of the interviews.

All interviews were transcribed verbatim along with written memos. All research materials were stored on OneDrive and were only accessible to the research team. Only the primary researcher has access to the personal information of participants. The interviews lasted between 42 and 108 minutes with the mean length of 63 minutes, excluding the preamble and debrief periods.

3. Discussion
This section respectively and critically discusses three aspects of our experiences on: i) moving qualitative research to an online space, ii) the impact on participants and iii) the impact on researcher.

3.1 Moving qualitative research to an online space

We found that conducting online interviews provided several benefits for PwD over face-to-face methods and should be encouraged since it can potentially make the research with and for PwD more inclusive (Dewing, 2008; Murphy et al., 2014). This is more important within the context of COVID-19 since PwD were socially isolated at the time (Manca et al., 2022). These benefits were:

Firstly, online interviews drew on the benefits of traditional face-to-face interviews including synchronous (real-time) interactions with participants while providing additional advantages for both the researcher and participants due to the online nature of the method (Davies et al., 2020; Salmons, 2016); that is, it removes geographical restrictions from both parties thus making research more accessible for those with existing internet skills. This makes research more inclusive to potential participants who live in rural areas (Deakin & Wakefield, 2013), are part of ‘hard to reach’ populations such as PwD (Sundstrom et al., 2016), or have
comorbidities which prevent them from leaving their homes without additional support (Deakin & Wakefield, 2013). These benefits are attested and demonstrated in the participants’ geographic distribution across Scotland. The primary researcher was also able to monitor and support participants in real-time as necessary, which was suitable for discussing a potentially sensitive topic such as ACP.

Secondly, using JDR as a recruitment platform seemed to mitigate the ethical issue of conducting research with PwD: negotiation for access to PwD with gatekeepers (West et al., 2017). PwD are often safeguarded by gatekeepers who often are HCPs or their carers; this gatekeeper involvement can be either negative or positive in terms of engaging PwD in research (Bethell et al., 2018; West et al., 2017). For example, gatekeepers can withhold information, thus preventing PwD from joining research, on the assumption that a PwD might not be able to decide whether to take part in research by themselves. Conversely, gatekeepers can assist PwD during the research process to ensure that they can more easily participate. This includes providing support to obtain PwD’s informed consent for researchers, or navigating technology for PwD, as needed (Author’s publication, 2021a). For this study, we found JDR conducive to the research process given that we could reach out to more PwD during the recruitment process whilst minimising the potential negative impact from gatekeepers. Moreover, family of PwD were also able to assist the PwD to participate with our research by assisting the informed consent process or setting up Microsoft Teams for PwD.

Thirdly, the use of online interviews seemed to create unique interactions during the interviews. The interactions on the online space seemed to differ from face-to-face interviews since the primary researcher was co-occupying the space virtually but not physically with participants.

As argued by Thunberg and Arnell (2022), this unique interaction and space seems to have both the characteristics of the formal process (joining an interview of a research project) in an informal setting (joining an interview from home) for participants that seems not to fit the traditional ethical framework. Participants could both feel more at ease since they are physically at home and more alert since the researchers intend to interview with them. As such, this might require a new framework to ensure that the nuances that happened online could be comprehensively captured and addressed. This assertion was evident within the
study as participants exerted more control over the interview process and how they would like to join the interview. For example, one PwD joined the online interview in their nightgown since they ‘feel more comfortable’ wearing that (Dyadic interview with Jackie and Donald) this clothing choice was unlikely to have happened for a face-to-face interview.

Nevertheless, despite the various advantages of online methods in the study, there were also several limitations that had been mitigated.

Firstly, given that the study used online interviews as the primary method, potential volunteers might not be willing to participate. This may be due to negative attitudes towards technology, or dementia or age group. Statistics show that those who are from the older age group (aged more than 65) have less access to the internet compared to younger age groups (van Deursen & Helsper, 2015); they also reported to generally have more negative attitudes towards technology (van Deursen & Helsper, 2015). For PwD, while we do not have specific data pertaining to the number of PwD who have access to the internet, it can be assumed that the internet penetration trend is like other older adults, if not less due to their fluctuating mental capacity.

To make this study more inclusive for participants who might not have access to or be willing to navigate Microsoft Teams, an alternative strategy using telephone interviews was used. This strategy has previously been reported as being convenient for seldom heard participants in research (Irani, 2018; Lo Iacono et al., 2016). The researchers can respond to participants’ reactions and inquiries in real time, which was similar to the online interview method where synchronicity of response was a key benefit (Deakin & Wakefield, 2013). Nevertheless, the researchers can only partially assess participants’ reactions through their tone of voice and cannot read their body language which proved problematic, especially for dementia participants who might get disorientated due to the lack of context that arose from the telephone interviews. Therefore, this method was only used as an alternative option only if participants felt uncomfortable using Microsoft Teams or otherwise preferred to converse over the telephone.

Secondly, an unstable internet connection could be potentially harmful to participants who were in distress and a contingency plan for such incidence is needed. This issue is one of the inherent challenge of online method (Carter et al., 2021; Keen et al., 2022). It is more
problematic, especially with a study that needed constant monitoring and assessment of participants’ interactions and well-being such as this one. Six online interviews were affected by delay signals from either the researcher’s side or from the participants’ sides. However, we created an extensive support and distress protocol to mitigate this limitation; this action proved to be useful since no harmful incidents occurred to participants during and after any interview. The primary researcher was also mindful to participants’ verbal and non-verbal cues as a mean of monitoring their ongoing well-being.

Thirdly, flexible informed consent procedures were required to accommodate the online process and the fluctuating abilities of the PwD. In this study, the primary researcher was not physically present with participants and had to obtain informed consent remotely. Obtaining informed consent from PwD has historically been perceived as burdensome by both PwD and researchers (Suver et al., 2020). For PwD, the perception of burdensomeness was related to lengthy, complex consent materials and study procedures which they found difficult to fully understand or memorise (Suver et al., 2020). Additionally, certain legislations can act as an ‘unethical governance’ that systematically exclude PwD to participate in research (Fletcher, 2020). As pointed out by Fletcher (2020), the absolutist legislation (for instance, the Mental Capacity Act in England and Wales) tend to incentivise the exclusion of PwD to join research since the Act asserts that all PwD have, by default, impaired cognition and capacity. Consequently, researchers ‘are legally required to satisfy the MCA’s relevant provisions, located in part 1, sections 30–34 of the Act’ (Fletcher, 2020, p. 300). This often means that researchers have to argue with the relevant ethical governmental body regarding PwDs’ capacity to consent to join any research; typically, a lengthy process which may go beyond the duration of their projects. This also happened to us when we initially submitted the ethical application in February 2020 and the officer requested that the Adult with Incapacity Act (AWI) form must be obtained from PwD who would join the study. We counterargued that the PwD for this study are living in their homes and do not have the AWI form yet. As such, according to AWI, PwD must be assumed to capable of making decisions by themselves. As a result, the officer concluded that the study was not ‘clinical’ research hence did not require participants’ completion of AWI forms.

There are strategies to safeguard PwD’s human right in research (Adrian Thorogood et al., 2018) which argue that the informed consent process with PwD needs to be flexible enough
to accommodate PwDs’ capacity to consent and fluctuating mental capacity (Dewing, 2008; Evans et al., 2020). In this study, we applied these strategies by using a flexible duration to consent and offering several methods for participants to provide their informed consent. Informed consent forms for PwD and for family carers were designed and sent to potential participants along with the patient information sheet which covered information related to the study after preliminary email and/or telephone communications. Potential participants had a minimum of one day and a maximum of five days to decide whether they wanted to join the study. Extra email communications were undertaken as needed to answer any questions participants had in relation to this study. Written informed consent was obtained via email communications. Another verbal consent was obtained directly prior to the interviews and was recorded as part of the interview process. For PwD who could have fluctuating mental capacity, the consent duration was more flexible. That is, if they were not able to decide whether to consent at the initial contact and five days had passed, another contact was made after one week to ensure that they were not prematurely excluded from the study. With these strategies employed, we argued that PwD were enabled to participate in research with limited restrictions, ensuring that their human rights were safeguarded.

The notion of validating participants’ identity is also important to discuss. As the study was conducted remotely, it is possible that participants might i) claim that they were another person or ii) falsely claim that they had dementia. This can happen in online studies where it is more challenging to validate participants’ identity, especially studies with asynchronous designs (Rodríguez, 2013; Sundstrom et al., 2016). This issue was less likely to have happened as, firstly, PwD had already been validated by the JDR officer during the registration process making it likely that they had been diagnosed with dementia. Secondly, and alongside such validation, the primary researcher is a medical doctor hence, his clinical experience and awareness of dementia helped to identify dementia symptoms in the conversations with PwD. Finally, the study utilised the social constructionist paradigm. As such, the ‘validation’ of truth -if the person actually has dementia- is less relevant. Instead, the focus was on how participants co-constructed their understanding together with the primary researcher.

Upon team reflection, we had identified one additional ethical consideration regarding the conducting online research with PwD: potential safeguarding issue over participants’
confidentiality (Carter et al., 2021). Due to the nature of the online interviews, participants were only visible in their ‘virtual screen’. As such, it was not possible to ascertain if there was anyone else in the room with PwD during the interviews beyond the screen. This potential issue was also applicable to telephone interviews since it was impossible to identify if the third persons exist beyond the telephone or not. We deduced that this issue was unlikely to happen in this study given that other family members (n=3) who helped PwD in setting up the device and Microsoft Teams for the online interview sessions always presented themselves to the primary researcher prior to the interview commencing. After a brief interaction with the researcher, they excused themselves and, it seemed, the PwD was left alone with the researcher. For the telephone interviews, the primary researcher asked participants to find a quiet, private place for the interviews hence this issue was also mitigated. For future studies, it is advisable to consider this issue of safeguarding participants’ confidentiality and advise participants as needed. This might include instructing participants to find a private area in their home or using headphones to ensure that their conversations will not be overheard.

This issue around safeguarding PwD goes beyond the confidentiality issue. Due to the context of COVID-19 lockdown, PwD might either ‘stain or sustain’ their relationships with the persons they were living with yet could have limited access to support (Tuijt et al., 2021). Still, researchers have a duty of care to ensure participants’ well-being within and beyond the context of their studies (Williamson & Burns, 2014). For this study, the primary researcher provided a verbal debrief immediately after each interview and asked if participants needed any support as a part of a post interview well-being check. The debriefing email sent to participants after the interview also contained contact details of support groups an invitation to contact the primary researcher as needed.

3.2 The impact on participants

There are researchers who support the ideas of utilising online methods and those who are against this approach (Thunberg & Arnell, 2022). For instance, Deakin and Wakefield (2013) argued that the data from their Skype interviews provided more in-depth information than face-to-face interviews. They found it easier to build up rapport with participants, which was another potential advantage of this approach. This argument over the benefits of online
methods resonated with other researchers who used online interviews as their chosen method (Lo Iacono et al., 2016; Salmons, 2016). Conversely, some researchers oppose the idea of using online interview method since it enables only partial monitoring of participants’ body language and reactions, making it challenging to provide sufficient support for participants (Davies et al., 2020; Thunberg & Arnell, 2022). These researchers are also critical of the need for technological literacy from participants to engage with online interviews which could potentially exacerbate the digital divide between researchers and people who are already marginalized (Davies et al., 2020).

From this study, we argued that using online methods provided more benefits for PwD and should be further utilised.

3.2.1 Participants’ familiar environment

The familiar environment for PwD—their homes—appeared to enable participants to take more control of the interview process while maintaining their familiarity and comfort which can help reduce anxiety, forgetfulness and power inequalities. Participants could choose when, how and where they would like to participate with the study. One example was from Dave who is living with young onset Alzheimer’s disease. He chose to join the online interview from his desktop. But when the interview was about to commence, there was a technical issue: no sound came out of his speaker. Dave apologised and moved to his kitchen and joined the interview from his tablet instead; all of these actions were not guided by the primary researcher at all, indicating that Dave could adapt to the situation and chose how he liked to join the interview by himself (fieldnote from online interview with Dave).

For family carers, they preferred joining online interviews due to various reasons. Apart from being able to stay compliant with the legal requirement of maintaining social distancing at the time (2020-2021), family carers also stated that they could take care of the PwD, as needed, as pointed out by Gail:

‘...if it had been the different era [without social distancing and lockdown], and I’ve been expecting to come and meet you [outside our house], that would be so much harder for me to leave [since I have to take care of mum]. This [online interview] is working brilliantly.’ – Online interview with Gail, a family carer of her mother
From these examples, we suggested that online interviews proved beneficial and appropriate, especially for PwD given that they might experience disorientation or anxiety if the interviews were conducted in a public space that they might not be familiar with or had limited control over the space (Authors' publication, 2021b).

3.2.2 Establishing trust and familiarity online with participants and the influences of social identities

It could be potentially challenging to establish trust online with participants due to the lack of proximity or limited opportunity to build up rapport (Davies et al., 2020). This is further complicated during the COVID-19 lockdown restrictions where most communication predominately occurred online (Cheng et al., 2023). As such, there was a need to establish trust between participants and the research team.

However, similar to Karagiannidou et al. (2022), we found JDR as a recruitment platform beneficial to establish trust with participants. Almost all of the participants seemed to perceive the research team as more trustworthy given that we informed participants at the initial contact how we gained access to their contact details via JDR and how the study has been approved and registered in the platform. Although two participants were initially sceptical of the primary researcher’s identity, this was addressed when he sent more detail to them for verification purpose (his supervisor email address and his public profile on the university website). After his identity has been confirmed, both were apologetic for their scepticism and participated in the study afterwards.

Regarding establishing the familiarity around the online space (Microsoft Teams virtual room), the initial contact period with participants proved useful to establish trust and rapport. The primary researcher provided information and supported participants on how to navigate Microsoft Teams and addressing the questions that participants might have. Consequently, when the actual interviews began, both parties were more familiar with each other. This support was similar to what literature suggested; that is researchers could use this strategy to establish trust and rapport with participants before the interviews (Deakin & Wakefield, 2013; Thunberg & Arnell, 2022).

The primary researcher also made his social identities explicit during the initial contact with participants and the interviews. This action proved useful to further establish trust with participants. For the initial contact, he informed potential participants that he was a PhD
student and a GP who was conducting research with PwD and their family carers. During the interviews, he also shared his experience as a family member of PwD and how his grandmother who lives with Alzheimer’s disease has changed over the years. These social identities positioned him variously as an insider, ‘inbetweener’ and outsider thus challenging the dualistic concept of researcher’s insideness-outsiderness (Adu-Ampong & Adams, 2019; Berger, 2015; Milligan, 2016).

Hayfield and Huxley (2015) argue that researchers can address their positionality with the researched either as an ‘insider’ or ‘outsider’. In their work, an insider can be defined as a researcher that shares a ‘cultural, linguistic, ethnic, national and religious heritage with their participants’ (Nowicka and Ryan, 2015, p. 2). Additionally, an insider can be associated with participants within the same organisation or share similar experiences with them, such as caring roles (Attia & Edge, 2017). Conversely, an ‘outsider’ does not share similar characteristics nor experiences with the researched (Hayfield & Huxley, 2015). Being an outsider places the researcher in a different position to ask questions and gain a deeper understanding that ‘insiders’ may overlook (Hayfield & Huxley, 2015; Milligan, 2016; Nowicka & Ryan, 2015).

For this study, the primary researcher initially positioned himself as an outsider given that he does not share culture, language, ethnicity, and religious associations with the participants; he is an international PhD student from Thailand and uses English as a second language. All of which contrasts with participants who are British, use English as a primary language, and have different cultural backgrounds and beliefs. He also has not been diagnosed with dementia. Although his grandmother has been living with Alzheimer’s disease, he is not her primary carer. Consequently, he does not share a similar disease or caring experience with participants; this assertion proved inaccurate.

On several occasions, participants assumed that the primary researcher would ‘know more’ about dementia than other researchers (who were not medically qualified) due to his professional background as a doctor (interview with Mike, Sarah, Hamish, Mickey). This type of assumption usually happens when researchers are perceived as insiders (in this case, as a doctor). If the researcher was perceived as an insider, participants might omit some details regarding the research topic on presumptions that they already shared such knowledge (Berger, 2015). One example was from an interview with Mike who is living with Alzheimer’s
disease and how he seemed to be reluctant to share his lived experience of living with dementia. Mike had been caring for both of his parents who had dementia. He further witnessed the changes of others who live with dementia due to his background as a minister which provided him several perspectives on dementia (his lived experience, his caring experience and his professional experience). Despite this wealth of experiences, he still perceived the primary researcher as the ‘expert’ since the initial email and telephone contacts and even during the interview:

[...] in most weeks, I would be in a care home or a hospital. Seeing some of my congregation who had Alzheimer’s. I have seen it a lot [dry chuckle, looked serious]. I...took [searching for words] services...funeral services for many, many people who have been having this [dementia]...[pause] so yeah...[I know what I will become in the future]

Interviewer: And how do those experiences affect you personally? Since you are also living with dementia, how does that affect you?

Mike: Yes it does...And errr I think that you know more of this [dementia] than me [since you are a doctor], but I don’t think anybody wants this [searching for words] particular diagnosis. – Online interview with Mike

This type of presumption also happened with others. For such instances, the primary researcher had to reassure participants that it was their personal understanding and experiences of ACP and dementia that he was interested in. With this reassurance, participants were more willing to share their thoughts, experiences and understandings afterwards.

There were several occasions when the primary researcher was perceived as either an outsider or ‘inbetweener’. For example, Tal and Ian (her husband, who has been living with vascular dementia) were very keen to join the study due to their background in academia. Tal mentioned via email communications how they would like to help the primary researcher with his thesis and how they found the topic very interesting. This put him as an initial insider due to their shared characteristics. However, there also were moments that he was perceived as an inbetweener.

During the interview, Tal recounted that she could understand her husband despite his ‘choice of confused words’ due to their long-term relationship. However, she was unsure if some ‘outsider or someone like you’ e.g., the primary researcher would understand Ian. This subtle conversation suggested that Tal did not perceive the primary researcher as an insider
at that moment. Instead, her choice of word (‘someone like you’), could be implied that she perceived him as an outsider or someone who was in between this duality.

From these examples, it was evident that the researcher’s positionality was not rigid nor dichotomous; rather, it could shift in-between, depending on the moments of interactions and how he reacted to such situations. This is similar to Berger (2015) when they reflected about their changing positionality during their fieldwork. In one of their three studies that they used as the foundation of their reflexivity article, Berger perceived how their positionality started to move from an outsider to that of an insider; in doing so, Berger began to re-examine ‘biases’ that were not present prior to this realisation (Berger, 2015).

As such, we propose that qualitative researchers should reflexively investigate how their social identities and positionalities may influence the research process. The focus should be on how the researchers position themselves and how they are positioned and perceived by others. This reflexivity is to ensure that we can capture the nuanced interactions between the researcher and the researched and demonstrate the complexity within the research process which will eventually lead to richer interpretation of the data and reflexivity.

3.2.3 Joining an online study to combat lockdown isolation
To our surprise, the majority of participants indicated another benefit of the study: it helped them combat loneliness and social isolation during the lockdown. Some PwD mentioned that the primary researcher was the first person they had interacted with outside their households since the lockdown; this also resonated with the family carers of PwD. Usually, participants are incentivised to join research with either primary or secondary gains (Zutlevics, 2016). Within the context of lockdown, it seemed that participants had more incentive to join the study and interacted with the primary researcher since it was challenging to experience a range of in-person social interactions at the time. This additional benefit of social interaction may be particularly important for PwD since research has indicated their markedly decreased social interactions during the lockdown period (Curelaru et al., 2021) which subsequently affected their cognition (Manca et al., 2022). Consequently, future studies may consider this benefit for participants for their study design, especially those who are hard-to-reach or seldom heard.
3.3 The impact on researcher

In this section, the first-person pronoun will be used given that it is the personal emotional reflexivity account of the primary researcher which was also discussed amongst the rest of the research team.

Due to the nature of the empirical study - discussing end-of-life plans with PwD and their family carers - I was emotionally affected and experienced vicarious trauma (secondary trauma) by the interactions with participants which was further compounded by the context of COVID-19 lockdown restrictions and the social isolations that participants felt. Vicarious trauma or secondary trauma is the ‘impact or indirect exposure to traumatic experiences’ (Williamson et al., 2020, p. 55). This usually happens with frontline healthcare workers or counsellors due to their empathetic engagement with their clients (Williamson et al., 2020). However, it can happen to qualitative researchers who conduct research in relation to potentially sensitive topics such as victims of gender-based violence or abuses due to their engagement with participants (Branson, 2019; Williamson et al., 2020).

The vicarious trauma happened to me when participants shared their innermost thoughts: secrets or struggles that they might not share with their family or others during the interviews. For instance, several PwD shared their distress in relation to their gradual loss of personhood and their growing dependency with others (Hennelly et al., 2021), as shown in this extract:

...I yeare and I miss for what I used to be, you know, at the time that I could do things. When I lost me job, or they took your driving license away at the start [of having been diagnosed with dementia], that was like taking away your independence and that [loss of independence] happen all at once. I became...[heavy tone] dependent on me wife...

Interviewer: [pause][broken voice] Your wife mhhm... -online interview with Christopher who is living with young onset dementia

Christopher compared his loss of personhood and the experience of living with dementia and the social isolation that he felt to the COVID-19 lockdown restrictions:

...This pandemic is actually a good thing to describe dementia because we were socially isolated anyway. [...] No one would really come to help us or to give you off the hook. You don’t recognise people’s faces since they are covered up with their mask on. You're on your own, not allowed to go outside, you have been told when can you go out, where can you go out. That's exactly what it was
like for people with dementia before [the pandemic]. We were in such social isolation before. Unfortunately, we’ll be still socially isolated after the pandemic’s over [broken voice]. It’s that sad. […] As soon as everything goes back to normal, we’re going to be left behind again…

Before I entered the field, I felt confident that I would be able to maintain my ‘emotional detachment’. This confidence came from my background as a GP, lecturer and a qualitative researcher. As a GP and lecturer, I have discussed ACP with lots of patients, amounting to potentially hundreds of conversations. I also have a great deal of experience of teaching undergraduate and postgraduate students about palliative and end-of-life care. As a researcher, I conducted several qualitative studies using various data generation methods (interviews, focus groups, photo elicitation and Delphi technique); these studies included researching potentially sensitive topics such as death and dying and body image in breast cancer survivors with participants from various sociocultural backgrounds (Author’s publications, 2017, 2019). These experiences enhanced my flexibility and made me more adaptable to changes when I conducted my interviews and analysed the data in the empirical study. Paradoxically, these backgrounds also gave me a sense of false immunity that I would be unaffected by the emotional nature of my study; that was totally inaccurate. On such occasions, I was aware that I became emotional. The feeling resurfaced when I read and reread the transcripts during my analysis: I could hear my voice become broken or stuttered when I relistened to the audio record. This might stem from how I was co-constructing these interactions and, consequently, the findings, with my participants through our subjectivities. This insight helped me to answer one key anecdotal perspective from literature that researchers should remain objective: it is impossible to remain absolutely objective with research. Rather, it is more beneficial to reflexively address how you might influence the research process, analysis and outcomes. I cannot be emotionally detached from the poignant experiences that my participants shared and vice versa.

There are several recommended strategies to support qualitative researchers who are prone to vicarious trauma such as conducting research interviews in pairs or seeking out mentorship or peer support from more experienced researchers (Smith et al., 2021). For this study, I discussed these experiences with other research team members, who were also my doctoral supervisors. We agreed to expand the support and distress protocol. The revised protocol included how we would deal with the situation if I became emotionally
overwhelmed due to the content of the interviews. Moreover, I had peer support from another colleague who was not involved with this study. Fortunately, the vicarious trauma did not happen again.

During the COVID-19 lockdowns, the dominant feelings I had at the time were surrealism and uncertainty. It was essential to address these feelings – as a part of emotional reflexivity- since they influenced how I engaged with and approached the study (Hamilton, 2022). These feelings stem from my complex qualitative study design that was the intersection of i) conducting online research, ii) conducting research with PwD and iii) conducting a sensitive topic. I acknowledged that as a qualitative researcher, I had prepared to iterate and pivot my research process as necessary (Creswell, 2018). Yet no literature that I read had suggested strategies to properly prepare a study during the global pandemic. Still, once I had started to make sense of these feelings and unpack the tasks that were needed to be done, the study looked more manageable. The rapid scoping review that I conducted in 2020 along with additional literature review made me feel more optimistic. I found relevant strategies, incorporated them as a part of the research protocol and managed to finish this study. As a result, I felt self-assured on my capability to circumnavigate complex research context and will apply what I had learnt for future research.

4. Conclusions

This article presents how we reflected on, adapted and embraced challenges during the research amidst the COVID-19 pandemic and generated a more robust online qualitative study design. We argue that online methods proved useful to enable and empower PwD to participate more with research. The chosen methods removed any geographical restrictions, created a new unique space of interactions that led to a more trusting and familiar environment for PwD to engage with research. We also critically discuss how the inherent limitations of using online methods and conducting sensitive research with PwD can be mitigated. We discussed how the researcher’s positionalities and social identities influenced the research process and the data that were generated. As such, it is critical for researchers
to reflexively examine their positionalities throughout for a more robust analysis of the data or, how they reach such analysis. Finally, we also justify how and why qualitative researchers should be mindful of the potential vicarious trauma that might occur and how we should anticipate, prepare and mitigate such instances in the research protocol.
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Declaration of interests

☒ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

☐ The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: