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A Rapid Review of Internet Mediated Research Methods with People with Dementia: Practical, Technical and Ethical Considerations

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Abstract

Doing research with People with Dementia (PwD) can be challenging given that disease symptoms of anxiety, forgetfulness, and fluctuating mental capacity can make recruitment and data collection difficult. Once COVID-19 made face-to-face data collection impractical, using internet-based methods became an alternative option to continue with research. However, data collection with PwD over the internet requires strategies to observe, support, and enable them to engage with research, especially with qualitative approaches. Nine articles were selected via a decade rapid scoping review (undertaken March-June 2020) to identify qualitative online methods used with PwD and associated challenges. Methods used were online interviews, clinical assessment/telemedicine, and textual analysis from blogs, forum posts, and Tweets created by PwD. Practical challenges identified: the researchers' limited ability to manage the physical and social environment. Technical challenges identified: the need for a high degree of technical support for participants prior and during data collection. Ethical challenges identified, negotiating confidentiality, obtaining valid informed consent, and ensuring data security. Implicit findings found related to how researchers perceived and treated online data retrieved from the internet and how the challenges mentioned in the included articles did not link to dementia symptoms.

Keywords

scoping review, dementia, online research, internet research, qualitative research, technology, inclusive research

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A Rapid Review of Internet Mediated Research Methods with People with Dementia: Practical, Technical, and Ethical Considerations

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Doing research with People with Dementia (PwD) can be challenging given that disease symptoms of anxiety, forgetfulness, and fluctuating mental capacity can make recruitment and data collection difficult. Once COVID-19 made face-to-face data collection impractical, using internet-based methods became an alternative option to continue with research. However, data collection with PwD over the internet requires strategies to observe, support, and enable them to engage with research, especially with qualitative approaches. Nine articles were selected via a decade rapid scoping review (undertaken March-June 2020) to identify qualitative online methods used with PwD and associated challenges. Methods used were online interviews, clinical assessment/telemedicine, and textual analysis from blogs, forum posts, and Tweets created by PwD. Practical challenges identified: the researchers' limited ability to manage the physical and social environment. Technical challenges identified: the need for a high degree of technical support for participants prior and during data collection. Ethical challenges identified, negotiating confidentiality, obtaining valid informed consent, and ensuring data security. Implicit findings found related to how researchers perceived and treated online data retrieved from the internet and how the challenges mentioned in the included articles did not link to dementia symptoms.

Keywords: scoping review, dementia, online research, internet research, qualitative research, technology, inclusive research

Introduction

Conducting research with people with dementia (PwD) can be challenging given that disease symptoms of anxiety, forgetfulness, and fluctuating mental capacity make recruiting PwD into projects and collecting data difficult (Beuscher & Grando, 2009). Typically, researchers employ face-to-face recruitment strategies and data collection methods when involving PwD in their research as means of facilitating a supportive, flexible approach to these disease symptoms. However, the COVID-19 pandemic disrupted face-to-face participant recruitment and data collection methods because regulations across the United Kingdom (UK), and many other countries, enforced social distancing (Teti et al., 2020). Consequently, researchers had to rethink how face-to-face recruitment and data collection could meaningfully be conducted online with PwD (Teti et al., 2020; Webb et al., 2020). In the UK, social distancing restrictions were imposed in March 2020 and are still in place to date (August 2021).

Researching online makes supporting people with cognitive and memory impairments more difficult since the body, social, and environmental cues are not as readily available to the researcher to gauge the impact of involvement on the person. This is especially difficult in the context of qualitative research as building rapport, maintaining dignity, explaining complex ideas, and ensuring the comfort and safety of participants with dementia is crucially important to gaining valuable qualitative data (Sixsmith & Sixsmith, 2021). It is important to ensure that PwD are included in research, despite such restrictions since, as Hampson and Morris (2018) suggest, their perspectives and experiences can support their sense of personhood, reduce social stigma around dementia and improve the quality of services and care they receive. Consequently, to maintain their inclusion in research, Internet-Mediated Research (IMR) methods are considered. This means that researchers must balance between keeping PwD safe, negotiating with gatekeepers, designing a robust data collection method, and building up relationships with potential participants while online. This balance can be more difficult to achieve when dealing remotely with participants given the need for sensitivity and the lack of body, social, and environmental cues.

The Definition and Advantages of Internet-Mediated Research

According to the British Psychological Society (BPS), IMR is "broadly defined as any research involving the remote acquisition of data from or about human participants using the internet and its associated technologies…" British Psychological Society (2021, p. 6). IMR has gained momentum in recent years for two main reasons. Firstly, people's increased access to the internet worldwide means that IMR is more feasible. For example, globally, more than 4.6 billion people had access to the internet in 2020 (Internet World Stats, 2020); in the UK, more than 91% of adults had access to the internet in 2019 with numbers expected to rise each year (Office for National Statistics, 2019). Secondly, several benefits of undertaking IMR, via online surveys or online interviews, have been identified for researchers and participants. These benefits include removal of geographical restrictions thus making research more accessible to people who live in rural and remote areas (Deakin & Wakefield, 2013; Lobe & Morgan, 2021) and increasing an opportunity to recruit hard-to-reach populations (Kaufmann & Tzanetakis, 2020; Sundstrom et al., 2016).

Challenges of Conducting IMR with PwD

Research suggests that older people access the internet less than people in other age groups (van Deursen & Helsper, 2015). For instance, 86% of young people in the UK use the internet regularly (Office for National Statistics, 2020), this reduces to only 67% of those aged over 65 age group. Older people's digital exclusion has been explained by their limited experience with, and negative attitudes to using, the internet (van Deursen & Helsper, 2015), alongside lower levels of literacy, education, and health issues (Fang et al., 2019). Although these barriers have lessened in recent years, digital exclusion needs to be considered as a barrier to actioning online research designs. Cognitive impairment can also make internet use more difficult (Sixsmith et al., 2021). Given that more than 7.1% of people over the age 65 have some form of dementia and that prevalence of dementia increases at older ages up to 16.67% in those over the age of 80 (Prince et al., 2014; Wittenberg et al., 2019), it can be assumed internet penetration for this group might be further reduced due to their fluctuating mental capacity, difficulties with language and concentration (Dempsey et al., 2016; Thorogood et al., 2018).

A further barrier to engagement in online research which can reduce the participation of PwD relates to the notion of gatekeepers (health and social care staff or family members of

PwD; Waite et al., 2019). Gatekeepers may seek, with the best of intentions, to protect PwD from being exploited, bypassing their wishes to join research on the assumption that they need safeguarding (Sixsmith et al., 2021; Thorogood et al., 2018). Obtaining valid informed consent from PwD who have fluctuating mental capacity is another challenge to online data collection, with concerns about how to ensure potential participants are fully informed of what the study entails (Franzke et al., 2019). In addition, the research design may not "fit" PwD (Webb et al., 2020) – that is, the study design could be too complex thus making it impractical to collect data with PwD.

Despite these challenges, conducting IMR with PwD may still be possible. However, this necessitates attention being paid to strategies to identify, recruit, observe, manage, support, and enable PwD to engage with online research (Dempsey et al., 2016; Webb et al., 2020). In face-to-face studies, researchers need to consider how to balance the needs and rights of PwD to participate in research whilst preventing them from being exploited and safeguarding their well-being (Sixsmith et al., 2021; Thorogood et al., 2018). The same is true for online research; however, this may be more difficult as the researchers are more restricted in their ability to observe PwD's body language and provide support in a flexible and timely manner.

Whilst recent studies are increasingly including PwD in research (Bamford et al., 2018; Wang et al., 2019), discussion of the challenges mentioned above are limited with respect to the inclusion of PwD in online research, particularly when qualitative research designs, with in-depth data generation, are utilised. Increased knowledge and understanding of how best to involve PwD is necessary if IMR with PwD is to be inclusive; that is, a research design that adequately addresses and employs strategies to mitigate the challenges stemming from IMR without exacerbating PwD's symptoms.

Purpose of the Present Study

A rapid scoping review was undertaken to identify current online data collection methods that have been utilised with PwD and to identify the practical, technical, and ethical challenges of doing online research with PwD. Gaining information in these domains will help to develop recommendations and guidelines for effective and equitable inclusion processes and practices in IMR. The following review questions were designed to expose the current knowledge available through existing studies and identify knowledge gaps which need attention when including PwD in qualitative IMR research:

1. What qualitative online methods have been used to collect data with PwD?
2. Which software /platforms have been used to collect online data with PwD?
3. What are the practical, technical, and ethical challenges of using online methods with PwD?

For this review, online data collection was defined as any qualitative study that collected data from participants via the internet. This included primary data collection methods (qualitative interviews, virtual medical assessments) and secondary data collection methods (analysing text from blogs and online discussion boards).

Researcher's Background Prior to This Review

Phenwan is a GP by background who is studying for a Ph.D. in the UK qualitatively exploring the initiation and implementation of Advanced Care Planning with PwD. Sixsmith, McSwiggan and Buchanan supervise this work. When social restrictions were introduced following the COVID-19 pandemic, face-to-face data collection was not possible, and this scoping review was undertaken to establish the feasibility and challenges of continuing online. The findings were used to redesign the research protocol and ethical application.

Methods

A rapid review is "a type of knowledge synthesis in which components of the systematic review process are simplified or omitted to produce information in a short period of time" (Tricco et al., 2015). This type of review was selected to balance the time required to complete the review process whilst simultaneously enabling the researchers to carefully interrogate the quality and credibility of the evidence (Campbell et al., 2019). The Population, Concept, and Context (PCC) mnemonic, as suggested by Joanna Briggs Institute (Peters et al., 2020), was applied to the topic area. PCC was used as opposed to any other framework such as PICO since the purpose of the review was not to compare the interventions nor the outcomes; rather, PCC provides a framework to formulate eligibility criteria and identify appropriate keywords, giving a clear and meaningful focus for the review. Articulation of the PCC is given below:

> **P**articipants: People with dementia, young onset dementia, Parkinson's disease, dyads of PwD
> **C**oncept: Qualitative/mixed methods, research methods, methodology
> **C**ontext: Online, internet, virtual, cyber research

The initial search terms used were: (dementia* or Alzheimer* or people with or vascular) AND (online or internet or twitter or blog* or virtual* or digital or platform* or application* or mobile or Facebook or YouTube or Podcast or Skype or social media or stream* or Zoom) AND (qualitative).

These were initially used in the PubMed database and adjusted to other databases. Three electronic databases were searched, PubMed, CINAHL, and PsycINFO) as they comprehensively cover medical, health, and social sciences literature, including methodological issues. Two grey literature databases were also searched: OpenSIGLE and OpenGrey to identify any literature from non-peer reviewed sources. Search terms were initially tested on PubMed and subsequently adjusted for the other databases. This resulted in 5,725 articles being identified for screening.

The five-year rapid scoping search was chosen to focus on up-to-date studies. The initial search yielded few articles (N = less than 20) eligible for full-text assessment. The search strategy was subsequently extended to a decade review and to include studies that collected data online from people with Parkinson's Disease (PD) – this decision was deemed appropriate because people with PD also experience cognitive decline over time along with the limited mobility and thus need support for inclusion in online research that is typically like PwD. Additional time frame also allowed the research team to identify the technology that were used to conduct studies and how they had changed over time.

The inclusion criteria used to select all relevant articles were articles written in English, published in the last 10 years (between 1st April 2010- 30th April 2020), and studies that collected qualitative data from PwD or people with PD via online methods. Articles that collected data from dyads of PwD, and their family carers were also included, the rationale being that PwD can require additional support to join research. Mixed-method studies were to ensure information from the qualitative aspects of these studies was captured.

Articles were excluded based on being written in a language other than English, published before 1st April 2010 or after 30th April 2020, or when data were not directly created by PwD, people with PD or their dyad. Articles that collected online data from older adults without dementia or PD were also excluded given that fluctuating mental capacity was a key consideration in this review. Studies that collected data via non-virtual methods, such as face-to-face interviews and reviews, were also excluded, along with studies with quantitative designs (see Table 1).

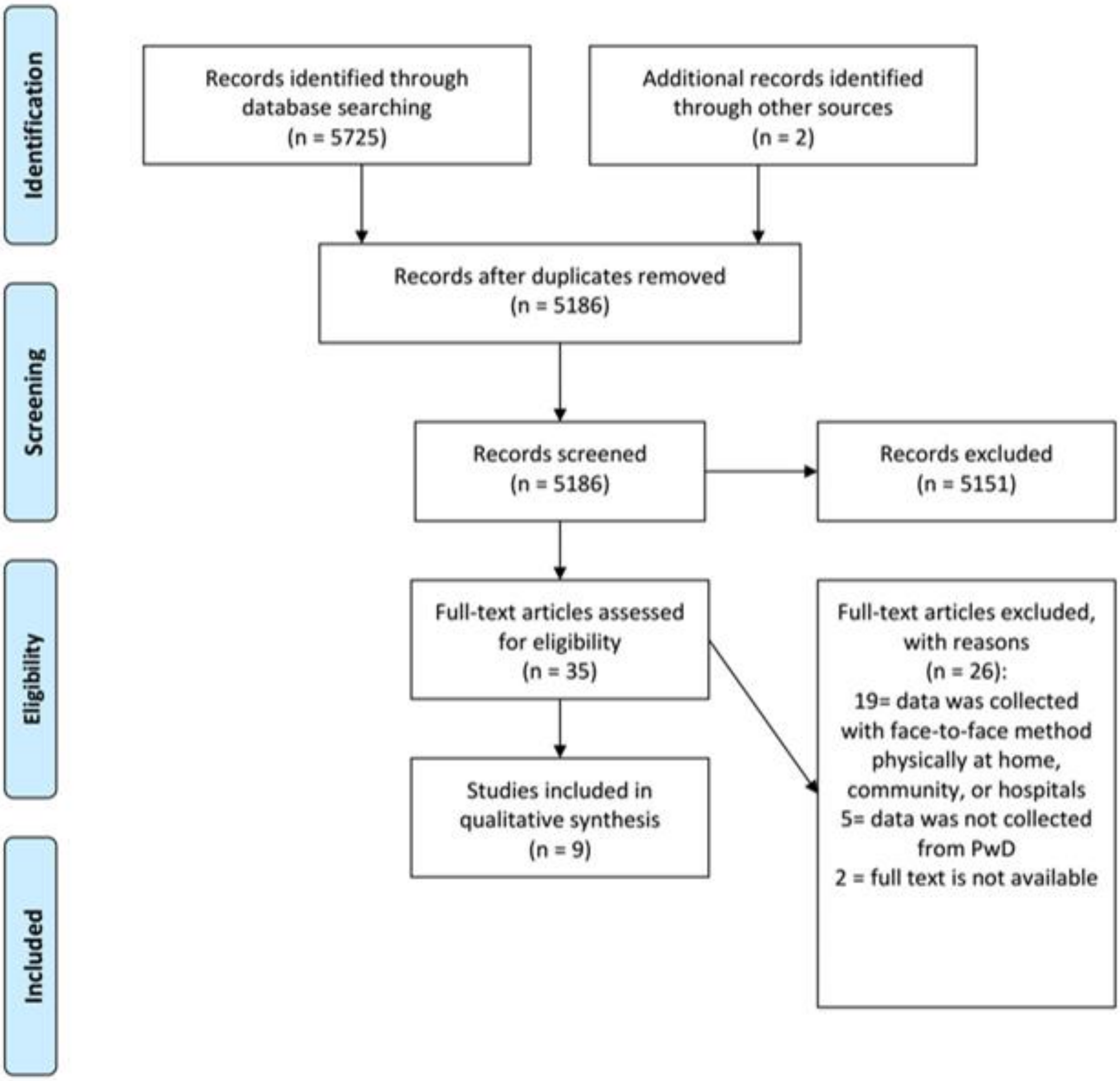
Table 1
Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
- Articles written in English -Articles reporting on studies that collected data using online methods from PwD or Parkinson's disease (including dyads) -Peer-reviewed articles and grey literature -Studies with qualitative designs -Studies with mixed-methods designs that collected qualitative data from PwD online	- Articles written in languages other than English - Articles reporting on studies that collected data using online methods from older people without dementia or Parkinson's Disease - Studies with quantitative designs - Systematic, narrative, or scoping reviews

After de-duplication, 5,186 articles remained for screening. Title and abstract screening were conducted using the inclusion and exclusion criteria above. Ten percent of articles were double screened by the research team to ensure consistency and rigour in the screening process. Full article screening was then undertaken on 35 articles (again, 10% double screened), resulting in a final set of nine articles for inclusion in the review. Figure 1 shows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart of the screening process.

The first author screened all the titles and abstracts, read the full articles, and assessed them by applying the inclusion and exclusion criteria. The articles were rechecked by a second reviewer and discrepancies were discussed. Final decisions made on each article were checked and confirmed by all four authors in terms of whether to: include an article in the review or not, and to agree the full dataset.

Figure 1
PRISMA Diagram



Data Extraction

A data extraction chart, created in Microsoft Excel, for this study was used to facilitate data analysis, focusing on:

1. data collection methods used to collect data with PwD
2. software/platforms used
3. challenges that were explicitly or implicitly mentioned in the articles (see Table 2).

Information concerning authors, dates and places of publication, strengths and limitations of each study and knowledge gaps were also extracted and entered the data chart.

Table 2
Included Articles for the Analysis

Author (Year) (Country)	Input/participant characteristics	Methodology	Data analysis	Explicit practical challenges identified within the study	Explicit technical challenges identified within the study	Explicit ethical challenges identified within the study
Synchronous methods						
Stillerova et al. (2016) (Australia)	-11 PD -face-to-face clinical assessment then Skype one week later using technology available at PD's home.	-MoCA face-to-face and videoconferencing -Open and closed-ended questionnaires; participants chose to answer via internet or posts.	-Descriptive statistics for demographic data -Inductive content analysis for participants' feedback	**Flexibility over data collection methods** -Participants joined the session via various devices (computers, smartphones, tablets) and platforms (Skype or Google+ Hangouts) **Limited ability to manage participants physical environment** -Distractions from participants' environments	**Extra support for participants** -Support from the researchers was provided for participants to use Skype before and during data collection **Technical difficulties** -Poor internet connection from participants -Software error	**Informed consent** -The study went through ethical approval process -Informed consent obtained **Data protection and security** -Data were stored securely
Lindauer et al. (2017) (USA)	-28 dyads of persons with AD and family carers -Direct-to-home telemedicine videoconferencing via a platform.	-Series of clinical tests or MoCA and CDR both in the clinical settings and via telemedicine visits -The research assistant checked the internet connection and assisted with the technology before the telemedicine session	-Test-retest reliability was assessed with Intraclass correlation (ICC) for continuous variables -Cohen's Kappa coefficient for the categorical variables	**Flexibility over data collection methods** -The clinician and family carers assisted people with AD during the sessions **Limited ability to manage participants physical environment** -Additional equipment for participants were provided (cameras, headphones, tablets) -Distractions from participants' environments	**Extra support for participants** -Shared screen function was used to accommodate the process **Technical difficulties** -Reduced audio or video quality	**Informed consent** -The study went through ethical approval process -Informed consent obtained (persons with AD assented, family carers gave telephone consent) **Confidentiality** -Headphones were used during the interviews. **Data protection and security** -Data were stored securely

Lovegrove et al. (2017) (UK)	-Two semi-structured Skype interviews and seven telephone interviews with PD	-Patient and Public Involvement (PPI) with constructivist epistemological framework - A pragmatic inquiry framework and inductive approach was used	-Thematic Analysis with inductive approach	**Flexibility over data collection methods** -Participants could join the study via various platforms (Skype interviews, telephone interviews, emails)	-Not explicitly mentioned	**Informed consent** -The study went through ethical approval process -Informed consent obtained (written consent via emails)
Mammen et al. (2018) (USA)	-Virtual house calls with 97 PD -Part of an RCT -Online surveys with open-ended questions after each virtual house call	-The study was a part of an RCT. The quantitative findings were published elsewhere	-Case-based qualitative content analysis -Quantitative sentiment analysis techniques	**Limited ability to manage participants physical environment** -Distractions from participants' environments	**Extra support for participants** -Additional training for both participants and physicians were needed **Technical difficulties** -Participants could not install/open the software -Reduced audio or video quality	**Informed consent:** -The study went through ethical approval process -Informed consent obtained **Data protection and security** -Secured videoconferencing was used
Asynchronous methods						
Year, Author (Country)	**Input/participant characteristics**	**Methodology**	**Data analysis**	**Explicit practical challenges identified within the study**	**Explicit technical challenges within the study**	**Explicit ethical challenges within the study**
Rodriquez (2013) (USA)	-Online forums -354 posts published by 32 users of an Internet forum between 2008 and 2009 -The forum is for AD patients only.	-Narrative inquiry (Illness narrative)	-Textual analysis with inductive approach	-Not explicitly mentioned	-Not explicitly mentioned	**Informed consent:** -The study was exempted from IRB -Informed consent was not obtained **Confidentiality and anonymity** -Pseudonyms were used by the researcher to protect PwD's identity
Astell et al. (2014) (UK)	-32 blog entries of 1 PwD -The researcher conducted 26 home visit 26 times over 12 months to help PwD re-learn previously used technologies and learn how to operate new technologies	-Case study and co-creation methods	-O'Neill's (2013) four stages of analysis	-Not explicitly mentioned	-Not explicitly mentioned	**Informed consent:** -The ethical approval process was not mentioned **Confidentiality:** -PwD's confidentiality was compromised (PwD was anonymised, but their real name was put as one of the authors)

Shapira et al. (2017) (Isarel)	-81 blogs of PD found via Google and other search engines	-Internet ethnography	-Thematic analysis -Content analysis	**Difficulties in Searching and Selecting Data** -The searching process of the blogs is not straightforward	-Not explicitly mentioned	**Informed consent:** -The ethical approval process was not mentioned **Data security:** -The research team created an additional blog to store the blog entries that were used for the analysis
Kannaley et al. (2018) (USA)	-19 blogs from people with ADRD and 44 blogs from care partners	-Illness narrative	-Thematic analysis with Inductive coding methods	-Not explicitly mentioned	-Not explicitly mentioned	**Informed consent:** -The authors argued that informed consent is not needed since the blog entries were public **Confidentiality and anonymity:** -The list of blogs was provided in the article thus ADRD's anonymity were compromised.
Talbot et al. (2020) (UK)	-2774 Tweets from Twitter and 12 PwD.	-Illness narrative	-Thematic analysis	**Difficulties in Searching and Selecting Data** -A programme (Tweetcatcher) was used to identify tweets post. The search was repeated every 24 hours for 30 days	-Not explicitly mentioned	**-Informed consent:** -Opt-out consent were sought from PwD; none of them chose to be excluded

Notes. AD: Alzheimer's disease; ADRD: Alzheimer's disease and related dementias; MoCA: Montreal Cognitive Assessment; PwD: People with dementia; PD: People with Parkinson's disease

Descriptive statistics were used to characterise the studies, participants and chosen methods. Reflexive thematic analysis (Braun & Clarke, 2019) was utilised to facilitate an abductive approach to data analysis. An abductive approach to analysis "rests on the cultivation of anomalous and surprising empirical findings against a background of multiple existing sociological theories and through systematic methodological analysis" (Timmermans & Tavory, 2012, p. 169). This was selected for data analysis, as opposed to inductive or deductive approaches, because this review did not aim to generate a new theory nor test existing ones; rather, it aimed to identify both implicit and explicit practical, technical, and ethical challenges from the articles. The analytical process involved:

1. the first author reading and rereading the articles to familiarise themselves with the contents.
2. The data extraction chart was then completed by the first author
3. Key information in relation to the research questions was thematically analysed using Braun and Clark's (date) 6 step process. After familiarization, codes were generated to capture meaning. For example, initial codes that were created from the extraction chart were "confidentiality," "technical limitations," and "support." These codes were generated across the articles to identify shared meanings. Explicit

challenges mentioned by the authors in the texts were identified and coded along with implicit challenges that were not mentioned – implicit challenges.

4. The codes were reviewed, analysed, and organised into potential themes by two of the research team members individually and then compared to establish reliability in coding and theme generation.
5. The themes were discussed and agreed between all research team members to produce a final set of themes. The ethical framework and guidelines for IMR from the British Psychological Society (BPS) and Association of Internet Researchers (2019) were consulted to ensure recognition of established ethical challenges encountered in the included studies along with previously unidentified challenges (British Psychological Society, 2021; Franzke et al., 2019).
6. Finally, writing the themes for this article was primarily undertaken by the first author and critically reviewed and amended by the team. At this point, the theme and subtheme titles were agreed.

Findings

General Descriptions of the Articles

Nine studies published between 2013 and 2020 were retained in the dataset. Over half of the articles (n=4) originated from the USA (Kannaley et al., 2018; Lindauer et al., 2017; Mammen et al., 2018; Rodriquez, 2013), three articles from the UK (Astell et al., 2014; Lovegrove et al., 2017; Talbot et al., 2020); one article from Australia (Stillerova et al., 2016) and one from Israel (Shapira et al., 2017). These articles reported on studies that utilised either synchronous methods (whereby data were collected in real time) or asynchronous methods (data were generated and collected by participants and researchers' preferred time; Salmons, 2016; Williams et al., 2012).

In terms of studies which used synchronous methods online, four studies involved online semi-structured interviews via Skype (Lovegrove et al., 2017; Stillerova et al., 2016) and by virtual clinical assessments that involved qualitative interviews with PwD and people with PD (Lindauer et al., 2017; Mammen et al., 2018; Stillerova et al., 2016). Five articles used asynchronous online methods by analysing existing texts created by PwD via a range of media: online forum posts (Rodriquez, 2013), blog entries (Astell et al., 2014; Kannaley et al., 2018; Shapira et al., 2017), and Tweets (considered as a form of microblogging) from Twitter (Talbot et al., 2020; see Table 2).

The findings concerning practical, technical, and ethical challenges when undertaking online data collection with PwD was constructed in three themes. The first theme concerns practical challenges with procedures whilst conducting the research. The second theme reveals technical challenges encountered with use of the online platforms. Finally, the third theme presents ethical challenges around online data collection methods with PwD, particularly concerning issues of valid informed consent, PwDs' confidentiality and anonymity, and data privacy. The three themes are presented below.

Practical Challenges with Procedures

This theme incorporated the practical challenges that arise during the data collection process with participants; content identification; and participants' identity verification if they have dementia. Two subthemes were generated relating to the different challenges between online synchronous methods and online asynchronous methods (see Table 3). Key challenges of flexibility, the impact of the physical environment, verification issues, and social context were emphasised. For synchronous methods, additional challenges that were unique to PwD, flexibility over data collection methods for PwD, were addressed and mitigated in all the included studies. Surprisingly, challenges identified from asynchronous methods were not related to dementia symptoms; rather, they were limitations inherent in the chosen methods and would be applicable to all participants. As such, researchers need to be aware of these limitations and how they may impact on the research process. These are presented in Table 3 and described in more detail below.

Table 3
Themes and Subthemes with Quotes from the Articles Around Practical Challenges Around Online Data Collection Methods

Themes	***Subthemes***	***Quotes***
Practical challenges when conducting online synchronous qualitative methods	-Flexibility over data collection methods	*"...Choices offered included telephone interviews, Skype interviews, email, or any other suggestions..." (Lovegrove et al., 2017, p. 496)* *"…We encouraged caregivers to take breaks to check on the patients if needed…" (Lindauer et al., 2017, p. e87)*
	-The researchers' limited ability to manage the impact of physical environment	*"...participants often had to be coached to close curtains, adjust lights, move chairs to maintain good quality..." (Lindauer et al., 2017, p. e89)*
Practical challenges with online asynchronous methods	-Difficulties in searching and selecting data	*"...Manually locating illness blogs is not a straightforward and linear process as they are spread across the internet without a major repository..." (Shapira et al., 2017, p. 686)*
	-Participants' verification and limited social context	*"…we do not know anything about the people who participated in the forum beyond the words they posted…much of the social context that produced the data is lost given the medium through which it is expressed..." (Rodriquez, 2013, p. 1225)*

Practical Challenges when Conducting Online Synchronous Qualitative Methods

Flexibility Over Data Collection Methods

The included studies justified that the data collection methods with PwD need to be flexible. The reason being PwD might have fluctuating mental capacity, thus, could not be fully engaged during the process. Therefore, an alternative option to participate in research was one strategy that could be utilised to ensure that PwD were not excluded. Lovegrove et al. (2017) demonstrated this flexible approach in their Patient and Public Involvement (PPI) study with people with PD; participants could join the study via Skype to take part in online interviews or via telephone individual interviews.

This flexibility of method provided more control for participants, and they could choose to join the study with the method that they preferred. Being present in real time also allowed the researcher to change the wording of questions during the interviews to facilitate understanding of people with PD thus enabling them to engage in conversations. Lindauer et al. (2017) further demonstrated this in their data collection period via telemedicine visits with dyads of PwD and family carers. Family carers could take care of PwD during data collection as needed from their houses thus the participants were more comfortable to engage in the interviews.

The Researchers' Limited Ability to Manage the Impact of Physical Environment

Articles reporting on synchronous qualitative data collection methods online all mentioned inherent limitations in managing participants' physical environments. In the face-to-face qualitative data capture, the researcher can specify time, place, and shape the interview setting. They may ask the participant where they feel comfortable to be interviewed, in which case, they cede environmental control to participants themselves. When research is taking place online, the researchers had little control over participants' locations where they joined the interviews (unless this had been agreed beforehand; Stillerova et al., 2016). As a result, this could potentially exacerbate PwD's symptoms and affect the interview process. Potential physical distractions mentioned were background noise or poor lighting. Still, practical advice such as suggesting participants to adjust their environment or use headphones to reduce distraction could be given to mitigate such limitations (Stillerova et al., 2016).

Practical Challenges with Asynchronous Online Methods

Difficulties in Searching *and* Selecting Data

Shapira et al. (2017) analysed the texts from blog entries of people with PD. They reflected that the searching process for relevant blogs for their study was not straightforward since some blogs could not be found via search engines. This limited the dataset that was included for the analysis. Textual analysis of tweets also presented a similar difficulty. Talbot et al. (2020), therefore, mitigated this challenge in the searching process by using a programme, Tweetcatcher, to collect tweets that contained keywords and had been posted online on the specified timeframe.

Participant Verification and Limited Social Context

In face-to-face data collection, there are aspects of participants' identity that are usually verifiable such as gender and age category. When online posts or tweets are used as data, it is not always possible to verify the creators' identity. This poses a problem as researchers must accept their participants' claimed identity as they present themselves on the internet (Rodriquez, 2013; Shapira et al., 2017; Talbot et al., 2020). In addition, Rodriquez (2013) expressed concerns over researchers limited insights into the social contexts of PwD from merely the written post entries. The researcher did not know their background or the circumstances of the PwD when they created the posts: their replies might be factual, fabricated, or distorted. This explicit challenge was applicable to all participants. However, this led to another implicit finding that PwD might or might not be lucid when they posted their answers. Consequently, the extent to which the trustworthiness of the texts that were used as a part of the analysis was, therefore, debatable.

Technical Challenges Around Online Data Collection Methods with PwD

This theme focuses on the technical challenges that stem from using platforms such as video conferencing to collect data and the associated difficulties faced by some PwD when they required digital skills to connect to and operate the software. Two subthemes were identified, both specific to synchronous data collection methods: (1) the need for a high degree of technical support for participants, and (2) technical difficulties deriving from the specific platforms used. These challenges could largely be overcome by offering support for PwD to install the programme, logon, and use the software. Nevertheless, even with support and instructions from the researchers, additional technical difficulties could occur during data collection, namely interrupted internet bandwidth and software errors which amplified PwD’s symptoms during the data collection (see Table 4). These sub-themes are detailed below.

Table 4
Theme and Subthemes with Quotes from the Articles Around Technical Challenges Around Online Data Collection Methods

Theme	***Subthemes***	***Quotes***
Technical challenges around online data collection methods with PwD	*-The need for a high degree of technical support for participants before and during the interviews*	*“...Prior to the telemedicine visit, a research assistant with technical expertise met with each caregiver via telephone and telemedicine to test the family’s Internet connection, assist in downloading the secure telemedicine link, and resolve technical challenges...” (Lindauer et al., 2017, p. e87)*
	-Technical challenges deriving from navigation of the platforms used	*“…Computer problems delayed the start. I had to remove an existing version of the software, empty the trash and then download and install a new one. I was assisted by staff, but the situation makes me anxious…”-substantiating quote from a person with Parkinson’s Disease (Mammen et al., 2018, p. 262)*

The Need for a High Degree of Technical Support for Participants Before and During the Interviews

Five articles highlighted the need for comprehensive support or training sessions for using the technologies chosen for data collection. In these studies, the majority of participants did not have prior experience of using the software, indicating researchers need to provide extensive support for participants before, during, and after the session to ensure that PwD have the necessary knowledge, skills and motivation to join the research with as few barriers as possible (Lindauer et al., 2017; Mammen et al., 2018). Mammen et al. (2018) mentioned the training sessions for PwD prior to the data collection. PwD undertook training to use the videoconference software effectively. A research assistant also checked the internet connection and assisted PwD before the telemedicine session (Lindauer et al., 2017) to ensure that they could connect to the internet with ease and prevent unnecessary distress. Additionally, extra equipment (tablets) was provided to participants as needed to ensure that they could join the study.

These rigorous preparations were implemented to ensure that PwD would be familiar with the technologies and were able to participate in the studies. Researchers can utilise the technologies to support their participants as well – in particular, the ability to share the researcher’s screen with participants was highlighted as a huge benefit of online synchronous interviews (Lindauer et al., 2017). Clinicians from the study used this function to assess PwD’s conditions virtually, ensuring that the assessment was clinically valid. The participant information sheet could be shared on screen whilst the researcher addresses any queries or concerns PwD had about the study aim, objectives, process of data collection or the technology. In this way, screen-sharing could ensure that participants fully understood the research and their part in it given their symptoms of fluctuating mental capacity.

Technical Challenges Deriving from Navigation of the Platforms Used

Reduced video or audio quality during online interviews was mentioned by both researchers and participants (Lindauer et al., 2017; Mammen et al., 2018). This stemmed from participants’ internet connection speed which was variable. Hardware and software malfunction from PwD’s site were also mentioned in the included studies. The research teams mitigated these challenges by conducting preliminary sessions to check internet speed before the scheduled interview sessions.

Ethical Challenges Around Online Data Collection Methods with PwD

Ethical challenges involved in data generation online with PwD were like ethical challenges that arise when using face-to-face data collection methods with PwD. However, additional ethical challenges unique to IMR were identified. The included studies had two approaches in relation to the privacy of online data.

First, the researchers perceived online data as public hence there is no need for further safeguarding participants. Second, online data is perceived by the researchers as private since it contains content creator' identity and sensitive information. Therefore, researchers need to protect their confidentiality and obtain their consent (see Table 5). Five subthemes were generated: Valid informed consent; Participant confidentiality and anonymity; Data security and storage; Limited control over the research platform and research input; The debatable public/private nature of online data.

Table 5

Theme, Subthemes and Categories with Quotes from the Articles Around Ethical Challenges Around Online Data Collection Methods

Theme	***Subthemes***	***Categories***	***Quotes***
Ethical challenges around online data collection methods with PwD	Valid informed consent	-The research team had valid, traceable consent -The study was exempted but the researcher took additional step to protect participants' identity. -There was no informed consent -Not mentioned in the study	*"...the caregiver served as the patient's authorized representative for research and consented for them. Patients assented…" (Lindauer et al., 2017, p. e86)* *"...informed consent was not obtained because tweets were posted on public accounts and, therefore, located within the public domain…" (Talbot et al., 2020, p. 114)*
	PwD' confidentiality and anonymity	-Participants' identities and confidentiality were protected - Participants' identities and confidentiality were compromised - Participants' identities and confidentiality were exposed	*"...I have taken the extra step of changing the original monikers used by forum participants, which were not linked to email addresses, to mask the identities of the parties involved…" (Rodriquez, 2013, p. 1219)* *"…caregivers reported that they and the patients were distressed when conversations between the caregivers and the clinicians were overheard by the patient (e.g., discussions about hygiene..." (Lindauer et al., 2017, p. e87)*
	Data security and storage	-The research team mentioned the data security and storage, with limited details. -The research team used commonly used platforms to conduct the study	*"…Using the Cisco Telepresence Content Server, the telemedicine visits were securely recorded and stored..." (Lindauer et al., 2017, p. e87)*
	Data ownership and limited control over the research input	-Limited control over the research input -Ownership of the contents that were	*"…the data may be limited by the tendency of individuals to write about the most poignant experiences in their blogs, rather than to report the*

	generated over the platform	*day-to-day experiences...” (Kannaley et al., 2018, p. 3083)*
The debateable public/private nature of online data	-Data were treated as public	*“…Twitter is considered a public platform and there is a general consensus among researchers that the content posted on Twitter can be used for research purposes...” (Talbot et al., 2020, p. 114)*
	-Data were treated as private	*“... [Skype] were regarded as acceptable by Medicare, who define technical requirements for a video consultation as capable of providing sufficient video quality for the clinical service being provided and sufficiently secure to ensure normal privacy requirements for health information are met...” (Stillerova et al., 2016, p. 278)*

Valid Informed Consent

Three studies did not explicitly mention the ethical approval process on the basis that their studies did not include human subject research (Kannaley et al., 2018; Rodriquez, 2013; Talbot et al., 2020). Four studies achieved formal ethical approval (Lindauer et al., 2017; Lovegrove et al., 2017; Mammen et al., 2018; Stillerova et al., 2016). PwD and/or their families from these studies were fully informed about being involved in research; they either assented or consented to join research in verbal or written form. The discussion of the use of research input in the future lack of capacity of PwD was also agreed upon.

For the remaining studies, the researchers approached the informed consent process differently. Rodriquez’s (2013) study analysed online posts from people with AD was exempted by the Institutional Review Board. The researcher did not need to obtain informed consents from participants since data used in this study “does not meet the federal definition of a human subject” (Rodriquez, 2013, p. 1219). In contrast, Talbot et al. (2020) chose to use opt-out consent for their text analysis of PwD’s tweets; they argued Tweets were posted and located in the public domain hence did not need informed consent. However, the use of direct quotes from public Tweets could easily be traced back to the account holders therefore they contacted the account holders and gave them opportunities to opt-out; none of PwD chose to do so. Similarly, Kannaley et al. (2018) argued that the blogs being analysed in their research were already in a public domain area, thus, did not need informed consent at all; they also did not implement any additional measures to protect the account holders. Finally, two studies did not mention the informed consent process in their study (Astell et al., 2014; Shapira et al., 2017).

PwDs’ Confidentiality and Anonymity

For all articles that utilised synchronous methods, participants were treated similarly to traditional data collection methods. PwD’s identities and names were anonymised. Within one study, additional care concerning sensitive topics was also applied (Lindauer et al., 2017). The research team advised participants to wear headphones during the interviews to prevent other family members from overhearing the conversation.

Conversely, amongst studies utilising online asynchronous methods, PwD’ identity and confidentiality were treated differently. Kannaley et al. (2018) listed the websites that were included for the analysis thus making it easy to track down their virtual identity. Astell et al. (2014) analysed one PwD’s blog entries for their study using a pseudonym for the PwD. However, that PwD was credited as one of the authors, thus, their identity was indirectly revealed. Shapira et al. (2017) created protection for the bloggers in their study by producing another blog as a platform to collate the data; they adjusted the privacy of that blog to give access only to the researchers and prevent it being found by search engines. This extra protection was also used by Rodriquez (2013). The researcher changed PwD's name on the online forum to protect their online identity since the forum that was used for the analysis was exclusive for people with AD and thus contained sensitive information about their health.

Data Security and Storage

Only three articles reported on how the researchers protected their data (Mammen et al., 2018; Shapira et al., 2017; Stillerova et al., 2016). Mammen et al. (2018) stated that participants in their study were receiving clinical assessments from physicians remotely via "secure video conferencing" but did not explicitly go into detail in relation to software security issues or processes regarding how they protected the data. Stillerova et al. (2016) used two commonly used video conferencing tools for their virtual clinical assessments with people with PD: Skype and Google+ Hangouts. The researchers argued that this software provided sufficient data security and privacy, citing that the security was in line with the Code of Ethics from World Federation of Occupational Therapists. However, this study was conducted in Australia where this approach was in line with regulations around data protection at that time. This level of data protection may not be applicable within other countries. Almost all the studies included in this review were conducted before the implementation of the General Data Protection Regulation (GDPR) therefore the degree of scrutiny around data protection would likely be less robust (UK Research and Innovation, 2018). Furthermore, six studies were undertaken in countries outside the EU and hence would be under different jurisdictions concerning data privacy and protection.

Data Ownership and Limited Control Over the Research Input

Ethical challenges concerning the ownership of research data such as interview conversations or blogs need to be considered, especially when data is collected online (British Psychological Society, 2021). PwD's mental capacity could change over time therefore a clear mutual agreement of the ownership of the data is needed. None of the articles selected for this review explicitly mentioned negotiation of data ownership. Usually, the web service provider and platform provider will own that content, unless stated otherwise. Thus, researchers who collect data online must check on the terms and conditions of that software platform they want to use and seek relevant permission before conducting their study to avoid infringement. Apart from that, researchers could have limited control over the data that was generated. Kannaley et al. (2018) pointed out that illness blog entries written by people with AD in their study tended to focus on poignant experiences in bloggers' lives thus underrepresenting their day-to-day lived experiences, rendering them less visible for analysis.

The Debateable Public/Private Nature of Online Data

All studies that used synchronous methods to collect online data treated interview data and virtual clinical assessments in a similar way to traditional data collection: the contents were deemed sensitive since they included participants' health status hence the data were stored securely (Mammen et al., 2018; Stillerova et al., 2016). Conversely, researchers who used asynchronous data collection methods argued against this approach in relation to data privacy. Talbot et al. (2020) claimed that Tweets were publicly available hence there is no need for additional protection of the data. This stance was like Kannaley et al. (2018)'s justification that blog entries are publicly available and could be easily accessed without a password. Therefore, extra protection for these public data is not necessary. Conversely, Rodriquez (2013) expressed concern that the online forum posts used in their study could be easily traced to PwD, thereby exposing their identity and making confidentiality problematic. Hence, the researcher changed some information to protect their identity, as discussed under PwDs' confidentiality and anonymity subtheme. This ethical challenge surrounding online data privacy, particularly concerning blogs, tweets, and other data existing in online forums and discussion groups have already been debated in the academic literature. While some disagreement exists, it is generally acknowledged that consent should be sought from the persons who created the content online to preserve and upheld their privacy and anonymity (British Psychological Society, 2021; Franzke et al., 2019; Sixsmith & Murray, 2001).

Discussion

This section will discuss each research question respectively in relation to the study findings. For the first review question, "What qualitative online methods have been used to collect data with PwD?" This rapid review has identified online methods that have been used to collect data with and from PwD. From the included studies, evidently, it is possible to collect data with PwD using online qualitative methods both synchronously and asynchronously using diverse methods. Furthermore, the findings indicate that PwD can participate in the design and process of the research through PPI processes (Lovegrove et al., 2017; Talbot et al., 2020); they can also be involved in co-authoring research (Astell et al., 2014). Their involvement in various stages of the research process shows the potential for involving PwD at various stages of IMR studies, amplifying their voice in research and ensuring that research is appropriate to their circumstances and situations. Nevertheless, careful evaluation and preparations by the researcher, working with PwD as individuals, are required to ensure the participation that is envisioned is possible.

The review also showed that, by collecting data online, PwD can contribute to research from the comfort of their own home and at their preferred pace and time. The familiarity of home and implicit control over their environment, compared to being interviewed in a more public or semi-public space, can be reassuring for PwD who might experience distress or sensory overload when faced with unfamiliar or complex environments (Astell et al., 2014; Thorogood et al., 2018). Enabling the PwD to adjust the pace and timing of the research to suit their daily routines can help them prepare well to provide the best quality of information possible. Generally, using synchronous methods such as interviews to collect data requires extensive preparation for PwD before and during the data collection process. This is to ensure they can manage the chosen technology, are comfortable in the research setting and are at less risk of being prematurely excluded from the study (Herron et al., 2019; Webb et al., 2020).

Studies using asynchronous data collection, however, raised important questions concerning the credibility and dependability of the data generated. This relates to epistemological and ontological assumptions within qualitative research: to what extent can we trust data produced by online participants when their identity is not verifiable? This challenge is perhaps amplified when participant social context is unknown: for example, when it is not possible to establish how, when, and with whom the data were generated (British Psychological Society, 2021; Franzke et al., 2019; Hewson, 2015). A further complication may be introduced with PwD when their mental state when producing data is not known. The included studies did not provide insights into this challenge hence this question remains to be answered in the future.

The second review question, "Which software /platforms have been used to collect online data with PwD?" explored which software/platforms have been used to collect online data with PwD. The data showed that a range of different software and platforms were used. Some researchers chose a "secure" videoconference software for their online interviews to comply with the ethical challenges. Others, however, chose popular platforms that have been widely used by the public such as Twitter or Skype instead. These choices differed, depending on what kind of data that the researchers aimed for and the extent of which that the researchers would reduce the power relation with participants.

A key challenge in synchronous online data collection lies in establishing appropriate power relations between the researcher and the researched, as evidenced in studies that utilised online interviews (Lovegrove et al., 2017; Mammen et al., 2018). These power differentials can be compounded when online interviews are being conducted with PwD since the researcher is typically more familiar with the technology being utilised (Salmons, 2016; Webb et al., 2020). Additionally, PwD can potentially be further disadvantaged due to symptoms of dementia such as confusion and forgetfulness. The studies included in this review, however, built-in extensive preparation with the participants to compensate for such difficulties and work towards equalising power relations as much as possible. Building online rapport with PwD during these preparation sessions was also effective in navigating software challenges (Stillerova et al., 2016)

The issue of power imbalance was less evident in asynchronous method use. That is, PwD in such studies created the data on their chosen platform (Twitter, blogs) and in their own time prior to the data collection process. However, this creates another contentious challenge in which the researchers can potentially harvest online data and use them without permission. Such actions shift the locus of control back over to the researchers and, therefore, is not advisable.

For the last review question, “What are the practical, technical, and ethical challenges of using online methods with PwD?” we found that researchers needed to consider additional practical, technical, and ethical challenges that go beyond those required for traditional data collection methods due to the unique characteristics of data that is generated in the online environment (Hewson, 2015). For studies using a synchronous approach, it is noteworthy that no explicit challenges identified in this review were linked to PwD symptoms or their fluctuating mental capacity. This may be partially explained by the study designs – that is, the researchers typically provided extensive preparation sessions for PwD prior to the interviews. Deakin and Wakefield, along with other researchers, claim that the online interview can provide rich data since participants can choose to “present” themselves as they would like to be seen by researchers (Deakin & Wakefield, 2013; Lo Iacono et al., 2016; Salmons, 2016). However, this introduces another challenge for online face-to-face research due to the researcher’s limited understanding of the physical and social environment in which the interview was taking place. Researchers cannot know what lies “beyond” the screen from the participants’ side where other family members may overhear the conversations (Lindauer et al., 2017). Physical challenges such as distractions from PwD’s environment could potentially affect the interview process as well. These sorts of limitations may restrict insights of participants’ context that differ from traditional face-to-face interviews where researchers can assess the impact of the physical and social environment on data collection more accurately.

Asynchronous methods also posed additional implicit challenges around participant verification and social context. For example, bots (automated programmes that can be set to generate Tweets as frequently as needed) are prevalent in Twitter masquerading as real people expressing their thoughts and opinions. If bot tweets are not identified and excluded from datasets, then there is a risk of non-authentic data being utilised in online asynchronous methods thus affecting the findings and analysis (British Psychological Society, 2021).

One key ethical challenge with online interviews relates to the ability of researchers to protect participants’ confidentiality given their limited knowledge and control over the online environment. This was highlighted in Lindauer’s (2017) study where PwD were distressed when they overheard the content of the individual interviews between the researcher and family care giver. Consequently, the research team advised participants to use headphones to prevent such incident afterwards. According to the BPS, research participants should be able to join a study, knowing that confidentiality is guaranteed (British Psychological Society, 2021). Therefore, researchers must ensure that participants' confidentiality is properly safeguarded and that they can participate in research as they wish, with or without the third person present. If a third person is present, then the implications of this need to be made clear to participants.

Finally, in terms of ethical challenges related to asynchronous online studies using data from PwD, the review exposed two stances on how researchers perceived and treated online data retrieved from the internet, especially from textual data. The first stance suggests that data from the internet is public hence there is no need for further safeguarding. The second suggests that such data is considered private and can potentially link back to those who created them. This contentious issue of the publicity of data and why researchers should safeguard participants' confidentiality has already been widely discussed in literature (British Psychological Society, 2021; Sixsmith & Murray, 2001). The BPS and the Association of Internet Researchers' guidelines clearly state that any data (blogs, tweets, and online discussion forum) generated online is deemed as data from human participants (British Psychological Society, 2021; Franzke et al., 2019). Therefore, extra care needs to be taken to ensure that researchers minimise harm to the participants and act in line with the regulations around data protection, such as GDPR, especially when research is conducted with vulnerable participants such as PwD.

Recommendations

Practical Challenges with Online Methods

Comprehensive procedural instruction is needed for both researchers and participants to cover practical, technical, and ethical challenges that can arise before, during and after online data collection. Flexible approaches to data collection such as offering options to participate in the study (online interview and/or telephone interview) are recommended so that participants who are reticent or less capable of participating in online research will not be excluded. A preparatory session prior to the data collection period is a step that can be included to ensure that PwD understand the research platform and how to navigate it, as well as covering the research process and their role in it, providing opportunities for researchers to identify any unanticipated practical challenges.

Technical Challenges with Online Methods

It is recommended that researchers are proficient with the software or platform that they intend to use; they need to think through and plan for difficulties PwD may have with the technology and be prepared to support them to use that chosen platform effectively. This may mean putting on training sessions, preparing and distributing materials to support participants to use the technologies with simple language and removing or replacing unnecessary technical terms. Remote support for participants plus preparatory sessions prior the data collection is highly recommended.

Ethical Challenges with Online Methods

Even if online methods are being employed, valid informed consent from PwD in a verbal or written form must be obtained. At times, a family member who acts as the PwD's proxy in relation to the research may be involved in the consent procedures. In this case, the family member is also fully informed about the study and formally give their consent to the PwD's participation Lindauer's (2017). This is to ensure that PwD's rights to be involved in the research are maintained whilst keeping the research ethically robust (Sixsmith et al., 2021). Additionally, the confidentiality and anonymity of the PwD, and any associated family members, must be protected throughout and stored securely in line with existing ethical and legal frameworks (British Psychological Society, 2021; Franzke et al., 2019).

For the asynchronous methods, the review suggests that researchers should reach out to the content creators of the data (blog entries, tweets) to ensure that they agreed to partake in research. Perhaps an opt-in to the research option, as opposed to the opt-out option that was used by Talbot et al. (2020) is preferred to ensure the consent of PwD has been sought and agreed upon. Additional advice to protect participant's confidentiality (using headphones during the interview, joining the interview from a private room) was also recommended (Lindauer et al., 2017).

How the Findings was Applied for the Researcher's Empirical Study

The findings from this review were used to revise the research protocol which employed online semi-structured interviews with PwD and their family carers. Anticipated practical, technical, and ethical challenges were outlined along with the strategies to mitigate them in the research protocol and ethical approval application. Feedback from four pilot individual online interviews with two PwD and two-family carers were used to improve the research protocol.

Limitations

A rapid review approach enables researchers to provide a timely review while maintaining quality in the review process. However, several limitations impact the usefulness of this review. First, articles included in this review varied widely in study design and the participants involved in the selected studies had varied disease symptoms and trajectories. PwD who are in the early stages of the disease will need different support to be involved in research, compared to those who are further advanced in their disease trajectory. Nevertheless, this review identified the methods that have been used with PwD and, in doing so, mapped a range of approaches that may be employed to facilitate inclusive participation in research. A more comprehensive systematic review is advisable to scrutinise this topic further.

Second, few studies (two) collected data from dyads (PwD and family member) and it is, therefore, less clear what the associated challenges of this approach may be. Whilst the opportunity to have the support of a family member during data collection may help ensure PwD are not excluded prematurely from participating in a study, the potential impact on the nature and volume of data collected requires further exploration.

Third, no papers were identified that focused explicitly on the methodological challenges of IMR; the papers identified were reporting on empirical studies and as such word limits may have precluded in-depth considerations of the inherent methodological challenges.

Fourth, the articles that were included were published in English language; there may be articles in other languages that have identified further challenges and these need to be included in future reviews on this topic.

Finally, despite the claim that IMR can enable researchers to better reach out to hard-to-reach groups such as PwD, this review highlights that this applies to PwD who have internet access and are familiar with and able to navigate the technologies (Lindauer et al., 2017; Mammen et al., 2018; Stillerova et al., 2016). This limitation, to some extent, counter-argues that IMR is inclusive in design. Better study designs that will enable PwD to participate in research who do not come from such backgrounds is still needed (Fang et al., 2019).

This review highlights the potential for undertaking online qualitative data collection with PwD. The challenges identified all derived from the realities of empirical work, as opposed to the theoretical debate and guidelines. The rigour of utilising an online approach, however, hinges on attending to practical, technical, and ethical challenges in a proactive and timely fashion. This, in turn, will help ensure the engagement, comfort and safety of PwD during the research process and, ultimately, the trustworthiness of the research findings.

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