Assessing the Use of Research Techniques for Supporting the Engagement of People Living with Dementia in Research

by

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Author’s declaration

This thesis consists of material all of which I authored or co-authored: see Statement of Contributions included in the thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Statement of Contributions

This thesis consists in part of three manuscripts that have been published or submitted for publication.

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As lead author of these three chapters, I was responsible for conceptualizing study design, carrying out data collection and analysis, and drafting and submitting manuscripts. My coauthors provided guidance during each step of the research and provided feedback on draft manuscripts. Dr. Carrie McAiney provided significant direction and editorial assistance throughout. Under Dr. Carrie McAiney's supervision, I also prepared the remaining chapters in this thesis, which were not written for publication.

Abstract

People with dementia often experience challenges communicating their experiences, which can impact their ability to participate in research. Adapted or modified research methods are needed to better promote the accessibility of research for people with dementia in support of their rights to participate. This manuscript-based thesis employed three studies to examine the use of adapted or modified research methods to engage people with dementia in research and evaluate the use of two techniques for their impact on the engagement of people with dementia in research and on the data produced. First, a scoping review of the current literature was conducted to identify studies that used adapted or modified research methods with people with dementia with the aim of understanding the extent of use of adapted methods with people with dementia in qualitative research. The review identified adapted methods used and examined how impacts on engagement as it relates to meeting accessibility needs were investigated. Two primary qualitative research studies were also conducted to examine two projective interviewing techniques, verbally-prompted storytelling and photo-prompted storytelling, and how these techniques impact the engagement of people with dementia and the data collected in qualitative interviews. Results from the scoping review suggest that a range of adaptations and modifications are made by researchers to their research projects, but limited evidence exists as to the effectiveness of these adaptations on improving engagement of people with dementia in research. The study of verbally-prompted storytelling techniques suggests these methods deepened reflection of impact of dementia on self and others, facilitated conversations when participants experienced challenges recalling a personal example, and enabled conversations about emotional topics. Additionally, the study of the photo-prompted storytelling technique suggests that participants tended to demonstrate deeper reflection of their own and other's experiences and that the photo-prompted storytelling technique helped overcome challenges with direct questioning and recall. As well, there was a statistically significant difference in observed engagement when participants were interviewed using photo-prompted storytelling techniques but not the verbally-prompted story telling technique. This dissertation contributes to the understanding of adapted and modified methods to engage people with dementia in research and provides preliminary evaluation of projective interviewing techniques for improving the engagement of people with dementia in qualitative research, and how such techniques impact data collected. Improving accessible research opportunities for people with dementia to share their experiences is essential for recognizing the human rights of people with dementia to have equal opportunities to participate. Future research should continue to explore and extend the application of these techniques with particular focus on the impact of the specific prompts used.

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Chapter 1: Introduction

In Canada, it is estimated that more than 730,000 older adults live with a diagnosis of dementia (Alzheimer Society of Canada, 2024). Further, the number of people affected by dementia is projected to increase as our population ages (Government of Canada, 2019). Dementia is a broad term that encompasses many diseases, all of which are characterized by progressive cognitive impairment (Alsawy et. al., 2017). Cognitive impairments in dementia can encompass deficits in memory, language, problem-solving and communication abilities (Alsawy et. al., 2017; Alzheimer Society, 2019). Further, there is a great individuality in how dementia progresses, and the specific course of dementia is unpredictable (Melis, Haaksma & Muniz-Terrera, 2018). The World Health Organization (WHO) (2017) and Public Health Agency of Canada (2020) have encouraged a commitment to research in dementia, and the translation of such research into policy and practice. However, the perspectives of people with dementia have been largely excluded from health and social research that informs policy and practice due to methodological and communicative challenges, as well as concerns about cognitive decline and capacity, and stigma (Alsawy et al., 2017; Cottrell & Schultz, 1993; Tyrrell, Genin, & Myslinski, 2006; Swaffer, 2014; Phillipson et al., 2019; Taylor, DeMers, Vig & Berson, 2012). To ensure the relevance of research outcomes and related policy and practice, the perspectives of people with dementia must be included.

Involving People with Dementia in Research

It is important to ensure that people living with dementia are included in decision making, and that their views are reflected in the development of their care and support. To this end, it is essential to understand how to best support people with dementia in research that informs care and support practices through the use of techniques and methods that meet their needs. Over the past several decades, researchers have studied the inclusion of people living with dementia in their care and support, and how this concept is related to decision making and autonomy. This focus on the inclusion of people with dementia by researchers represents a shift in the conceptualization of people with dementia and their care from an emphasis on safety, protection, and physical care to a focus on social engagement, empowerment, and autonomy (Morgan-Brown et al., 2018). Shifts in care contexts to include people with dementia in decisions about their care, and a focus on the broader inclusion of people with dementia in other contexts such as research and society, signals a trend towards inclusion beyond the individual level to include program, organizational, and system level inclusion of people with dementia. Further, developments and growth in research on the inclusion of people with dementia have yielded important considerations for involving people living with dementia in care, supports, and research more broadly. Indeed, both societal barriers as well as the nature of impairment that many people living with dementia experience can serve to limit their inclusion in various contexts, including research (Hackett et al., 2019; Bartlett, 2014a). The concept of the marginalization of people with dementia from society, which extends across the past two decades, has highlighted the ways that stigma, social exclusion, and marginalization have excluded people with dementia and their lived experiences from dementia research, policy, and practice (Innes et al., 2004; Hand, 2019; Reynolds et al., 2017; Gilmour et al., 2010). Researchers have long identified the invisibility of people with dementia, which is thought to be compounded by stereotypes and perpetuated by a biomedical model that privileges the generation of knowledge of dementia as a disease over the lived experiences of people with dementia (Gilmour et al., 2010). While education and awareness campaigns have applied considerable effort to dispel stigma that surrounds dementia, Innes et al. (2021b) identify that dementia remains misunderstood by many, and this perpetuates dementia related stigma and the social exclusion that many living with dementia experience.

Initiatives to include people with dementia

Including people with dementia in research, policy, and practice is essential to supporting that their voices are heard in the development of supports, services, and care (Innes et al., 2021b; Bethell et al., 2018; Gove et al., 2018). Indeed, research supports that people living with dementia can contribute to practice and policy development (Mockford et al., 2017; Innes et al., 2021b). Shifting from research ‘on’ to research ‘with’ those with lived experience has been a growing trend in dementia research, especially in the United Kingdom, where there has been demand over the past decade for transparency in grant proposals for how people with lived experiences are involved in research (Swarbrick et al., 2016).

Initiatives more broadly (outside of dementia research specifically) over the past thirty years in the UK have focused on patient and public involvement, such as ‘INVOLVE’ which promotes and supports public involvement in healthcare (Swarbrick et al., 2016). Initiatives like INVOLVE have promoted the involvement of people with lived experience and have encouraged the enablement of people with lived experience to participate in research through collaborative partnerships (Swarbrick et al., 2016). In the field of dementia specifically, the concept of patient and public involvement, or PPI, has expanded globally over the past twenty years with several initiatives focused on involving people with dementia in research as a way to foster improvements in healthcare and the relevance of research outcomes, and create communities that are ‘dementia friendly’ (Harris et al., 1999; Tanner, 2012; Barlett et al., 2007; Swarbrick et al., 2016). In 2015, authors Harrison and Johnson positioned the lived experience or involvement ‘movement’ of people with dementia as being in its infancy stages and still working to overcome the historical positioning of people with dementia as research ‘subjects’ and finding ways to meaningfully involve and engage people with dementia in research. Since then, renewed focus in this area has led to the development of several initiatives to include people with dementia.

Efforts in the United States (like the Dementia Advocacy and Support Network International), the UK (like the Dementia Engagement and Empowerment initiative), Scotland (the Scottish Dementia Working Group), Canada (Dementia Advocacy Canada, in past), and globally (Dementia Alliance International) have demonstrated a commitment to movements such as ‘nothing about us without us’ evidenced through the involvement of people with dementia in developing services and policies (Clare et al., 2008; Williamson, 2012). Through challenging stigma and assumptions about capacity and ability, these initiatives serve to empower people with dementia to contribute to research, policy, and practice (Bartlett, 2014a; Shakespeare et al., 2019). However, it remains unclear the impact of such groups and initiatives as they have not been evaluated in terms of outcomes (Innes et al., 2021b; Phinney et al., 2016). Indeed, work by Dupuis et al. (2012) supports that it is not enough to solely listen or hear the perspectives of people with dementia – it is argued that researchers and policy makers must actively involve people with dementia in decision making through supporting their participation however necessary. The Dementia Associates Panel, developed out of work in the UK focused on co-designing research with people with dementia, is one recent example of an initiative that was created in response to such calls to action to reimagine the participation of people with dementia with regard to decision making (Bowker et al., 2020). A study of this initiative in 2021(b) by Innes et al. reported that people with dementia involved in the Panel shared about feelings of improved wellbeing through communicating their lived experiences, as well as the role that being seen as experts played in supporting confidence and independence. Indeed, research supports that being enabled to share one's experience with dementia has both the potential to influence outcomes in policy, research, and practice, and supports the wellbeing of people with dementia (Innes et al., 2021b; Littlechild et al., 2015). Wied et al. (2019) report that people with dementia should be encouraged to share their preferences and perspectives actively and suggest conversational interviewing styles as a potential mechanism for fostering participation in decision making. As well, the use of visual aids such as props or pictures are thought to help support understanding and potentially compensate for memory impairments (Fetherstonhaugh et al., 2016; Smebye et al., 2012).

As discussed, researchers have long identified a need to enable people with disabilities, including those with dementia, to participate in society on an equal basis with others (Bartlett, 2014; Barton, 1993; Jayasooria, 1999; Van-Houten et al., 2002; Bartlett et al., 2010). However, while this concept has been applied and studied in different contexts and settings, a common definition is lacking for what it means to meaningfully involve or engage people with dementia (Innes et al., 2021a). Concepts such as dementia friendly, social citizenship, engagement, inclusion, and more have all been used to describe initiatives and movements aimed at supporting the participation and empowerment of people with dementia in research, care, and broader decision making. Indeed, the concept of social citizenship specifically has had important implications in broader social movements to promote the autonomy and greater advocacy of people with dementia – including promoting participation and inclusion in one's care and in research and policy or governance initiatives (Bartlett et al, 2007; Innes et al., 2021a; Baldwin et al., 2016). Engaging in social citizenship has also been identified as having benefits for people with dementia, including in supporting decision making (Dupuis et al., 2016; Wiersma et al., 2016). Social citizenship approaches also highlight that people with dementia can contribute to society as active participants and that engaging people with dementia in research projects can work to achieve the goals of social citizenship (Bartlett et al., 2007; Dupuis et al., 2012; Innes et al., 2021b).

Reflecting on the concept of citizenship, Bartlett (2014a) has explored the experiences of those living with dementia in engaging in campaigns for social change. Bartlett (2014a) identifies that when considering the concept of citizenship and applications for people with dementia, it is essential to ensure an inclusive approach to defining citizenship given that the nature of dementia can threaten one's identity and capacity to be considered as an 'effective' citizen in society. A diagnosis of dementia may be thought to be evidence that a person is unable to participate in society (Gilleard et al., 2014; Beard et al., 2013; Behuniak, 2011). While there exist both attitudinal barriers to the participation of people with dementia as citizens in society, there also exist barriers related to the impairment caused by dementia for many of those living with it – contributing to a layering of barriers that in combination effectively impede one's ability to participate in society on an equal basis with others (Bartlett, 2014a). However, people with dementia can and do serve as effective citizens despite these barriers (Bartlett, 2014a). The social inclusion of people with dementia is a priority across the globe with advancements in support for people with dementia to participate and contribute as advocates (Bartlett, 2014a; Beard, 2004; MacRae, 2008; Clare, 2002). In the UK specifically, the last decade has given rise to numerous examples of people with dementia resisting negative stereotypes and becoming influential in policy domains through advocacy (Clare et al., 2008; MacRae, 2008; Bartlett, 2014b; Gilmour et al., 2010), as well as in shaping broader attitudes about dementia in the public (Weaks et al., 2012), and in healthcare specifically (Hope et al., 2007). A 2012 campaign in the UK promoting the timely diagnosis of dementia has also been credited with the increase in research to learn more about the experiences of people with dementia as well as a greater number of self-advocates (Bartlett, 2014a).

Supporting the autonomy of people with dementia

The involvement of people with dementia is also more broadly linked to concepts of autonomy and decision making. Indeed, while dementia can impact one's ability to make decisions, people living with dementia often have a need to make decisions about their care. There exists a tension between the autonomy of people living with dementia and the role of care partners and health and social care providers in protecting those who may require decisions to be made on their behalf due to progressive cognitive impairments. Decisions surrounding care, including end-of-life care, and moving into institutionalized care settings, are frequently necessary for those living with dementia (Geddis-Regan et al., 2020). Supporting people with dementia to make decisions about their own care and maintaining their autonomy may be accomplished through shared decision making, which focuses on collaboration between the individual, their care partners, and health and social care providers (Geddis-Regan et al., 2020). However, the progressive nature of dementia often means that more support is required from care partners to enable decision making and increases the potential for decisions to be made that may not align with the individual’s preferences (Shalowitz et al., 2006).

Empowering people with dementia and their care partners to plan for and make decisions together is important to ensure the perspectives of people with dementia are reflected in decisions about their care, and that individual’s preferences are clearly understood so that shared decision making is enabled in the future. Further, involving people with dementia in the design and delivery of supports and services has been identified as a way to enhance their involvement in decision making (Innes et al., 2021; Mayrhofer et al., 2018). Research has demonstrated that people with dementia can participate in decision making, and further, that care partners often do not accurately reflect the individual’s values and preferences (Reamy et al., 2011; Bass et al., 2014, Carpenter et al., 2007; Clark et al., 2008; Whitlatch et al., 2005). Thus, it is both essential and logical that people living with dementia are involved in decision making to ensure that their needs, preferences, and values are reflected in their care, and that care partners are enabled to augment decision making, aligning with their preferences and values, where necessary. Geddis-Regan et al. (2020) report that improved communication led to greater satisfaction with decision-making processes for care partners and people living with dementia. Interestingly, Geddis-Regan et al. (2020) identified that a key feature of interventions to improve communication in shared decision making approaches is that of the documentation of future preferences. However, the ability to communicate and document future preferences hinges on the individual with dementia to imagine and consider future support needs and preferences. Given the challenges that many living with dementia experience with relation to abstract conceptualizations and verbal fluency, this may be challenging to accomplish in practice. Importantly, results from Geddis-Regan et al.'s (2020) inquiry into decision making with people with dementia highlights that no approaches identified in their review were evaluated for their effectiveness in supporting people with dementia to make decisions, including supporting co-decision making with care partners that aligned to the individual's values.

Supporting the participation of people with dementia in society

Extending beyond care contexts, research has also focused on the need to include people living with dementia in communities and broader society. Supporting the involvement of people with dementia in this way has been conceptualized by some as 'dementia friendly'. Within the UK, several policy initiatives, dating from 2012, have been implemented to support outcomes that are dementia friendly both in community and care (Department of Health, 2012). This commitment to dementia friendly initiatives in the UK has sparked an international focus on the creation of dementia friendly communities (Lin, 2017; Hebert et al., 2019). The concept of dementia friendly has also been reflected upon and extended by scholars in the disability inclusion movement (Lin et al., 2015), who posit that while the concept of dementia friendly is centered on a desire to include those with dementia, it does not fully acknowledge dementia as a disability and thus fails to adequately mobilize needed supports and services that promote the inclusion of people with dementia in broader society. Adequately involving people living with dementia has also been identified as a mechanism by which to achieve positive outcomes of dementia friendly communities and care – including supports and services (Innes et al., 2021a; Lin 2017). The involvement of people with dementia has been explored with respect to policy directives and human rights (Wied et al., 2019), care planning and decision making (Geddis-Regan et al., 2021), and everyday decision making (Perach et al., 2021) – with authors highlighting the importance of involving people with dementia and developing strategies for their inclusion along a spectrum of activities, care, and support.

While it is has been acknowledged that people with dementia should be included in research activities, and there exist numerous examples of their inclusion in more recent projects (e.g., Bethell et al., 2018; Gove et al., 2018; Poland et al., 2019; Walsh et al., 2020; Stevenson et al., 2019), researchers continue to grapple with how to involve people with dementia equitably, meet individual support needs, and maximize the contributions of people with dementia in research (Innes et al., 2021a). While involvement in research has been reported to promote feelings of purpose and inclusion for people with dementia (Innes et al., 2021b), there are challenges in ensuring people with dementia are adequately engaged, and researchers identify that while it is possible, adaptations to the research process are often required (Goeman et al., 2019; Ven et al., 2017; Donnelly et al., 2019). Even still, the relatively limited involvement of people with dementia in decision making in general and in research specifically signals that addressing how to include people with dementia meaningfully remains a challenge (Ven et al., 2017; Osterholk et al., 2016). Enabling conversations with people with dementia through different modes of communication (i.e., non-verbal communication like observing body language, leveraging augmented forms of communication like Talking Mats) has been identified as an important mechanism to enhance how people with dementia are involved (Osterholk et al., 2016). Due to the nature of dementia, it is reported that it can be challenging to support a person living with dementia to share their lived experiences, and to ensure these experiences are captured in such a way that ensures they are listened to and acted upon (Shakespeare et al., 2019).

The need for creative ways to support and engage those living with dementia has been well established by researchers (Bellass et al. 2018, Phillipson et al., 2018). Creative approaches have been conceptualized both in the expected sense using the arts, but also in more abstract applications through everyday interactions, like observing interactions with meaningful objects and clothing (Bellass et al., 2018; Bazooband et al., 2021). Indeed, creative and flexible approaches to the inclusion of people with dementia have been identified as a mechanism to support participation, autonomy, and person-centered approaches across spectrums of engagement, from care, to policy, research, practice and beyond (Phillipson et al., 2018). Researchers have identified a need to focus on methods to involve and include people with dementia, particularly in areas of care and support, as well as a need to evaluate such methods for their potential to achieve involvement (Innes et al., 2021a). Innes et al. (2021a), while focusing on applications related to care, identify that future research is needed to understand how the concepts of social inclusion, shared decision making, and citizenship can be applied to promote the inclusion of people with dementia, and further, to understand how and when such initiatives are successful in achieving inclusion.

It is argued that achieving the inclusion of people with dementia in broader society means hearing their voices – understanding their perspectives and experiences through capturing their lived experiences or narratives and recognizing them as important (Baldwin, 2008). The concept of lived experiences and narratives is important when considering how, as reported by Baldwin (2008), the stories we tell and listen to have the ability to empower others, or to control others – and the intersection of this idea with that of the broader inclusion and citizenship of people with dementia means that ensuring the voices of people with dementia are heard can serve to legitimize their place in broader society. The notions of involvement and empowerment are also inherently linked through the concept of voice – empowering people with dementia is seen to entail a broader process where people with dementia are respected, have their voices heard, are involved in decision making about their lives, and are enabled to have the opportunity to create change (McConnell et al., 2019). Through challenging the historical exclusion of people with dementia, as well as assumptions that people with dementia are incapable of having voice or a role in decision making, people with dementia are positioned as active rather than passive citizens, which promotes their inclusion and engagement in society (Bartlett et al., 2007).

Human Rights and Research Ethics

Connecting concepts of involvement, decision making, and autonomy in dementia research centers on human rights. At its core, autonomy is a human right that is defined as freedom to make one’s own choices and this right cannot be bypassed in the case of people with disabilities, as it is maintained through the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) that people with disabilities including those with dementia have legal capacity regardless of their impairments

(UN CRPD, 2006). Thus, people with dementia must be enabled to make decisions through whatever support is necessary (UN CRPD, 2006). Further, the importance of autonomy in health and social care contexts for people with disabilities has been underscored in previous decades and is reflected in an increasing emphasis being placed on the role of people with lived experience in decision making (Wied et al., 2019; Wilkinson, 2001). The World Health Organization's (2015) Global Disability Action Plan recognizes disability as a public health and human rights matter. The WHO (2015) states that people with disabilities, including those living with dementia, experience stigmatization, discrimination, and inequality to a degree that violates their rights. The WHO (2015) Plan states that while people with disabilities, including those living with dementia, have unique experiences and insights, they have been excluded from the development of policies, laws, and services that impact their lives. People with dementia should be involved in efforts to remove barriers that limit access to the assertion of their rights, including in research (WHO, 2015). Involving people with dementia in research, policy, and service sectors is essential for supporting their human rights.

Within Canada, the Alzheimer Society of Canada alongside people living with dementia have developed the Canadian Charter of Rights for People with Dementia, which challenges stigma and aims to increase awareness of human rights related to dementia. One of the main issues addressed in the Charter is stigma, and how the pervasiveness of stigma impacts human rights. Stigma is tied to the discrimination that people with dementia experience and the stereotype of persons with dementia as incapable, incompetent, and vulnerable (Mann, 2020). Persons with dementia have rights to appropriate information and support that enables decision-making about their lives, including care decisions from diagnosis to end of life. Protection of the rights of persons living with dementia means respecting them as capable, appreciated, and important members of society (Mann, 2020). As well, the development of this Charter signals the collective desire of people living with dementia to participate in decisions about their lives, including through policy and research.

People with dementia have historically been excluded from research due to challenges with communication as well as concerns about cognitive decline and capacity (Alsawy et al., 2017; Cottrell &

Schultz, 1993; Tyrrell, Genin, & Myslinski, 2006; Swaffer, 2014). However, research supports that people with dementia are often able to articulate their experiences and offer valuable contributions to research on, for example, relevant supports and services (Alsawy et al., 2017; Dewing 2007; Benbow & Kingston, 2016). As well, while many people with dementia contribute meaningfully to research and broader society, not all people with dementia desire to engage in advocacy work or research, and for some, the cumulative impacts of other comorbidities alongside dementia may necessitate additional support of others to exercise their rights to contribute to their communities (Innes et al., 2021b; Birt et al., 2017).

Addressing communication challenges in research can promote a more inclusive environment for people with dementia and can support autonomy. This in turn can support the recognition and respect of the rights of people with dementia in research. This is especially relevant in consideration of the key principles of research ethics – Respect for Persons, Concern for Welfare, and Justice (Tri-Council Policy Statement [TCPS]) 2, 2018). The TCPS 2 supports the inclusion of populations typically considered to be vulnerable, like persons with dementia, as it violates the principle of justice to exclude vulnerable groups without accommodations. For example, the TCPS 2 states that persons considered to be vulnerable, like those with dementia, should be supported to provide informed consent if they wish to participate, instead of being unfairly excluded based on judgements about capacity (TCPS 2, 2018). This is compounded by the UN CRPD (2006) and its emphasis on shared decision making and balancing autonomy and protection against harm. The UN CRPD and research extending from its principles have sought to empower both people living with disabilities, including those with dementia, to be included in decision making about their lives, which necessitates a paradigm shift in research to actively incorporate the perceptions and experiences of those with dementia (Wied et al., 2019; De Boer et al., 2007; Von Kutzleben et al., 2012). Thus, ensuring the human rights of people with dementia are respected in research and wider society means recognizing how the concepts of autonomy, decision making, and inclusion are inherently linked. To enable the autonomy of people with dementia, which means to empower them to be involved in the decision making about their lives, requires the inclusion of their lived experiences in research, policy, and practice. Indeed, research supports that the results of information about a person’s preferences and experiences should be taken forward and integrated into decision making processes (Tyrrell et al., 2016). To fulfill the legal obligations and political objectives of the UN CRPD (2006), it is essential to consider how the concepts of participation, involvement, and engagement are linked and how they support autonomy or decision making (Wied et al., 2019).

Impact of Dementia on Communication

Cognitive and communication challenges are increasingly prevalent amongst those with more moderate to advanced dementia, and thus most research involving people with dementia focuses on those in earlier stages. These challenges can include changes to memory abilities, which can impact abstract thinking and judgement, ability to use language, and ability to recognize objects or people (Dröes, Van Der Roest, Van Mierlo, & Meiland, 2011). Further, people with dementia may experience challenges with word finding, writing, and understanding complex language (Alsawy et. al., 2017). In moderate stages, dementia is associated with challenges in understanding spoken language, understanding written instructions or content, and difficulty following instructions with multiple steps (Alsawy et. al., 2017; Bourgeois, 1991). It is important to include a range of experiences in research, as dementia impacts individuals differently. People with dementia are also most often older adults, and thus their experience of dementia is not in isolation from their experience of other age-related changes. For example, older adults with dementia often experience hearing impairment that is not improved with the use of hearing aids, as well as hearing impairment that results in auditory hallucinations or tinnitus (Hardy et. al., 2016). Older adults with dementia commonly experience challenges with following conversations, especially where background noise is present. (Hardy et. al., 2016; Lin et al., 2011).

Dementia is also related to both visual impairment, such as decreased processing speed, and visual abnormalities, like hallucinations (Armstrong & Kergoat, 2015). Older adults with dementia may experience vision loss related to age and/or difficulties processing visual information due to the cognitive impacts of dementia (Armstrong & Kergoat, 2015; Alzheimer Society, 2019). Problems with vision associated with dementia include the loss of visual acuity, deficits in colour vision and reading ability, and challenges with identifying and naming objects (Armstrong & Kergoat, 2015). Vision loss in dementia can exacerbate communication difficulties and can limit one's ability to use common memory aids such as visual prompts (Hendriks et al., 2014; Alzheimer Society, 2019).

The ability of some older adults living with dementia to participate in research activities hinges on many factors. Multimorbidity – the presence of two or more chronic conditions – is common in older adults, and even more common in people with dementia (Welsh, 2019). Because most people with dementia are over the age of sixty-five, their experience of dementia occurs within the context of their age and other co-existing diseases or syndromes (Melis et al., 2018). Conditions like stroke, diabetes, osteoarthritis, and heart failure, in combination with age and the experience of dementia, all have a profound impact on one's life as well as one's ability to participate in research (Welsh, 2019). However, research supports that people with dementia are often able to articulate their experiences and offer valuable contributions to research on relevant supports and services (Alsawy et al., 2017; Dewing 2007; Benbow & Kingston, 2016).

There is often a need to adopt or revise traditional ways of research to support people with dementia to participate in research. Adaptations to existing methods, such as semi-structured or structured interviews, may be sufficient to support participation for some people. However, these approaches are often inadequate to support participation of people with dementia at various stages of the disease trajectory (Phillipson & Hammond, 2018). This is due to the dependence of these methods on abstraction, memory, and verbal communication; areas that often pose challenges for people with dementia (Phillipson & Hammond, 2018). Thus, adapted, or modified methods are warranted for use in populations of people with dementia.

Accessibility and Utility of Methods to Improve Engagement and Active Participation

Traditional quantitative methods that investigate the experiences of people with dementia typically rely on reading and writing, which may be inaccessible to many participants (Aldridge, 2014; Phillipson & Hammond, 2018). Further, quantitative methods like questionnaires and surveys can be challenging for people with dementia because they often require abstract reasoning and verbal fluency (Aldridge, 2014; Nygård, 2006). It is important to recognize that the aims of quantitative and qualitative research are different. Qualitative methods often promote the inclusion of populations that have been excluded from traditional quantitative research, such as people with dementia. Moreover, qualitative methods are argued to be more flexible and adaptable, which is necessary when working with people with dementia (Aldridge, 2014). Understanding the lived experiences, preferences, and abilities of people with dementia is key to the development of adequate and relevant supports and services. However, the nature of dementia as a disease means that for many, verbal communication of one's experiences can be challenging. Qualitative methods that support communication and accommodate an individual's needs may be able to help facilitate improved engagement in research activities, such as data collection.

While the engagement of people with dementia in *research* activities, at the time of writing, has not been studied or previously defined for the purposes of its measurement and evaluation, the engagement of people with dementia in *recreational* activities has been defined by Cohen-Mansfield et. al. (2009). They define engagement as the act of being involved with objects, activities, and other persons. Further, engagement in this sense is also defined by Kahn (1990) as the state in which individuals express themselves physically, cognitively, and emotionally. The measurement of the engagement of people with dementia in *recreational* activities has been developed by researchers Jones, Sung, and Moyle (2018) through the Engagement of a Person with Dementia scale. For this thesis, in lieu of a definition and measurement of engagement of people with dementia in *research* activities, work in *recreational* activities is extended and applied to include *research* activities such as data collection. In previous research on engagement in recreation, engagement is typically considered as either social interaction or activity participation, and is usually assessed through behavioural observations (Jones, Sung, & Moyle, 2018). It is noted that most research in this area has focused on the effectiveness of psychosocial interventions that can promote meaningful activity, stimulation, and well-being through an increase in positive affect and an improvement in activities of daily living, and quality of life – and not on the active participation and engagement of people with dementia in research projects (Ballard et al., 2005; Gitlin et al., 2009; Moyle et al., 2013; Van Der Ploeg et al., 2013; Materne, Luszcz, & Goodwin-Smith, 2014; and Schreiner, Yamamoto, & Shiotani, 2005). Even still, very few interventions aimed at supporting people with dementia have been evaluated for their effectiveness in whether they achieved their goals of promoting the engagement of people with dementia – authors rarely describe specific outcomes of chosen interventions that seek to include people with dementia, instead focusing on the underlying needs of people with dementia as their aim (Wied et al., 2019). This leaves a gap in terms of the study of the effectiveness of interventions for engagement both in care and research settings. Researchers who have studied the engagement of people living with dementia in recreational activities highlight that this type of engagement supports well-being by encouraging individuals to feel good about themselves, brings meaning to their lives, and helps them feel a sense of belonging through providing opportunities for using their skills (Jones, Sung, & Moyle, 2018; Morgan-Brown et al., 2018). Engagement in activities is observed to have positive impacts on people with dementia themselves (Jones, Sung, & Moyle, 2018; Cohen-Mansfield et al., 2009), and thus, may potentially have positive impacts on data collected when people with dementia are engaged in the data collection process. Through extending the application of work by Jones, Sung and Moyle to include research activities, this thesis adopts the operational definition of engagement as meaningfully participating in activities. This includes elements of social interaction and connection, for example, engaging in conversation about deep and meaningful topics. In contrast to the concept of disengagement, engagement of people with dementia is defined as the expression of emotionality (in contrast to affective blunting seen in disengagement), social connectivity (in comparison to infrequent participation), and social engagement when a person with dementia uses the activity or stimulus/object as a communication mechanism to interact with others (Jones, Sung, & Moyle, 2018). By this definition, it is thus conceptualized in this thesis that improved engagement in research data collection activities may also in turn result in improved quality in data collected.

While there is a relative dearth of information or studies evaluating the impact of research methods on the involvement of people with dementia in research (Conway et al., 2023), researchers have explored evaluating interventions, such as community-based art activities, delivered to people with dementia in a recreational or therapeutic capacity (Bazooband et al., 2021). They highlight that evaluations of such activities should consider methods or techniques that seek to gain more insight into participants' perspectives (Bazooband et al., 2021). Specific outcome measures are highlighted as an important consideration for evaluating methods that seek to engage people with dementia in general, although research in this area has mainly focused on evaluating impacts of intervention programs on outcomes such as cognitive ability, wellbeing, and quality of life, and not whether or not interventions achieved outcomes in terms of engagement or meeting accessibility needs to participate (Bazooband et al., 2021).

It has been noted by authors that it can be challenging and difficult to measure engagement in people with dementia, even in recreational or therapeutic activities. Moreover, the measurement of engagement in *data collection activities* with people with dementia, and the extent to which adapted or modified methods influence the data produced, has yet to be investigated. Jones, Sung, and Moyle (2018) report that conventional self-report methods for engagement can be challenging for people with dementia, as they may struggle to remember activities in which they participate, recall how they felt during activities, and report accurately on their experiences. Thus, observational methods are preferred. However, at the time of writing, no observational methods have been employed to study the engagement of people with dementia in data collection activities for research purposes. It is also necessary to consider both the level of engagement in data collection activities, as well as how different levels of engagement may impact the data that is collected in terms of quality, depth, and other factors as they are relevant. Engagement and active participation in data collection efforts is important to ensure the data collected is reflective of an individual's experiences. This can include reducing barriers to active participation by adapting and modifying data collection approaches to meet the participation needs of people with dementia.

Involving people with dementia in research and supporting their active participation is key to working towards producing equitable research that is implemented in practice. Gaps remain in identifying and establishing the accessibility and utility of methods to support active participation and engagement in research with people with dementia. As mentioned, communication challenges are increasingly prevalent amongst individuals with moderate to advanced stages of dementia, and most research with people with dementia focuses on those in earlier stages. It is important to include a range of experiences in research including those at various stages of their dementia journey, as dementia impacts individuals differently. Further, in data collection activities, the needs of each individual person with dementia are also unique, as well as the contexts of their individual experiences. Due to the interplay of age, multimorbidity, and dementia, an individual's ability to participate in research can vary widely. Strategies like projective techniques have merit in recognizing and respecting the rights of people with dementia to actively participate in research, as they support autonomy by working to address communication challenges.

Methods to support the inclusion of people with dementia in research

Methods to support the involvement of people with dementia in research has been approached through different types of techniques across topics and contexts. One such method that has reported success in involving people with dementia in research is Photovoice. Photographic methods, such as Photovoice, provide an effective way for participants to show researchers their experiences when they cannot verbally express them (Aldridge, 2014). Photovoice works to enable participants to express their experiences by capturing photographs that reflect their reality. These photographs serve to enable participants to reflect their strengths and concerns, which can be helpful for the promotion of critical dialogue about important issues that can be brought forward through research and policy (Wang et al., 1997; Novek et al., 2012). Methods like Photovoice hold exceptional promise for illustrating a person's experiences in such a way that meaningfully honors their perspectives (Aldridge, 2014; Baker et al., 2006). Photovoice can promote access to hard-to-reach locations and 'hidden experiences' through providing key contextual information, which can help to build relationships between researcher and participant (Aldridge, 2014; Baker et al., 2006). However, the use of Photovoice with persons with dementia is associated with difficulties, including challenges with operating camera equipment and remembering the context and meaning of photos taken (Phillipson et al., 2018; Wang et al., 1997; Genoe et al., 2013).

Photo elicitation is another method that seeks to support the inclusion of people with dementia through having participants capture photographs and reflect on the content of the photographs through interviews. It is thought that the photographs alongside the verbal interview serve as a description of one's own lived experience (Pilcher et al., 2015). While these methods have been reported to have benefits for participants, there are challenges with their applications in practice given that they rely on a participant's ability to comprehend and follow instructions, as well as recall the context of the photos taken (Lood et al., 2023). Studies in this area encourage comparison of interviews with and without prompts such as participant-driven photo elicitation techniques in order to further evaluate the potential of leveraging photographs in interviews to support participation (Lood et al., 2023). There also exists researcher-driven photo elicitation techniques, where preexisting photos are leveraged. However, both of these methods focus on the photographs, without necessarily adapting or modifying the interview component (i.e., still relying on direct questioning) that is typically used to explore the content or context of the photo (Phillipson et al., 2018; Banks et al., 2015). Visual methods such as Photovoice and photo elicitation are also unlikely to be accessible to those experiencing challenges with their vision, and as such, other adaptations or approaches are warranted.

Another method that has been identified as supporting the inclusion of people with dementia in research is walk-along interviews (Kullberg et al., 2018; Scottish Dementia Working Group, 2014). With this method, participants are often asked to lead a walk in their neighborhood or other location of significance, with the idea that their presence in the setting would prompt the sharing of experiences (Kullberg et al., 2018). This method is highlighted as a mechanism for participants to exercise more control over the interview process as they are tasked with determining the route and pace of the walk (Odzakovic et al., 2020). Further, walk-along interviews have been demonstrated to enable conversations with participants, although their application with participants with dementia is limited (Carpiano, 2009; Kullberg et al., 2018). While walk-along interviews offer an opportunity to learn from participant's engagement with their environment, they are inaccessible to those experiencing mobility challenges and require the interviewer and participant to be relatively co-located.

Supporting participation in interviews has been suggested as a mechanism by which to evaluate whether a method is useful (Hubbard et al., 2003). Researchers have suggested the careful examination of a method to determine the extent to which it facilitates the inclusion of people with dementia and enhances opportunities to elicit their perceptions and capture their experiences (Hubbard et al., 2003). A project undertaking this type of evaluation by Hubbard et al. (2003) highlighted that when asked direct questions in an interview, participants were unable to recall personal details, and this experience resulted the person becoming agitated and distressed. The authors report that on these occasions, the direct questions in the interview served as a “cruel reminder of their memory difficulties” (Hubbard et al., 2003, pp. 356). Thus, supporting participation for people with dementia may necessitate additional adaptations and modifications to the interview process itself to meet the communication needs of participants with dementia, which methods like Photovoice, photo elicitation, or walking interviews are not typically positioned to address as they serve as ways to augment a traditional interview. Indeed, authors Hubbard et al. (2003) highlight that in their project, should the researchers have relied solely on standard interviewing with direct questioning as the data collection technique, the voices of participants with dementia who experienced challenges with communicating and their memory would have been effectively ignored. A method that does seek to address communication challenges in interviews to meet participation needs is that of projective techniques.

Projective Techniques

Projective techniques are derived from the psychological theory of projection, which posits that people will perceive stimuli in the context of their own expectations and motives, and will credit others with their own attitudes, beliefs, and dispositions (Regan & Liaschenko, 2008). Projective techniques are considered appropriate for use when participants may have preconceptions preventing them from responding or responding honestly. This can occur in situations where topics are very personal, as participants may condition their responses to be “socially acceptable” (Mesias & Escribano, 2018). Projective techniques are based on the principle that when presented with an ambiguous situation, participants will project their unconscious desires and feelings onto their answers (Mesias & Escribano, 2018).

Implicit knowledge structures, or cognitive frames, are abstract mental schema that structure assumptions, attitudes, and beliefs (Regan & Liaschenko, 2008). Cognitive frames are assumed to allow people to generate meaning in any situation, which in turn shapes their actions (Regan & Liaschenko, 2008). Cognitive frames evolve over the lifespan, and are influenced by a complex interplay of genetics, experiences, education, and sociocultural contexts (Regan & Liaschenko, 2008). Understanding why people act in the ways they do requires an understanding of their cognitive frames. Projective techniques have historically been utilized in psychology, for both clinical and research purposes. However, few research studies have examined the utility or feasibility of these methods for studying implicit motivations, and virtually none have examined these methods for their utility in engaging with people with dementia.

In a study by Regan and Liaschenko (2008), researchers applied a type of projective technique to understand the underlying motivations of clinicians in nursing practice. The rationale for employing a projective technique, in this case a variant of the Thematic Apperception Test (Murray, 1943), was that learning about a person's cognitive framing of a topic is typically beyond the reach of conscious thought and thus not readily accessible. The researchers presented participants, nurses in a labour and delivery ward of a hospital, with an ambiguous photo of a labouring woman and recorded their responses to understand how they cognitively framed childbirth, specifically if the participants discussed caesarian section. The participants were asked to come up with a storyline of the photo they were presented. The researchers compared the narrative responses of participants to a "normative standard" response, which was an agreed upon generic, uneventful storyline about the photo. When comparing the participants' response to the normative standard response, they considered the degree of variation from the standard response, as well as the language used by participants. Their analysis included the language used by participants around the story's protagonist, a labouring woman, which the authors emphasize was revealing of the narrator's own values and beliefs as it is thought that the participants projected their own characteristics on to those of the story's protagonist.

Researchers Karnieli-Miller, Nissim, and Goldberg (2017) conducted a study that employed projective techniques, in the form of illustrated metaphorical cards, to construct and understand the narratives of people living with severe mental illness. Participants were invited to share a story or narrative about their participation in a clubhouse (where participants were recruited from), and at the end of their story, to pick a card that best represented their story, and explain why. The authors highlight that the use of the projective technique enhanced the participants' ability to express their personal narratives and facilitated more comprehensive stories and descriptions. They emphasize that the use of the illustrative metaphorical cards allowed for participants to express their experiences and emotions more freely. Projective techniques have also been associated with success over and above usual interviewing or questioning techniques when seeking to understand sensitive issues (Sutton, 2011; Han & Oliffe, 2015).

The use of personal narratives in research is valuable for understanding the lived experiences of people with disabilities (Karnieli-Miller, Nissim, & Goldberg, 2017). Karnieli-Miller, Nissim, and Goldberg (2017) discussed the potential difficulty faced by participants, being those living with disabilities, in expressing their experiences, either because the topic of conversation was sensitive or painful or abstract and difficult to verbalize, or because the participants themselves had difficulties expressing themselves with verbal or nonverbal language. The researchers stated that the use of projective techniques, specifically the illustrated metaphorical cards, was seen as a useful mechanism for overcoming the participants' potential expressive and linguistic difficulties (Karnieli-Miller, Nissim, & Goldberg, 2017). Further, it is also suggested that in situations where questionnaires or direct questioning in interviews may produce limited data, the use of projective techniques may be beneficial (Levin-Rozalis, 2006). Projective techniques have the potential to provide the participant with a means of expressing their lived experiences, values, and beliefs (Levin-Rozalis, 2006).

Types of Projective Techniques

While all projective techniques fall under the same umbrella in terms of general principles, there are normally thought to be 4 different categories of projective techniques: Association, Completion, Expression, and Construction. Association techniques ask the participant to respond to a situation with the first thing that comes to mind (Mesias & Escribano, 2018). This could be a word, sentence, or list, and their answers are thought to represent a pattern of responses that can be used to determine the underlying attitudes or feelings of the participant about the topic (Mesias & Escribano, 2018). Association techniques can include tasks like word associations (Mesias & Escribano, 2018).

Completion techniques involve the participant completing an incomplete scenario for which an ambiguous sentence, conversation, or story has been provided (Mesias & Escribano, 2018). In sentence completion tasks, participants are presented with an incomplete sentence and asked to fill in the blanks with whatever first comes to mind (Mesias & Escribano, 2018). Expressive techniques typically involve the presentation of a verbal or visual situation and the participant is asked to describe what the feelings or attitudes of the other people in the situation might be (Mesias & Escribano, 2018). The answers are obtained through role playing or third-person techniques, which can be helpful when participants may be hesitant of expressing their own beliefs and attitudes directly (Mesias & Escribano, 2018).

Construction techniques can be either verbal or visual, and the participant is asked to respond to a situation by creating a story or description (Mesias & Escribano, 2018). A classic example of construction techniques is the Thematic Apperception Test (Murray, 1943). The thematic apperception test involves a set of ambiguous pictures which are shown to the participant to elicit a storyline, and the participant's answer is thought to be representative (a projection) of their own attitudes or feelings (Mesias & Escribano, 2018). Construction techniques can also involve storytelling, where the participant is asked to create a story related to an image or verbal prompt. Construction techniques are the focus of this thesis.

Storytelling with People with Dementia

Researchers have demonstrated the resilience of storytelling in people with dementia, highlighting the retained ability to express one's personal narratives even when coping with progressive cognitive impairment (Fels & Astell, 2011). Conversational approaches like storytelling or life-story methods have been shown to support people with dementia in expressing their experiences (Alsawy et al., 2017; McKeown, Ryan, Ingleton, & Clarke, 2015). As many people with dementia often have difficulties expressing themselves and participating in social interactions and conversations, especially when recalling and discussing current events, some find it more accessible to reflect on past experiences from earlier in their lives (Fels & Astell, 2011). Storytelling through reminiscence has social benefits for people with dementia, including engaging and sharing memories with others, using social skills, and participating on an equal basis with others in social situations (Fels & Astell, 2011). Learning more about lived experiences through storytelling by people with dementia enables them to enhance their own dignity through the expression of personal narratives (Heggestad & Slettebo, 2015).

In research, the use of generic prompts and photographs has been demonstrated to successfully stimulate recollection of personal narratives (Astell et al., 2010). Further, the use of generic photographs is thought to be more accessible to people with dementia as a conversation prompt, as it does not require them to recall a specific memory or report on a photograph with any accuracy – which would be expected if the photographs used were personal to the participant (Fels & Astell, 2011). The use of generic photographs removes the expectation that the participant will tell the "right" story (Fels & Astell, 2011). Also, direct questioning in interviews adds social pressure to participants to answer in a socially acceptable manner, and for people with dementia, this can include feeling pressured to answer a question "correctly" (Heggestad & Slettebo, 2015). Storytelling, and especially when using projective techniques, can work to remove additional pressures and promote discussion, as the person with dementia is seen as the expert on their story (Heggestad & Slettebo, 2015). As Heggestad and Slettebo (2015) state, people with dementia may feel lost when questioned about the present, but when offered the opportunity to discuss their past and story, it can promote confidence and safety.

A gap remains, however, in terms of the potential of storytelling and projective techniques in supporting the active participation and improving the engagement of people with dementia in research. It is also important to understand the influence of such techniques on the data collected in projects where they are employed. For example, as described above, improved engagement of people with dementia is likely to result in improved data quality – as engagement includes concepts of social connection and discussion of emotional and meaningful topics. This connection is especially salient when considering the potential impacts of disengagement – affective blunting (i.e., reduced display of emotion), and inactivity or inattention. Projective techniques hold promise for improving the engagement of people with dementia in research activities, in turn promoting improved data quality.

Chapter 2: Opening Remarks

Rationale

Qualitative research often requires participants to recall information about their experiences and express these experiences, most often in a verbal interview. This can be quite challenging for older adults with dementia, as many qualitative tools rely on recall and verbal expression (Phillipson & Hammond, 2018). Research must examine strategies to minimize confusion and maximize meaningful engagement wherever possible, especially when examining the individual lived experiences of dementia (Phillipson & Hammond, 2018). Research methods like projective techniques have potential for improving engagement of people with dementia in research. Despite the growing use of different innovative methods in dementia research, there is limited research on the effectiveness of these methods on improving engagement in research activities with people with dementia. Even still, methods that have been evaluated for people with dementia often rely on more traditional tools to do so, such as surveys, interviews, and focus groups (Phillipson & Hammond, 2018). Further, the COVID-19 pandemic has brought changes to the way that research is conducted with people with dementia in Canada, providing additional opportunities to engage in research online or by phone. This dissertation, particularly the primary studies, sought to examine how the use of projective techniques in a virtual setting impacted interviews conducted with people with dementia.

The experiences of people with dementia in accessing supports and services in Canada was chosen as the topic through which to study the impact of projective interviewing techniques. It is becoming more regularly acknowledged that people living with dementia are frequent active “users” of services, instead of passive “recipients”, and thus should be involved in their design and delivery (Litherland & Capstick, 2014). Improved and relevant supports and services for people with dementia are possible through conducting research that incorporates the needs, desires, and abilities of people with dementia. However, challenges exist to the participation of people with dementia in research that informs support and service development. Researchers have identified an urgent need for new methods that work to engage people with dementia in research to incorporate their perspectives into support and service development, and engaging people with dementia successfully will in turn improve the quality of data that is utilized to develop supports and services for people with dementia (Heggestad, Noetvedt, & Slettebo, 2013; McKeown, Clarke, Ingleton, & Repper, 2010).

Further, improving engagement in research for people with dementia can, in turn, support their human rights as it promotes the equal participation of people with dementia in broader society. Research that fully engages with people with dementia to learn about their needs, desires, and abilities can result in evidence that can be used to inform policy and practice. Improving engagement in research can improve the collection of information about the experiences, needs, and preferences of people with dementia, as well as the uptake of this information in policy and practice, reflected in the development of tailored supports and services for people with dementia. The central focus of the studies making up this dissertation was to explore how the inclusion of people with dementia could be facilitated – and thereby their human rights to autonomy ensured, by meeting communication needs. Further, these studies sought to examine the extent to which techniques aimed at meeting communication needs actually engage people with dementia and how research studies more broadly might be impacted by the use of techniques in terms of data collection – following the notion that when people with dementia have their communication needs met, they may be more empowered or able to share their lived experiences, supporting their human rights to autonomy and likely improving the collection of these perspectives so that they are translated into more relevant outcomes.

As discussed, different techniques have been employed in attempts to involve people with dementia more meaningfully in research. The method selected for study in the primary studies making up this dissertation is projective techniques, as they work directly to meet communication needs and reduce barriers to the participation of people with dementia through addressing burdens associated with recall, communication, and memory abilities. As well, these techniques were selected for their flexibility in application which was necessary given the timeline of the studies (i.e., conducted during the COVID-19 pandemic and associated restrictions), low cost to use, and overall fit with the topic and scope of study.

Participants in the primary studies of this dissertation took part in the study activities completely remotely during the pandemic, and as such, the method was chosen as it was determined to be flexible enough for participants to reasonably take part without significant assistance (which would have likely been required if participants were to engage in photography directly). The use of generic, researcher-driven prompts that could be displayed over a video call was thought to likely support the participation of people with dementia within the context of the study timeline.

Research Approach & Framework

Within the broader context of dementia research and scholarship, as well as continued advocacy efforts from those living and supporting those with dementia, connections to broader social justice movements in the disability field have raised issues of human rights, justice, accessibility, and inclusion. This thesis is centered on a social and human rights model of disability. The social model of disability proposes that disability is not solely a medical condition but is influenced by societal attitudes and structures (Oliver, 2013). As extended in this thesis, the social model of disability advocates for structural and attitudinal changes to create a more inclusive society for individuals with disabilities, including those living with dementia (Oliver, 2013; Hogan, 2019). Building on the social model of disability, this thesis also incorporates the key tenets of the human rights model of disability, which recognizes disability as a natural part of human diversity that must be respected and supported in all forms, emphasizing that people with disabilities have equal rights, and disability should not be used as a reason to restrict their rights (Lawson & Beckett, 2021). This model is underpinned by the United Nations Convention on the Rights of Persons with Disabilities (2006) which emphasizes equality, fairness, and living a life free from fear, harassment, or discrimination for individuals with disabilities. These models, as aligned to the goals of this thesis, promote the recognition and respect of people with disabilities – including those living with dementia, and advocate for policies and practices that support full inclusion and participation for individuals with disabilities (Lawson & Beckett, 2021). Together these models provide a lens through which this dissertation and its associated research questions are explored. This dissertation is centred on applying the central concepts of the social and human rights models of disability to the exploration of adapted, modified, and novel research methods that support the inclusion and in turn the human rights of people living with dementia.

Research Questions and Objectives

This thesis examines the use of adapted or modified methods for engaging in research with people with dementia. As well, this thesis explores the use of constructive projective interviewing techniques, with either verbal or photo prompts, in facilitating improved engagement of people with dementia in research and in turn their influence on data collected. This thesis was guided by several research questions informing each of the included manuscripts. The research questions of focus for this thesis were:

1. What types of adapted or modified methods are used to involve people with dementia as participants in research?
2. Is the use of adapted or modified methods discussed in terms of improving engagement in research activities for people with dementia?
3. How do researchers describe their rationale for using adapted or modified methods with people with dementia in research?
4. Does the use of verbally-prompted and photo-prompted storytelling techniques with people with dementia impact engagement in research activities?
5. How does engagement in research activities impact the data collected in interviews with direct questioning, verbally-prompted storytelling, and photo-prompted storytelling?

To address these research questions, three studies were conducted. Presented first (Chapter 3) is a scoping review of research studies that involve people with dementia as participants and use modified or adapted data collection techniques. This review examines the rationale(s) provided by authors for using such techniques. Further, this review presents a synthesis of what types of modified or adapted methods have been used to engage people with dementia as participants, why such methods were employed, and how the use of such methods was justified. A scoping review protocol was developed according to the Joanna

Briggs Institute for Evidence Synthesis and in collaboration with a Liaison Librarian in the School of Public Health Sciences at the University of Waterloo.

The second and third studies examined the impact of two types of projective techniques on the engagement of persons living with dementia in research. The second study (Chapter 4) examined the use of a verbally-prompted storytelling technique and its impact on engagement of people with dementia. The third study (Chapter 5) examined the use of a photo-prompted storytelling technique. The same methodology was used for both studies, but the specific interviewing technique being examined differed. Each method of interviewing was compared with a traditional semi-structured interview with direct questioning to determine similarities and differences in the data collected. As well, the level of engagement of participants in each interview was examined utilizing an observational measurement scale.

Statement of Positionality

As reflected on by Scharp and Thomas (2019), it is important for researchers to consider how their own positions and experiences contribute to their understandings of the lived experiences of others. Throughout my experiences as a student and beyond, I have had a deep appreciation for the perspectives of people living with disabilities, including dementia. My development as a researcher has been informed by my personal experiences with dementia in my family, as my grandmother lives with dementia, and is inseparable from occurrences of bearing witness to the outcomes of experiencing ageism and dementia-related stigma and discrimination. Having worked as a research assistant on several dementia-related research projects and having the opportunity to be involved in focus groups and interviews with people living with dementia and their care partners, as well as working as a recreation therapist in a community dementia program, I had the opportunity to learn from the experiences of others including their experiences of stigma and discrimination that they shared with me. These experiences have informed the lens through which I approach this research as well as the shaping of my general worldview. Ensuring the human rights of those who have been historically and presently discriminated against, in this case people living with dementia, are respected and recognized has been a central focus of my research, inspired in part by my perspectives. I am aware of my biases towards initiatives and efforts to promote inclusion and accessibility and acknowledge the utility in leveraging objective frameworks to approach this research critically.

My position as a researcher, having been developed through my past experiences and shaped by perspectives related to social justice – being that I personally believe that everyone should be accommodated to participate should they wish to do so, has guided my work on this dissertation from the beginning stages of conceptualizing the research idea and focus to the interpretation of the data and outcomes. While the aims of this research were to understand and examine the ways in which people with dementia could be more engaged in research, as well as the ways in which research may be made more inclusive and accessible – acknowledging exclusion from research that has occurred in the past, I acknowledge that as a person not presently living with dementia, the ways in which I approached this research are informed by the lived experiences of those I have had the opportunity to learn from over the course of my lifetime through personal, professional, and academic experiences. I have been closely involved in the care of people with dementia, both through personal experiences with my family members living with dementia and professionally through my experiences as a recreational therapist in a community dementia program. As a student and researcher, I have been involved in several dementia related research projects where I have had the opportunity to learn from people living with dementia, care partners, and other researchers in the field. As a researcher, I also had to consider and reflect on how my perspectives may have affected what I observed over the course of this study, including how the results were interpreted, given that I led the design, data collection, and analysis of the included works. The findings resulting from the analysis of the data produced through this study are likely influenced by my position as a researcher and my personal desire to support the engagement of people with dementia in research. Using objective frameworks, including the scoping review guidelines and observational scale measurements, alongside strategies to enhance the rigour of the studies, helped me to approach this research critically and reflect on the motivations that have shaped this work.

Chapter 3: Use of Adapted or Modified Methods with People with Dementia in Research: A Scoping Review

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Overview

Background: People with dementia are excluded from research due to methodological challenges, stigma, and discrimination. Including perspectives of people with dementia across a spectrum of abilities is essential to understanding their perspectives and experiences. Engaging people living with dementia in qualitative research can require adaptation of methods.

Purpose: Qualitative research is typically considered when researchers seek to understand the perspectives, lived experiences, or opinions of individuals' social reality. This scoping review explores current use of adapted methods with people with dementia in qualitative research, including methods used and impacts on the engagement as it relates to meeting accessibility needs. This review considered rationales for adaptations provided by authors, particularly whether authors identified a human rights or justice rationale for adapting methods to promote accessibility and engagement.

Design/Methods: This review began with a search of primary studies using qualitative research methods published in English in OECD countries from 2017 to 2022. Two reviewers screened titles and abstracts for inclusion. Full texts were reviewed, and data from included studies were extracted using a pre-determined chart. Content analysis of rationales was conducted and reviewed by all authors. Studies were assessed for findings related to impacts of adapted methods.

Results: Twenty-eight studies met inclusion criteria. Adaptations to qualitative research methods ranged from minor changes, such as maintaining a familiar interviewer, to more extensive novel methods such as photo-elicitation techniques. Twenty-seven studies provided a rationale for adapting their methods. No studies assessed impacts of their methodology on engagement or accessibility. Five studies observed that their methodology supported engagement.

Conclusions: This review helps understand the breadth of adaptations that researchers have made to qualitative research methods to include people with dementia in research. Research is needed to explore adaptations and their impact on engagement of persons with dementia with a range of abilities and backgrounds.

Keywords

Qualitative research, Accessibility, Adapted research methods, Engagement, Dementia, Human Rights

Introduction

People with dementia have historically been excluded from research due to challenges with communication as well as concerns about cognitive decline and capacity (Alsawy et al., 2017; Cottrell & Schultz, 1993; Tyrrell et al., 2006; Swaffer, 2016). People living with dementia have also been routinely excluded from research due to stigma that exists about their ability to provide consent to participate in research and engage in decision making (Tanner, 2012; Wilkinson, 2002). Further, there exists a broad lack of understanding about dementia, and many people may assume that people living with dementia cannot contribute meaningfully to research activities (Phillipson & Hammond, 2018).

Barriers to the participation of people with dementia in research exist due to changes common with dementia, but also because of researchers' ability to accommodate these changes. People living with dementia often experience significant challenges with several cognitive domains, including memory, attention, perception, language, and executive function, which can negatively impact an individual's ability to participate in, or engage with, traditional approaches to research (Waite et al., 2019). In addition, most people living with dementia live with other chronic conditions that can make engagement in research challenging (Jellinger & Attems, 2015; Tonelli et al., 2017; Griffith et al., 2016).

Each person living with dementia is unique. Dementia as a disease is heterogeneous in presentation in the areas of cognition, function, behaviour, and affect (Cohen-Mansfield, 2000). Indeed, many people living with dementia express a desire to be included in research that shapes policy and practice which impacts their lives (Dementia Action Alliance, 2010). While the experiences, concerns, needs of people living with dementia vary at an individual level, so too do their capabilities, and thus needs for support to engage in research activities vary. To understand the diverse lived experience and needs, desires, and abilities of people with dementia, it is necessary to include people with a range of capabilities to gain a fulsome understanding of their experiences and needs (Heggestad et al., 2013; McKeown et al., 2010). Adapted and modified research methods can serve to promote the inclusion of a diverse range of people living with dementia, especially those who may require additional accommodations to support their participation.

The involvement of people living with dementia in research is also a human rights concern. The World Health Organization (WHO) (2015) Plan states that people with disabilities, including those living with dementia, have unique experiences and insights but have been excluded from the development of policies, laws, and services that impact their lives. People with disabilities should be involved in efforts to remove barriers that limit access to the assertion of their rights, including research (WHO, 2015). It is also important to consider the role of research ethics in the engagement of people with dementia as research participants. The Belmont Report (1978) identified that all research participants must be afforded three basic ethical principles – Respect for Persons, Beneficence, and Justice. The principle of Justice is especially relevant for research with people with dementia, as they are often systematically excluded based on assumptions about their capacity without consideration of their actual abilities (Rushford & Harvey, 2016). The principle of Justice relates to the equitable treatment of research participants, and states that that participants should not be denied from potential benefits of the research without ‘good reason’, or have any burden placed on their participation unduly. Participants should not be systematically excluded due to their race or ethnicity, health status, or age. Further, participants should be selected for reasons directly related to the problem being studied (The Belmont Report, 1978).

While ethical principles, as outlined above, support the inclusion of people living with dementia in research – institutional research ethics procedures often pose barriers to their inclusion. The procedural requirements of institutional research ethics boards and committees may lead researchers to exclude people with dementia from their research as a method of avoiding barriers imposed by institutional ethics boards relating to the mental capacity of people with dementia (Fletcher, 2020). While research ethics boards may consider all people with dementia to lack the capability to provide informed consent research and broader policy supports that individuals with diminished capacity have the right to participate in research, if desired, and can provide reliable accounts of their personal experiences (O’Connor et al., 2021; Beattie et al., 2015; Rushford et al., 2016; & National Health and Medical Research Council, 2007). As supported by O’Connor et al. (2021), representation from people living with dementia across all stages is necessary to improve quality of care and life. *Dementia Enquirers*, an independent research initiative in the UK, supports people living with dementia to conceive, lead, and carry out research independent of traditional frameworks. This approach focuses on the priorities and leadership of people with dementia within research, recognizing that institutional rules intended to protect people with dementia exclude them in practice (Davies et al., 2021). Further, involving a diverse range of people with dementia, in research and policy is essential for supporting their human rights and upholding the ethical principle of Justice in research.

Qualitative research is typically considered when researchers seek to understand individuals' social reality, including their attitudes, beliefs, and motivations. When looking to understand the perspectives and experiences of people living with disabilities, including people living with dementia, qualitative research is often argued to be the most appropriate mechanism of study (O'Day et al., 2002). However, qualitative research often requires participants to recall information about their experiences and express these experiences, most often in a verbal interview and this approach can be quite challenging for older adults with dementia (Phillipson et al., 2019).

For the purposes of this review, accessible research methods were broadly defined as adapted or modified techniques that attempt to support the participation of people with dementia in qualitative research by making the process of research easier. These techniques can include adapting to the hearing, visual, cognition, memory, and communication needs of people with dementia in the data collection process. Accessible strategies to minimize confusion, maximize meaningful engagement, and support the abilities of people with dementia are necessary when examining the individual lived experiences of dementia (Phillipson & Hammond, 2018). Facilitators to engaging people with dementia can include ensuring clear, accessible communication and maintaining flexible attitudes and approaches to research while considering an individual's strengths, skills, preferences, and needs (Waite et al., 2019). Engagement in research activities can also include active participation during data collection efforts. Additional challenges related to ethical and consent processes as well as recruitment often need to be navigated when engaging people living with dementia as participants in research.

Phillipson et al. (2019) have identified that accessible methods are needed in dementia research to help capture the perspectives of people living with dementia in research who may require additional supports to participate. Outside of traditional institutional research, researchers in the field of creative methods in dementia research have prioritized the inclusion of people living with dementia. Examples include *Cracked: new light on dementia*, a stigma-challenging play and film, and *Well-making*, which examines crafts and creative arts as avenues for expression and reflexive research (Kontos et al., 2020; Rana et al., 2020). Researchers have also identified an urgent need for new methods that work to engage people with dementia in research to incorporate their perspectives (Heggestad et al., 2013; McKeown et al., 2010). The use of adapted or modified methods in qualitative research with people with dementia is necessary to include the perspectives of people living with dementia in research. Further, it is important to understand the methods currently being used in research with people with dementia, why they are used, and if they are effective at achieving the goal of making research more accessible. Understanding the use and impact of adapted methods can enable the inclusion of a more diverse range of people with dementia in research.

Review Questions

1. What types of adapted or modified methods are used to involve people with dementia as participants in qualitative research studies?
2. How do researchers describe their rationale for using adapted or modified methods with people with dementia in qualitative research?
3. How is the use of adapted or modified methods discussed in relation to improving engagement of people with dementia in research activities?

Methods

This scoping review was conducted in accordance with the guidelines set by the Joanna Briggs Institute (JBI) Manual for Evidence Synthesis (2020). The JBI Manual for Evidence Synthesis brings together scoping review methods proposed by Arksey and O’Malley (2005) and Levac et al. (2010) and thus adds consistency in methodology and reporting through developing a scoping review standard

(Tricco et al., 2016). The scoping review conforms to the reporting standard of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2016).

Inclusion Criteria

Participants. Participants of selected studies included people living with dementia of any age and gender. Sources included participants that either had a diagnosis of dementia or self-identified as a person living with dementia. Dementia is generally defined as loss or impairment of memory, language, problem-solving, and other thinking abilities that are severe enough to interfere with daily life (Gaugler et al., 2021).

Concepts. Adapted or modified methods are defined as flexible and adaptable strategies that promote meaningful communication, such as supportive modifications (i.e., promoting the comfort of participants by allowing for choice in location or time of participation), communication techniques (i.e., modifying traditional research methods like interviews to be more accessible), conversational approaches (i.e. storytelling), augmentative and alternative communication methods (i.e. picture boards, speech-generating technologies), or any other non-observational method that moves beyond traditional interviews or surveys (i.e. arts-based methods, Photovoice).

The overarching concept of interest was to understand the current use of adapted or modified methods, why such methods are used, and their impact on the engagement or accessibility of research for people with dementia. Human rights or ethical principles of justice approaches to the use of adapted or modified methods to improve the engagement of people living with dementia in qualitative research is also of interest to gauge the extent to which current research refers to adaptations and modifications as a way to meet the needs of people with dementia to exercise their right to participate. Human rights or ethical principles of justice approaches are defined as overarching frameworks connected to declarations protecting people from discrimination and promoting equality, such as the United Nations Convention on the Rights of Persons with Disabilities (United Nations General Assembly, 2007), Canadian Charter of Rights and Freedoms (1982), Universal Declaration of Human Rights (United Nations, 1948), or

Research Ethics Statements such as the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2018), and The Belmont Report (1978).

Engagement is defined as "the act of being occupied or involved with an external stimulus" (Cohen-Mansfield et al., 2011, pg. 860) which includes duration (time in seconds that the participant is involved with a stimulus), attention (manipulation of the stimulus, gaze, and verbal behavior directed to the stimulus), attitude (positive or negative stance toward the stimulus), and refusal (acceptance or rejection of the stimulus) (Cohen-Mansfield et al., 2011). Thus, increased engagement would generally include increased duration and attention to a stimulus (e.g., a research activity or data collection activity), positive attitude towards the activity, and decreased refusal or rejection of the activity.

Types of Sources. In this review, we considered published primary studies that involved people with dementia as direct participants and had descriptions of the types of adaptations or modifications made to their methods. Studies identifying a qualitative research design, or a mixed-method design with qualitative methods, were included. For mixed methods studies, only qualitative data and findings were included. Although some have recommended that scoping reviews include both published and grey literature (Pham et al., 2014; Tricco et al., 2016), this study focused only on published peer-reviewed articles because the aim is not solely to identify the use of these concepts in general but also to map the way scholars use the concept of adapted and modified methods in relation to dementia, human rights or justice approaches, and engagement.

Search Strategy

All searches were conducted between May 2022 and December 2022 across PubMed, Scopus, PsycINFO, and CINAHL databases.

Peer-reviewed literature. The search strategy was developed in collaboration with a research librarian at the University of Waterloo. Search strings included keywords such as: "qualitative", "adapted", "modified", "accessible", "dementia", "engagement", as well as their related terms, MeSH terms, and synonyms. To align with the JBI method, a three-step search strategy was used. The first step of the scoping review involved an initial limited search of PubMed and Scopus. This was followed by an analysis of the text words contained in the titles and abstracts of retrieved papers, and of the index terms used to describe the articles to determine additional search terms. A second search using all identified keywords and index terms was then undertaken across all included databases. Third, the reference lists of the sources that were selected were searched for additional sources. Only sources published between 2017 and 2022 and in the English language and in an OECD country were included to capture the current state of the literature.

Selection of sources of evidence

Results of the search were collated and uploaded into Covidence (Veritas Health Innovation, n.d.) and duplicates were removed. Titles and abstracts were screened by two reviewers, the first author (E.C.) and a trained research assistant, using the inclusion criteria for the review. Disagreements were resolved through discussions with a member of the research team (C.M.). Full texts of references were retrieved and assessed by two reviewers against the inclusion and exclusion criteria.

Charting the data

Included sources were examined to extract key information of the source, author, reference, and methods relevant to the review questions. Specifically, the included sources were examined for study design, data collection methods and procedures, the type of adaptation or modification included, and information about the participants, sample size, inclusion and exclusion criteria, study location, and recruitment methods. The study outcomes were also extracted, focusing on any outcomes of adaptations made to the study method or procedure, and any findings related to accessibility, inclusion, or engagement. The rationales for adaptations or modifications made were also captured. Information on whether a rationale was a given, and if so, if it related to human rights or ethical principles of justice was extracted. If a rationale was discussed that was not related to the two aforementioned categories, it was detailed for further examination and categorization.

Collating, summarizing, and reporting results

After completion of the data extraction, the characteristics of all included studies were tabulated. A descriptive qualitative content analysis (Creswell & Poth, 2016) was conducted using NVivo 12 (QSR

International) to examine and categorize the rationales for use of adapted or modified methods provided by authors. A summary of data coded is provided in the form of categories. A narrative summary describing how the results relate to the objectives of the review was created, including a discussion of gaps in the literature.

Results

The database search identified 1895 abstracts. After the removal of duplicates, 1085 articles remained. A total of 975 articles were excluded after title and abstract review, and 110 articles underwent full-text review. Eight conflicts were identified at the full-text stage and a third reviewer (C.M.) was involved to resolve the conflicts. The final sample included 28 peer-reviewed articles (see Figure 1).

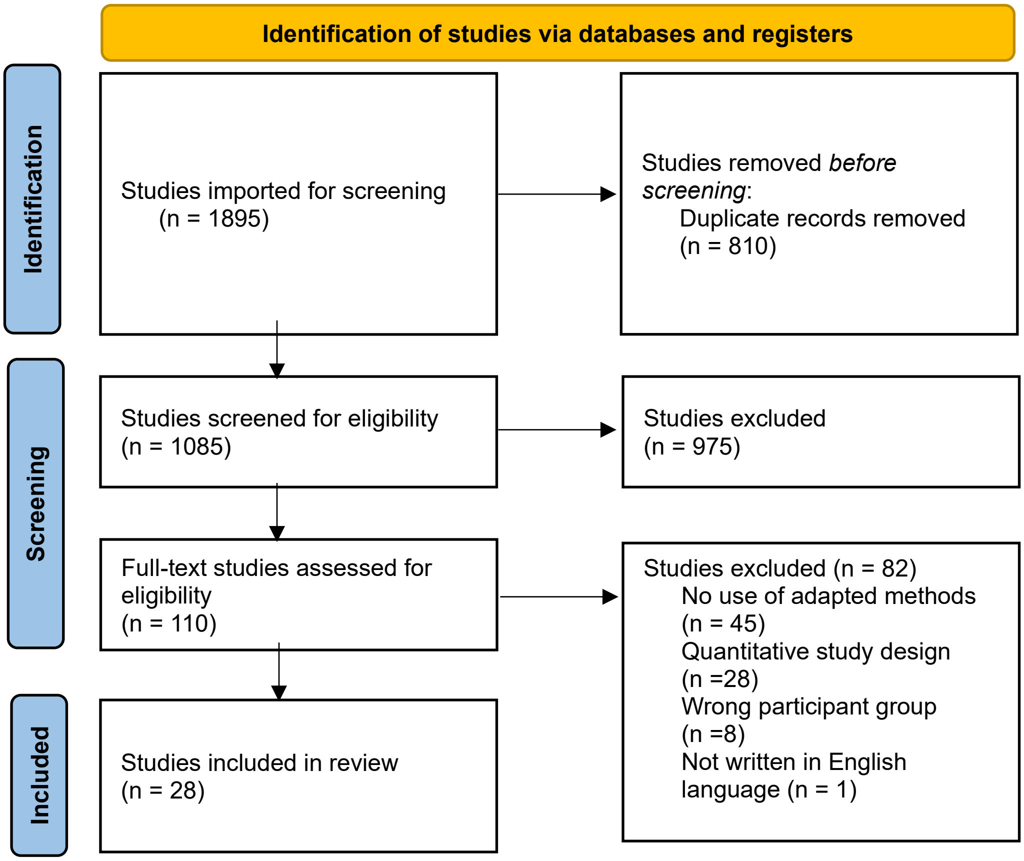

Figure 1. PRISMA Diagram of Scoping Review Process

Characteristics of included studies

Studies included were from the UK (n=15), Canada (n=2), Australia (n=2), the USA (n=1) and other countries (n=8). Research on this topic has grown over time. None of the included studies were published in 2017; 7% were published in 2018, 32% in 2019, 14% in 2020, 39% in 2021, and 7% in 2022. The majority (79%) of studies cited a qualitative research design, and the remainder were identified as mixed methods. All studies included people with dementia (n=439). Studies also included care partners (n=380) and health and social care providers or other stakeholders (n=263). A comprehensive, descriptive table (Table 8) detailing characteristics of all included studies is presented in Appendix 1.

Table 1. Characteristics of included studies

Total number of sources of evidence: 28

Country of Publication	Number of studies, per year	Types of studies	Rationale Type	Outcomes	Summary of rationales
UK: 15 Canada: 2 Australia: 2 USA: 1 Other: 8	2017: 0 2018: 2 2019: 9 2020: 4 2021: 11 2022: 2	Qualitative: 24 Mixed methods: 4	Human Rights: 9 Ethical/Justice: 9 No rationale: 1 Other (not classified in any of the above): 19	No studies assessed the impacts of their methodology on engagement. 5 studies observed that their methodology supported engagement.	Adaptations ensure voices are included: 8 Adaptations promote conversation: 7 Adaptations are best practice: 4 Improve overall research output: 2 Adaptations promote comfort: 1

Types of adaptations and modifications made

While all studies included in this review necessarily used adapted or modified data collection methods, the types of adaptations and modifications made varied. Seventeen studies included cognitive and communication accessible strategies, such as providing interview questions in advance to support participation and using easy-to-understand language. Fifteen studies adapted to personal preference, such as maintaining a familiar interviewer or researcher, and encouraging participants to engage in the data collection activity at a time or place comfortable to them. Eleven studies included novel data collection approaches, such as photo-elicitation techniques (e.g., using visual images to elicit comments) and nominal group sessions (e.g., structured small group sessions to reach decisions). Eight studies employed flexibility in data collection methods, such as giving options for participation (e.g., participant could choose between a survey, interview, and the method of data collection such as in person or over the phone). Four studies included modifications to capture non-verbal communication, such as capturing the interview activities on video or taking notes on body language. Details of adaptations and modifications made in included sources are presented in Table 2.

Table 2. Characteristics of Adaptations and Modifications

Adaptation/Modification Type	Details	Citations (First Author, Year)
Accessible communication strategies	Providing clear communication in data collection, such as plain-language consent forms and information sheets, providing interview questions in advance, using easy-to-understand language and direct questions in interview guides, displaying interview questions visually, reducing the number of questions asked, providing prompts when participants experienced challenges responding, and giving ample time for response.	Barrado-Martin, 2019 Asghar, 2020 Ward, 2020 Sheth, 2019 Stephan, 2018 Krein, 2020 Novek, 2021 Gebhard, 2021 Tetrault, 2022 Kwak, 2018 Hoel, 2021 Talbot, 2021 Capstick, 2021 Morbey, 2019 Fleetwood-Smith, 2021 Keogh, 2021 Tiersen, 2021
Adapting to personal preference	Supporting the comfort and preferences of the participant. Strategies may include keeping a consistent or familiar interviewer/researcher, conducting data collection at a time or place preferred by the participant, including the option to have a support person or care partner present, creating a sense of security	Barrado-Martin, 2019 Thompson, 2022 Keyes, 2019 Ward, 2020 Weeks, 2020 Krein, 2020 Novek, 2021 Gebhard, 2021 Funnell, 2019 Tetrault, 2022 Kwak, 2018 Schnelli, 2021 Fleetwood-Smith, 2021 Keogh, 2021 Bartlett, 2019
Novel data collection approaches	Think-aloud techniques; narrative interviews using objects, pictures, or photographs from around the participant's home; photo-elicitation techniques; nominal group sessions (e.g., structured group brainstorming); invitation to respond techniques (e.g., direct calls to respond from interviewer); using life story books; walking interviews; reflective storytelling techniques; and a café method.	McCombie, 2020 Kindell, 2019 Ward, 2020 Sheth, 2019 Funnell, 2019 Kwak, 2018 Hicks, 2021 Talbot, 2021 Capstick, 2021 Keogh, 2021 Bartlett, 2019
Flexibility in data collection methods	Using general or broad interview questions (i.e., not conforming to	Øksnebjerg, 2019 Krein, 2020

	any one particular interviewing technique but purposely being flexible), giving options for participation (i.e., through a survey or interview).	Novek, 2021 Stamou, 2022 Hicks, 2021 Hoel, 2021 Morbey, 2019 Fleetwood-Smith, 2021
Capturing non-verbal communication	Capture non-verbal communication expressed by participants.	Barrado-Martin, 2019 Ward 2020, Capstick, 2021 Fleetwood-Smith, 2021

Types of rationales provided

Of the included studies, 27 of the 28 provided rationales for adapting or modifying methods used with participants with dementia, and some studies provided more than one rationale. Studies could be broadly considered to have provided ethical considerations, to promote justice, and/or methodological considerations, to promote participation. Nine studies rationalized adaptations or modifications on the basis of ethical principles of justice, which reflect that it is unjust to exclude people with dementia without accommodations. Nine studies provided rationales related to human rights, that is, people living with dementia have the right to participate in research if they so choose. Eight studies provided rationales for adaptations or modifications made to methods related to ensuring the participant’s voice was included, however, did not discuss such inclusion in terms of relation to an ethical principle of justice approach. Seven justified the adaptations or modifications made to promote conversation. For example, Barrado-Martín et al. (2019) emphasized that utilizing an invitation-to-respond technique was necessary to facilitate and promote the involvement of participants in conversation. Four rationalized the adaptations or modifications made as aligning to best practice or guidance from experts, such as Keyes et al. (2019), who cite the work of Clarke and Keady (2002) in the development of their inclusive data collection procedure. Two justified the adaptation or modification of methods as a way to improve the relevance of the research output through including ‘end users’ in the research process. One study provided a rationale for adapting or modifying methods to promote the comfort of participants involved, which included emphasizing the role of the data collection facilitator in promoting participant comfort through feelings of safety. There were no clear connections identified between the type of rationale and the type of adaptation employed by the authors. Characteristics of rationales provided in included sources are presented in Table 3.

Table 3. Characteristics of rationales provided for adapting or modifying methods

Rationale	Characteristics	Citations (First Author, Year)	Total
Ethical rationales promoting justice	Rationales related to ethical principles of justice, e.g., adapting or modifying methods to ensure participation as it is unjust to exclude people on the basis of disability	Ward, 2020 Krein, 2019 Funnell, 2019 Hoel, 2021 Capstick, 2021 Morbey, 2019 Schnelli, 2020 Fleetwood-Smith, 2021 Bartlett, 2019	9
	Rationales related to human rights of people with dementia to participate on an equal basis with others	Ward, 2020 Weeks, 2020 Stephan, 2018 Funnell, 2019 Tetrault, 2022 Capstick, 2021 Fleetwood-Smith, 2021 Tiersen, 2021 Bartlett, 2019	9
	Rationales related to ensuring participants voices were included	McCombie, 2021 Sheth, 2019 Novek, 2021 Gebhard, 2021 Hicks, 2021 Talbot, 2021 Keogh, 2021 Ward, 2020	8
Methodological rationales promoting participation	Rationales justifying the use of adaptations or modifications to methods through highlighting the need for adaptations to promote conversation with people with dementia	Barrado-Martín, 2019 Sheth, 2019 Kwak, 2018 Krein, 2019 Gebhard, 2021 Asghar, 2020 Thompson, 2022	7
	Rationales that discussed adaptations or modifications to methods being made as they were considered to be best practice or advised by experts	Kindell, 2019 Keyes, 2019 Tiersen, 2021 Krein, 2019	4
	Rationales related to including people with	Øksnebjerg, 2019	2

	dementia through adapted or modified methods to improve the research outcomes in terms of their relevance or applicability	Asghar, 2020	
	Rationale was related to ensuring participants felt comfortable during the interviews	Thompson, 2022	1
No rationale provided	No rationale for making adaptations or modifications to methods	Stamou, 2021	1

Supporting the engagement of people living with dementia in research

While all included studies included adaptations or modifications with participants with dementia, no studies assessed the impact of adaptations or modifications on the engagement of participants. Five studies observed that adaptations or modifications increased the engagement of participants, such as reporting that participants seemed more open to discussions about their feelings (Bartlett et al., 2019), seemed more relaxed (Hicks et al., 2021), participated in more conversation (Capstick et al., 2021), experienced reduced barriers (Morbey et al., 2019), and provided more information in their responses (Fleetwood-Smith et al., 2021).

Discussion

The purpose of this review was to understand the ways in which qualitative research methods have been adapted and modified to involve people living with dementia and research. The review mapped the nature of adaptations and modifications, as well as any discussions of how these adaptations or modifications might impact the accessibility of research methods. Adaptations and modifications ranged from supportive changes, such as promoting comfort through using a familiar facilitator, to more extensive modifications, such as using photograph prompts and novel methods. The accessibility of research methods, as tied to the adaptations or modifications made to accommodate the participation needs of individuals with dementia, was also examined in light of any discussions of improved engagement for participants with dementia.

As supported by the results of this review, various adaptations and modifications can be made to support the participation of people with dementia in research activities. The impact of these adaptations or modifications on the engagement of people with dementia in research (i.e., whether they are effective at accommodating participants needs) and the data produced remains relatively unstudied. Indeed, no studies identified in this review provided any evaluation of how adapted or modified methods being used impacted the engagement of people with dementia, or the outcomes of the research. Ensuring methods employed are effective at capturing a diverse range of perspectives of people living with dementia is essential to integrating such perspectives in policy and practice. It is argued that in order for the rights of people with dementia to be upheld, and for the outcomes of research to be translated into policies, laws, and services that impact their lives, rigorous research methodology must be employed to ensure maximum uptake and transferability of results into practice (WHO, 2015). A recent study by McArthur et al. (2023) identified that barriers exist to the inclusion of people living with dementia in research, highlighting the importance of adapted or modified research methods to engage people living with dementia in research. In alignment with the present review, the authors emphasize the need to examine the effect of including people living with dementia in research (McArthur et al., 2023). It is concluded that future research should seek to examine the methodological rigour of such adapted and modified methods.

A secondary focus of this review was to examine the rationales used by researchers who involved people with dementia in qualitative research activities through using adapted or modified methods. Researchers have a role in ensuring their studies are accessible to their participants. Creating a safe and accessible study procedure can support people with dementia’s right to participate (Cridland et al., 2016; Novek & Wilkinson, 2019; Wilkinson, 2002). Ensuring accessibility in research promotes the inclusion and participation of people living with dementia (Hobson et al., 2019). Future research should seek to include transparent discussions of methods employed to promote the uptake of accessible methods to engage people living with dementia.

In this scoping review, we identified 28 studies that included adaptations or modifications to their study methods for including people living with dementia. Twenty-seven of the included studies provided a rationale for adapting or modifying their methods. How authors rationalize adaptations and modifications is important when considering how this impacts the rights of people living with dementia to participate. Understanding why adaptations and modifications are made can help to encourage future research to incorporate accessibility adaptations that support participation for people living with dementia. In turn, this can help to support more accessible research for people with dementia in the future. While 5 studies observed that the adaptations or modifications made had an impact on the engagement of people with dementia in research, no studies assessed the impact of adaptations or modifications on the engagement of participants. As such, there is a gap within the literature of understanding how such adaptations or modifications may impact engagement, as well as research outcomes.

Limitations

This review was limited to English-language, peer-reviewed literature published between 2017 and 2022. While a rigorous search method was employed, it is possible that relevant literature could have been missed. The conclusions drawn from this review are based on the included descriptions of adaptations or modifications, and assessments made are limited to the level of detail provided by authors. Our understanding of the scope of the literature concerning the use of adapted or modified methods with people living with dementia is also limited to information published in English, and thus may not capture approaches to engaging with people living with dementia present in non-English literature – including culturally specific approaches. Thus, it is possible that this review presents an under-estimation of adaptations or modifications occurring in practice.

Conclusion

Globally, calls have been made to improve the inclusion of people living with disabilities, including those living with dementia, in research that impacts policy and practice as a way to recognize their rights to participate on an equal basis with others. However, inadequate information exists to support researchers to promote engagement of people living with dementia in research and support their participation with accessible research methods. While included studies showcase a range of adaptations and modifications that can be made to research methods for studies seeking to involve people living with dementia in research, there is limited information on how adaptations or modifications were chosen and implemented, and no assessment of how such adaptations or modifications actually impacted participants' experiences with participating. Such limited evidence makes it difficult to prioritize the meaningful inclusion of people living with dementia in future studies. Comprehensive methodology sections with highly specific details of adaptations, modifications, and their impacts on engagement of people with dementia in the research process are needed to enhance the understanding of the opportunities for adaptations and modifications. This in turn can help to promote the recognition of the rights of people with dementia to participate in research. Future research should examine the impact of adaptations or modifications to methods in studies that include people with dementia as research participants on engagement.

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Chapter 4: “If she’s anything like me…”: Exploring the use of verbally-prompted storytelling techniques in research with people living with dementia

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Overview

Introduction: Despite existing approaches to address challenges in supporting the participation of people living with dementia, these approaches are rarely evaluated. It is necessary to evaluate the influence of adaptive strategies for their utility in engaging people with dementia as research participants. This study sought to examine the influence of verbally-prompted storytelling techniques for facilitating the engagement of people with dementia in a qualitative research project.

Methods: Participants (n=12) completed a series of interviews utilizing both traditional semi-structured interviewing techniques with direct questioning and verbally-prompted storytelling techniques. Responses in both interviews were analyzed and compared to evaluate similarities and differences in the resulting data through qualitative content analysis. Observational data was also collected and analyzed to assess the level of engagement in the two types of interviews utilizing the Engagement of a Person with Dementia Scale.

Results: Results from a qualitative content analysis suggest that when compared to traditional semi-structured interviews, verbally-prompted storytelling techniques supported deeper and broader reflection of the impact of one's experiences on oneself and others, facilitated richer conversations when participants had difficulty recalling a personal example, and enabled conversations about emotional topics. The observed engagement scores across interview types were similar ($p=0.19$).

Conclusion: Results of this study suggest that verbally-prompted storytelling techniques influence data-elicited from qualitative interviews. Specifically, the use of verbally-prompted storytelling techniques with people living with dementia in qualitative research is a promising technique to support research participation for this population, as well as to support improved communication for other purposes, such as during care conversations. Continued investigations into the application of these techniques in wider populations of people living with dementia at different stages of their dementia journey will help to establish the usefulness of these techniques more broadly.

Introduction

Globally, more than 55 million people are living with dementia (WHO, 2023). In Canada, it is estimated that more than 730,000 older adults live with a diagnosis of dementia (Alzheimer Society of Canada, 2024). Dementia can be caused by many diseases and is characterized by progressive cognitive impairment sufficient to impair activities of daily living (Alsawy et. al., 2017). Cognitive impairments in dementia can encompass deficits in memory, language, problem-solving and communication abilities (Alsawy et. al., 2017; Alzheimer Society, 2019). Despite these challenges, research has found that people with dementia are often able to articulate their experiences and offer valuable contributions to research (Alsawy et al., 2017; Dewing 2007; Benbow & Kingston, 2016). Groups such as the World Health Organization (WHO) (2017) and Public Health Agency of Canada (2020) have encouraged a commitment to research in dementia and the translation of such research into policy and practice. However, the perspectives of people with dementia have been largely excluded from health and social research that informs policy and practice due to methodological and communicative challenges, as well as concerns about cognitive decline and capacity, and stigma (Alsawy et al., 2017; Cottrell & Schultz, 1993; Tyrrell, Genin, & Myslinski, 2006; Swaffer, 2014; Phillipson et al., 2019; Taylor, DeMers, Vig & Berson, 2012). The inclusion of people living with dementia in research is essential to recognizing their human rights to participate, and ensure policy and practice is developed with their needs, desires, and abilities in mind.

Engagement, or active participation, is typically considered as either social interaction or activity participation, and is usually assessed through behavioural observations (Jones, Sung, & Moyle, 2018). It is noted that most research in this area has focused on the effectiveness of psychosocial interventions that can promote meaningful activity, stimulation, and well-being through an increase in positive affect and an improvement in activities of daily living, and quality of life – and not the assessment of engagement in research activities (Ballard et al., 2005; Gitlin et al., 2009; Moyle et al., 2013; Van Der Ploeg et al., 2013; Materne, Luszcz, & Goodwin-Smith, 2014; and Schreiner, Yamamoto, & Shiotani, 2005). There is often a need to adapt or revise traditional ways of conducting research to support people with dementia to actively participate or be engaged in research, especially as symptoms progress. Methods that support communication and accommodate an individual’s needs could help to facilitate improved engagement in research activities, such as data collection. Engagement in data collection efforts is important to ensure the data reflects individual experiences – however, at present, no studies have been conducted to evaluate the influence of adapted or modified methods for their utility in supporting the active participation or engagement of people with dementia in research (Conway et al., 2023).

Projective Techniques

Strategies such as projective techniques have the potential to positively impact the engagement of people living with dementia in research through addressing communication challenges. Projective techniques are derived from the psychological theory of projection, which posits that people will perceive stimuli in the context of their own expectations and motives, and will credit others with their own attitudes, beliefs, and dispositions (Regan & Liaschenko, 2008). Projective techniques are based on the principle that when presented with an ambiguous situation, participants will project their unconscious desires and feelings onto their answers (Mesias & Escribano, 2018). This study will examine construction projective techniques, which involve the participant being asked to respond to a situation by making up a story or description (Mesias & Escribano, 2018).

Researchers have demonstrated the resilience of storytelling in people with dementia, highlighting the retained ability to express personal narratives even when coping with progressive cognitive impairment (Fels & Astell, 2011). Conversational approaches like storytelling or life-story methods have been shown to support people with dementia in expressing their experiences (Alsawy et al., 2017; McKeown, Ryan, Ingleton, & Clarke, 2015). Some people with dementia find it more accessible to reflect on past experiences from earlier in their lives than to interact in social situations (Fels & Astell, 2011). Elucidations of lived experiences of people with dementia through storytelling enables them to enhance their own dignity through the expression of personal narratives (Heggestad & Slettebo, 2015). For the purposes of this study, construction projective techniques with verbal prompts are referred to as “verbally-prompted storytelling techniques”.

Direct questioning in interviews may add social pressure to participants to answer in a socially acceptable manner, and for people with dementia, this can include feeling pressured to answer a question “correctly” (Heggestad & Slettebo, 2015). In research, the use of generic prompts has been demonstrated to successfully stimulate recollection of personal narratives (Astell et al., 2010). A gap remains, however, in terms of establishing the potential of verbally-prompted storytelling techniques in improving the engagement of people with dementia in research. As Heggestad and Slettebo (2015) state, people with dementia may have difficulty when questioned about the present, but when offered the opportunity to discuss their past and their life story, it can promote confidence and safety.

Research Questions

This study sought to address the following research questions:

1. How does the use of verbally-prompted storytelling techniques impact the data collected as compared to semi-structured interviewing techniques?
2. How does the use of verbally-prompted storytelling techniques with people with dementia impact research engagement?

Methods

Design

This qualitative study was part of a broader research project taking place between May 2022 to February 2023 that used a multimethod research design which involved (1) employing different interviewing techniques with people with dementia and (2) observing a video recording these interviews to assess engagement of participants (Tashakkori & Teddie, 2010). Although the project collected interview data across three interviewing techniques (traditional semi-structured, photo-prompted, and verbally-prompted techniques), this article focuses only on the interviews involving verbally-prompted storytelling techniques and traditional semi-structured interviewing techniques with direct questioning.

Sampling and Recruitment

People living with dementia were invited to participate in this study if they identified as a person living with dementia, resided in the community (i.e., not living in a long-term care or other institutional care setting) in Canada, and had access to a device with videoconferencing capability. People who could not provide informed consent and/or participate in virtual interviews due to significant communication challenges (e.g., hearing challenges, inability to converse comfortably in English) were excluded. Recruitment materials were distributed through community organizations in Southwestern Ontario, as well as via social media networks. A total of 17 people were recruited to the project. Four people were excluded at screening due to significant communication challenges (e.g., hearing challenges [n=2], comprehension [n=1], and/or vision challenges [n=1]), and 1 person died prior to the commencement of data collection. All data collection took place virtually due to the associated COVID-19 pandemic restrictions that were in place during the study.

The study was reviewed and received ethics clearance from the University of Waterloo (REB 44329). All participants were able to provide verbal consent to participate in this study. Information about the study and the consent form were provided to participants by email in advance of the initial study screening interview. At the time of the screening interview, the interviewer reviewed the study information and consent form with the participant, asking questions to confirm their eligibility and understanding of what was involved in participating in the study. If the participant understood the nature of participation, verbal consent was obtained and demographic information such as the participant’s age and gender were collected. At the time of the first interview, and for each subsequent interview, verbal consent was again obtained.

Interviewing Techniques

Interview guides employed for each type of interview were developed in parallel with adaptations made to suit the type of interviewing technique being used (e.g., direct questions for interviews with traditional semi-structured techniques, and storytelling prompts for interviews with verbally-prompted storytelling techniques). The interviewing techniques are described below.

Traditional semi-structured interviewing techniques with direct questioning: Participants were interviewed about their experiences with community supports and services using a standard semi-structured interviewing technique and process with direct questioning. The interview guide focused on exploring activities that the participant found challenging in their everyday life, their experience with support and/or service use (including during the COVID-19 pandemic), and what services they might look to utilize in the future if their needs were to change.

Verbally-prompted storytelling techniques: Participants were also interviewed using verbally-prompted storytelling techniques. In these interviews, participants were presented first with a general description of the character, *Norma*, who was said to be living with dementia. Participants were then guided through a series of prompts where the experiences of *Norma* were explored with relation to community supports and services. These techniques involved the use of prompts instead of direct questioning about the participant's experience. In these interviews, the interviewer presented a series of prompts verbally and the participant was asked to respond and create/complete a story of a person living with dementia who is receiving supports or services in the community.

Observational Scale

An observational scale, the Engagement of a Person with Dementia Scale (EPWDS) was modified and used to examine the engagement of participants in the interviews (Jones, Sung, & Moyle, 2018). The EPWDS has established content validity and psychometric properties for the assessment of behavioural and emotional expressions and responses of engagement by people with dementia across five areas: affective, visual, verbal, behavioural, and social engagement. The content validity of the EPWDS was supported by a panel of 15 experts in a Delphi study, resulting in an overall agreement of 81.4% (Jones, Sung, & Moyle, 2018). The internal consistency of the scale is reported to be $\alpha = 0.94$, and overall inter-rater reliability scores as measured by intraclass correlations (ICC) ranged from 0.75 to 0.95, $p < 0.001$.

Data Collection

As part of the larger project, participants took part in 3 interviews, 1 week apart, over a 3-week period. During the screening call, if participants agreed to participate in the study and provided consent, a demographic questionnaire was administered to collect descriptive information about those that participated (age, gender, race, marital status, etc.). Interviews were scheduled at a time preferred by the participant and took place at the same time and day of the week where possible. The order in which the techniques were employed and with each participant alternated according to a pre-defined and counter-balanced ordering to reduce ordering effects. To minimize carry over and memory effects, an interval of at least 1 week between interviews was maintained. In this paper, data from 2 interviews per participant (one with traditional, semi-structured interviewing techniques and one with verbally-prompted storytelling techniques) are examined.

Data Analysis

Two analyses were conducted to address the research questions. Interviews were audio and video recorded. Audio recordings were transcribed verbatim, cleaned, and anonymized prior to analysis. The transcripts were analyzed using qualitative content analysis. Content analysis is an analytical approach typically used in qualitative descriptive studies (Miles et al., 2014). An inductive analysis was conducted with 2 coders, the first author and a trained research assistant, following an iterative process of data familiarization and generation of initial impressions, thoughts, and analysis, line-by-line coding, discussion with the broader research team, and meaningful categorization of ideas and codes (Hsieh & Shannon, 2005). Following the initial content analysis of the data sets from each type of interview, identified categories were compared across interview types to identify similarities and differences in responses. The identified categories of similarities and differences were then examined at the participant level across data sets inductively to assess fit and applicability. The analysis was reviewed by all authors through investigator triangulation to confirm categorical relevancy, organization, and interpretation. NVivo 12 (QSR International Pty Ltd, 2018) was used to support data coding and analysis. Reflexivity journals were also kept by the interviewer and reviewed throughout the analysis to support with immersion and gaining a sense of the whole of the dataset.

Video recordings were used to facilitate assessment of the engagement of participants in the interviews. The engagement of participants in the interviews was assessed using an observational scale (EPWDS) (Jones, Sung, & Moyle, 2018). Modifications to the EPWDS for the present study included the omittance of 1 subscale (behavioural engagement), as there were no physical materials associated with this study. The EPWDS was applied to video recordings of interviews, which marks a deviation from the original application to in-person observations. This modification was necessary due to the restrictions on in-person research that were in place during the study period. Each video recording was scored based on the coder's interpretation of the participant's level of engagement in the interview. Both the first author and the research assistant reviewed the coding framework and criteria in-depth prior to conducting the coding. The first author and the research assistant first coded a sample of videos independently, and then compared scores, discussing any substantial differences in coding. Once consensus was reached, the research assistant coded the remaining videos independently. The total engagement score across all included subscales can range from 10 to 40, with a higher total score indicating a higher level of positive engagement exhibited by the participant. Conversely, the lower the total score, the higher the level of disengagement or negative engagement exhibited by the person with dementia. To evaluate the significance of this difference in engagement scores, a paired t-test was conducted to compare the effect of interview type on participant's overall engagement score.

Methods to Enhance Rigour

Several strategies were employed to enhance the rigour of the study, including the use of researcher reflexivity journaling and triangulation. Following each interview, the interviewer completed a reflexivity journal detailing any methodological decisions and the reasons for them, the logistics of the interview, and a reflection upon what happened during the interview. Throughout the data analysis, the journals were reviewed and noted to support the analysts in staying "close to the data" (Lincoln & Guba, 1985). Further, all researchers involved in the data analysis engaged in regular peer debriefing. To ensure credibility of the findings, the interviewing process and techniques were reviewed by all authors. As well, all involved in data collection and analysis were trained to ensure that they had the required knowledge and skills to perform their roles – including conducting interviews, qualitative content analysis, and analysis of video recordings. Dependability of the findings was maintained through the development of thorough and detailed descriptions of study methods and procedures and detailed record keeping. Reflexivity and triangulation activities supported the confirmability of the findings – the lead author maintained reflexivity journals, and methodological, data source, and investigator triangulation took place through the multiple methods of data collection and analysis, multiple data sources, and multiple observers and coders. Transferability of the findings was supported by the method and results descriptions, and further evidenced by the depth and quality of the data presented. With respect to confirmability, quotations are used to support the categorization of the analysis.

Findings

Interviews were conducted with 12 people living with dementia. The average age of participants was 70.8 years, ranging from 58 to 92 years. Seven participants identified as women and 5 identified as men. Seven participants lived with their spouse or family, while 5 participants lived alone. All participants identified as white. All participants self-identified as having been diagnosed with dementia and considered themselves to be in early to middle stages of their dementia journey.

Content Analysis: Similarities and Differences Across Interview Types

The initial qualitative content analysis identified the following categories: (1) lack of and barriers to accessing supports and services; (2) experiences of living with dementia: coping, challenges, and ability; and (3) the importance of social connections and self-care. The second step in the analysis resulted in the identification of several similarities and differences between the two interviewing techniques (see Table 4 for summary). Specifically, compared with traditional, semi-structured interviewing techniques, verbally-prompted storytelling techniques: (1) supported deeper and broader reflection of impact of one’s own experiences and beyond, (2) facilitated richer conversations when participants had difficulty recalling a personal example, and (3) enabled richer conversations about emotional topics. Excerpts from interviews are presented in the following sections to demonstrate areas of similarity and difference across interview types. Responses from interviews with semi-structured interviewing techniques with direct questioning are denoted with a ‘d’ and responses from interviews with verbally-prompted storytelling techniques are denoted with a ‘v’.

Table 4. Summary of similarities and differences identified from a cross-comparison of interview types

Impact identified	Summary
Verbally-prompted storytelling techniques supported deeper and broader reflection of impact of one’s own experiences and beyond	In interviews with semi-structured techniques where direct questioning was used, responses tended to focus on personal experiences, and were often brief and direct. In contrast, when interviewed with verbally-prompted storytelling techniques, responses involved more reflective dialogue, where participants extended on the experiences of the character in the story to explore the impact of their own experiences and that of others the participants identified (i.e., family and friends).
Verbally-prompted storytelling techniques facilitated richer conversations when participants had difficulty recalling a personal example.	In interviews with semi-structured techniques with direct questioning, there were often instances where the participant either couldn’t recall a personal example or had difficulty identifying a personal connection with the question (e.g., when asked about what supports or services they might access if their needs were to change in the future). However, when interviewed with verbally-prompted storytelling techniques, the use of the character’s narrative seemed to allow for scaffolding within the interview to prompt the participant to explore their own experiences, as well as consider their dementia journey more holistically (e.g., think to the future) through exploring the hypothetical experiences of the character in the story.
Verbally-prompted storytelling techniques enabled richer conversations about emotional topics.	While participants did occasionally share about personal challenges and difficulties dealing with medical professionals in interviews with semi-structured techniques, conversations tended to be much richer in terms of connections to emotional topics when interviewed with verbally-prompted storytelling techniques. The construction of the story narrative seemed to serve to share their own experiences with challenges, how they felt or how their difficulties have impacted them. Further, the exploration of more sensitive topics, such as the participants experience of isolation and stigma, was only brought forward through the construction of the character’s story in interviews with verbally-prompted storytelling techniques.

Verbally-prompted storytelling techniques supported deeper and broader reflection of impact of one’s own experiences and beyond

When interviewed with verbally-prompted storytelling techniques, participants tended to discuss the impact of the hypothetical experiences of the character, *Norma*, and extend to their own experiences, as well as other friends or family. This contrasts with responses in interviews where semi-structured direct questioning techniques were used, where participants often responded with brief or direct answers to questions with a list of impacts rather than a reflection on how their feelings or perspectives changed as a result of those impacts. For example, when asked about challenges in their day-to-day life in an interview with semi-structured techniques, one participant shared,

> “I find cooking very challenging. My husband does most of the cooking. But I keep trying. But it's difficult. Because I don't have a driver's license, my independence is somewhat curtailed. And that has sort of changed my personal style of living. And I can't seem to get my day plan completed in a day. It seems as though I have enough energy for the morning hours but the afternoon hours, I don't have much energy left to do anything of any consequence.” P1d

Through the construction of the character’s story in the interview where verbally-prompted storytelling techniques were leveraged, the participants also reflected on their own experiences and challenges. Through exploring the story of Norma, the same participant reflected on the diagnosis experience when asked about the support needs of the character:

> “When they first get their diagnosis, I think most people sort of cocoon themselves for a period of time, and I think that's a normal behavior, because of the severity of what they're going through. But once something breaks through that cocoon, and says to the person with dementia, ‘you can live well, you have a right to live well, you have a responsibility to live well.’ Then, I believe with all my heart, that people need to be told that. And it's as necessary as eating to live well, you need to have things outside merely taking a breath and having enough food to keep you alive. That social network is just as vital.” P1v

Others discussed a sense of feeling more disorganized than they used to or getting distracted very easily leading to challenges with completing daily tasks in traditional semi-structured interviews. Some participants reflected on challenges with their memory, especially for things like remembering to take medications or attend appointments. As one participant stated,

> "Well, I try every day, you know, I get up and do everything like get dressed…" P4d

Exploring the experiences of the character allowed for personal reflection for some participants, allowing for a deeper connection to the concepts being discussed. This is demonstrated by the same participant response in the verbally-prompted story telling technique when the participant asked what challenges the character may face in their day-to-day life, where participant shared,

> "I guess she had to do just about everything that I was doing, that I had been doing. And I've been doing this now for almost a year. And, and I don't know if I'm getting better or worse, but I'm trying hard. And I'm doing pretty good." P4v

When asked about their personal experiences with dementia and any day-to-day challenges faced in traditional semi-structured interviews, participants tended to give brief and direct responses. This is demonstrated through a response from one participant who shared,

> "Doing up watches [is challenging] because I can't use my right hand because of my stroke. So, that is weird for me. And when I go outside, I'm kind of wobbly and I have to use a walker. I find that kind of frustrating…" P8d

Personal connections to the character's experience of trying to live well with dementia and engage in self-care were prominent in interviews where verbally-prompted storytelling techniques were used. The same participant as above shared their own experience of triumph through perseverance and committing to living well. This participant, who identified as a woman, shared,

> "Maybe with her husband has thought that might be a good thing for her to keep her active to do exercises, and move around, not be so dependent but become more independent…Well, I know for me, at any rate, is the ability…her husband could have told her 'Oh, it's good. It will be great; you can do it'. For me, it's arts and crafts. And maybe I thought I couldn't do it. But then I saw that with help…you realize 'Hey, I can do this'…Just like yes, I can do it. I can be independent. Maybe she now wants to do her arts

> and crafts at home. And she can now get the stuff and do it at home and it doesn't have to be great, it doesn't have to sell for a million dollars at the Louvre. It can be just as beautiful because you made it. And I think it'll make her more likely feel better about herself." P8v

Verbally-prompted storytelling techniques facilitated richer conversations when participants had difficulty recalling a personal example.

When participants were interviewed with semi-structured interviewing techniques, they often reported that they didn't experience challenges or difficulties living with dementia, and seemed to have difficulty connecting to the topic of conversation if they couldn't recall a personal example of a challenge or experience when asked directly. In turn, participants often discussed their own experiences and abilities in semi-structured interviews as being less difficult or challenging than others. Participants also discussed how they felt they fared better than most through the isolation during the pandemic when interviewed with semi-structured techniques. One participant reflected this notion, stating,

> "Fortunately for me, I'm doing well, and I have everything I need… I'm pretty self reliant." P3d

Whereas in interviews with verbally-prompted storytelling techniques, the same participant, when asked about what challenges they thought the character might experience in their day-to-day life as a person living with dementia, shared:

> "Following a routine. If she's anything like me, housecleaning, remembering what she needs to do. She probably makes up a list, but she forgets where the list is, which I've done. Remembering to eat. That's about it. As far as food, I guess Norma and her husband would have trouble shopping." P3v

When interviewed with traditional semi-structured techniques, participants often responded in brief, as demonstrated by one participant who shared the following when asked about challenges they experience in their day-to-day life:

> "Remembering things, short term." P9d

In contrast, this participant connected to their own experience through exploring the characters storyline when interviewed with verbally-prompted storytelling, sharing,

> “I know when I was in her place, I went in looking for a cure. Not a way to deal with it.” P9v

The following excerpts emphasize the direct nature of responses in interviews with semi-structured techniques and showcase the often-brief responses shared by participants when asked directly about their experiences. As one participant shared,

> “I'd have to say no, I personally am not having the kind of problems that I see a lot of my friends who have a diagnosis of dementia are having.” P2d

Another stated,

> “So far, I haven't really had a need. Well, I only attended the Alzheimer's group. And that was for over a year. But other than that, I haven't really had a need to use anything.” P14d

While participants when interviewed with semi-structured interviewing techniques often didn’t report experiencing severe distress about challenges in their day-to-day life, and when interviewed with verbally-prompted storytelling techniques, participants tended to share many examples of challenges the character might face, followed by linkages to their own experiences by stating “if she’s anything like me…” or “I know I do that.” For example, one participant reflected,

> “She feels as though her independence has been greatly curtailed…it's when you're doing stuff that you've done all your life and for some reason, there's a disconnect in the brain as to how to use that thing or how to avoid situations like that type of thing. Like I'm really just down to very basic things that I do on a daily basis because you know, all of the stuff I was busy with in the past, it just is too much for me now.” P1v

The construction of the story narrative also often served as a way for participants to share their experiences with challenges – particularly how they felt or how their difficulties have impacted them. For example, one participant shared,

> “It depends if she has a car, and so on. And, like, I lost my license so that's a drag I don't know if she's got a car or whatever. And, and when, sometimes, when she goes out, she, she sees her friends and someone, and she starts to stutter. And, and it drives her nuts herself because she knows what it's all about. I don't know anything else like it…Oh yeah, for sure, like you know, when people, when I get stuck like that. I'm sort of stuttering a bit. And it's just, I just get redder in the face like you know because I'm just so awkward about the whole thing.” P4v

The emotional connection to experiencing challenges living with dementia was especially salient during interviews where verbally-prompted storytelling techniques were used. As one participant reflected,

> “If the person asking questions and stuff if they use a word that she may not know anymore, she might have used to, but may not remember. She'll feel very nervous and awkward about asking what it means. She'll say 'oh, yeah, yep'. I know I do that.” P8v

Verbally-prompted storytelling techniques enabled richer conversations about emotional topics. When interviewed with traditional semi-structured interviewing techniques with direct questioning, participants did not often share their experiences with challenging situations and emotional topics. It was observed that when interviewed with verbally-prompted storytelling techniques, participants tended to engage in much richer discussions of emotional topics like stigma, isolation, and depression. Thinking about the experiences the characters in the story gave an opening for participants to reflect on their own experiences. As discussed by one participant,

> “There was absolutely nothing there for someone like me…it [day program] just didn't appeal to me one tiny little bit…They're singing in the background, ‘*the wheels on the bus go round’*… And I've been a musician all my life, right. And I've kept up with some of the modern music and stuff like that…the wheels on the bus are not going to cut it for me.” P12v

Discussions of emotional or sensitive topics were infrequent in interviews with traditional semi-structured techniques. As such, direct contrasting excerpts between interview types were limited, and excerpts from interviews verbally-prompted storytelling techniques are presented in contrast with the absence of a related example from interviews with traditional semi-structured techniques as these instances were so limited. When participants did share their experiences with emotional or sensitive topics in interviews with traditional semi-structured techniques, albeit infrequently, it was observed that participants tended to share examples of experiences where they had felt they received inadequate care or instances where they were frustrated with their interactions with others. For example, one participant discussed their interactions with their geriatrician, stating,

> "My geriatric or dementia doctor that's here, her and I don't get along, because she talks over me, my doctor, my dementia doctor talks over me, right, and will talk to my daughter. She discounts a lot of the things that are going on with me." P13d

Other participants echoed this experience, sharing,

> "What I'm not finding helpful is the medical community. I got referred from my doctor to the gerontologist, it was hopeless. I will go no further other than to say hopeless. She was neither understanding nor helpful. And that was her specialty. Ouch." P16d

Participants reflected on the role of stigma much more deeply through exploring the character's experience of dementia in interviews with verbally-prompted storytelling. One participant, as quoted below, extrapolated this concept to their own experience and reflected on the experience of others, stating,

> "Be patient. You're not alone. Don't be afraid to open up with your close friends and family. Let them know because that's something I didn't do when I when I first had problems. But don't be afraid. Dementia now is where cancer was 30 years ago. We couldn't say the 'C' word. You were embarrassed to say you got cancer. Now, dementia is the same way. The stigma. And it's important you feel comfortable." P3v

Further, when interviewed with verbally-prompted storytelling techniques, participants discussed the impacts of emotional topics such as isolation during the pandemic – both for the characters in the story being constructed, and themselves. One participant shared in detail what she thought the characters might have been going through during the pandemic, illustrating the depth of connection to the storyline, stating,

> “Norma was absolutely devastated by the lack of support. After she had spent some period of time having that support, particularly the social network. She fell through some cracks; she has ended up in long-term care in a very desperate situation. She's become nonverbal because she lost that support, which has devastated her husband because he feels as though he no longer is the person that was beside her…” P1v

Isolation was a difficult experience for many participants. While constructing Norma’s story, they shared pieces of their own experience, especially around receiving a diagnosis and trying to access needed supports and services during the pandemic. One participant reported just how difficult it was to live through the pandemic, stating,

> “My diagnosis was really at the beginning of COVID. I went through all that…that in itself is difficult, because, you know, you're not out of the house. And her partner probably said, no, no, I'll go shopping on my own, or I'll pick up whatever you need. And so, like the isolation of all of that COVID goes down very, a very steep slope…goes quickly.” P13v

Observational Analysis: Participant Engagement

A total of 24 video recordings of each interview (2 per participant) were analyzed. Participants’ engagement scores (Table 5) were not statistically significant different between interview types, F (1, 11) = 1.91, p = 0.19.

Table 5. Descriptive Statistics of Overall Engagement Score

Interview Type	Mean	Standard Deviation	N
Regular interviewing	33.17	5.11	12
Verbal projective techniques	35.75	2.66	12

Discussion

This study examined how the use of verbally-prompted storytelling techniques impacted the data collected among people living with dementia compared to traditional semi-structured interviewing techniques with direct questioning. This study also sought to explore how the use of verbally-prompted storytelling techniques impacted the engagement of people living with dementia using a validated quantitative assessment. Our results suggest that engagement was similar in both interview approaches, but that verbally-prompted storytelling techniques resulted in deeper and richer reflections on living well with dementia. A recent study concluded that while researchers often make adaptations and modifications to data collection approaches to include people with dementia in research, there has been little evaluation of the impact of such adapted or modified data collection techniques on the engagement of people with dementia (Conway et al. 2023). The present study addresses this gap by engaging in a comprehensive analysis of the impact of a data collection technique for improving the content of interview responses and engagement of people with dementia in research.

A key observation resulting from the content analysis centers around the communication of emotions in interviews with verbally-prompted storytelling techniques. The use of the character's narrative as a way for participants to scaffold and explore their own experiences seemed to offer the opportunity to engage in deep and emotional reflection of their personal circumstances. This is important as people with dementia, as well as research participants more generally, often experience difficulties sharing about emotional experiences (Steeman et al., 2007; Parker et al., 2020; Bondi, 2016). Beyond the research setting, these techniques may hold additional value for engaging people living with dementia in conversations with care partners and beyond. As Mitchell (2011) explores, in asking people to share stories through qualitative interviews, the emotional potential of qualitative interviewing may come to be realized by both researcher and participant. Indeed, the discussion of emotions in interviews holds significance in learning about the lived experiences of those being interviewed (Mitchell, 2011). This finding is aligned with the observations of Phillipson et al. (2023), who report that the projective techniques leveraged in their study seemed to prompt emotional reflections from participants on their own experiences. The techniques may provide value trough supporting people with dementia in conversations with care partners, researchers, and beyond about challenging or emotional topics, facilitating outcomes that are reflective of and more aligned with the needs, desires, and abilities of people living with dementia (Parker et al., 2007).

This study makes an important contribution to the study of supportive research methods for people living with dementia as it provides an in-depth and detailed account of interviews conducted in two different modalities – contrasting traditional semi-structured interviews with a more novel projective technique. Indeed, researchers have identified the need for the inclusion of people living with dementia as active participants in research (Hellstrom et al., 2007; McKeown et al., 2010. Research by Phillipson et al. (2023) also supports the utility of projective techniques for research engaging with people with dementia in virtual settings. It is important to note that while previous studies have observed positive influences of such techniques, such impacts were in isolation and not contrasted with traditional semi-structured interviewing. This study further enhances our knowledge of storytelling techniques in research with people living with dementia through the exploration of how interviews with verbally-prompted storytelling techniques are different to those conducted with traditional semi-structured techniques with direct questioning.

While storytelling techniques have been limitedly applied, and not previously evaluated to our knowledge, in research with people with dementia - their use in other research applications is more robust. The use of storytelling techniques in research with those living with cognitive, intellectual, and physical disabilities is often observed to have positive influence on the active participation of research participants, especially when techniques involve creative expression (Musicka-Williams, & Cook, 2022; Teachman & Gibson, 2013; Williams et al., 2022). For example, Musicka-Williams and Cook (2022) examined the impact of storytelling within a broader drama therapy technique with participants living with cognitive, intellectual, and/or physical disabilities. They report that participants displayed an increased level of engagement in interviews with the use of such techniques - specifically, the authors report that participants connected more deeply to their own narratives through the use of storytelling, and this increased their “representation of voice in the research” (pg. 18) as they were more engaged in the interview process than they might have been without the use of such techniques (Musicka-Williams, & Cook, 2022). Aligned with the results of the present study, work by Musicka-Williams and Cook (2022) reports that participants communicated about their experiences and challenging emotions (such as grief) in interviews where storytelling techniques were used.

Indeed, creative approaches, such as storytelling and arts-based methods, to research have been identified as a mechanism to improve the accessibility of research for people living with disabilities through improving engagement - Musicka-Williams and Cook (2022) suggest that ensuring participants living with disabilities are active participants in research can serve to make the research process more inclusive, accessible, and empowering. As well, in the broader field of disability studies, considerable effort has been undertaken to improve the accessibility of research to support the participation of people living with disabilities through enhancing their engagement in research (Schwartz et al., 2020; Rios et al., 2016; Hall, 2013; Gilbert, 2004). However, while previous studies have anecdotally observed positive impacts leveraging similar techniques in other populations, the present study is the first, to our knowledge, to evaluate such impacts for participants living with dementia (Conway et al., 2023). For example, Hyden et al. (2013) observed that the use of storytelling with people living with dementia may have supported participants to overcome challenges with cognitive functions like remembering and communication. Holm et al. (2005) highlight that storytelling was observed to have supported conversations in a study with people living with dementia, and further, that storytelling engaged participants to participate and facilitated recall and associations through collaborative dialogue. Thus, results of the present study bring needed evidence to support our understanding of the use of such techniques in populations living with dementia through contrasting responses between traditional semi-structured interviews with direct questioning and verbally-prompted storytelling techniques.

While differences in depth and richness of responses were identified through the content analysis, results from the observational measurement of engagement through the application of the Engagement of a Person with Dementia Scale (EPWDS) indicate that engagement scores were not statistically different between interview types. While overall, interviews with verbally-prompted storytelling techniques were described as having a high level (average of 35.75 out of a possible score of 40) of observed engagement, interviews with traditional semi-structured techniques also had relatively high engagement scores (33.17). It is possible that the analysis was underpowered due to the small sample size, and it is also possible that verbally-prompted storytelling techniques may not impact elements of observed engagement more or less than traditional semi-structured interviewing.

Strengths and Limitations

While this study presents an in-depth account of the application of verbally-prompted storytelling techniques in interviews with people with dementia, the transferability of the findings to other contexts must still be evaluated considering the present study's sample size limitations, as well as the geography of the study which may not capture cultural differences. Recruitment for this study was impacted by the COVID-19 pandemic, and as such, recruitment efforts were shifted mostly online, which could have impacted the range of people with dementia recruited as participants. While this research aimed to recruit as diverse of a sample as possible, it is possible that the nature of the inclusion criteria and method of interviewing (online) may have inadvertently excluded those in middle to late stages of their dementia journey, as well as those without access to the needed hardware required to participate (i.e., computer/tablet, Internet). Efforts were made to support the participation of people at various stages of their dementia journey, such as including adaptations to recruitment methods and materials, however, recruitment of a diverse group of participants was challenging. As well, the study was open to individuals Canada-wide who met the inclusion criteria. Results from the content analysis support that verbally-prompted storytelling techniques did support the active participation and engagement of participants. In contrast, results from the observational analysis indicate that there was not a statistically significant difference in engagement scores, and results should be interpreted considering the limitations discussed herein.

This study also maintained key elements of the verbally-prompted storytelling technique stable across interviews. This allowed for a comprehensive analysis of responses both across interview types and participants. However, responses in interviews with verbally-prompted storytelling techniques may also have been impacted by the use of a consistent character which was not adapted to mirror the participant's gender or other characteristics. Variations in responses through different modalities of interviewing, as reported in this study, are important to consider when designing research to capture the experiences of people living with dementia. For example, it is important to consider the interviewing modality with relation to the research questions and desired outcomes. Studies seeking to explore the experiences of people with dementia deeply may consider more creative approaches such as verbally-prompted storytelling techniques to support the engagement of people with dementia in interviews. Future research should seek to examine the extent to which varying the story character to align more closely with the experiences of the participant impacts the data produced.

Conclusion

Improving engagement in research for people with dementia can improve the collection of information about the experiences, needs, and preferences of people with dementia, as well as the uptake of this information in policy and practice in a manner that promotes the reflection of this information in supports and services. This study explored the utility and accessibility of a projective interviewing technique, verbally-prompted storytelling, to provide a means of increasing and enhancing participation in research of persons with dementia in virtual research. This research contributes to the understanding of research engagement for people with dementia, as well as providing an opportunity for this population to be involved in research that shapes future inquiry and practice. As the World Health Organization (2017) and Dementia Strategy for Canada (2019) highlight, increasing dementia research is a national priority. The present research provides an opportunity to consider how projective techniques can better facilitate the participation of people with dementia, in turn creating more opportunities to be involved in research that informs supports and services. Future research should consider extending the concepts of study in this research to different contexts and topics. Further, researchers should consider the types and mix of techniques used in interviews, such as bringing in objects and photographs to further stimulate and support conversation in research with people with dementia.

Chapter 5: "If I were in his shoes": Photo-prompted storytelling in interviews with people living with dementia

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Overview

Introduction: Supportive approaches to engaging with people living with dementia in research are needed to ensure the accessibility of research methods and the incorporation of their experiences. To examine the utility of a novel research method for supporting the engagement of people with dementia in qualitative research, this study sought to explore how the use of a photo-prompted storytelling technique impacted both the data collected as well as the engagement of people living with dementia.

Methods: This paper presents findings from a larger multimethod research project which employed different interviewing techniques with people with dementia and video recorded these interviews for the purposes of observational analysis. In the present study, data from interviews with traditional semi-structured interviews with direct questioning are compared and contrasted with data from interviews where a photo-prompted storytelling technique through qualitative content analysis. Video recordings of interviews were used to facilitate observation of the engagement of participants in the interviews. An observational scale, the Engagement of a Person with Dementia Scale (EPWDS) was modified and used to examine the engagement of participants in the interviews.

Results: A total of 12 people living with dementia participated in this study and took part in a series of interviews with each interviewing technique. Qualitative content analysis resulted in the identification of several key areas of impact. When interviewed with the photo-prompted storytelling technique, participants tended to engage in reflection of their own experiences and beyond, and the photo-prompted storytelling technique also supported challenges with direct questioning and recall. It was also identified that there were content differences related to the photograph prompts. A repeated measures analysis of variance was performed to examine differences in observed engagement scores on the EPWDS and there was a statistically significant difference in engagement scores when participants were interviewed using semi-structured techniques or photo-prompted storytelling techniques.

Conclusion: Findings from this study reinforce the utility of photo-prompted storytelling techniques in supporting the accessibility of qualitative interviews with people living with dementia. Results support that these techniques may impact the types of data collected through interviews, as well as the engagement of people with dementia in interviews. Further research is needed to determine the impact of photograph prompts on the data produced in interviews, as well as the application of photo-prompted storytelling techniques in a broader range of people living with dementia.

Keywords: dementia, projective techniques, accessibility, inclusion

Introduction

The experience of dementia is individual and unique. As such, including the diverse voices of people living with dementia in research is important to gain a better understanding of their perspectives. While the experience of dementia may include some shared features across individuals, such as challenges with memory, hearing, vision, and communication, the extent to which each person is impacted varies. As such, methods used to facilitate the involvement of people living with dementia in research must also be varied and adaptable to individual needs.

People living with dementia have been routinely excluded from research and activities in broader society due to assumptions about abilities, stigma, and discrimination (Alsawy et al., 2017; Cottrell & Schultz, 1993; Tyrrell, Genin, & Myslinski, 2006; Swaffer, 2014). Actively involving people with dementia in research means acknowledging that they are the experts on their own lives (Clarke et al., 2018). This type of knowledge is vastly different than the empirical types of knowledge that are utilized by professionals in dementia care or derived through theory (Clarke et al., 2018). Understanding the lived experiences, preferences, and abilities of persons living with dementia is key to the development of adequate and relevant supports and services. However, the nature of dementia as a disease means that, for many, verbal communication of one's experiences can be challenging. Qualitative methods that support communication and accommodate an individual's needs can help to facilitate improved engagement in research activities.

The inclusion of people living with dementia in research is becoming more prominent in social and health research that seeks to explore their lived experiences and perspectives (Alsawy et al., 2017; Benbow & Kingston, 2016). Qualitative research is often thought to be best suited to investigations of lived experiences, of dementia as well as other conditions (Aldridge, 2014). However, qualitative research often requires participants to recall information about their experiences and express these experiences, most often in a verbal interview, which can be quite challenging for people with dementia (Phillipson & Hammond, 2018). Persons with dementia may also experience challenges with reporting and comprehension due to cognitive impairments or challenges with memory, vision, and hearing (Phillipson

& Hammond, 2018). In a review by Alsawy et. Al. (2017), it was identified that effective communication for older adults with dementia involves several factors, including not speaking for the person with dementia and adapting to changing conversational abilities (Alsawy et. Al., 2017). Purves (2009) highlights that it can be problematic when proxies speak for a person with dementia, as the person may be unable to communicate their agreement or disagreement with what is being communicated. Optimizing research for persons with dementia can include frequent consultations to ensure that the conversations are supportive of the person with dementia's needs and views and allowing time to express disagreement if the understanding of their needs is incorrect (Alsawy et. al., 2017). Facilitating a positive relationship when communicating can also support the interpretation of nonverbal expressions (Alsawy et. al., 2017). Further, video-recording conversations can help in interpreting nonverbal expressions that may have been missed in the initial interaction, such as body movements or gesturing (Alsawy et. al., 2017).

Many researchers utilize accessibility modifications, novel or creative methods, or other adaptations to support the inclusion of people living with dementia in research projects. However, the extent to which adapted and modified methods impact the engagement of people with dementia in research, as well as data collected, is relatively unknown. Garnering a comprehensive understanding of which methods are supportive of the inclusion and engagement of people with dementia in research is necessary to inform selection of research methodology, ensure high quality evidence is produced, and maximizing meaningful engagement during research participation (Phillipson & Hammond, 2018).

Several strategies for supporting participation have been identified, including using short sentences and closed-ended questions – as well as additional supports such as introducing objects, like photographs, that have meaning or value to the individual, changes to physical space such as lighting, and changes to social demands, including prompts and encouragement (The Alzheimer Society, 2019; Trahan, Kuo, Carlson, & Gitlin, 2014). When persons with dementia have further changes to their hearing, vision, and memory due to age, additional strategies may be necessary to optimize participation. Alternative means of supporting communication such as scrapbooks, biographical books, and reminiscence boxes can be helpful for older adults with dementia who have additional age-related changes to their vision, hearing, and memory (Alsawy et. al., 2017). Approaches to conversations in the form of storytelling are often helpful in promoting the expression of one's experiences (Alsawy et. al., 2017). As Phillipson and Hammond (2018) highlight, innovative and creative methods in dementia research provide insight into the abilities of persons living with dementia, emphasizing engagement in research projects where they can share their experiences. Further, conversational approaches like storytelling or life-story methods have been shown to support persons with dementia in expressing their experiences (Alsawy et al., 2017; McKeown, Ryan, Ingleton, & Clarke, 2015).

This study sought to examine a combination of visual (photograph) prompting and storytelling strategies through the use of projective interviewing techniques. Projective techniques are based on the principle that, when presented with an ambiguous situation, participants will project their unconscious desires and feelings onto their answers (Mesias & Escribano, 2018). As a way to understand why people act in the ways they do, projective techniques are thought to uncover a person's cognitive frames – implicit knowledge structures of assumptions, attitudes, and beliefs developed over the course of a lifetime (Regan & Liaschenko, 2008). In this study, the specific projective technique utilized was a construction technique – where the participant is asked to respond to a situation by creating a story or description (Mesias & Escribano, 2018). A classic example of construction techniques is the Thematic Apperception Test (Murray, 1943) which involves a set of ambiguous pictures which are shown to the participant to elicit a storyline, and the participant's response is thought to be representative of their own attitudes or feelings (Mesias & Escribano, 2018). In this study, this involved a set of photos alongside ambiguous prompts.

Construction projective techniques, such as storytelling, alongside photograph prompts, can be employed to further support the participation of people with dementia in research by connecting relevant pictures to a discussion. Visual methods that incorporate images can help to promote communication when there are deficits in expression abilities (Phillipson & Hammond, 2018). The use of visual methods in qualitative data collection offer the opportunity to include groups that may typically be considered vulnerable by providing more accessible opportunities to participate.

Purpose

The purpose of this study is to examine the use of visual construction projective techniques (for the purposes of this paper, referred to as photo-prompted storytelling) in dementia research. Specifically, this study seeks to examine whether photo-prompted storytelling techniques impact the data collected through improving research engagement for the purposes of understanding the lived experiences of older adults living with dementia as it relates to supports and services in community settings. The examination of photo-prompted storytelling in this study centers on establishing whether these techniques can increase engagement for people with dementia compared to traditional semi-structured interviewing with direct questioning, and how the use of such techniques may impact the data collected.

Research Questions

This study sought to address the following research questions:

1. How does the use of photo-prompted storytelling techniques impact the data collected as compared to semi-structured interviewing techniques in interviews with people with dementia?
2. Does the use of photo-prompted storytelling techniques with people with dementia impact research engagement?

Methods

Design

This qualitative study was part of a broader research project that took place from May 2022 to February 2023, and which used a multimethod research design (Tashakkori & Teddie, 2010) that involved: 1) employing different interviewing techniques with people with dementia; and 2) video recording these interviews with different interviewing techniques for the purposes of observational analysis. Multimethod research is characterised by the coexistence of methodologies – in this case, both interview and observational (Anguera et al. 2014). The broader research project collected data using three different interviewing techniques: 1) traditional, semi-structured interviewing techniques, 2) verbally-prompted storytelling, and 3) photo-prompted storytelling techniques where photographs were used alongside verbal prompts. The present study focuses only on data from interviews that used semi-structured interviewing techniques and photo-prompted storytelling techniques.

Sampling and Recruitment

Participants were invited to participate in this study if they identified as a person living with dementia who resided in the community (i.e., not living in a long-term care or other institutional care setting) in Canada and had access to a device with videoconferencing capability. Participants who could not provide informed consent and/or participate in virtual interviews due to significant communication challenges (e.g., hearing challenges, inability to converse comfortably in English) were excluded. Recruitment materials were distributed through community organizations in Southwestern Ontario, as well as via social media networks. A total of 17 participants were recruited as part of the project. Four participants were excluded at screening due to significant communication challenges (e.g., hearing challenges and/or vision challenges), and 1 participant died prior to the commencement of the interview phase of the study.

The study was reviewed and received ethics clearance from the University of Waterloo (REB 44329). All data collection took place virtually due to the COVID-19 pandemic physical distancing requirements. Information about the study and the consent form were provided to participants by email in advance of the initial study screening interview. At the time of the screening interview, the interviewer reviewed the study information and consent form with the participant, asking questions to confirm their eligibility and understanding of what was involved in participating in the study. If the participant understood the nature of participation, verbal consent was obtained and demographic information such as the participant's age and gender were collected. At the time of the first interview, and for each subsequent interview, verbal consent was again obtained. All participants were able to provide verbal consent to participate in this study.

Interviewing Techniques

In the present study, data from 2 types of interviews for each participant were examined: traditional semi-structured interviews and photo-prompted storytelling interviews. The interview guides for each interviewing technique (traditional semi-structured and photo-prompted storytelling) were developed to be near-identical, varying only in the delivery of the questions. The interview guides were developed in parallel for each type of interview – for example, direct questions in the traditional semi-structured interview were translated into prompts for the photo-prompted storytelling interviews. The two interviewing techniques are described below.

1. Traditional semi-structured interviewing techniques with direct questioning. Participants were interviewed about their experiences with community supports and services using a standard semi-structured interviewing technique and process. The interview was guided by a set of questions that explored tasks and activities in day-to-day life, their current and past support and/or service use, their experience accessing supports and/or services during the COVID-19 pandemic, as well as what services they might seek to access should their needs change in the future. This interviewing technique involved direct questioning.
2. Photo-prompted storytelling techniques. Participants were interviewed utilizing photo-prompted storytelling techniques, which involved the interviewer reading a series of prompts for the participant to respond to with the goal of having the participant create a story of the person living with dementia in the photos who is receiving supports or services in the community. In the story, participants were initially presented with a general description of the character, *Frank*, who was said to be living with dementia. As the interview progressed, participants were guided through a series of photographs and prompts where the experiences of *Frank* were explored in relation to community supports and services.

Data Collection Procedure

Upon expression of interest in the study, potential participants were contacted to schedule a time at their convenience to complete a screening interview and demographic questionnaire. During the screening interview, the purpose of the study was explained and informed consent was sought. All participants in this study were able to provide informed consent as determined through the use of the University of California San Diego Assessing Consent to Participate in Research protocol; however, a proxy-consent process was also prepared in the event that a participant could not provide informed consent. Once the participant consented to participate in the study, the 3 interviews were scheduled and a demographic questionnaire (age, sex, marital and living status, and racial, ethnic, or cultural origins) was completed. In total, as part of the larger project, participants took part in 3 interviews, 1 week apart, over a 3-week period. Interviews were scheduled at a time preferred by the participant and took place at the same time and day of the week where possible. All participants participated in both interviews, and all participants were shown the same photographs in interviews with photo-prompted storytelling techniques (see Appendix 8). Questions in the traditional semi-structured interviews were asked directly to participants, where questions in photo-prompted storytelling interviews were phrased as prompts about the character in the story instead of the participant themselves. For example, in interviews where direct questioning was used, the participants were asked “if your needs changed in the future, what types of supports or services do you think you might access?”, and in interviews with photo-prompted storytelling techniques, participants were asked “if Frank’s needs were to change in the future, what types of supports or services do you think would be helpful for Frank?”. In the present study, interview data from 2 interviews in which the participants took part in are examined. The order in which the interviewing techniques were employed with each participant alternated according to a pre-defined and counter-balanced ordering to reduce ordering effects. To minimize carry over and memory effects, an interval of at least 1 week between interviews was maintained.

Data Analysis

Interviews were audio and video recorded. Two analyses were conducted to address the research questions. First, audio recordings were transcribed verbatim, cleaned, and anonymized prior to analysis. Following data preparation, the transcripts were analyzed using qualitative content analysis. Content analysis is an analytical approach typically used in qualitative descriptive studies (Miles et al., 2014). An inductive analysis was conducted with 2 coders, the first author and a trained research assistant, following an iterative process of data familiarization and generation of initial impressions, thoughts, and analysis, line-by-line coding, discussion with the broader research team, and meaningful categorization (Hsieh &

Shannon, 2005). First, a content analysis for each set of interview data (traditional semi-structured and photo-prompted storytelling) was conducted. Then, responses across interviews were analyzed, and categories resulting from the primary content analysis were contrasted to support the identification of similarities and differences in the data. The content analysis categories from each analysis (i.e., traditional semi-structured interviews and photo-prompted storytelling techniques) were first compared to examine similarities or differences across interview types. From there, responses from each participant were compared with key focus on the identified similarities and differences across the two data sets. The focus of the analysis was to explore the ways in which participants engaged with the interview questions and prompts. The findings were reviewed iteratively by all authors to confirm categorical relevancy, organization, and interpretation. NVivo 12 (QSR International Pty Ltd, 2018) was used to support data coding and analysis. Reflexivity journals were also kept by the interviewer and reviewed throughout the analysis in order to support with familiarization and gaining a sense of the whole of the dataset.

Video recordings were used to facilitate observation of the engagement of participants in the interviews. An observational scale, the Engagement of a Person with Dementia Scale (EPWDS) was modified and used to examine the engagement of participants in the interviews. The EPWDS has established content validity and psychometric properties for the assessment of behavioural and emotional expressions and responses of engagement by people with dementia across five areas: affective, visual, verbal, behavioural, and social engagement. The content validity of the EPWDS was supported by a panel of 15 experts in a Delphi study, resulting in an overall agreement of 81.4% (Jones, Sung, & Moyle, 2018). The internal consistency of the scale is reported to be $\alpha = 0.94$, and overall inter-rater reliability scores as measured by intraclass correlations (ICC) ranged from 0.75 to 0.95, $p < 0.001$ (For complete psychometric properties of the scale, see Jones, Sung, & Moyle, 2018). The EPWDS was modified for use in virtual settings as in-person observations of engagement were not possible due to the COVID-19 pandemic. As participants participated via videoconference, the observational items on the scale were applied to the video recordings of their interviews. As there are no physical materials associated with this study, the Behavioural Engagement items were not assessed (see Jones, Sung, & Moyle, 2018). Videos were scored across the subscales (dimensions) of the EPWDS and summed to produce a total score. As not all items (i.e., the Behavioural Engagement items were not assessed) across the five dimensions of the EPWDS were measured, the total score ranged from 10 to 40. The higher the total score, the higher the level of positive engagement exhibited by the person with dementia. The lower the total score, the higher the level of disengagement or negative engagement exhibited by the person with dementia. Each video recording was scored based on the coder's interpretation of the participant's level of engagement in the interview. Both the first author and the research assistant reviewed the coding framework and criteria in-depth prior to conducting the coding. The first author and the research assistant first coded a sample of videos independently, and then compared scores, discussing any substantial differences in coding. Once consensus was reached, the research assistant coded the remaining videos independently. To evaluate whether there were statistically significant differences in participants' engagement scores obtained using the two different interview techniques, a repeated measures analysis of variance (ANOVA) was conducted.

Methods to Enhance Rigour

Several strategies were employed to enhance the rigour of the study, including the use of researcher reflexivity journaling and triangulation. Following each interview, the interviewer completed a reflexivity journal detailing any methodological decisions and the reasons for them, the logistics of the interview, and a reflection upon what happened during the interview. Throughout the data analysis, the journals were reviewed and noted to support the analysts in staying "close to the data" (Lincoln & Guba, 1985). To promote credibility, dependability, and transferability, a detailed overview of the study methods, analysis framework, procedure, and findings are included in this paper. With respect to confirmability, researcher triangulation took place throughout the project, and quotations are used to support the categorization of the analysis. Credibility of the findings was supported by ensuring involvement of all authors throughout the research process, including reviewing the interviewing procedures and techniques and through peer debriefing. Those involved in data collection and analysis also received training to ensure they had the required knowledge and skills. Dependability was supported through the development of a rich description of the study methods as well as detailed record keeping. Reflexivity journals kept by the lead author as well as several triangulation strategies (methodological, data source, and investigator) helped to maintain confirmability. Finally, transferability of the findings was supported by the detailed descriptions of both the methods and the findings of the study.

Findings

Interviews were conducted with 12 people living with dementia. The age of participants ranged from 58 to 92 years (avg. 70), 7 participants identified as women, 5 identified as men, and all participants identified as being white.

Content Analysis

Similarities and differences across interview techniques were identified through the cross-examination of the categories identified through two content analyses – one conducted on the traditional semi-structured interviewing techniques data set, and one conducted on the photo-prompted storytelling techniques data set. The results of these two content analyses were compared and contrasted to examine similarities and differences in the ways participants responded to and engaged with the interviewing techniques. Findings from the cross-analysis were then applied to the individual transcripts for each participant to support with the identification of similarities and differences across the data sets.

The qualitative content analysis resulted in the identification of the following similarities and differences (see Table 6) in the ways participants responded in interviews: 1) Photo-prompted storytelling techniques garnered reflection of own experiences and beyond, 2) Photo-prompted storytelling techniques addressed challenges with direct questioning and recall, and 3) Content differences related to photograph prompts. An overarching finding of the analysis was that the topical areas of interviews, regardless of interviewing technique employed, was in general similar (i.e., there was overlap in categories from the content analysis and a convergence of categories;); however, the central difference was in how the participants spoke *about* these topics in the different interviews. Thus, the presentation of the results focuses on the identified impact on the findings across interviewing techniques. Quotations from interviews are provided to demonstrate the concepts of each impact identified. Quotations from interviews where semi-structured, direct questioning, technique was used are denoted with an ‘s’ following the excerpt, and quotations from interviews where photo-prompted storytelling techniques were used are denoted with a ‘p’. When interviewed with photo-prompted storytelling techniques, participants often referenced the photograph and/or the character *Frank* when expanding on their own experiences through the construction of the storyline (see Appendix 8 for the photographs used in the photo-prompted storytelling interviews).

Table 6. Summary of impacts identified through content analysis categories

Impact Identified	Summary
1) Photo-prompted storytelling techniques garnered reflection of own experiences and beyond:	
a) Expanding on challenges faced through exploring personal experiences as well as the experiences of others	Participants typically gave short or conservative responses when asked directly about challenges they faced in interviews with traditional semi-structured techniques. However, in interviews with photo-prompted storytelling techniques, participants expanded on challenges they faced, providing in-depth examples through the exploration of the character’s narrative.
b) Exploring sensitive and emotional topics in more depth	Participants discussed sensitive and emotional topics in more depth when interviewed with photo-prompted storytelling techniques. Participants did discuss feeling discriminated against when talked down to in support groups in interviews with traditional semi-structured techniques, but typically from the perspective of overcoming stigma and empowerment. The emotional impact of experiences with stigma and discrimination were discussed in much more depth and detail in interviews with photo-prompted storytelling techniques.
c) Moving beyond listing examples to discuss impact of experiences	Participants were observed to go beyond listing examples to discuss the impact of certain experiences when interviewed with photo-prompted storytelling techniques. When asked about their own experiences with supports in interviews with semi-structured techniques, participants listed off examples, without discussion of the impact of such supports. In interviews with photo-prompted storytelling, participants focused on the *impact* of receiving or not receiving supports as a person with dementia.

2) Photo-prompted storytelling techniques addressed challenges with direct questioning and recall	Participants generally had a more difficult time thinking imaginatively (e.g., thinking about other types of supports not currently accessed themselves, thinking about future support needs) in interviews with traditional semi-structured techniques than in those with photo-prompted storytelling techniques. The discussion was often blunted in interviews with traditional interviewing techniques when participants had difficulty thinking of personal examples. In interviews with photo-prompted storytelling techniques, participants leveraged the storyline as scaffolding to imagine examples of challenges or future support needs for themselves and the character.
3) Content differences related to photograph prompts	Participants perceived the character to be living alone, and to be experiencing unhappiness and/or isolation. As such, participants didn't discuss supports needed for character's family, and there was limited discussion of the role of care partners in interviews with photo-prompted storytelling techniques.

Photo-prompted storytelling techniques garnered reflection of own experiences and beyond

Interviews with photo-prompted storytelling techniques seemed to encourage participants to reflect on their own experiences in more detail than in interviews with semi-structured techniques. This was evident through discussions on challenges faced, and sensitive or emotional topics such as discrimination, depression, and isolation. As well, interviews with photo-prompted techniques also seemed to provide participants with an opportunity to go beyond simply listing examples of supports or services they had or hadn't accessed (as occurred in interviews with semi-structured techniques) to explore the deeper impact of these experiences. In this category, areas demonstrating participants' reflection of their own experiences and beyond are explored through three subcategories: *expanding on challenges faced*, *exploring sensitive or emotional topics in more depth*, and *moving beyond listing to discuss impact of experiences*.

Expanding on challenges faced. When interviewed with semi-structured techniques, many participants reported experiencing few challenges in their day-to-day life, and overall, considered themselves to be faring better than others or "doing fine". This is demonstrated by one participant who explored how their own embodiment of "living well" inspired others, showcasing a focus on one's perception of self as faring better than others, and a shift away from any challenges experienced.

> "I know a woman who, a number of years ago, she got the diagnosis and went home and basically shut the door…it was only when she read a little article in a newsletter from the

> Alzheimer’s Society that had a little item about something I had done and my picture and she thought, ‘you know what, he can do it, so can I’. So, she started coming to our support group.” P5s

This concept was further demonstrated by a participant who shared about empowerment to address and overcome internalized stigma. This excerpt, like the one above, represents the focus or tone of the interview as positive, with a tendency to minimize any challenges one may have experienced and position oneself as faring better than others. As this participant explored,

> “The reason why I became [a dementia] advocate is there’s a lot of people who have stigma, they’re ashamed, they're embarrassed. They don't want people to know. They have trouble expressing what they need or want, simply because people don't understand why they're doing this. And I speak for those who can’t or won’t. I'm willing to tell my story. And I have helped a number of people get over the stigma and I enjoy it.” P3s

However, when interviewed with photo-prompted storytelling techniques, participants did connect to concepts of struggle and strife, especially around coping with one’s diagnosis. One participant articulated this concept, stating,

> “I think he [Frank] would more than likely try to empower somebody else, even though he's feeling horrible. And he doesn't have anything to do about his own situation. But he would never want anybody else to be in that situation. So, you know, he'd try to lift them up somehow…I still think even if he is giving good, uplifting advice, I think he's really torn with himself that ‘why can't I take my own advice?’” P13p

Further to this, some participants reflected on their own difficulties living with dementia and strategies they took to feel empowered through the construction of the character’s narrative in interviews with photo-prompted storytelling techniques. As one participant reflected,

> “I say just don't be afraid. It's okay to ask for help. It's okay. Just remember to survive, and fight and have a smile on your face. And, on the other side of the coin, it's okay to have bad days. And you have to recognize that something good has come out of a

> horrible situation. And I wouldn't wish it on my worst enemies, but if you do it [try to live well] and keep on fighting, the rest is history." P8p

Participants seemed to reflect more deeply on the concepts of resilience and living well in interviews with photo-prompted storytelling techniques – sharing perhaps a more realistic look into the struggles and daily challenges than in interviews with semi-structured techniques where participants tended to maintain an overall positive tone. This was evident when examining how participants discussed the pandemic. In interviews with semi-structured techniques, participants often reported coping fine with pandemic restrictions or stated that they weren't greatly impacted. For example, one participant shared,

> "You know, I don't think it affected me as deeply as it did some people" P12s

However, when the same participants were interviewed with photo-prompted storytelling techniques, they often expanded on the experiences of the character to share their own perspectives and circumstances during the pandemic with relation to isolation. As one participant stated,

> "I imagine his social isolation would be amplified…the first part of the pandemic I really got along really quite well, because I'm the type of person who likes to be by myself. But after the first year, I started really feeling the effects of being isolated, not having people to talk to and, and all of that…so, I know when I went in first went into the COVID, I didn't have a whole lot of hope, or any kind of a future to anticipate so..." P12p

Another area of contrast between interviewing techniques involved discussions of day-to-day challenges. When interviewed with semi-structured techniques, participants often did not report any challenges with daily living and would typically respond that they were doing fine or had nothing to complain about. Interestingly, when participants were asked about what they thought the character might have trouble with as a person living with dementia, this seemed to offer an opportunity to explore their own experiences through the construction of the character's story. This concept is emphasized through the quotation below.

> "Counting money and change might definitely be a difficulty. Getting up and down stairs, to go into places, getting out of the bedroom, into the bed. And if he lives alone, being

> afraid of taking his medicine, I mean, of forgetting his medicines, more than likely. Or forgetting to brush his teeth, like I sometimes do." P8p

This concept was also articulated by another participant in connecting the constructed storyline to their own experiences.

> "Yeah, he doesn't have to worry about leaving the stove on which can drain electricity. I've done that many times. I relate to Frank…If the meals have to be heated up either on the stove, or the microwave, he'd need related instructions. And the backend, depending on how far along he is, like me, I know myself, I have trouble following instructions. And he probably would have the same difficulty." P3p

In contrast, when interviewed with traditional semi-structured techniques, the same participant shared the following when asked about challenges they face,

> "The odd time shopping. I keep telling myself to make the list and then when I look, I don't have a list. That's basically it." P3s

Exploring sensitive or emotional topics in more depth. Interviews with photo-prompted storytelling techniques also tended to result in more in-depth discussions of sensitive or emotional topics. Participants discussed stigma and discrimination in both interviews, however, in interviews with semi-structured techniques, conversations tended to be focused on the participants' experience overcoming stigma and developing resilience, and in interviews with photo-prompted storytelling techniques, participants explored the emotional impact of such experiences with stigma or discrimination in much more detail. The photo-prompted interviewing techniques, on some occasions, were often quite moving to participants, and several became overcome with emotional during discussions of topics like grief, isolation, and coping. As contrasted in the following excerpts, participants seemed encouraged by the co-constructed narrative of *Frank* to share their often emotionally challenging experiences with injustice, stigma, and discrimination. To demonstrate this concept, presented below is an excerpt from a participant interviewed with semi-structured techniques. When asked about challenges they face and supports or services they accessed, they stated,

> "The Alzheimer Society has something like a café or something like that, but that's mainly for caregivers. The support groups for people living with dementia have disappeared. That's wrong…" P3s

Another participant explored this concept when reflecting on their own experiences in an interview with semi-structured techniques. They shared about their own experience with accessing supports and services, and how they had felt stigmatized. This participant stated,

> "Sometimes I feel like they talk down to us because of the dementias we have, and I don't think that's right." P8s

Another shared about challenges with the medical community, stating,

> "My doctor said, 'well, it's common as you age'…but it took me eight years to find someone who would take me seriously… I couldn't find any kind of support any kind of anyone with any kind of understanding as to what I was going through" P12s

The same participant demonstrates that the concept of stigma and discrimination was more deeply explored in interviews where photo-prompted storytelling techniques were used. This participant seemed to create storylines for Frank that related to their own experience with challenges and exploring their needs, sharing,

> "I find that as my dementia progresses, I'm a lot less aware of things that other people think and a lot more self centered - I have to really work at keeping things in my head, just the schedules and things like that. It's really working overtime for me to remember everything that I have on my list for that day. And I don't know that he [Frank] would necessarily have much of anything to advise to other people, he's probably so consumed in his own thoughts and needs that he may not be in a position to be able to express exactly what it is that he needs." P12p

Participants also seemed to scaffold off the constructed narrative, building on to the character's storyline with their own experiences and perspectives. One participant demonstrated this notion through sharing,

> “Usually, I like to be as positive as I can but recently I had a very difficult situation arise, where stigma reared its ugly head…the person said, ‘but you have dementia’, and thought that I was unable to do anything by myself and so they followed me literally every step, and it was the most disconcerting couple of days I've ever had in my life…it hurts me to my core, and it caused me to rethink my abilities or disability. [Stigma] does a great deal of harm.” P1p

Moving beyond listing to discuss impact of experiences. Participants often described their experiences by listing examples in interviews with traditional semi-structured techniques. When interviewed with photo-prompted techniques, participants moved beyond listing examples to exploring the *impact* of such examples and experiences, both on themselves and others. Participants tended to use the co-constructed narrative of the character as leverage to expand on their own experience, reflecting on the impact of experiences and the emotional connections to topics in much more depth. For example, while participants did share examples of experiences with discrimination in interviews with semi-structured techniques, they did not discuss the *impact* of this experience. This concept also extended to discussions of stigma and isolation above and beyond those in traditional semi-structured interviews. This was also evidenced through discussions of the COVID-19 pandemic. For example, several participants discussed their experiences with friends or acquaintances met through supports and services that had a very hard time when restrictions were in place, as shown through the below excerpt.

> “Well, when you talk about Covid-19 and people with dementia, I personally know three people who passed - they are people with dementia, who used to be in a support group, and I believe part of the fact that they passed so quickly, was that they had no support at all.” P1p

This is contrasted with the response from the same participant in the interview with traditional semi-structured techniques when asked about their experience with the COVID-19 pandemic, where they stated,

> “We pretty much carried on. We did the masks. We had all this sort of health things that you needed to do. We may have missed just a few sessions, but then we did online [support groups].” P1s

When asked about whether the pandemic would have impacted the character, this participant stated,

> “Oh greatly, because so much of what was being done here like at the dementia cafe, all the programs...they just came to a very abrupt end and there were people who I know who have gone downhill rapidly, because of the lack of socialization.” P2p

In comparison, when asked about their experience with the pandemic in the interview with traditional semi-structured techniques, the same participant shared,

> “I've been fortunate I really have not had any, what I would consider to be bad experiences with this.” P2s

The photo-prompted storytelling techniques also seemed to encourage participants to consider different perspectives – as one participant explores in the below excerpt, the storytelling exercise prompted them to reflect on how parallels could be drawn across both the characters and their own experiences of living with dementia.

> “This conversation makes me smile because in some ways all we're doing is making assumptions on the basis of one picture and as far as dementia and people's interactions with those with dementia, they all make assumptions…and they write you off. So, I just I just think this is quite funny, we're all making assumptions which is reflective of society.” P5p

The photo-prompted storytelling techniques seemed to give participants the opportunity to reflect on their own experience more deeply, especially with relation to grappling with difficult emotions after a diagnosis or experiencing isolation from friends and family after disclosure of a diagnosis of dementia. This idea is demonstrated through the below excerpts where participants were heard to reflect on their own experience through constructing the character’s story.

> "Frank looks really sad to me. Perhaps he's really thinking through his diagnosis and what life is going to be like for him in the years ahead. I think he's really wrestling with how best to get through. Yeah, that's really interesting, that was sort of what it was like when I was diagnosed. It took me rather a long time to get through that, I think it was nearly 18 months, but once I was finished feeling sorry for myself, then I could actually move on with a really positive attitude so yeah…there's truth to that." P1p

Another participant shared the impact of experiencing stigma and isolation after sharing their diagnosis with friends, stating,

> "If I were in his shoes, I think I would be thinking [about] where all the people in my life have gone. I know once I came out of the closet, in regard to my dementia, I lost like all my friends, but one. And now when we run into people that we know, they talk to my husband, and they don't talk to me, as if I can't understand what they're saying...So, I would think, perhaps he's just pondering over his life, wondering where he went wrong as far as having somebody in his life when he needs them so badly." P12p

While this participant didn't discuss their experience with stigma or isolation when they were interviewed with traditional semi-structured techniques, they did share about their experience connecting with others living with dementia, stating,

> "When we got together, it was like we were all on an equal playing field. We all knew exactly what everybody else was going through." P12s

One participant articulated this concept by connecting their own experience to their perception of the character's experience to explore the impact of isolation, stating,

> "Well, he's totally on his own, right, in his house and he's looking around and he's thinking 'what's it all about', like a lot of times I'm sitting there like that, right? And I'm just wondering is this gonna be me? I think about that all the time." P4p

To contrast, when interviewed with traditional semi-structured techniques, this participant shared,

> "I can do that all of that stuff. Yeah, I get groceries and I lost my license because of yeah…so that was that was a killer, that was too bad." P4s

Further supporting the idea that the photo-prompted storytelling techniques helped to encourage imagination and explore one's own experiences, some participants mentioned how they engaged with the storytelling technique from their perspective. As one participant shared,

> "I just think that was very, very interesting little thing to do, because it did make me think about things that I hadn't thought about in a while. Some of the stuff that I was saying is stuff that I myself have actually had. It makes you more aware of your own situation. And think 'oh, yeah, I think I feel like he looks'. So, it triggers things. And I think that's a really good thing." P15p

Photo-prompted storytelling techniques addressed challenges with direct questioning and recall

The second category of impact identified involved the notion that photo-prompted storytelling interviews tended to result in more imaginative responses, and in many cases, seemed to facilitate conversations when contrasted with interviews with traditional techniques. For example, participants were asked directly about the challenges they experienced in their day-to-day lives in traditional interviews, and what challenges they thought Frank experienced in his day-to-day life. In response to direct questioning, participants would often respond that they didn't experience challenges, or that they couldn't think of anything. However, when the same participants were interviewed with the photo-prompted storytelling techniques, they often scaffolded off the co-constructed narrative of Frank to share their own experiences with day-to-day challenges. This concept is demonstrated by one participant, who shared,

> "I think he can wash and dry his clothing, but I think putting it away is difficult. I think changing his bed is difficult for various reasons. I think deciding what to cook and eat is also difficult. He can have lots of groceries and his fridge, but it's difficult for him to decide what to cook for himself. I think a lot of the daily chores like, well they're not even daily, like washing our windows and ironing and things like that, I don't think Frank gets around to doing." P1p

In comparison, when interviewed with traditional semi-structured techniques, this participant shared,

> “My husband provides my transportation and I do have a cart. So, it's the best of a poor situation, I would rather be hundred percent independent. We do have a housekeeper that comes once a month for maybe an hour. That's about all I can think of.” P1s

Another section of the interviews across techniques focused on thinking about what supports or services one might consider accessing now or that one might need to access in the future should their needs change. When interviewed with traditional semi-structured techniques, some participants either didn’t feel they needed to access supports and services or didn’t have them available to them. This seemed to hinder the conversation in terms of imagining about their future support and/or service needs, and what they might access in the future. When asked about supports or services they might access if their needs changed, some participants reported not being able to think of anything or gave general responses that they would seek out help as they needed it – but didn’t mention specific supports or services as seen in the interviews with photo-prompted storytelling techniques. This notion is demonstrated in the below excerpts from participants who shared,

> “No, I don't do those sorts of things. So, I don't have anything in my area that I would want to take part in. Besides, I'm comfortable with myself. I don't need people around me.” P3s

The challenges thinking of future support needs were further demonstrated as participants shared,

> “I'm trying not access anything, just trying to make it work.” P5s

And,

> “I don't even know.” P8s

Participants were also asked about what supports or services they might access in the future if their needs were to change. Most participants seemed to find this a difficult question to conceptualize, and often had a hard time coming up with examples or envisioning how their own needs may change. This concept is demonstrated through the excerpt presented below.

> “I can't think it of...well it's hard just to guess what you would do until you realize what you can't do, you know.” P14s

When interviewed with photo-prompted techniques, participants expanded on the character’s story to explore their own experiences. For example, one participant explored future supports or services the character might look to access, stating,

> “I think there may be an Alzheimer society, there will probably be some sort of a senior’s community. I think that's where he could really benefit from by being with others his age and perhaps, they have dementia support within the senior’s community - in our town, we have that, and I do that, and it is just a chance for people to be with other people.” P1p

This concept of imaginative thinking is also demonstrated in the below excerpt from a participant who explores different examples of support in one’s community, sharing,

> “Maybe if he's part of a church group, to have someone visiting for the church group, or faith group…get connected with the other people and with the services that are out there, figuring out how to get what you need, because that's definitely a bit of a mission. Maybe he just wants to be in touch with people to say, ‘come to my place for a game of Euchre’.” P16p

Content differences related to photograph prompts

Impact of the photo-prompted techniques on the interview outcomes was also identified with relation to the content of the interviews and the photograph prompts chosen. Through examining how participants responded to the prompts in these interviews, it was identified that differences in discussions could have been influenced by the content of the photograph prompts used. For example, participants often perceived Frank to be isolated and feeling unhappy. One participant commented,

> “I'm not sure just looking at that picture he's in a position to give advice to anybody. I think he's the one who needs advice.” P2p

Further, participants discussed the importance of having supports in place for their family and friend care partners in interviews with semi-structured techniques. While discussed in interviews with photo-prompted storytelling techniques, these instances were often infrequent, potentially due to most participants constructing a narrative for the character where he was living alone, either due to being widowed, or otherwise socially isolated. That is to say, Frank's story often didn't include a spouse or other care partner that supported him in his home. In fact, participant's often felt as though his wife must have died some time ago, and nearly all participants constructed his circumstances around him living alone. As one participant shared,

> "When I look at him, I see that his wife has already passed. He now has dementia. His family is not as attentive as what he'd always felt they would be. And he's just sitting there in the morning having his coffee without his wife without his family without support. That's what he looks like to me." P13p

As many participants thought that Frank lived alone, they didn't often discuss how family support impacted him, but rather, how the lack of support may have contributed to depression and isolation. Thus, it was more common for participants to discuss their own care partners and/or spouses in interviews where semi-structured techniques were used.

Observational Analysis

A total of 24 video recordings of each interview (2 per participant) were analyzed and scored for engagement on 4 subscales, with total possible scores ranging from 10 to 40. For interviews where photo-prompted storytelling techniques were used, the engagement scores were observed to be higher on average than when participants were interviewed with semi-structured interviewing techniques (see Table 7). There was a statistically significant difference in engagement score between the two interview types, F (1, 11) = 4.94, p = 0.04. Therefore, it is suggested that there is a statistically significant difference in engagement scores when participants are interviewed using semi-structured techniques or photo-prompted storytelling techniques.

Table 7. Descriptive Statistics of Overall Engagement Score

Interview Type	Mean	Standard Deviation	N
Semi-structured techniques	33.17	5.11	12
Photo-prompted storytelling techniques	37.33	1.92	12

Discussion

This study makes an important contribution to the body of research related to involving people living with dementia in qualitative research that focuses on understanding lived experiences and perspectives. This study enhances our understanding of photo-prompted storytelling techniques as a mechanism of engaging people with dementia in interviews. Findings from this study reinforce the utility of photo-prompted storytelling techniques in supporting the participation of people living with dementia in qualitative interviews (Phillipson et al., 2023). Together, results from a qualitative content analysis and observational analysis support that these techniques may impact the types of data collected through interviews, as well as the engagement of people with dementia in interviews.

Projective (storytelling) techniques are rooted in psychology with historical applications in consumer research and more recently, broader health research. While few studies have examined the application of projective (storytelling) techniques in research with persons with dementia, literature does exist to support its utility in disability and health research. As aligned with work by Porr et al. (2011), who reflect that the use of projective (storytelling) techniques enabled participants to give voice to their inner thoughts and emotions, this study supports that photo-prompted storytelling techniques have utility in supporting participation and the expression of one’s emotions. Further, a general goal of projective (storytelling) techniques is to overcome response barriers – including participants feeling uncomfortable discussing sensitive topics or the social pressure to answer in the ‘right’ way – barriers especially relevant to those living with dementia who may experience pressure to remember the ‘correct’ answer or report on events accurately. As discussed by Wiehagen et al. (2007), projective (storytelling) techniques are conceptualized as being instrumental in supporting participants in overcoming response barriers, including social and language obstacles in health research. This study supports that projective techniques, in this case, photo-prompted storytelling techniques, have potential in supporting the expression of people living with dementia on topics considered sensitive in nature – such as disclosing a diagnosis of dementia, experiencing mental health difficulties, and experiencing challenges with personal care. This concept is also supported by Clarke et al. (2019), who discuss storytelling techniques as a viable method of circumventing obstacles to self-report. Further, this study supports that photo-prompted storytelling techniques may impact the types of data collected through interviews. Participants in this study were observed to provide more rich and thorough responses when interviewed with photo-prompted storytelling techniques.

Like results of a historical study by McGrath et al. (1993), the present study reports that when questioned directly, participants tended to respond with direct, neutral, or superficial answers. McGrath et al. (1993) also report that when interviewed with projective (storytelling) techniques, participants gave responses that were more complex, imaginative, and creative than when questioned directly. These findings are aligned with the results of the present study, which support that photo-prompted storytelling techniques tended to engage participants in more creative and imaginative expression through engaging with the photograph prompts and story character. Further, results from a study by Phillipson et al. (2023) support that photo-prompted storytelling appear to lessen some of the demands of direct questioning for people living with dementia who are engaged in research by allowing for imaginative responses and offering additional conversational prompts. The present study reinforces that photo-prompted storytelling techniques offer an opportunity for participants to explore topics creatively, take different perspectives, and reflect on their own experience through the construction of a storyline and with the support of prompting photographs, similar to findings from Teachman et al. (2013), who explored the utility of storytelling through vignettes in applied research with children living with disabilities and found that such techniques facilitated more dynamic conversations. As demonstrated, participants provided rich, intimate descriptions of their experience with grief following a diagnosis, as well as the resilience developed – all through exploring their experiences in the construction of the character's story. While on the surface, general topics were explored in both types of interviews, responses in semi-structured interviews tended to be surface level descriptions or examples of experiences. This is in contrast to responses in interviews with photo-prompted storytelling techniques, where similar topics were discussed in much more detail, and where participants expanded on the character's narrative by bringing in their own perspectives on the impact of such experiences, and reflecting on the interplay between living well and still experiencing challenges – above and beyond recalling lists of examples as observed in interviews with semi-structured techniques. This aligns with findings from a recent study by Phillipson et al. (2023), who reported that the use of photo-prompting techniques supported personal reflections in research with people living with dementia. Specifically, this study reported that the techniques promoted empathy and supported reflections on the needs and experiences of a hypothetical character (Phillipson et al., 2023).

Participants also discussed highly sensitive topics, including their experiences of stigma and discrimination in interviews with photo-prompted storytelling techniques. This occurrence confirms the supportive nature of photo-prompted storytelling techniques in enabling the discussion of such topics. This concept is also reported by researchers Gram et al. (2023), who examined the utility of storytelling techniques to examine lived experiences of sensitive health issues. The authors reported that when researching perspectives on prostate cancer, the use of projective (storytelling) techniques tended to encourage emotional openness amongst participants and facilitated the discussion of one's emotions with respect to the topic (Gram et al., 2023). Results from the current study's observational analysis also support that photo-prompted storytelling techniques may impact the engagement, in this case being defined as active participation, of people with dementia in interviews. While a secondary evidence source, the results of this analysis do suggest that on average, when interviewed with photo-prompted storytelling techniques, participants in this study were observed to show higher levels of positive engagement than when interviewed with semi-structured techniques.

Future research should seek to expand the application of photo-prompted storytelling techniques in different settings (e.g., in person) and with different populations (e.g., with participants at different staged of their dementia journey or experiencing dementia alongside multimorbidity impacting communication abilities) to examine the utility of the techniques across research projects. It will also be important to examine the extent to which the photographs chosen as prompts impact the results of the research – this study supports that aspects of the photographs chosen may influence the topics discussed. Responses in photo-prompted storytelling technique interviews often tended to cluster around perceptions of the character in the photos (e.g., in the case of this study, all participants perceived the character to be unhappy and living alone). As relatively recent research has observed, varying a key feature of the story in storytelling techniques has produced mixed evidence as to whether responses also vary – for example, when varying key features in a story completion exercise on body hair, responses were not observed to be markedly different between groups (Clarke & Braun, 2018; Jennings et al., 2018). While participants unanimously constructed the character as living alone, this still offered the opportunity for participants to contrast their own experience if they didn't live alone, and to relate to their experience if they did. This concept is referenced by Clarke et al. (2019), who state that a benefit to storytelling techniques is that they allow for connections to topics even if the participant lacks personal experience.

Strengths and Limitations

The current study presents an in-depth account of the application of a photo-prompted storytelling technique in research with people with dementia. This research offers a unique contribution to the field of inclusive research methods and delivers results to support the extended use of such techniques in future research through a comprehensive analysis of similarities and differences across traditional, semi-structured interviewing techniques with direct questioning and photo-prompted storytelling techniques. The overall study was impacted by the pandemic, as recruitment and participation were shifted to be virtual/online. As such, the diversity of the study sample was likely impacted, as the nature of the inclusion criteria and the method of participation was not fully inclusive or accessible to all people living with dementia (for example, those living remotely or without internet access). Participants were also excluded if they were not able to partake in virtual interviews due to significant challenges with communication (e.g., hearing challenges, uncomfortable conversing in English). As physical distancing restrictions have been lifted and in-person research has resumed, future research should seek to explore the utility of these methods in in-person settings and examine ways to improve the accessibility of the method to engage a broader group of people living with dementia (e.g., people who may have challenges participating in virtual research).

As a potential mitigation strategy to the recruitment challenges this study faced, recruitment was open to individuals across Canada to include as many people living with dementia and as diverse a sample as possible. While inclusive and accessible recruitment for this study was challenging, the study procedures overall included several accessibility modifications to maximize the meaningful participation of participants who took part in the study. This included process consent procedures, modifications to study materials, flexible participation options, and ample time scheduled to support rapport development.

The sample size of this study is also relatively small – as 12 participants completed the interviews. Further, several participants in this study self-identified as activists in the dementia community and may have been more likely to agree to participate. As a qualitative-driven multi-methods study, the purpose of this study was not to produce statistical generalizable results. The rich and detailed description of the study and findings supports transferability and allows for readers to determine the relevance of the study's conclusions for their own contexts (Firestone, 1993). A secondary goal of this study was to examine observational engagement scores across interview types. Thus, statistical analyses of observed engagement scores were conducted to quantify the observed difference in scores and serve to contextualize the results from the qualitative component of this study. Results should be interpreted with consideration of the strengths and limitations of this study, including the sample size.

Another potential limitation of this study was that the same photograph prompts were used for every participant. Because the photograph and character were described as a man, participants identifying as women may have connected differently to the prompts if were of a woman character and if the photographs used depicted a woman. Further research should seek to examine the impact of photograph prompts on the types of results generated, that is, changing the photographs to reflect each participants characteristics may have produced different results.

Conclusion

Including older adults with dementia in research helps to ensure services and supports are developed and implemented in such a way that is relevant to the needs, desires, and abilities of persons with dementia. This can, in turn, improve wellbeing and enhance social connectedness, which has many other benefits for older adults with dementia. Many of the symptoms associated with dementia including challenges with memory, language, and spatial recognition can make it very challenging for persons with dementia to become engaged in a variety of different activities including research (Trahan et al., 2014). These symptoms coupled with the health and sensory-related changes experienced by many older adults justify modifying research activities to enhance engagement for older adults living with dementia.

Qualitative research can be optimized for older adults with dementia. Because qualitative research relies on the participant to communicate their experiences, researchers must consider how factors related to both age-related changes and dementia can intersect to further complicate the ability to communicate. Further, as dementia impacts a person's abilities on an individual basis, it is important for researchers to consider the individual needs of each participant, as they are likely to vary given the wide range of experiences with age and dementia-related changes to memory, hearing, vision, and communication. Improving the accessibility of research methods for studies that involve people with dementia as participants is essential to supporting meaningful engagement in research. Further, understanding the impacts of adopting creative or modified approaches to research with people with dementia is important to our understanding of how adaptations or modifications may impact the data collected in these types of projects and any implications for the evidence produced. High quality evidence and results are essential to improving the quality of life and care of people living with dementia, especially from studies researching the lived experience and perspectives of people living with dementia themselves.

Chapter 6: Discussion

The central aim of this dissertation was to address gaps in knowledge and support an understanding of the use of adapted or modified methods in research with people with dementia, as well as evaluate two novel interviewing techniques for supporting active participation and engaging people with dementia in qualitative research. While several adaptations and modifications to research methods were identified through a scoping review (Chapter 3), none had been evaluated for their impact on the engagement of people with dementia in the research process, nor on the data collected, emphasizing the need for ongoing evaluations of such methods for their impact on the engagement of people with dementia as well as their impact on the research data itself. To address this gap, two primary studies were conducted (Chapters 4 and 5) to evaluate the use of verbally-prompted storytelling techniques (Chapter 4) and photo-prompted storytelling techniques (Chapter 5). When compared to traditional semi-structured interviewing with direct questioning, verbally-prompted storytelling techniques were found to have had an impact on the data obtained during interviews with people with dementia through supporting participants to engage in deeper reflection, facilitating conversations when participants experienced challenges recalling a personal example, and enabling conversations about emotional topics. However, the observed engagement scores across interview types (traditional and verbally-prompted) were similar ($p=0.19$).

In interviews with photo-prompted storytelling techniques, participants provided more in-depth responses and were able to call on more numerous and richer examples of personal experiences than when interviewed with traditional semi-structured techniques. The photograph prompts also seemed to impact how participants responded – specifically, many participants interpreting the character in the photo as living alone and experiencing loneliness. This suggests that photographs used in these types of interviews may influence the ways in which participants respond, and thus should be chosen with care. Finally, there was a statistically significant difference in engagement scores when participants were interviewed using photo-prompted storytelling techniques as compared to semi-structured interviews with direct questioning ($p=0.04$).

Applications and evaluations of projective interviewing techniques

While the application of projective techniques is fairly limited in dementia research, the historical foundations of the techniques mean that their application is much more robust in fields of abnormal psychology, cognitive impairment, and research with children or other populations typically considered to be vulnerable. Examining literature in the fields of disability studies and psychology, the use of projective techniques has been found to have supported those with communication difficulties, such as those living with dyslexia (Carawan & Nalavany, 2010), intellectual disabilities (Dykens et al., 2007); and children with disabilities (Kelly, 2007) across various topics but centering on those related to one's personal experiences and perspectives. Drawing parallels with findings reported in the two primary studies of this dissertation, the application of projective techniques, specifically verbally and photo-prompted storytelling techniques, to explorations of the personal experiences of those who may typically be considered vulnerable, such as those living with disabilities like dementia, holds promise. Indeed, as Kelly (2007) reports from a study of children with disabilities, the use of photo prompts and verbal projective techniques greatly increased responsiveness for participants with communication challenges.

The use of artefact- and photo-prompts are often discussed as generating conversations and personal reflections for participants (Kelly, 2007; Carawan & Nalavany, 2010; Kyolo et al., 2023), and while to our knowledge not previously contrasted to verbal-only prompting, results of such studies align with the broader findings of the primary studies of this dissertation, where only the photo-prompted storytelling produced statistically significant differences in engagement scores amongst participants with disabilities and/or communication challenges. Indeed, a historical study by Collier (1957) first reported that interviews that included photographs were significantly longer and more detailed than those without. As well, the inclusion of photographs during interviews has been reported to prompt participants to engage in deeper reflection of their experiences in comparison to verbal questioning (Harrison, 2002; Van Auken et al., 2010). The use of photographs in interviews has been reported to improve communication when exploring emotional topics by allowing the participant to divert the conversation from their own personal experience to the photograph (Affleck & Macdonald, 2012; Bugos et al., 2014; Jurkowski &

Paul-Ward, 2007). Researchers Sigstad and Garrels (2021) also highlight that the use of such techniques with participants living with intellectual disabilities promoted research participation as the techniques mirrored the level of support these individuals required in everyday life, and in doing so, reduced barriers to participation such as those that exist with other data collection methods with higher cognitive demands (such as traditional interviewing). It is essential to consider, however, that introducing artefacts such as photos, or verbal prompting, are likely not to be neutral to the research process, and thus, understanding the scope of their influence on the data collected and outcomes produced is necessary when such findings are likely to be transferred to the broader generativity of knowledge on a topic, or carried through to policy and practice. Findings across the primary studies of this dissertation alongside the general trend in the literature towards photo and artefact-based methods of prompting may illustrate the greater potential of these techniques to enable active participation over verbal-only prompting, although more research in this area is needed to confirm such conclusions.

Few evaluations of projective interviewing techniques as a data collection method have been conducted. The utility of projective interviewing techniques is typically discussed by authors employing the method in their projects, but without a direct comparison or other evaluation of the techniques with other data collection methods. Of the published evaluations of projective techniques that have been conducted, the majority tend to focus on evaluating the utility of such techniques in therapeutic or psychological assessment applications, not as a data collection method for research (Cole et al., 2008; Reynolds et al., 2008). For the studies that have evaluated projective interviewing techniques against other types of interviewing or questioning as a data collection method, this was typically done by comparing responses elicited through projective techniques to those from direct questions, such as in one project by Ostapczuk and Much (2011). In this project, authors Ostapczuk and Much (2011) conducted a quantitative analysis to compare responses from a survey-based direct questioning framework, a projective questioning framework, and a third technique called a randomized response technique that adds an additional layer of scrambling in an attempt to reduce social desirability bias. Authors reported that the randomized response technique, a more specialized projective technique, reduced bias more than the standard projective questioning framework through assuring respondents of confidentiality of their responses – which was especially relevant given their focus of study was to understand public perceptions of people with disabilities (Ostapczuk & Much, 2011). A similar study by Begin and Boizin (1980) examined different questionnaire-based projective techniques, similar to the projective questioning framework in the study discussed above, by comparing responses from the same set of participants and analyzing differences in responses quantitatively. Authors Begin and Boizin (1980) report similar findings to those of Ostapczuk and Much (2011), that a randomized response technique produced results that were more closely aligned to participants 'true' feelings by reducing social desirability bias than the standard projective technique through ensuring participants confidentiality, and that both techniques were favored over direct questioning. Another study by Hindley and Font (2018) compared responses on different types of survey-based projective questioning to examine their impact on reducing social desirability bias by engaging in a quantitative analysis of response variation. They compared collage, choice ordering, word association, photo elicitation, and a scenario expressive technique, and reported that word association techniques were found to reduce social desirability the most, and photo elicitation techniques the least (Hindley & Font, 2018). At the time of writing, no studies were identified that evaluated the application of projective techniques in interviews as a qualitative data collection method. The application of projective techniques extends outside of data collection methods in practice - for example, these techniques are also used in psychological assessments, marketing activities, therapeutic interventions, interviewing techniques and beyond, and as such, it is essential to consider the intended purpose and application of the techniques and structure evaluations of their effectiveness or utility according to how they are being applied.

Applications in dementia research

The use of storytelling in research with people with dementia has been explored in relatively limited applications in past research, and most often for its use as a therapeutic intervention and not a data collection method (Holm et al., 2004; Rios Rincon et al., 2022; Heggestad & Slettebø, 2015). One study by Astell et al. (2010) examined the use of both generic and family photographs as prompts in storytelling research with people with dementia for the purposes of prompting stories and social reminiscing. The authors report that in response to family photograph prompts, participants with dementia responded with very limited information and told very few stories. In contrast, when prompted with generic photographs, participants produced quite detailed and emotional stories that were personally significant. These findings align to those of both primary studies, where the use of generic prompts, both verbal and photograph, produced more in-depth and emotional responses as compared to when participants were asked about their own experiences directly. When considering the findings reported in Chapter 5 alongside those reported by Astell et al. (2010), the use of generic photographs or prompts in general may be more effective in supporting conversations with people with dementia over familiar prompts. However, the necessity of researcher reflection and care in choosing which photographs are presented is underscored as the photographs may to support engagement and in turn influence the content of participants' responses above and beyond when familiar prompts or photographs are used.

Storytelling more broadly has also been associated with therapeutic outcomes for people with dementia in a study by Holm et al. (2004) and Rios Rincon et al. (2022). While not leveraged to collect data directly, researchers report that the verbal storytelling intervention supported conversations amongst participants and helped participants to remember and explore previous experiences (Holm et al., 2004). In a systematic review by Rios Rincon et al. (2022) on the use of storytelling with people with dementia, the authors highlight that the primary purpose of storytelling has been to support memory, reminiscence, identity, and self-confidence. Of importance, however, is that the authors note across the 34 studies reviewed, the level of evidence of the effectiveness of storytelling to accomplish these aims was low (Rios Rincon et al., 2022). While there was convergence in the findings from the qualitative content analysis of the two primary studies of this dissertation the otherwise relative dearth of information on the application of such techniques as a research method for collecting data about the experiences of people with dementia highlights the need for future research.

In a study by Phillipson et al. (2023), a researcher-driven photo-elicitation technique, similar to that used in Chapter 5, was reported to promote empathy and support personal reflection amongst participants with dementia who were asked about the diagnostic experience of a hypothetical character. Phillipson et al. (2023) also explored a word-association technique alongside the researcher-driven photo-elicitation technique, and reported that across the two, the techniques elicited reflections on personal experience and societal perspectives of dementia, and seemed to lessen demands of direct questioning amongst participants. This finding supports those reported in Chapters 4 and 5 and highlights the utility of projective techniques across different topics, as researchers in this case applied similar techniques to the study of diagnostic and post-diagnostic experiences of people living with dementia. Phillipson et al. (2023) examined the use of projective techniques across 3 domains of manageability, meaningfulness, comprehensibility and reported that the techniques were not meaningful (i.e., supported a connection with the research topic) or manageable (i.e., easy to complete the essential steps in the research process) for all participants, prompting a need for further research into their application and usefulness across a diverse range of participation needs. Indeed, the authors reported that the stage of dementia as well as communication challenges like hearing loss made the process more challenging for some participants with dementia (Phillipson et al., 2023). While this finding was not observed in the present studies of this dissertation, participants with significant communication difficulties that prevented them from providing consent were excluded at recruitment. This raises important questions about the process of ethics and the standard informed consent process in the application of such techniques, as the research ethics board requirements of the primary studies of this dissertation may have inadvertently limited the robustness of the studies through attempts to balance participant autonomy and safety – participants had to be able to complete the consent process to take part in the interviews, and those experiencing significant communication difficulties did not meet the criteria to provide informed consent in this case.

An important reflection on the use of such techniques centers on their potential to evoke strong emotional responses amongst participants. It was observed in both the primary studies of this dissertation and in the study by Phillipson et al. (2023) that the use of photo-prompting in interviewing techniques seemed to trigger emotional responses for participants, often surfacing difficult experiences around stigma, discrimination, and isolation in the primary studies of this dissertation. While no participants exhibited extreme distress or emotional disturbances in these studies, balancing with the Tri-Council Policy Statement 2 (TCPS-2) principle of non-maleficence is an essential consideration for researchers seeking to employ such techniques to ensure they are not employed with the potential to cause undue harm or stress to participants. This could be especially applicable when exploring more inherently emotional or distressing topics related to dementia, such as Medical Assistance in Dying (MAiD). Indeed, the topic of study for which projective techniques in general are applied has been much scrutinized in the field of psychology for decades since the formalization of the Thematic Apperception Technique and Rorschach scales in in the 1920's and 30's (Garb et al., 2002). Reports of their application in clinical and forensic settings to make inaccurate or harmful diagnoses or judgements when used in isolation from other assessment techniques have rightfully raised concerns, and thus their use is recommended to be limited to exploration rather than assessment domains (Garb et al., 2002). This is highly relevant to the use of projective techniques in populations of people with dementia, and as such, future research should explore how projective techniques should be best employed with a focus on exploring experiences and perspectives – and whether boundaries should be drawn with respect to their potential applications in a clinical or diagnostic setting. As explored through the scoping review in this dissertation, it is essential for researchers to carefully examine how adaptations and modifications to their data collection techniques, such as using projective techniques, may impact both the participants and the data and outcomes produced.

Centered in the principles of the social and human rights models of disabilities, the studies included in this thesis sought to examine and facilitate the rights and inclusion of people with disabilities, in this case, people living with dementia. Social and human rights models are aimed at understanding the lived experiences of people with disabilities as described in their own words (Lawson & Beckett, 2021). This dissertation has explored how typical research processes may serve as barriers to exclude individuals, and how adapted and modified methods can reduce such barriers to explore the lived experiences of people living with dementia. Indeed, methods which emphasize recall skills and communication can be exclusionary and stressful for people with dementia and contribute to the broader absence of the voices of people with dementia from the literature (McKillop & Wilkinson, 2004; Lim & Sharmeen, 2018). This dissertation sought to examine how the active participation or engagement of people living with dementia in research can serve as a mechanism to acknowledge their rights to participate on an equal basis with others through meeting their participation needs.

As reported in the scoping review (Chapter 3) of this dissertation, while many researchers are taking steps to promote the inclusion of people with dementia in research through adapting and modifying methods, the extent to which these methods actually meet the accessibility and participation needs of participants with dementia has not been evaluated outside observational accounts, and the extent to which adapted or modified methods influence the data collected and outcomes of research studies where they are employed, to the best of our knowledge, has not previously been evaluated (Conway et al., 2023). To this end, evidence from both Chapters 4 and 5 support that evaluations of adapted, modified, or novel research methods for their utility and impact on engagement and data are possible and yield important insights into their use. However, it is important to note that only one of the techniques, the photo-prompted storytelling technique, was observed to have statistically significant differences in engagement scores on the EWPDS. While other impacts were identified through the qualitative content analysis for the verbally-prompted storytelling techniques, there were no statistically significant differences in engagement scores on the EWPDS when compared to semi-structured interviews with direct questioning. This may indicate that while verbally-prompted storytelling techniques were observed to impact the ways in which people with dementia responded during interviews, without the photo-prompts, levels of engagement may be similar to semi-structured interviewing with direct questioning. The value of both techniques in their impact on the data produced is evident still, as participants when interviewed with either technique were observed to respond with more in-depth examples, connect more deeply to emotional topics, and overcome challenges with recall despite mixed evidence in terms of scores on the EPWDS. As well, the EWPDS was adapted for use on data collection activities from its original development for assessing engagement in recreational settings, and it is possible that this scale may not adequately capture more nuanced differences specific to data collection activities.

Another important point of discussion is the impact of prompts, both verbal and photographic, on the content of interviews and how they may influence the responses of participants. Nearly all participants when interviewed with photo-prompted storytelling techniques perceived the character to be isolated, living alone, depressed, or otherwise struggling. This finding suggests that the photographs chosen may influence the tone and topics discussed in interviews. Consequently, future research should explore the extent of this finding, and how the use of photographs as prompts may be leveraged to focus responses on particular topics or situations of interest. For example, work by Clarke et al. (2019) highlights that varying prompts and materials used in story-completion research has been a technique leveraged by researchers across disciplines to examine key characteristics of stories and how they influence participants' responses.

Implications and Contributions

The inclusion of people with disabilities and specifically those living with dementia in research is essential to recognizing their rights to participate and share their experiences on an equal basis with others (Thoft, Ward, & Youell, 2020). As reflected in the social and human rights model of disability, it is vital to include the voices of those living with disabilities and for their experiences to be reflected in broader society (Lawson & Beckett, 2021). The active participation or engagement of people with dementia in data collection processes is essential to ensuring that their voices and experiences are captured in research, and in turn, to produce outcomes that are reflective of their experiences (Phillipson & Hammond, 2018). This aligns to broader research demonstrating the utility of projective interviewing techniques on facilitating the engagement of participants with disabilities in research in general (Sigstad & Garrel, 2021; Kelly, 2007; Carawan & Nalavany, 2010; Kyolo et al., 2023) and of participants with dementia specifically (Phillipson et al., 2023). Indeed, when participants are engaged in the data collection process, their responses were deeper, more reflective, and explored more emotional topics as observed through the findings presented in Chapters 4 and 5 of this dissertation. Particularly, when participants are engaged in the research process, as observed through the 2 primary studies of this dissertation, their responses in interviews are longer, deeper, and provide more insight into their experiences (Collier, 1957; Harrison, 2002; Van Auken et al., 2010).

This dissertation builds on previous research seeking to include people with dementia and offers opportunities to advance the inclusion of people with dementia in future research. Work conducted as part of this dissertation demonstrates how people with dementia can be actively engaged in sharing their experiences, in turn promoting their inclusion and allowing for knowledge generation about the lived experiences of dementia which directly addresses findings of recent research that highlights that dementia remains misunderstood by many (Innes et al., 2021b). Further, this dissertation contributes to knowledge on how research methods that seek to include people with dementia may be evaluated for outcomes on engagement and active participation – an area identified as lacking in past (Innes et al., 2021b; Phinney et al., 2016). As identified by Dupuis et al. (2012), it is insufficient for researchers and policy makers to solely hear about the experiences of people living with dementia – we must seek out opportunities to actively include and involve people with dementia as participants in research. The primary studies of this dissertation contribute to the broader field of inclusive dementia research through highlighting how specific techniques can promote active participation and can support the participation of people with dementia. Specifically, this work addresses findings from Wied et al. (2019) who report on conversational interviewing styles as a potential mechanism for encouraging people with dementia to participate actively and extends on work by Fetherstonhaugh et al. (2016) and Smebye et al. (2012) who discussed the potential of visual aids to help support understanding and potentially compensate for memory impairments. The primary studies conducted as part of this dissertation directly contribute to the evidence base for the use of projective interviewing techniques with verbal and photograph prompts through evaluating their usefulness in supporting the involvement of people with dementia in research through meeting communication needs.

This dissertation also contributes to knowledge on how researchers can effectively reduce both attitudinal or stigma related barriers and impairment related barriers that impede the ability of people with dementia to participate. As identified by Bartlett (2014a), the layering of barriers experienced by people with dementia, related to experiences of stigma as well as impairments associated with dementia, can hinder the participation of people with dementia in broader society. Through examining the effectiveness of projective interviewing techniques, the primary studies of this dissertation reinforce that people with dementia can be included in research about their lived experiences meaningfully and offers evidence for future researchers to consider how these techniques may be used to reduce impairment related barriers, for example, supporting discussions when participants experience challenges with memory or recall.

A central concept when thinking about the inclusion of people with dementia and intersections with autonomy, research, and care, is the impact of communication and impairments related to dementia itself. As reported by relatively recent research related to health and social care by Geddis-Regan et al. (2020), improved communication in the decision making process in care settings has been demonstrated to lead to greater satisfaction with decision-making processes for care partners and people living with dementia. As well, enabling conversations with people with dementia can enhance their involvement in decisions (Osterholk et al., 2016). This is important as due to the nature of dementia, it can be challenging for people living with dementia to share their lived experiences, and for researchers, health and social care providers, and policy makers to capture these experiences in such a way that ensures they are listened to and acted upon (Shakespeare et al., 2019). The work undertaken in this dissertation directly addresses the previously identified need for creative ways to support and engage those living with dementia so that their rights to autonomy and inclusion are acknowledged and acted upon when it comes to participating in research (Bellass et al. 2018, Phillipson et al., 2018). Intersecting with the findings of this study around the utility of the projective interviewing techniques to support deeper reflection on future support needs, Geddis-Regan et al. (2020) identified the documentation of future preferences as a key method of improving communication in shared decision making approaches in care settings. The techniques examined in the primary studies of this dissertation highlight how people with dementia can be supported to communicate and imagine future support needs and preferences, which has important implications when prioritizing the inclusion and autonomy of people with dementia in settings outside of research. Indeed, research supports that involving people living with dementia and ensuring their voices are heard can also work to achieve the positive outcomes associated with dementia friendly communities and care – including in supports and services (Innes et al., 2021a; Lin 2017).

Research conducted through this dissertation also has important implications when considering how emotions are connected to autonomy and thus decision making. The techniques examined in the primary studies of this dissertation both had identified impacts on how participants connected to and discussed emotional topics – with both types of prompting seeming to encourage discussions on more emotional topics. Interestingly, researchers have argued that emotion is inherently intertwined with decision making, and that people living with dementia often experience impairment in emotional regulation that impacts their ability to engage in decision making – and emotional dysregulation in turn can have detrimental impacts on their wellbeing and the extent to which they are supported to express their autonomy and engage in decision making independently (Perach et al., 2020). Supporting people with dementia to communicate about emotional topics may serve as a mechanism to support emotional regulation in conversations about decisions and care. This is important to consider when reflecting on broader discourse on the involvement of people with dementia in decision making as a mechanism for acknowledging their rights, especially as research highlights that emotional regulation plays a key role in promoting decision making for people with dementia (Perach et al., 2020). The role of the interviewing techniques in supporting connections to emotions is an area for future research to explore, especially given connections to broader movements seeking to include people with dementia in decision making that influences their lives – through research, policy, and care.

Another important contribution of this dissertation is that of furthering the understanding of the impact and influence of techniques that seek to promote the inclusion and engagement of people with dementia in research through the evaluation conducted. As identified by previous research, many interventions that aim to support the involvement of people with dementia have not been evaluated to determine their effectiveness (Geddis-Regan et al., 2021). While researchers have identified a need to focus on methods to involve and include people with dementia, particularly in areas of care and support, there remains a need to evaluate such methods for their potential to achieve engagement (Innes et al., 2021a). Work conducted through this dissertation directly addresses these gaps by providing an evaluation of how interviewing techniques designed to support communication needs of people with dementia can foster their engagement, in turn creating the potential for additional opportunities to support autonomy or decision making in wider contexts as well as in research. In order to achieve meaningful inclusion of people with dementia in broader society, we must support people with dementia to communicate about their perspectives and experiences, and this research provides evidence on how researchers can work to better support people with dementia to communicate about their experiences (Baldwin, 2008).

While this dissertation identifies the current state of adapted and modified methods and examines two novel interviewing techniques for engaging in research with people with dementia, future research is needed to expand the application of such techniques in broader topics and with diverse populations of people living with dementia in order to establish their usefulness in a variety of research projects as compared to traditional interviewing techniques. It is important that future research examines the types of prompts used and the extent to which they may also impact the data produced, and the engagement of people with dementia when participating in such research. For example, future research should examine whether varying or customizing prompts to align with participant characteristics (e.g., gender, age, etc.) and experiences further impacts the active participation and engagement of people with dementia. This has been explored outside of the broader field of disability studies in work by Clarke et al. (2019), who examined how varying aspects of prompts can change how the story is completed by the participant. It will also be necessary to examine the impact of other types of accessibility adaptations and modifications, such as dementia-friendly communication modifications (e.g., adapting sentence structure and prompts) to ensure that the needs of people with dementia are met when participating in research, and that any impacts on the research itself are evaluated (Eastham & Cox, 2017). As well, while this research independently demonstrates the impact of verbally-prompted and photo-prompted storytelling techniques, future research should consider a comparison of both techniques with each other to determine application relevance in different settings, as well as the extent to which they compare with each other.

Additional avenues for evaluation of these techniques should also be explored. While research, such as that conducted by Astell et al. (2010), supports that generic photograph prompts can support the engagement of people with dementia, the extent to which they support engagement above and beyond generic verbal prompts has yet to be established directly – and compounded by observations from the primary study in this dissertation that photographs tended to influence how participants responded, future research should consider how and when such techniques are best applied. For example, the application of verbally-prompted storytelling may be more engaging for participants experiencing challenges with their vision, and for certain topics such as those expected to be particularly emotionally distressing, the use of traditional interviewing with direct questioning may be more appropriate.

Strengths and Limitations

A key strength of the primary studies conducted as part of this dissertation was that a consistent sample of participants was used across the evaluated techniques. Participants participated in all 3 types of interviews employed in manuscripts 2 and 3 (Chapters 4 and 5), and the order of their participation was counterbalanced to reduce ordering effects. As well, consistent interview guides, prompts, and photographs (where applicable) allowed for a focused evaluation of similarities and differences in the ways participants participated in each of the interview types in the primary studies. This allowed for direct comparisons to be made across interview types (i.e., direct questioning, storytelling techniques), and meaningful conclusions to be drawn. At the time of writing, it is my understanding that the primary studies undertaken in this thesis are the first to undertake an evaluation of the impact of adapted and modified research methods that seek to engage more deeply with people with dementia in qualitative research. The present primary studies have produced a rich depth of knowledge in this field through providing thorough and detailed accounts of the application of two novel interviewing techniques in research with people with dementia. The transferability of the findings also needs to be carefully considered. While the sample size was relatively small, it was sufficient to examine the scope of the interviewing techniques evaluated in the primary studies of the dissertation, evidenced by the depth and quality of the data produced, the variation of the categories identified through the analysis, and detailed depiction of the impact of the techniques that was produced (Morse, 2015). Thus, while future research should be conducted to examine the transferability of the findings of the primary studies of this dissertation to other contexts, the criteria for transferability as related to the concept of rigor established by Guba and Lincoln (1985) is considered satisfied.

A potential limitation of this research is that some participants in the sample of the primary studies identified themselves as dementia advocates – for example, being involved in dementia advocacy groups, or identifying as active participants in the broader dementia community (Chapters 4 and 5). This may have impacted how these participants connected to and engaged with the storytelling techniques, as they presumably are involved in the wider dementia community and may have a broader range of examples to draw on and reflect in their responses during the interviews. The extent to which this characteristic influenced the outcomes of the study is unknown, as participants were not directly asked about whether or not they identified as an advocate, and several participants did not identify a connection to advocacy through the course of the interviews. Thus, the results of the studies should be interpreted with this context in mind especially with respect to the robustness of differences observed between interviewing types. An additional shortcoming of the primary studies is also reflected in the inability to recruit people with dementia at different stages of their dementia journey. All participants self-identified as early to middle stages, and many positioned themselves as dementia advocates. While the primary studies did have favorable variation in terms of participant gender (7 identified as women, 5 as men), and living arrangements (7 lived with family/spouse, 5 lived alone), all identified their race as white. As well, the use of consistent characters and story completion prompts across all participants may have influenced how participants engaged with and responded in the interviews. Further to this, the two techniques were not compared with each other to examine how they may have impacted engagement and/or the nature of the data collected.

It should be noted as well that while the interview guides were developed to be near-identical across the interview types (traditional, semi-structured, verbally-prompted, photo-prompted), there were some prompts that were asked in the storytelling interviews and not asked in the traditional semi-structured interviews. In order to set up the story and character, participants were asked to imagine what the character was thinking or feeling. In contrast, participants were not asked to imagine what they themselves were thinking or feeling in the interviews with semi-structured interviews. While this method of prompting is consistent with traditional semi-structured interviews and storytelling techniques, it may have amplified observed differences between interviews when considering emotional responses, as participants were directly prompted to think about what the character was thinking or feeling. Finally, an additional limitation of the primary studies of the dissertation was that participants were not involved in a reflection of their own engagement during the study. While some participants did provide unsolicited feedback on their experience participating in the different types of interviews, they were not directly asked to reflect on their experience. In order to gain more insight into how the techniques were experienced by participants, future research could consider exploring this aspect. However, care should be taken to preserve the counter-balancing order of the interview schedule and mitigate recall and ordering effects. Further, research supports the use of observational methods to evaluate the engagement of people with dementia over self-report measures (Jones et al., 2018). Thus, while the analysis supports that the techniques facilitated engagement, it is unknown whether all participants felt it impacted their own engagement or participation in the interviewing experience.

Rigour

Strategies to establish rigour and trustworthiness across the dissertation are discussed below, with specific reference to the four-dimensions criteria identified by Guba and Lincoln (1985). These criteria include credibility, dependability, confirmability, and transferability, and are explored with relation to this dissertation below. A brief overview of strategies to enhance rigour for each of the primary studies of this dissertation are also included within each manuscript.

Credibility

Credibility centers on establishing confidence that the results are believable and true from the perspective of the participants (Guba et al., 1985). Through all manuscripts included in this dissertation, rich descriptions of the study methods were prepared. This included developing a scoping review protocol in advance of the scoping review being conducted, as well as the development of the dissertation proposal which outlined the methods for each of the primary studies. The interviewing process and techniques for the primary studies were also reviewed through the dissertation proposal process by all committee members. Investigator authority, or knowledge and skills, is another aspect of credibility identified by Guba and Lincoln (1985). This aspect was supported by ensuring that all involved in data collection, extraction and analysis (i.e., myself (EC) and the research assistants (RAs)), had the required knowledge and skills to perform their roles which included screening abstracts and full-texts in the scoping review (EC and RAs), conducting interviews with people living with dementia (EC), conducting qualitative content analysis (EC and RAs), and conducting analysis of video recordings (EC and RAs). All field notes including reflexivity journals were collected and stored securely on a shared research drive between myself (EC) and my supervisor (CM). Credibility of the studies making up this dissertation was also supported through peer debriefing between myself (EC) and my supervisor (CM). To enhance credibility of the findings of the primary studies, quotations are presented alongside the categories.

Dependability

The concept of dependability as identified by Guba and Lincoln (1985) involves ensuring that the findings are repeatable if the study were to reoccur with the same participants, research team or coders, and context. To establish dependability, each manuscript included in this dissertation provided a rich description of the study methods which were developed through the drafting of protocols and research proposals. Further, detailed records were kept with respect to the data collected to allow for the development of an audit trail. The coding conducted by the relevant research team members (EC and RAs) was guided by best practices for conducting scoping reviews and qualitative content analysis, as well as the observational scale employed (Joanna Briggs Institute Manual for Evidence Synthesis, 2020; Creswell et al., 2016).

Confirmability

Confirmability of the works making up this dissertation was enhanced through establishing reflexivity and triangulation activities. Specifically, I (EC) maintained reflexivity journals throughout the study process for both primary studies included in this dissertation. Regular meetings with my supervisor (CM) were also held to promote reflexivity during the research process. Several triangulation techniques were also applied throughout the studies, including methodological (multiple methods of data collection and analysis), data source (transcripts and video recordings), and investigator (multiple observers and coders).

Transferability

Transferability traditionally refers to the extent to which the results can be transferred to other contexts or settings. The primary studies included in this dissertation present in-depth accounts of the application of various interviewing techniques, and due to challenges with recruitment and the subsequent lack of a diverse sample, the transferability of the findings to other contexts is unclear. However, the detailed descriptions presented of the study as well as the findings supports transferability and allows for readers to determine the relevance of the study conclusions for their own contexts (Firestone, 1993). As well, the sample size was sufficient to examine the scope of the interviewing techniques evaluated in the primary studies of the dissertation, which is evidenced by the depth and quality of the data, the variation of the categories identified, and detailed representation of the impact of the techniques produced (Morse, 2015).

Recommendations

For researchers seeking to implement strategies to promote the active participation of people with dementia in their projects, several recommendations have been developed stemming from the conclusions of the research conducted as part of this dissertation. Results of the primary studies of this dissertation support the use of projective interviewing techniques in research with people with dementia. Related to the use of projective interviewing techniques specifically, it is recommended that researchers seeking to use such techniques in research with people with dementia carefully consider whether such techniques are likely to facilitate involvement in relation to the topic of study. For example, highly emotional topics or those likely to result in distress to the participant may not be most appropriate for the use of these techniques given their demonstrated influence on participants with respect to emotional topics. It is also recommended that researchers seeking to learn about the lived experiences of people with dementia directly from people living with dementia consider the ways in which communication needs may be supported with techniques like those explored in this dissertation. As explored in the introductory sections of this dissertation, several methods exist that are aimed at including the voices of those who have historically been excluded – methods like Photovoice, photo elicitation, and walk-about interviews. However, many methods such as these focus on augmenting or supplementing a semi-structured interview and may not directly address communication barriers that hinder the meaningful participation of people with dementia and support them to share their experiences. Thus, it is recommended that researchers consider using techniques like those employed in the primary studies of this dissertation when seeking to support communication needs during interviews with people with dementia. Focusing on prompts in the storytelling interviews, it is recommended that researchers align closely with the core principles of projective techniques and ensure prompts, both verbal and photographic, are as ambiguous as possible to allow for projection to occur. This may include 'stripping down' interview guides and/or characters that are presented in the interview so that they have very few predetermined characteristics to allow for participants to decide these features themselves (for example, selecting a gender-neutral name for the character, or leveraging sketches and drawings over photographs).

Stemming from the conclusions of the scoping review, it is essential that researchers consider and critically examine whether the methods they use in their research are effective at supporting the engagement of people with dementia. Researchers should conduct evaluations of their chosen methods, especially when adaptations or modifications are made, to examine whether they are meeting the accessibility needs of participants with dementia. Based on recommendations from previous research, for example that conducted by Jones, Sung, and Moyle (2018), and the outcomes of the primary studies from this dissertation, it is recommended that observational methods of evaluation should be considered when studying the effectiveness of methods that seek to involve people with dementia more meaningfully.

Observational methods may have merit in avoiding placing additional burdens on participants to recall which activities they took part in and how they may have felt during.

Conclusion

In conclusion, results from this dissertation support that there is value in adapting and modifying methods to support the active participation and engagement of people living with dementia in research that seeks to understand their lived experiences. Further, this dissertation supports that both verbally-prompted, and photo-prompted storytelling techniques hold promise for supporting the engagement of people with dementia in such research endeavors. This dissertation seeks to establish that employing such techniques aligns with calls to action to further recognize, respect, and uphold the human rights of people with dementia to participate in society, and research, on an equal basis with others. The present thesis supports that research can be undertaken in a manner that both meets the ethical requirements of rigorous academic research and the support needs of those living with dementia to actively participate and share their experiences.

This dissertation also makes several key contributions to knowledge. The studies undertaken and presented in this dissertation support and reinforce the need to evaluate strategies for their effectiveness in engaging or supporting the active participation of people with dementia to foster their inclusion. As well, results of the primary studies of this dissertation further the understanding of how addressing barriers in interviews through techniques that specifically target communication needs can work to improve the engagement and active participation of people with dementia, supporting them to share their lived experiences and perspectives, and thus working to support the inclusion of these experiences in research outcomes in future. Works included in this dissertation also contribute to the broader discourse on challenging stigmatizing stereotypes about people with dementia – while participants in this study took part in traditional interviews with direct questioning, they also shared their experiences in creative ways through the storytelling techniques, thus demonstrating how people with dementia can be meaningfully included and supported to share their lived experiences in different ways. Finally, the primary studies undertaken through this dissertation contribute to the evidence base on the use of projective techniques through evaluating them for their utility and effectiveness in fostering inclusion and meeting participation needs through applying observational methods.

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Chapter 1

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Appendices

Appendix 1: Summary of studies

Table 8. Summary of studies that have used adapted or modified methods to involve people with dementia

Authors	Year	Title	Aim	Sample	Setting	Adaptation or modification used
Kwak, Won Han, & Ha	2018	Telling life stories: a dyadic intervention for older Korean couples affected by mild Alzheimer's disease	Examine how older Korean couples dealing with dementia experience the life story approach intervention through examining responses to a survey, as well as through interviews	56	Community	Researchers were provided with training to encourage participation. Supported communication by referring to old photographs, repeating questions and giving ample time to respond. Utilized the Life Story Book to support conversation. Used short sentences to help participants understand the interview questions
Stephan, Bieber, Hopper, Joyce, & Irving et al.	2018	Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries	Explore the barriers and facilitators of formal care for persons with dementia, their care partners, and health professionals through focus groups	51	Nursing home	Focus groups were kept smaller. Pictures showing typical caregiving situations were included in the focus groups to promote conversation and ensure understanding of the topic
Bartlett & Brannelly	2019	On being outdoors: How people with dementia experience and deal with vulnerabilities	Understand how vulnerability is experienced by people with dementia in the outdoor environment through walking interviews	Phase 1: 16, Phase 2: 15	Community	The method of walking interviews was employed by combining observations and interviews with participants with dementia during their everyday routine. Supported rapport building and conversation through situating the interview in a comfortable space. Participants engaged in conversation when

						supported through the walking interview and when the researchers showed an interest in their life. The length of the walking interviews was based on the participants' needs. Attention was paid to how the person responded during the research process and participation was abandoned if any distress was shown
Barrado-Martín, Heward, Polman, & Nyman	2019	Acceptability of a Dyadic Tai Chi Intervention for Older People Living with Dementia and Their Informal Carers	Investigate acceptability of Tai Chi exercise interventions in meeting the needs of PWD and care partners through focus groups, observations, field notes, and instructor feedback	10	Community	The facilitators of the focus groups were familiar. Non-verbal communication was noted. To facilitate conversation, printed copies of the focus group questions were provided to the participants
Funnell, Garriock, Shirley, & Williamson	2019	Dementia-friendly design of television news broadcasts	Understand the factors that influence the viewing of television news programs by participants with dementia and identify ways to improve the experience through focus groups	5, 11, and 4	Community	To support some participants who struggled with direct questioning, views were drawn out in a conversational manner using an invitation to respond technique. This technique encourages participants to join into the conversation through group interaction
Keyes, Clarke, & Gibb	2019	Living with dementia, interdependence, and citizenship: narratives of everyday decision-making	Examine the ways people living with dementia managed information about themselves and dementia through interviews	16	Community	Interviews were iterative and sequential. Importance of developing rapport evident, interviewers allow for participants to set the pace of the interviews to their own needs and preferences. Participants chose to be interviewed alone or with their care partner, location of interviews

Kindell, Wilkinson, & Keady	2019	From conversation to connection: a cross-case analysis of life-story work with five couples where one partner has semantic dementia	Examine conversations of people with dementia and investigate the utility of life-story work in facilitating communication through home visits, biographical interviews, and video/audio data	5	Community	Narrative interviews were employed. The interviewers used objects, pictures, or photographs from around the participants home to support those with dementia to participate. Care partners also provided support where necessary to enable participation
Krein, Jeon, & Miller Amberber	2019	Development of a new tool for the early identification of communication support needs in people living with dementia: An Australian face-validation study	Establish the face validity of the communication-support needs assessment tool for dementia by consulting people living with dementia and their close family/others who provide support	7	Community	Participants were given several options for feedback provision, including written feedback, or a combination of written and verbal feedback, with or without the support of a care partner to address potential communication difficulties. Participants were provided with the item pool and interview questions in advance
Morbey, Harding, Swarbrick, Ahmed, Elvish, Keady, Williamson, & Reilly	2019	Involving people living with dementia in research: an accessible modified Delphi survey for core outcome set development	Design an accessible Delphi survey with people living with dementia and care partners using the COINED model of co-research to structure consultations through interviews and group sessions	18	Community	The researchers adapted the Delphi method and consulted with people living with dementia to design the methodology. Adaptations were made in the consultation sessions including re-reading statements to clarify meaning. The authors modified the rating scale to include 3 instead of 5 items and stated this modification enabled participation. Additional modifications to engage with participants verbally were made. Approaches to accommodate individual means of participation were

						employed. Direct contact time to develop rapport with people living with dementia and working at their pace was necessary
Øksnebjerg, Woods, & Waldemar	2019	Designing the ReACT App to Support Self-Management of People with Dementia: An Iterative User-Involving Process	Understand how to design and deploy an assistive technology app through involving people with dementia in a user-centered design process	28	Community	Interview questions were purposefully general to enable participants to share their experiences and be flexible to their needs. To guide the interviews, and support attention and memory, questions were presented on posters
Sheth	2019	Intellectual disability and dementia: perspectives on environmental influences	Improve understandings of environmental influences on participation in routine and familiar activities for people with intellectual disabilities and dementia	4	Not specified	Consent forms were adapted to maximize cognitive accessibility. None of the participants were aware of their diagnosis, the term dementia or Alzheimer’s was not included in any recruitment, or consent procedures. Nominal group technique sessions were used. The methodology provided structure to support meaningful engagement in sharing perspectives
Asghar, Cang, & Yu	2020	The impact of assistive software application to facilitate people with dementia through participatory research	Analyze the impacts of the Assistive Brotherhood Community application through case studies and interviews with people with dementia	8	Community	The structure of the questions was kept simple, and the number of questions was reduced to accommodate potential challenges with concentration
Schnelli, Hirt, & Zeller	2020	People with dementia as internet users: what are their needs? A qualitative study	Identify the needs and expectations of people with dementia regarding dementia-related information on the internet concerning	5	Community	Followed recommendations for interviewing people with dementia including identifying willingness to participate, facilitating/stimulating the flow of the interview, creating a

			content, presentation, navigation, language, and design through interviews			sense of security, adapting the interview in terms of physical and cognitive skills, and ensuring an optimal interview environment and the presence of trusted people. Developed rapport prior to the interview and ensured flexibility
Ward, Shack Thoft, Lomax, & Parkes	2020	A visual and creative approach to exploring people with dementia's experiences of being students at a school in Denmark	Explore the experiences of participants with dementia attending an adult school. This study utilized photo elicitation to learn more about the participants perspectives of the service. The photographs taken by participants were used to support focus groups	10	Community	The recruitment process undertaken in a familiar place to foster collaboration in the research process. Participants were given an easy-to-use digital camera for the photo elicitation phase of the study. Instructions were also attached to the camera. Researchers selected the photos to reduce burden on the participants. Small focus groups were deliberately designed to foster engagement. Questions were focused on personal experiences and emotions, rather than memory. Video recordings were made to capture nonverbal communication. Poems, storyboards, and storybooks were developed through the focus group sessions to represent the participants experiences
Weeks, MacQuarrie, & Vihvelin	2020	Planning an Intergenerational Shared Site: Nursing Home Resident Perspectives	Explore the effectiveness of an intergenerational visitation program for participants with dementia through interviews	12	Nursing home	Conversational interviewing was employed to facilitate engagement with the residents in a location that was comfortable to them. A less structured interview was intended to create a conversation-like

						atmosphere to prompt participants to engage with the researcher
Capstick, Dennison, Oyebode, Healy, Surr, Parveen, Sass, & Drury	2021	Drawn from life: Cocreating narrative and graphic vignettes of lived experience with people affected by dementia	Include participants with dementia who have varied cognitive abilities by adapting the Patient and Public Involvement and Engagement process through narrative elicitation to create vignettes of experiences with dementia services	9	Community	Use of storytelling/narrative elicitation enforced a person-centered approach to amplify stories of participants. The method was modified to support participation by using photo-elicitation, informal conversation, and observation. Photographs were used alongside the questions. Participants were encouraged to answer the questions through person narratives or stories
Gebhard & Mir	2021	What Moves People Living with Dementia? Exploring Barriers and Motivators for Physical Activity Perceived by People Living with Dementia in Care Homes	Investigate motivators and barriers concerning physical activity in people living with dementia in care homes in terms of the social-ecological model	10	LTC	The interview guide was created, and procedure developed, to enable participation. Interview questions were asked one at a time to reduce complexity. The study also pre-tested the interview guides with people at various stages of their dementia journey to ensure the interview guide was feasible. Included pictures alongside the interview questions to support verbal communication
Hicks, Innes, & Nyman	2021	Experiences of rural life among community-dwelling older men with dementia and their implications for social inclusion	Address the issue of social exclusion for rural-dwelling older men with dementia within an English county through a technological initiative through interviews	17	Community	Utilization of open interviews to enable meaningful insights into experiences. Walking interviews were offered
Hoel, Mork Rokstad, Hjorth	2021	Person-centered dementia care in homecare	Understand how participants with dementia	12	Community	The interviews were flexible to support ease of participation through

Feiring, Lichtwarck, Selbaek, & Bergh		services - highly recommended but still challenging to obtain: a qualitative interview study	experience home care services through individual in-depth interviews			moving to close-ended questions where needed. Participants were supported by experienced researchers. Consent form was written in simple language to support the participants ability to understand the information about the study
Keogh, Carney, & O'Shea	2021	Innovative methods for involving people with dementia and carers in the policymaking process	Increase the involvement of participants with dementia and care partners using innovative methods, such as a policy cafe and a carer's assembly for care partners	10	Community	The cafe method is discussed as being flexible and adaptable. The topics discussed were kept on the wall and tables to help participants stay on track. An information sheet was provided for clarity purposes. The venue was selected as it was familiar to participants. Decisions from the cafe proceedings were drawn out by an artist. The participants determined the length of the session
McCombie, Cort, Gould, Kiosses, Alexopoulos, Howard, & Lawrence	2021	Adapting and Optimizing Problem Adaptation Therapy (PATH) for People with Mild-Moderate Dementia and Depression	Adapt and optimize problem adaptation therapy for depression in dementia through interviews and focus groups	16	Not specified	Interviewers used think-aloud techniques to guide sessions, to encourage open talk about how they were experiencing the intervention session as it happened, removing the need to recall session details in an interview later
Novek & Menec	2021	Age, Dementia, and Diagnostic Candidacy: Examining the Diagnosis of Young Onset Dementia Using the Candidacy Framework	Understand through semi-structured interviews the experience of accessing and receiving a diagnosis of young-onset dementia	6	Community	Flexible methodology was employed. The consent process was described as inclusive and rigorous. Open-ended questions were used to support conversations. Demographic information was provided by care partners. Throughout the interview, the interviewer sought

						ongoing process consent through restating the study aims, and monitoring for signs of discomfort. When signs of distress were observed, the interviewer offered to pause or change topics. To promote a positive interview experience, the interview sessions concluded with questions centered on the participants strengths and supports
Stamou, La Fontaine, O'Malley, Jones, Parkes, Carter, & Oyebode	2021	Helpful post-diagnostic services for young onset dementia: Findings and recommendations from the Angela project	Examine experiences of dementia service use from the perspective of people living with young-onset dementia and care partners	10	Community	The interview guide was developed to accommodate different degrees of cognitive impairment through two different approaches. A researcher contacted the participant by phone in advance to determine if the participant could recall the survey. A direct approach focused on in-depth discussion of participants’ survey responses was used for those who were able to recall their survey responses. An open approach was employed for those not able to recall the survey
Talbot, Dwyer, Clare, & Heaton	2021	The use of Twitter by people with young-onset dementia: A qualitative analysis of narratives and identity formation in the age of social media	Examine the role of using Twitter for people with dementia through interviews	11	Community	Interview guide was reviewed by 2 people with dementia to ensure that the topics were relevant, and the language used was accessible. Participants were asked questions in the interview and encouraged to engage in reflective storytelling about their experiences. In the second section of the interviews, the participants were

						shown a past Tweet of theirs which supported the conversation
Tiersen, Batey, Harrison, Naar, Serban, Daniels, & Calvo	2021	Smart Home Sensing and Monitoring in Households with Dementia: User-Centered Design Approach	Examine the needs of participants with dementia, care partners, and health and social care providers about smart home systems through a user-centered design process	Phase 1: 9, Phase 2: 2, Workshops: 35	Community	People living with dementia were included in the design process of smart home technologies through participatory design approaches. The data collection approaches were discussed as being aligned to participants' abilities to foster their inclusion in the study
Fleetwood-Smith, Tischler, & Robson	2022	Using creative, sensory and embodied research methods when working with people with dementia: a method story	Explore the use of creative, sensory, and embodied research methods to understand the significance of clothing for participants with dementia in care homes through three cycles of research	Not specified	Care home	Researchers adapted the environment during the study to suit the participants with dementia's needs. Objects were used to elicit sensory and nonverbal communication. The approaches used were highlighted as enabling participants with dementia to engage in research by supporting flexible communication. The researchers volunteered at the care home prior to the study to develop rapport with the participants
Thompson, Tamplin, Clark, & Baker	2022	Therapeutic Choirs for Families Living with Dementia: A Phenomenological Study	Examine the benefits and experiences of participants with dementia and care partners who took part in community-based, therapeutic choirs through interviews	7	Community	Participants with dementia were provided with prompts when facing challenges with communication or recall. The interviewers built rapport with participants before the interview to maintain engagement
Tetrault, Nyback, Vaartio-Rajalin, & Fagerstrom	2022	Advance care planning in dementia care: Wants, beliefs, and insight	Explore the experiences and perspectives of people with early dementia about planning for future care	10	Community	Information about the study was provided in an accessible format. Language was chosen to be easy to understand

	through interviews	

Appendix 2: Scoping Review PRISMA-ScR Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Click here to enter text.
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Click here to enter text.
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Click here to enter text.
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Click here to enter text.
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Click here to enter text.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Click here to enter text.
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Click here to enter text.
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Click here to enter text.
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Click here to enter text.
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Click here to enter text.
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Click here to enter text.
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Click here to enter text.

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Click here to enter text.
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Click here to enter text.
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Click here to enter text.
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Click here to enter text.
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Click here to enter text.
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Click here to enter text.
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Click here to enter text.
Limitations	20	Discuss the limitations of the scoping review process.	Click here to enter text.
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Click here to enter text.
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Click here to enter text.

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018; 169:467–473. doi: 10.7326/M18-0850.

Appendix 3: Scoping Review Eligibility, Inclusion, and Exclusion Criteria

Eligibility criteria	Inclusion	Exclusion
Participants – people with dementia	Directly involved people with dementia as participants, or care partner-person with dementia dyads, in data collection. If more than one type of participant is included, findings must be reported separately for people with dementia. Participants living in any setting (i.e., community, retirement homes, or long-term care homes)	Involved only care partners, caregivers, healthcare professionals, practitioners, or care staff as participants. Did not include key participant group as participants in data collection activities.
Concept/Intervention – involvement/engagement	Studies include the direct involvement of people with dementia as research participants, where data is collected directly from them.	Passive involvement (i.e., observation, chart review, ethnography/participant observation)
Context – methods/types of data collection	Studies use methods that are described as modified, adapted, accessible, dementia-friendly, inclusive, flexible, innovative, novel, creative, strengths-based, person-centered, arts-based, visual, involving storytelling, projective, or reflexive. Includes only qualitative research methods, such as semi-structured, structured, or unstructured interviews with modification or adaptation.	Involve methods that are only quantitative, or qualitative but have not been modified or adapted for accessibility.
Study Design	Study design includes a component where people with dementia are direct participants.	Study design does not involve people with dementia as participants.
Analysis Framework	No inclusion/exclusion criteria; any type of analysis method.	

Appendix 4: Scoping Review Search Strategy

This search strategy is initially developed for PubMed and was adapted for use in other included databases such as Scopus, PsycINFO, and CINAHL.

Concepts	Design	Adapted or modified	Engagement	Dementia
Keywords	Interview* OR "semi-structured" OR semi structured OR unstructured OR informal OR "in-depth" OR "in depth" OR "face-to-face" OR Structured OR guide OR discussion* OR focus group* OR qualitative OR ethnograph* OR fieldwork OR "field work"	Adapted OR Modified OR Accessible OR Innovative OR Novel OR “Accessible Research Methods” OR Accessibility	Participatory OR Communicat* OR Involve* OR Engage* OR Contribution* OR "Meaningful contribution*" OR Inclusi* OR Empower* OR Self-express* OR Flexib* OR Meaningful OR Participat* OR “Participation in research” OR “Participatory Research” OR “Collaborative Research” OR “Experiential Knowledge” OR “Lived Experience” OR “User Involvement”	Dementia OR Alzheimer*
MeSH [mesh] [mesh:noexp]	Interviews as a topic	Music Play and playthings Creativity	Patient participation	Dementia

Appendix 5: Engagement of a Person with Dementia Scale

The Engagement of a Person with Dementia Scale (EPWDS) measures the behavioural and emotional expressions and responses of people with dementia when presented with a psychosocial activity (i.e., non-pharmacological). The scale is designed to examine whether an individual with dementia exhibits an emotional or behavioural expression/response of engagement with, in, or following the introduction of the activity. To capture different expressions of engagement towards a psychosocial activity, the EPWDS measures five dimensions of engagement: *affective, visual, verbal, behavioural,* and *social*.

Each dimension of engagement should be assessed separately but interpreted collectively to generate a comprehensive overview of the person with dementia's experience of engagement toward the stimulus. Every dimension consists of a subscale that measures positive engagement and a subscale that measures disengagement or negative engagement. The EPWDS acknowledges that not all psychosocial activity involves the five dimensions of engagement, but a low score on a certain dimension of engagement may suggest a limitation of the psychosocial activity for the person with dementia assessed.

The EPWDS is developed primarily for research with people with dementia across settings (e.g., acute, community and long-term care). It is recommended that the EPWDS be used for observational periods with minimum observation duration of 10 min. The EPWDS can be used to establish a baseline comparison prior to the introduction of the psychosocial activity.

Each item is measured on a 1–5 Likert scale. The "not applicable" option should only be used when a certain type of engagement is irrelevant or unable to be determined for the person with dementia (e.g., a person who has lost verbal capability after a stroke). Of the 10 items, items 2, 4, 6, 8 and 10 are reverse scored items. After scoring the observational period on the EPWDS, simply reverse the numerical scoring of items 2, 4, 6, 8 and 10. This means that, a score of 5 becomes 1, 4 becomes 2, 3 remains as 3, 2 becomes 4 and 1 becomes 5. After reverse scoring items 2, 4, 6, 8 and 10, add the scores for all 10 items to get an overall measure of engagement for the person with dementia. If all items across the five dimensions of the EPWDS are measured, the total score will range from 10 to 50. The higher the total score, the higher the level of positive engagement exhibited by the person with dementia. The lower the total score, the higher the level of disengagement or negative engagement exhibited by the person with dementia. To examine and control for environmental effects on the engagement level of the person with dementia, an inter-correlation analysis can be conducted between the total EPWDS score and the environmental rating under the section titled "Details of Observation Period and Psychosocial Activity".

Details of Observation Period and Psychosocial Activity:

Start Time of Observation Period:____________________ End Time of
Observation Period: ____________________

Total Duration of Observation Period: ____________________ Type of Psychosocial
Activity: ____________________

Group or Individual Psychosocial Activity:____________________ Location of
Psychosocial Activity:____________________

Appropriateness of the Environment:

Please indicate the extent to which you agree or disagree to the following statement:

The overall environment (e.g., lighting, noise level, and presence of other) is appropria te for the target psychosocial activity to induce positive engagement in people with dementia.	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree

	Affective Engagement Please indicate the extent to which you agree or disagree to the following statements: the person with dementia…						N/A ☐ Not applicable
1.	Displays positive affect such as pleasure, contentment or excitement (e.g., smiling, laughing, delight, joy, interest and/or enthusiasm).	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree	
2.	Displays negative affect such as apathy, anger, anxiety, fear, or sadness (e.g., disinterest, distressed, restlessness, repetitive rubbing of limbs or torso, repeated movement, frowning, crying, moaning, and/or yelling).	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree	

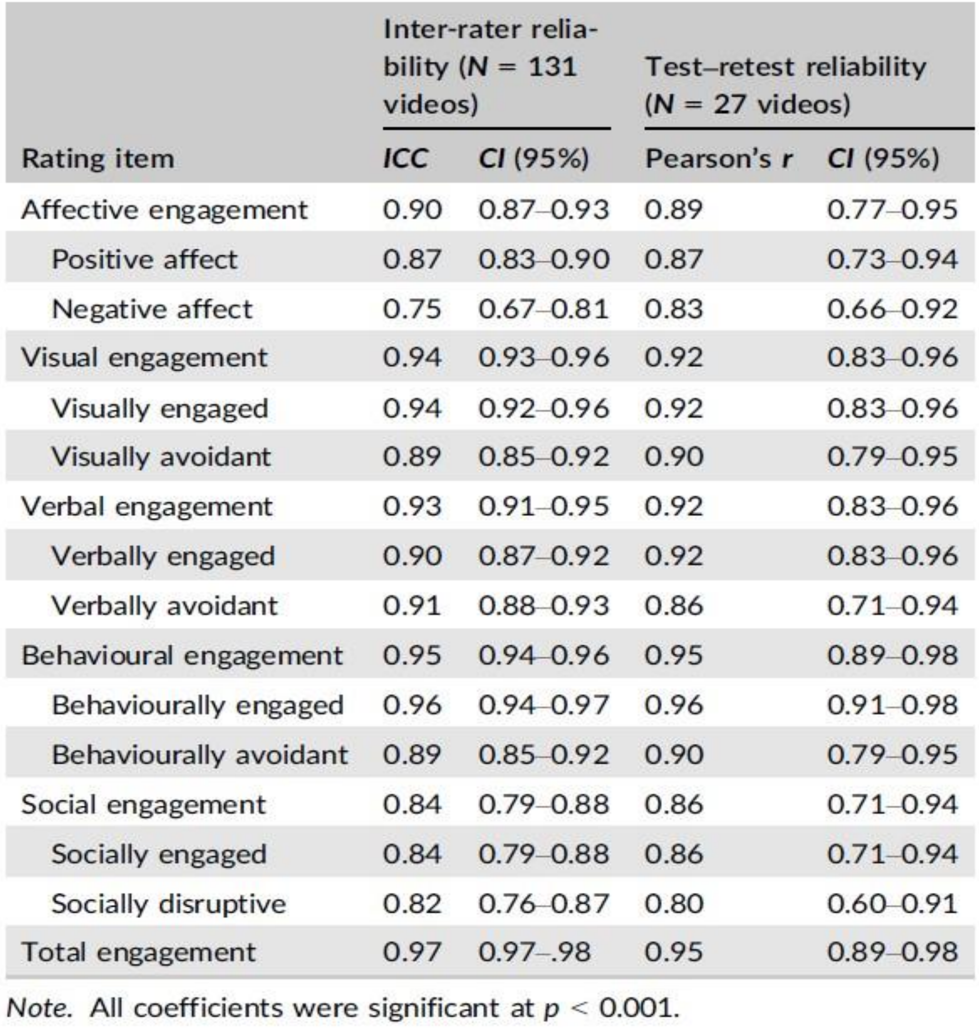
	Behavioural Engagement Please indicate the extent to which you agree or disagree to the following statements: the person with dementia…						N/A ☐ Not applicable
7.	Responds to an activity by approaching, reaching out, touching, holding or handling the activity, the material used, or the person/s involved.	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree	
8.	Responds to an activity by avoiding, shoving away, pulling back from, hitting, or mishandling the activity, the material used, or the person/s involved.	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree	

	Verbal Engagement Please indicate the extent to which you agree or disagree to the following statements: the person with dementia…						N/A ☐ Not applicable
5.	Initiates, participates, or maintains verbal conversation, sounds or gestures (e.g., nodding) in response to the activity, or the materials used, or the person/s involved.	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree	
6.	Refuses to participate in the activity or in a conversation related to the activity by verbalising e.g. “no”, “stop”, etc. <u>OR</u> verbalises negative comment, complaint, and sound (e.g., groaning, or cursing, or swearing) in response to or related to the activity, or the materials used, or the person/s involved.	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree	

	Social Engagement Please indicate the extent to which you agree or disagree to the following statements: the person with dementia…						N/A ☐ Not applicable
9.	Uses the activity or the material/s to encourage others to interact, or as a communication channel to interact and talk with others (e.g., staff and other residents).	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree	
10.	In response to the activity, is distracting or disrupting others (e.g., staff/facilitator and other residents).	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree	

	Visual Engagement Please indicate the extent to which you agree or disagree to the following statements: the person with dementia…						N/A ☐ Not applicable
3.	Maintains eye contact with the activity, materials used, or the person/s involved.	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree	
4.	Appears inattentive, has an unfocused stare or turns head/eyes away from the activity, materials used, or the person/s involved.	1 ☐ Strongly disagree	2 ☐	3 ☐	4 ☐	5 ☐ Strongly agree	

Appendix 6: Inter-rater reliability (ICC) and test–retest (r) results for the engagement of person with dementia scale



	Inter-rater reliability (*N* = 131 videos)		Test–retest reliability (*N* = 27 videos)	
Rating item	*ICC*	*CI* (95%)	Pearson's *r*	*CI* (95%)
Affective engagement	0.90	0.87–0.93	0.89	0.77–0.95
Positive affect	0.87	0.83–0.90	0.87	0.73–0.94
Negative affect	0.75	0.67–0.81	0.83	0.66–0.92
Visual engagement	0.94	0.93–0.96	0.92	0.83–0.96
Visually engaged	0.94	0.92–0.96	0.92	0.83–0.96
Visually avoidant	0.89	0.85–0.92	0.90	0.79–0.95
Verbal engagement	0.93	0.91–0.95	0.92	0.83–0.96
Verbally engaged	0.90	0.87–0.92	0.92	0.83–0.96
Verbally avoidant	0.91	0.88–0.93	0.86	0.71–0.94
Behavioural engagement	0.95	0.94–0.96	0.95	0.89–0.98
Behaviourally engaged	0.96	0.94–0.97	0.96	0.91–0.98
Behaviourally avoidant	0.89	0.85–0.92	0.90	0.79–0.95
Social engagement	0.84	0.79–0.88	0.86	0.71–0.94
Socially engaged	0.84	0.79–0.88	0.86	0.71–0.94
Socially disruptive	0.82	0.76–0.87	0.80	0.60–0.91
Total engagement	0.97	0.97–.98	0.95	0.89–0.98

Note. All coefficients were significant at $p < 0.001$.

Appendix 7: Interview Guides

Semi-structured Interviews with Traditional Interviewing Techniques, Interviews with Verbal Projective Techniques, and Interviews with Visual Projective Techniques

Traditional Semi-structured Interview	Verbal Projective Technique Interview	Visual Projective Technique Interview
Interviewer introduces themselves, explains what the interview will be about, goes through consent script for audio/video recording	Interviewer introduces themselves, explains what the interview will be about, goes through consent script for audio/video recording	Interviewer introduces themselves, explains what the interview will be about, goes through consent script for audio/video recording
Interviewer explains purpose of the interview	Interviewer explains storytelling technique	Interviewer explains storytelling technique, displays photo on screen
Could you tell me a bit about the supports and/or services you have accessed in the past or currently access [add examples from preliminary screening call]? [If you don't currently access any supports or services, are there any that you would like to access - for example, meal services, support groups, help around the house, help with ADLs? Why or why not?] Additional questions: What types of tasks do you find challenging [for example, ADLs, social support, assistance with yard maintenance/groceries etc.]?	I would like to introduce you to the people in the story. There is a person [gender] named [name], and her [care partner – daughter, spouse, etc. name]. In this story, [name] has [insert example of support or service]. S/he is here because [insert role of support or service]. I want you to try and put yourself in [name]'s place for a moment and imagine what it is like for [name]. What is s/he feeling at this moment? What is s/he thinking? Additional questions: What types of tasks do you think [name] finds challenging [for example, ADLs, social support, assistance with yard maintenance/groceries etc.]?	I would like to introduce you to the people in this picture. The person is [name], and the [reflect if there is another person in the photo], [name]. In this picture, [name] has [insert example of support or service]. S/he is here because [insert role of support or service]. I want you to try and put yourself in [name]'s place for a moment. So, I want you to look at this picture and keep trying to imagine what it is like for [name]. What is s/he feeling at this moment? What is s/he thinking? Additional questions: What types of tasks do you think [name] finds challenging [for example, ADLs, social support, assistance with yard maintenance/groceries etc.]?
What prompted you to begin accessing this support/service? [If you don't access supports or services, is there something that would prompt you to do so i.e., experiencing illness/injury etc.?]	What do you think prompted [name] to begin accessing this support/service?	What do you think prompted [name] to begin accessing this support/service?
What about this support/service has worked well for you? And has this support/service had an impact on your family? [If you don't access supports/services, does your spouse or family member?]	What about this support/service do you think has worked well for [name], and [name of care partner]?	What about this support/service, that [name] is doing in this picture [follow example given initially], do you think has worked well for [name], and [name, other person in photo if applicable]?
What about this support/service could be improved? [If you don't access supports/services – do you know about supports and	So, let's imagine that a few weeks have now past since [name] has been using [support/service]. I want you to	So, in this picture, a few weeks have now past since [name] has been using [support/service]. I want you to try

services in your area? What do you think about them?]	try and imagine what [name] has been going through. What about this support/service do you think could be improved for [name], and [name of care partner]? [Additional prompts: Over the past few weeks, what has s/he been feeling? What has s/he been thinking? What questions does s/he have? What has s/he been doing?]	and imagine what [name] has been going through. What about this support/service do you think could be improved for [name], and [name, other person in photo if applicable]? [Additional prompts: Over the past few weeks, what has s/he been feeling? What has s/he been thinking? What questions does s/he have? What has s/he been doing?]
Did you have to access any of these services in a different way than you did before COVID-19 (for example, by phone, online)? If so, what was this experience like for you? [If you don't access supports/services, is it because of the current pandemic restrictions? If restrictions were to be lifted, would you access supports/services? If so, what types?]	How do you think COVID-19 impacted this support/service? What do you think this experience was like for [name]?	How do you think COVID-19 impacted this support/service? What do you think this experience was like for [name]?
What types of supports/services do you think are currently available to you? How do you feel about supports and service that are currently available to you/for people with dementia?	What types of supports/services do you think are currently available for [name], and [name of care partner]? How do you feel about supports and service that are currently available to them?	What types of supports/services do you think are currently available for [name], and [name, other person in photo if applicable]? How do you feel about supports and service that are currently available to them?
What other supports/services do you think would be helpful to you?	What other supports/services do you think would be helpful to [name] or [name of care partner]?	What other supports/services do you think would be helpful to [name] or [name, other person in photo if applicable]?
What advice would you give to others going through what you are now?	What advice do you think [name] and [name of care partner] would you give to others going through what they are now?	What advice do you think [name] and [name, other person in photo if applicable] would you give to others going through what they are now?

Appendix 8: Photograph Prompts

Picture a – first photograph prompt.

Picture b – second photograph prompt.

Appendix 9: Scoping Review Data Extraction

Table 9. Scoping Review Data Extraction

Author(s):

Year of publication:

Origin/country of origin, Institution and Department (where the source was conducted):

Aims/purpose:

Population and sample size within the source of evidence, location of study (i.e., LTC home, community; age):

Methodology/data collection methods:

Outcomes and details of these (e.g., how measured), particularly those related to any increases in engagement noted by researchers:

Key findings that relate to the scoping review questions:
- Rationale for data collection method used (full description of method)
- Human right based rationale cited (Y/N)
- Ethical principle of justice rationale cited (Y/N)

Appendix 10: Scoping Review Presentations of Results

Table 10. Scoping Review Presentation of Results

Parameter	Results
Numbers of publications	Total number of sources of evidence Total numbers between 2017 until 2022 Number of publications per year
Types of studies	Involve people with dementia as direct participants (qualitative, mixed-methods, or includes a component where people with dementia are direct participants)
Populations identified	People with dementia - younger adults 18-64 People with dementia - older adults 65-74 People with dementia - older adults 75+ Care partners - younger adults 18-64 Care partners - older adults 65-74 Care partners - older adults 75+ Others (not classified in any of the above)
Approaches used	Human Rights Ethical/Justice Other (not classified in any of the above)
Outcomes	Impact of method on engagement (method of assessment, findings)
Summary of findings	
Thematic analysis results	Analysis of rationales provided for use of adapted or modified methods