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# More than talking: A scoping review of innovative approaches to qualitative research involving people with dementia

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## **Abstract**

Participation in qualitative research frequently relies upon recall and verbal expression, which may be difficult for some people with dementia. While the use of arts-based and visual methods are transforming dementia care, exploratory research and evaluation methods have lagged behind with regard to the use of innovative qualitative approaches. This scoping review identified innovative qualitative methods that have been used to effectively engage and involve people with dementia in social and health research. Systematic searches of academic databases, Google Scholar, and hand searches identified 24 peer-reviewed articles published since 2010 for inclusion. Analysis focused on a description of both the motivation and methods ascribed by the researchers and how the capacities of people with dementia were engaged as part of the research process. The most frequently used innovative method was Photovoice. Action research, case study, narrative production, ethnography, participatory filmmaking and theater, co-research, and mixed methods were also used. Regardless of methodology, most studies used a participatory approach that incorporated visual methods alongside adapted semistructured or unstructured interviews. Researchers were focused on inclusion, empowerment, self-expression, flexibility, and communication when selecting methods. Providing an appropriate research environment and committing time for repeat contact, observation, and engagement were important considerations.

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# More Than Talking: A Scoping Review of Innovative Approaches to Qualitative Research Involving People With Dementia

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## Abstract

Participation in qualitative research frequently relies upon recall and verbal expression, which may be difficult for some people with dementia. While the use of arts-based and visual methods are transforming dementia care, exploratory research and evaluation methods have lagged behind with regard to the use of innovative qualitative approaches. This scoping review identified innovative qualitative methods that have been used to effectively engage and involve people with dementia in social and health research. Systematic searches of academic databases, Google Scholar, and hand searches identified 24 peer-reviewed articles published since 2010 for inclusion. Analysis focused on a description of both the motivation and methods ascribed by the researchers and how the capacities of people with dementia were engaged as part of the research process. The most frequently used innovative method was Photovoice. Action research, case study, narrative production, ethnography, participatory filmmaking and theater, co-research, and mixed methods were also used. Regardless of methodology, most studies used a participatory approach that incorporated visual methods alongside adapted semistructured or unstructured interviews. Researchers were focused on inclusion, empowerment, self-expression, flexibility, and communication when selecting methods. Providing an appropriate research environment and committing time for repeat contact, observation, and engagement were important considerations.

## Keywords

methods in qualitative inquiry, qualitative meta-analysis/synthesis, photo elicitation, participatory action research, narrative research

## What Is Already Known?

- Semistructured and structured interviews have limitations when used with people with dementia.
- While the use of arts-based and visual methods are transforming dementia care, innovative exploratory research and evaluation methods have been less common.

## What This Paper Adds?

- Insights into the capacity of people with dementia for meaningful research involvement when engaged using innovative qualitative methods.
- The needs for training and support of health and social researchers in innovative methods to better equip them for the inclusion of people with dementia in qualitative research.

## Introduction

Dementia is a chronic, progressive syndrome associated with deteriorating cognitive functions such as memory, speech, and comprehension. Globally, dementia has been identified as a public health priority due to the increasing social and economic demands it places on health systems, families, and communities (World Health Organization, 2012).

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The experiences and implications of living with dementia are unique to each individual and family who is affected. As such, in order to understand the lived experience and needs of people with dementia, it is imperative that they are included as participants in social and health research (Heggstad, Noetvedt, & Slettebo, 2012; McKeown, Clarke, Ingleton, & Repper, 2010). Guides for strategies that promote inclusive research and participation with people with dementia have been published and highlight the need for adapted strategies to support consent, maximize responses, tell the story, and ensure positive research experiences (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). Despite these adaptations, people with dementia are still too often excluded from research (Taylor, DeMers, Vig, & Borson, 2012) either due to the perceived difficulties associated with consent or participation or the limited perceived value for their inclusion (Wilkinson, 2002).

Innovation in research methods has been described as the creation of new concepts, designs, and ways of doing things (Taylor & Coffey, 2008). It is also associated with advancement, adaptation, and development of existing research methods. Such adaptations and advances are frequently motivated by the moral or practical need to improve some aspect of study design and implementation for a particular group of participants, including those who may be vulnerable (Aldridge, 2014). In the last 10–15 years, qualitative research techniques such as the semistructured interview have been used to engage people with mild to moderate dementia in research exploring: identity (Caddell & Clare, 2011; Griffin, Oyebode, & Allen, 2015), spousal relationships (Hellstrom & Torres, 2014; Molyneaux, Butchard, Simpson, & Murray, 2011), and the evaluation of creative arts interventions (Burnside, Knecht, Hopley, & Logsdon, 2015; Stevens, 2011). Associated with this, adaptations have been made to semistructured interview techniques (Cridland, Phillipson, Brennan-Horley, & Swaffer, 2016; Murphy et al., 2015) and quantitative interview tools to assess areas such as health-related quality of life of people with dementia (Hoe, Katona, Roch, & Livingston, 2005; Smith et al., 2006).

However, for people with dementia, semistructured and structured interviews continue to have limitations due to their reliance on abstraction, recall, and verbal reporting (Beuscher & Grando, 2009). Also, while creative, participatory, narrative, and visual approaches have been incorporated into the care and support of people with dementia (Clark & Morriss, 2015; Wiles, Pain, & Crow, 2010), researchers evaluating these interventions have often continued to rely on interviews, questionnaires, or focus group to evaluate their impact (e.g., see Burnside et al., 2015; Guzman-Garcia, Mukaetova-Ladinska, & James, 2012; Stevens, 2011; Zeilig, 2015).

This scoping review explored innovative qualitative methods being used to involve people with dementia in exploratory or evaluative research. Our analysis highlights researchers' motivations regarding selection of methods, as well as describing the methods themselves. In particular, we were interested in providing insight into the capacity of people with dementia to engage in meaningful research that provides them with opportunities for "more than talking."

## Method

This scoping review was conducted using the five-stage framework described by Arksey and O'Malley (2005): identifying the research question; identifying relevant studies; study selection; charting the data; and collating, summarizing, and reporting the results. An additional stage encompassing quality review has been identified as a valuable addition to the original framework (Daudt, van Mossel, & Scott, 2013). However, we did not undertake a quality review of the included studies. This is because our focus was on methods rather than outcomes or on processes rather than results. Subsequently, the rigor of the included studies is of less interest than might usually be expected. We did however note the authors' conclusions about the effectiveness of the research methods used.

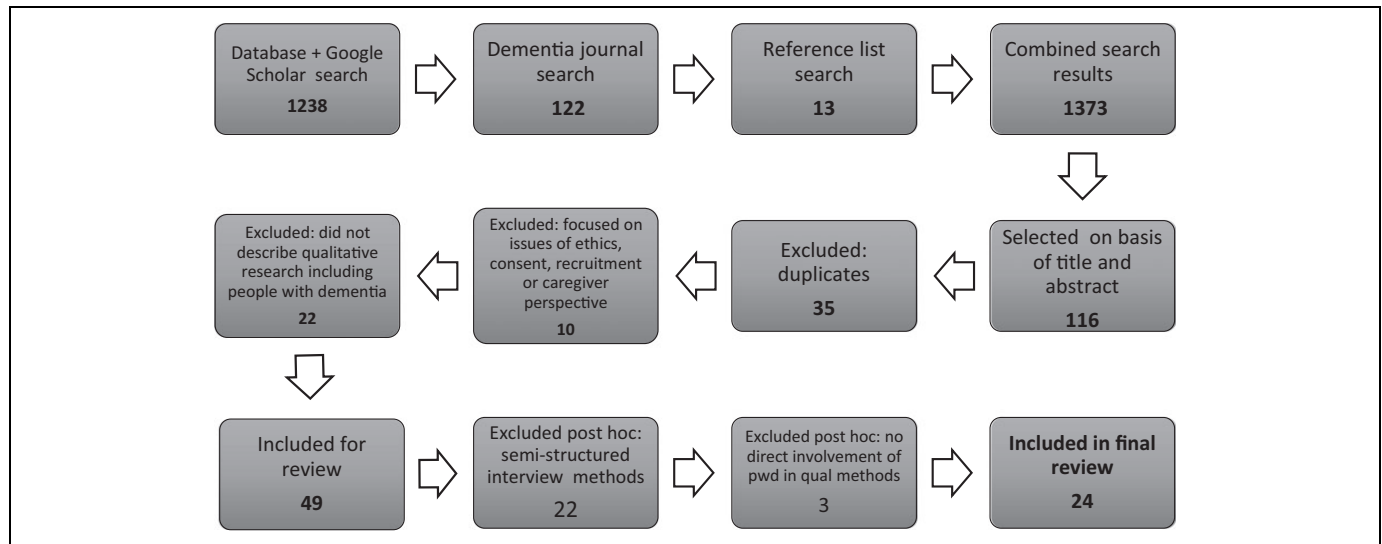
The question used to guide the scoping review was, "What innovative methods are currently being used to enhance the involvement of people with dementia in qualitative research?" For the purposes of this review, we defined "innovative" as qualitative methods other than semistructured interviews. However, studies were included for consideration if they used semistructured interviews with adaptations that aimed to enhance inclusion for people with dementia or if they were utilized in combination with other approaches. We additionally made a distinction between studies exploring the use of innovative interventions and studies exploring the use of innovative research methods.

### Identifying Relevant Studies and Study Selection

An electronic search was conducted using academic databases and the online search engine Google Scholar in September 2016. Databases searched were Scopus, SocINDEX, PsycINFO, and CINAHL. Article reference lists were hand searched and the electronic journal *Dementia* was searched as a stand-alone source. This international peer-reviewed journal was chosen as it is dementia-specific and has an articulated focus on social and experiential research—areas in which qualitative methods are frequently utilized.

Search terms used in academic databases were dementia, methods, research, qualitative, inclusion (includ\*), involvement (involv\*), and innovative (innovat\*). Google Scholar was searched using the phrases "innovative methods of dementia research" and "qualitative dementia research methods." The Google Scholar searches each returned upward of 50,000 results. As these results are ranked by the search engine to reflect relevance and research quality (through author, institution, and citation profiling), only the first 20 pages of results (approximately 200 results for each search phrase) were viewed. As we were interested in making an assessment about current methods, studies published in and after 2010 were included.

In total, the electronic search returned 1,360 results. A further 13 articles located through reference list searching were included giving a total of 1,373 search results. Based on title and abstract, 116 articles were selected for appraisal. From these 116 articles, 35 duplicates were removed and



**Figure 1.** Flowchart depicting search results and exclusions.

81 articles were appraised using the inclusion and exclusion criteria in Table 1.

As a result of the appraisal process, 32 papers were excluded. Ten articles were excluded as they focused either on the perspective of caregivers or on the issues of consent, ethics, or recruitment. Another 20 articles did not describe qualitative research directly involving people with dementia. Many of these were discussion or evaluation papers that—although valuable—did not specifically address the review question. Two articles were excluded as they described quantitative, not qualitative research.

After exclusions, 49 articles remained for appraisal. All were read in full and post hoc exclusions were made. Post hoc exclusions are an accepted part of the scoping review process and commonly occur as familiarity with articles increases (Arksey & O'Malley, 2005). In this instance, increasing familiarity showed 22 articles considered potentially innovative actually used semistructured interviews with no adaptations. Therefore, those 22 articles were excluded. Three further studies were excluded as they had no direct involvement of people with dementia in qualitative methods. This left 24 studies included in the review. A flowchart depicting the search process and exclusions can be seen in Figure 1.

### Charting the Data

A charting process was undertaken to sort and organize the 24 included studies and elicit information and insights relevant to our review question, “What innovative methods are currently being used to involve people with dementia in qualitative research?” The charting process elicited information about region, setting, sample size, and participants.

Charting identified the methods used in each study, the expected benefits of those methods, any techniques used to support the involvement of people with dementia, and the

**Table 1.** Inclusion and Exclusion Criteria.

Inclusion	Exclusion
English language	Language other than English
Published in or after 2010	Published before 2010
Peer reviewed	Editorial, letter, opinion, conference proceedings
Describes qualitative research directly involving people with dementia	Does not describe qualitative research involving people with dementia
Includes description/discussion of methods	Focused on caregiver or on issues of ethics/consent/recruitment

authors' conclusions about the effectiveness of the method used. For details see Table 2.

Of 24 studies, 13 originated from the United Kingdom, with others from Sweden (2), Australia (1), America (1), Israel (1), Portugal (1), Canada (2), the Netherlands (1), New Zealand (1), and Belgium (1). Seventeen studies recruited only people with dementia, seven recruited people with dementia plus family carers, and two of those also recruited staff of residential care facilities. Studies were typically small with fewer than 10 participants with dementia seen in 14 studies, between 10 and 20 in 6 studies, and 20 or more participants with dementia seen in 5 studies (Benbow & Kingston, 2014; Buse & Twigg, 2014, 2015; Morgan, Ataie, Carder, & Hoffman, 2013; Murphy, Gray, van Achterberg, Wyke, & Cox, 2010).

Different approaches were used to assess the capacity of people with dementia to participate in research. These included the application of cognitive tools such as the Mini Mental State Examination (Morgan et al., 2013) or functional assessment tools such as the Barthel Index (Guerra, Rodrigues, Demain, Figueiredo, & Sousa, 2012). More often, screening was not clearly outlined but resulted in the recruitment of participants who were described as “early stage,” experiencing “mild” or

Table 2. Description of Included Studies.

Lead Author (Year), Country	Aim	Setting and Participants	Methods	Perceived Advantages of Method	Techniques to Enhance Involvement	Conclusions About Method
Arieli (2013), Israel	Explore interaction as mutual, equal, and multidimensional as opposed to a therapeutic act	Closed unit in nursing home for the "mentally frail" in Israel. $n = 11$ M early/middle stage	Action research theory. Single researcher visiting single participant. Action-reflection-action cycle used to explore interpersonal communication	Can be used when verbal dialogue not optional. Shifts traditional therapeutic/medical lens	Continue seeing the person as they have always been seen. Engage them as a reflexive partner—joint construction of meaning. Humor. Sense of togetherness.	AR lens allows communication and actions to be exploratory not therapeutic. Supports mutual personal relationships
Bartlett (2012), England, UK	Share insights on modifying and using diary interview method with people with dementia	Interviews in participants' homes. $n = 16$ "high functioning" person	Participatory diary interview + ethnographic observation Pre and post diary interviews Verbal and photo elicitation techniques	Capture rich data Access specific, recent data so reduce recall error Lower burden as respondent chooses how and when to record thoughts and feelings Self-expression Heightened involvement in research process Diary keeping a recognized (normal) process	Person as valued informant Provide options to control data collection type Researcher contact during data collection period Unhurried sensitive approach Breaks Person as diary author Person as valued informant	Puts participant in control of data collection. Month long time frame sometimes onerous or overwhelming. Slower paced, increased reflexivity. Enhanced connectivity between participant, researcher and project Whole person context Extensive potential versus limitations: fatigue, disinterest, confronting diminished skills
Benbow (2014), England, UK	Investigate how narratives can be produced and used by families living with dementia—hypothesized process will be beneficial and lead to learning about experiences	$n = 20$ person with dementia + 21 carers Early stage	Narrative production. Written, audio, or video narrative facilitated by researcher. Narratives analyzed thematically	Enhance perception of patient experience. Contributes to more balanced evidence based Produces structured account of events	Person chooses method of data collection Question and additional prompts sent in writing before narrative production took place Person as storyteller Person as valued informant Person-centered participatory research	Narratives useful to service providers. Promotes patient story through use of personal and relational lens
Bisiani (2013), Australia	Examine impact of baby doll as therapeutic tool for person living with dementia	Residential aged care facility. $n = 1$ IF moderately advanced Alzheimer's	Case study, qual and quant. Ethnographic observation, field notes, Aged Care Funding Instrument—frequency based behavioral tool Pre- and postassessment of doll therapy intervention	Observe communication and behaviors in context Record person with dementia's behavior and interactions with others Involvement of staff Inclusive of participant	Inclusionary consent, ongoing explanations Honesty + openness. Meetings + info for staff Research outcome secondary to participant well-being Person as responsive to stimulus Person as valued informant Small groups	Case study appropriate to assess potential benefits of intervention
Boman (2014), Sweden	Develop a concept for a videophone for use by person with dementia	$n = 6$ person with dementia 3M, 3F	Focus groups Interactive design development	Client-centered design approach Inclusive Able to capture thoughts, feelings, and experiences of person with dementia	Facilitators experienced in working with person with dementia Everyday language Task-related questions Person as responsive to stimulus Person as critical analyst Person as designer Person as valued informant	Illuminated conflicts of opinion between person with dementia and carers/health professionals Generated insights into design as well as personal needs of person with dementia
Bronsson (2014), Sweden	Identify problematic situations for person with dementia at zebra crossings	Dementia association meeting rooms and participants' homes. $n = 6$ (3M, 3F) person with dementia	Photofilm documentation, focus groups, interviews, photo elicitation using film sequences. Grounded theory analysis	Allows exploration of problematic situations Rich data Film sequence triggers include real actions and sounds Ethical way to expose participants to dangerous situations	Undisturbed environment Familiar location Participants known to each other Small groups Response to stimulus Person as analyst Person as valued informant	Focus groups facilitated interparticipant interactions Participant fatigue—too many film sequences

(continued)

**Table 2. (continued)**

Lead Author (Year), Country	Aim	Setting and Participants	Methods	Perceived Advantages of Method	Techniques to Enhance Involvement	Conclusions About Method
Buse (2014), England, UK	Explore how handbags give insight into embodied world of women with dementia. Address role of material objects in experiences of dementia	Homes of person with dementia and care homes. n = 23F; mild to severe dementia n = 29 carers + 28 staff members.	Ethnographic observation, interviews, reminiscence groups, wardrobe interviews	Utilize sensory environment and physical objects to support verbal communication	Observations inclusive of people with advanced dementia Nonverbal responses and reactions considered Person in relationship—carer included in wardrobe interviews to increase insight and depth Person in situ Person as valued informant	Objects can assist person with dementia to tell their stories and express who they are when verbal communication is impaired Material culture lens valuable to illuminate embodied experiences of person with dementia
Buse (2015), England, UK	Use the materiality of dress to explore narratives of person with dementia	Homes of person with dementia + care homes n = 32 person with dementia 9M 23F	Ethnography, Narrative approach Observations, wardrobe interviews, semistructured interviews	New way to represent ageing—challenge static views and create individual context Is not inhibited by short term memory impairment Strengthens identity of person with dementia Objects act as memory triggers Film forms visual autobiography Person with dementia prefer moving images Iterative, personalized process	Visual and sensory methods to support communication Varied data collection methods Time spent interacting with person with dementia Person in situ Person as valued informant	Clothes facilitate storytelling and identity construction Narrative approach maintains personal history and identity Wardrobe interviews provide rich data and insights
Capstick (2015), England, UK	Assess impact of filmmaking on well-being and social participation	Long-term care facility. n = 10 8F, 2M	Participatory filmmaking Observation, ethnographic field notes, audio-recording, filmmaking, photo elicitation	Visual methods enhance conceptualization and improve communication Nontraditional way of communicating Expansive, allows diversity Researchers see participant world view Photos enhance memory	Rapport building Immersive process over several months Participant led process Person as filmmaker Person responding to stimulus Person as valued informant Repeat interviewing increases rapport building Participant led process Person as photographer Person as analyst	Place memories and stories may be metaphors for present day circumstances Dementia better understood through whole-life narrative
Genoe (2013), Canada	Explore meanings of leisure for people with dementia	n = 4 community dwelling person with dementia, 2M, 2F; early stage	Photovoice Participatory action research method Disposable cameras, person with dementia asked to capture objects and subjects. Meaningful to their leisure Multiple semistructured interviews + participant observation	Visual methods enhance conceptualization and improve communication Nontraditional way of communicating Expansive, allows diversity Researchers see participant world view Photos enhance memory	Person responding to stimulus Repeat interviewing increases rapport building Participant led process Person as photographer Person as analyst	Photos insightful and revealing Increased understanding gained Limitations included ethics and consent processes, use of equipment and impaired memory for person with dementia Advantages far outweighed challenges
Guerra (2012), Portugal	Evaluation of proFamilies dementia program using participatory methodology	Participants homes n = 5 person with dementia 3M, 2F + n = 6 family members	Photovoice Photo elicitation focus group Participatory Theater, Image Theater Creative workshops Acting Filmmaking	Highly flexible Empowering Promotes participatory evaluation Inclusive, collaborative, strengths based	Not discussed. Not clear if person with dementia actually took photos as paper refers to “families” participating Person responding to stimulus	Reflexive and spontaneous process that serves both participants and researchers needs Photos promote dialogue and make concrete thoughts and feelings Data analysis complex and time-consuming Produces collective insight Communicate sociological understandings Promote public discussion Reach academic and nonacademic audiences
Jenkins(2016), England, UK	Discuss the creation of four theatrical vignettes to representing everyday life with early onset dementia	Scottish Storytelling Centre. n = 4 persons with early onset dementia + n = 6 family members	Participatory Theater, Image Theater Creative workshops Acting Filmmaking	Give voice to marginalized groups Provide snapshot of phenomena Stimulate creativity, resilience, and cognitive functioning Contribute to public sociology of dementia	Consent conversations including person with dementia Rapport building Theatrical improvisation Person as actor	Methods ensured involvement of all key stakeholders Person with dementia made direct contributions to design and evaluation of assisted living technology Participatory design holds ethical issues as cannot show HREC exactly what the design will be
Martin (2013), England, UK	Explore if technology can provide night time assistance and support using ambient and therapeutic interventions	Homes of person with dementia. n = 8 person with dementia	Participatory design Qualitative observations, adapted interviews, analysis of system usage	Directly involve person with dementia in research Describe lived experience of person with dementia Design user-based technology	Process consent method Involving carers User-centered design approach Continuity Extended time frame Repeated home visits Person as design analyst	Methods ensured involvement of all key stakeholders Person with dementia made direct contributions to design and evaluation of assisted living technology Participatory design holds ethical issues as cannot show HREC exactly what the design will be

(continued)

Table 2. (continued)

Lead Author (Year), Country	Aim	Setting and Participants	Methods	Perceived Advantages of Method	Techniques to Enhance Involvement	Conclusions About Method
McKeown (2015), England, UK	Understand the experiences of person with dementia, carers and staff using life story work	n = 4 person with dementia within NHS social care settings + n = 14 staff and family members	Multiple case study design Constructivist, participatory approach Observations, field notes, conversations, semistructured interviews, document analysis Photovoice, individual interviews, dyadic interviews	Flexible, sensitive to context Explore experiences, views, and practices Increased stakeholder involvement Stimulate ideas Trigger memories Allow co-construction Participant led Increase depth and detail Easier logistics than focus groups	Not discussed	Not discussed
Morgan (2013), United States	Describe dyadic interviews as technique for qualitative data collection	Setting not described n = 20 person with dementia 13F early stage			Discovery phase Minimize distractions, create safe space, and facilitate connection/discussion with one other person Reduce anxiety around disclosure of sensitive issues Time to overcome dementia related communication barriers Encouragement from other dyad participant Person in relationship Person as photographer Person as valued informant	Dyadic interviews + photo elicitation helped revise and refine emerging analysis Rich data Clarity Safety and openness Facilitated increased flow of shared stories Candid, dialogues, highly interactive, in-depth discussions Camaraderie & collective identity Reduced effort for moderator
Murphy (2010), Scotland, UK	Explore effectiveness of Talking Mats to support communication of person with dementia about their well-being	Homes of person with dementia and care homes n = 31 person with dementia 10 early, 11 moderate, and 10 late stage	Video recorded interviews using Talking Mats framework Unstructured, structured conversation plus Talking Mats visual scale Quantitative analysis	Support better communication for person with dementia Inexpensive, low-tech, accessible Flexible Promote expression of views and opinions when verbal communication is compromised	Person treated as autonomous Adaptation of consent forms Advisory group included person with dementia Person as respected informant	Talking Mats framework effective in helping person with dementia express their views Talking Mats have increased effectiveness in moderate and late stage dementia Promotes person-centered care Multiple practical applications Can inform care planning
Murphy (2013), England, UK	Explore whether Talking Mats help person with dementia and family carers to feel more involved in decision-making about daily living	n = 18 person with dementia living at home 10M, 8F 3 Early, 13 moderate, and 2 late stage. + n = 18 carers	Video recorded interviews of couples using Talking Mat versus couples using usual communication methods	Can be used at early, middle, and late stage dementia Provide visual record of conversations Support negotiations around daily living for person with dementia and carers	Adaptation of consent forms Continuity Person as valued informant Person in relationship	Promotes understanding Participants more satisfied with outcomes of conversations Innovative, positive approach Safe, nonconfrontational, reduces anxiety
O'Sullivan (2014), New Zealand	Uncover and interpret the support needs of person with dementia in New Zealand	n = 11 person with dementia mild to moderate + n = 11 family carers	Action research Meetings/interviews Field observations Focus group discussions	Facilitate collaboration with participants Recognizes injustice, that is, marginalization of person with dementia Flexible Generate knowledge and action that brings about change	Two-year data collection Participant led question development Participants identify what is important in data and what is not Consensus sought on analysis Person as analyst Person as valued informant	Consultative, collaborative Participants maintained involvement over long periods of time Increased involvement of participants
Pipon-Young (2011), England, UK	Develop broad understanding of experiences of younger people with dementia Understand beneficial support, identify areas for change, and develop action based on problems identified	n = 8 pw early onset dementia	Action research Individual interviews Action research groups Development of written resource by participants	Problem-focused Participant-generated Collaborative Provides mean to take action and make change Emancipatory. Promotes deep understanding Meaningful and useful	Use of action research: collaborative, participatory Person as valued informant Person as creator/maker	Required commitment to full participant of participants Cognitive difficulties meant participant were not trained to take part in analysis Levels of contribution varied across participants Need to identify appropriate level of collaboration for each group

(continued)



**Table 2. (continued)**

Lead Author (Year), Country	Aim	Setting and Participants	Methods	Perceived Advantages of Method	Techniques to Enhance Involvement	Conclusions About Method
Tanner (2012), England, UK	Discuss implications for people with dementia when involved as co-researchers	n = 3 person with dementia living at home as co-researchers n = 5 participants	Interviews conducted by person with dementia and researcher together	Opportunities for social activity and peer support Include service users Explore potential for person with dementia to act as co-researchers	Process model of consent Preparation + orientation sessions Known venue Responding to visual stimulus Develop trust Debriefing Person as co-researcher Person as valued informant	Co-researchers created relaxed informal atmosphere Shared identity between co-researchers and participants was valuable Emotional connection may be more valuable than eliciting facts Relationships crucial but energy consuming Briefing/debriefing vital Co-researchers provide hope and reassurance to participants
Van Hoof (2015), the Netherlands	Investigate needs of person with dementia relating to interior design in built environment within nursing home	n = 7 person with dementia in psychogeriatric nursing home in city of Eindhoven, the Netherlands 7F, moderate	Participatory design principles 3 hr creative workshop for mood board production Interviews.	Support verbal methods Aligns with practice development approach Mutual learning process Creativity linked to memory and personal competence, allows illustration of unspoken emotions	Known venue Researcher involvement Instructions printed on cards and placed on tables and walls Reminders about aim of exercise given Participants "in charge" of their own process (?) Open questions Person as valued informant Person responding to stimulus Known venue Person responding to visual and site prompts	One-on-one assistance recommended during creative session Helps people express themselves nonverbally
Van Steenwinkel (2014), Belgium	Gain understanding of how people with dementia experience and use space	n = 1 F person with dementia "Mary" Home of person with dementia	Case study Situates semistructured interviews Photo and visual prompts	Articulate in-depth understanding Exploratory approach can reveal multiple possibilities	Mixed methods provide inclusive data collection strategies In situ conversations do not require recall Photo prompts—person responding to stimulus Inclusion of family carers—person in relationship Participant led Person in situ Person as valued informant	Case study provides a start point for further research Rich data
Ward (2013), England, UK	Consider approaches to investigating appearance and maintenance of appearance in dementia	8 Care based hair salons in North West England	Mixed methods Semistructured interviews In situ conversations Discussion groups Mapping Participant observation Video Appearance biographies Ethnographic events	Give consideration to sensory and experiential dimensions of appearance Generate rich description Explore meanings	Person as valued informant Mixed methods provide inclusive data collection strategies In situ conversations do not require recall Photo prompts—person responding to stimulus Inclusion of family carers—person in relationship Participant led Person in situ Person as valued informant	Filming captures nonverbal data from person with dementia In situ conversations have particular benefits for person with dementia Appearance biographies useful for gathering insights into embodied histories Mixed methods allowed different ways of seeing
Wiersma (2011), Canada	Understand how Photovoice can be used as a methodology with person with dementia	n = 4 person with dementia, 3M, 1F Early stage dementia	Photovoice Participants use disposable camera to take photos Photos used as prompts in interviews Focus group	Meets calls for more creative forms of social science research Privilege participant voices as well as and artistic representations Participatory Challenges stigma Capture complexity of lived experiences Allow readers to connect with participant stories	Person as valued informant Meetings with researcher Logistical issues discussed transparently Person as creator—brochure developed to describe study Person as valued informant	Exciting tool Various challenges outweighed by benefits Opportunities to promote social and cultural change

Note. NHS = National Health Service, HREC = Human Research Ethics Committee.

“moderate” dementia or being “high functioning.” Four studies included some participants who were experiencing what was described as “severe” or “late stage” dementia (Buse & Twigg, 2014; Murphy et al., 2010; Murphy & Oliver, 2013; Ward & Campbell, 2013). No studies were conducted exclusively with this group. Two explanations were commonly cited for the screening and exclusion of people with advanced dementia including concerns about communication and memory and concerns about informed consent.

The use of familiar locations, reminders, repeat contact with researchers, and dedicated time for relationship building were cited as contributing to a safe and productive research environment (Bartlett, 2012; Bisiani & Angus, 2013; Jenkins, Keyes, & Strange, 2016; Wiersma, 2011). Several studies identified that they used a “process consent” approach whereby informed consent is sought at multiple ongoing time points in order to facilitate a more genuine experience of choice and control for the person with dementia (Martin et al., 2013; Tanner, 2012).

Researchers displayed significant cohesion in their expectations of the perceived benefits of using innovative research methods. These were predominately focused on inclusion, empowerment, self-expression, and flexibility. Innovative methods were reported to support communication (Arieli, 2013; Murphy & Oliver, 2013), increase understanding (Boman, Nygård, & Rosenberg, 2014; Capstick & Ludwin, 2015), and generate rich insights (Genoe & Dupuis, 2013; Jenkins et al., 2016), all critical components of meaningful qualitative research.

Acknowledgment of the challenges related to including people with dementia in research was made in most studies. Difficulties with recall, reporting, and comprehension were perceived as an inevitable reality of conducting research with people with dementia. However, researchers used varied strategies to minimize confusion and distress as well as to maximize meaningful and respectful engagement with participants.

Charting allowed us to identify the frequency with which particular methods had been used. The complete range of methods as identified by researchers included: Photovoice (4), action research (3), case study (3), participatory design (3), Talking Mats (2), ethnography (2), narrative production (1), participatory filmmaking (1), participatory theater (1), participatory diary interview (1), photo/film documentation (1), co-research (1), and mixed methods (1).

However, it was apparent that the named method in each study did not always reflect the varied individual research activities that were undertaken. For example, a study using the named method “participatory diary interviews” involved research activities including ethnographic observation, photo elicitation, narrative production, diary keeping, and adapted semistructured interviews (Bartlett, 2012).

### *Collating, Summarizing, and Reporting the Results*

When collating and discussing scoping review results, it is common to create a thematic framework in order to give some structure and meaning to results (Arksey & O'Malley, 2005; Daudt et al., 2013). In this instance, the most straightforward

way to answer the first research questions was to group studies by the type of methods used. For this, five categories were derived from the named methods in the articles included in this review and including case studies, action and co-research, visual methods, participatory methods, and ethnography. These categories have been used to organize the reporting of the results of this review. The activities of people with dementia as actors in the research were described.

### *Case Studies*

The inherent flexibility of case study methods was demonstrated in three studies from the United Kingdom, Belgium, and Australia (Bisiani & Angus, 2013; McKeown, Ryan, Ingleton, & Clarke, 2015; Van Steenwinkel, Audenhove, & Heylighen, 2014). Two single and one multiple case explorations investigated diverse topics including doll therapy, relationship to the physical environment, and the experience of undertaking life story work. Although topics were diverse, a shared theoretical approach was evident. A constructivist approach underpinned these case studies which therefore acknowledge multiple valid constructions of reality and the consequent co-existence of varied ideas and beliefs, all of which are equally deserving of being given a “voice” (Bisiani & Angus, 2013; McKeown et al., 2015). This approach aligns with the highly regarded and much discussed work of Kitwood (1997), who argued for a person-centered, participatory approach privileging the voice of people with dementia in research (Bisiani & Angus, 2013).

As is typical of case studies, a combination of research activities including observation, interview, document analysis, and field notes was utilized. To successfully undertake this range of activities, some researchers established cooperation with carers and staff in residential care facilities (Bisiani & Angus, 2013; McKeown et al., 2015). One study in particular described a high level of transparency and shared goal development with staff who were trained to collect data through the use of field notes and a quantitative frequency-based tool (Bisiani & Angus, 2013). This demonstrated the potential for case study methods to build capacity and engender mutually beneficial relationships between researchers and care staff. In contrast, the method was also used to explore the experiences of an individual person with dementia living at home, without the inclusion of any family or carers (Van Steenwinkel et al., 2014). In this instance, the depth and personal nature of data generated using case study methods was highlighted.

### *Action and Co-Research*

Four studies utilized action and co-research methods in varied ways but with similar intentions: to deepen understanding, facilitate collaboration, and create change (Arieli, 2013; Pison-Young, Lee, Jones, & Guss, 2011; O'Sullivan, Hocking, & Spence, 2014; Tanner, 2012). Action research was employed as a pragmatic approach to identify and act on problems or injustices, interpreted as areas in need of change (Pison-

Young et al., 2011; O'Sullivan et al., 2014). It was also used as a theoretical approach to explore personal relationships and develop a reflective cycle to enhance communication (Arieli, 2013). Despite existing frameworks developed to guide action research, a flexible interpretation of the process was evident. This flexibility was noted as an anticipated benefit of the method.

People with dementia were involved in one study using a co-research approach (Tanner, 2012). Co-research was based on a similar participatory and emancipatory philosophy as action research but arguably demonstrated more significant personal benefits for participants. This highly innovative approach integrated people with dementia into the research team as trained interviewers who conducted interviews with participants, also diagnosed with dementia. For interviewers, this technique built capacity, enhanced self-esteem, and supported social skills. For interviewees, shared identity with the co-researchers engendered unexpected authenticity and connection (Tanner, 2012). Both action and co-research were associated with the development of ongoing relationships with participants and as such required considerable personal investment from the researcher.

### *Visual Methods*

Two types of visual methods were used: those in which participants produced their own photographs and films (Genoe & Dupuis, 2013; Guerra et al., 2012; Morgan et al., 2013; Wiersma, 2011) and those that incorporated preexisting photographs, films, or visual tools (Brorsson, Öhman, Lundberg, & Nygård, 2014; Murphy et al., 2010; Murphy & Oliver, 2013). Visual methods had diverse applications including identifying problematic real-world situations, exploring meaning and evaluating programs. Almost all studies using visual methods utilized semistructured interviews or discussion groups of some kind, reflecting the common practice of using verbal interaction to explore and contextualize visual material (Banks & Zeitlyn, 2015).

Researchers anticipated that visual methods would support and extend communication and allow co-construction of meaning (Morgan et al., 2013). In particular, Photovoice was identified as an inclusive, empowering technique that facilitated collaboration and supported shared understandings. The Photovoice method involves participants independently taking photographs that provide insight into their world (Wang & Burris, 1997). For older people with dementia, Photovoice posed challenges including operating equipment, navigating complex consent processes, forgetting the context or meaning of photos, or forgetting to photograph something that they subsequently identified as meaningful (Genoe & Dupuis, 2013). However, benefits of Photovoice were perceived to outweigh these challenges (Guerra et al., 2012; Wiersma, 2011).

Talking Mats were developed as a visual tool to counteract challenges associated with deteriorating verbal communication and comprehension for people with dementia. They are positioned as a low-tech, low-cost tool that promotes self-

expression when verbal abilities are compromised (Murphy et al., 2010). Talking Mats use a semistructured framework incorporating a visual scale to elicit views on a range of topics and have been shown to increase effective communication, particularly for those in the later stages of dementia (Murphy et al., 2010; Murphy & Oliver, 2013). This is significant considering the lack of engagement of people with advanced dementia in qualitative research, premised on a decline in their communicative abilities.

### *Participatory Methods*

Participatory methods were used to involve people with dementia in hands-on processes including filmmaking (Capstick & Ludwin, 2015), writing and acting (Jenkins et al., 2016), diary keeping (Bartlett, 2012), design (Boman et al., 2014; Martin et al., 2013; van Hoof, Sprong, Marston, & Jansen, 2015), and autobiographical narrative production (Benbow & Kingston, 2014). In these studies, innovation was consistently demonstrated in both the hands-on processes and the methods used to explore them. For example, the development of new assistive technology was explored using a user-centered design approach (Martin et al., 2013); both the process (developing assistive technology) and the approach to exploration (user-centered design) were innovative.

Participatory methods were seen as a way to explore creative processes while developing deep understanding of participant experiences and worldviews (Capstick & Ludwin, 2015; Jenkins et al., 2016) although arguably this was not always achieved successfully. It was evident that richer data and insights were achieved when relationships between researchers and people with dementia were sustained over time, although this was noted as a challenge of participatory methods (Bartlett, 2012; Martin et al., 2013). Researcher reflexivity and theoretical grounding were observed to contribute to the robustness of participatory methods.

The therapeutic potential of engaging in participatory studies was highlighted (Benbow & Kingston, 2014; van Hoof et al., 2015), but participatory methods also included creative processes whose purpose extended beyond the therapeutic. Tangible outputs included the development and testing of assistive technology (Boman et al., 2014; Martin et al., 2013) and the production of filmed theatrical vignettes used for public and academic education (Jenkins et al., 2016). Participatory methods were identified as paying particular attention to issues of power and inclusion and the construction of shared understandings. Researchers' expectations that participatory methods would increase rapport and support communication were met.

### *Ethnography*

Studies using ethnographic techniques to explore material and embodied experiences were of particular interest. Three studies built rich data sets using observation, immersion, situated interviews, video recording, mapping techniques, and biographies (Buse & Twigg, 2014, 2015; Ward & Campbell, 2013). All

from the UK, the studies explored aspects of material culture and embodiment through the lens of clothing, appearance, and identity. The authors share an articulated desire to promote innovative methods in dementia research including narrative and biographical approaches (Buse & Twigg, 2015) as well as mixed methods (Ward & Campbell, 2013). The depth and sensitivity of the insights and understandings developed through these techniques are notable.

The involvement of people with dementia was enhanced by the use of methods that supported and extended memory and communication and reduced reliance on recall. What Ward and Campbell (2013) has called “in situ conversations” took place on the spot, as participants were actually experiencing events in real time. These events were also filmed to capture embodied practices and interactions between people with dementia, the physical environment, and people without dementia who participated in the study. Semistructured interviews were extended and adapted using sensory and visual techniques including “wardrobe interviews” in which people with dementia showed and discussed their clothing with researchers (Buse & Twigg, 2015).

Unsurprisingly, observation was a key research activity in ethnographic studies—which traditionally use immersive naturalistic observation as a key element of data collection (Whitehead, 2005). Observations took place in varied environments including public (hair salons), private (homes), and residential care settings. Although many studies in this review used observations, ethnographic studies demonstrated particularly nuanced understanding of how observation can be used to facilitate the inclusion of people with dementia in research.

## Discussion

This review describes innovative qualitative methods that have been used to involve people with dementia in research published since 2010. In this instance, innovative methods were defined as those that used methods other than semistructured interviews or focus groups in their conduct.

While most studies reported their participants were people with mild to moderate dementia, few formally assessed cognition or function as requirement for participation (Guerra et al., 2012; Morgan et al., 2013). The process of assessment appeared less important than the process of consent, and in a minority of instances, people with dementia were excluded when researchers cited concern for communication and capacity for informed consent. This suggests that the ongoing intentional exclusion of people with dementia from research may be a limitation associated more with the mind-set of some researchers than with the capacity of people with dementia to participate in well-designed studies (J. S. Taylor et al., 2012).

Frequently used innovative methods included ethnographic observation, photo elicitation, visual and sensory adaptations to interviews, and participatory techniques that prioritized the hands-on involvement of people with dementia in varied projects. The most commonly used participatory technique was

Photovoice, a visual method in which participants take photographs to reflect and express their worldview (Wang & Burris, 1997). Photovoice is often used with marginalized and vulnerable groups (Sutton-Brown, 2014) and therefore may be seen as appropriate for people with dementia, who are sometimes positioned as excluded and disadvantaged (Hellstrom, Nolan, Nordenfelt, & Lundh, 2007).

Other visual methods including filmmaking, photography, photo elicitation, and video recording were used frequently. This reflects a growing interest in visual methods and supports suggestions that the persistent perception of qualitative research as rigidly text based may be shifting (Banks & Zeitlyn, 2015; Mannay, 2016). Talking Mats (J. Murphy & Oliver, 2013) were one method which combined both visual and conversational elements and were developed specifically to enhance communication. We propose that the capacity of Talking Mats to extend and support verbal communication may have strong practical applications when involving people with dementia in qualitative research, particularly considering the continued reliance on semistructured interviews as a data collection method.

Overall, this article has highlighted the potential of people with mild to moderate dementia to act as active, insightful, and meaningful contributors to the research process. In the studies reviewed here, people with dementia participate through a series of processes including talking to researchers and others; making, creating, or doing something tangible; responding to an introduced physical or visual stimulus; and experiencing a life event in context or “in situ” and/or through a willingness to be observed or filmed. The innovative methods described here have engaged people with dementia as conversation partners, storytellers, thinkers, designers, filmmakers, photographers, actors, observers, analysts, meaning makers, and co-researchers. This is in stark contrast to much medical and health research regarding people with dementia which has been critiqued for the use of stigmatizing language and the portrayal of people through a deficit-based pathological lens (Behuniak, 2011; Kitwood, 1997).

The review also illuminates the work of a particular type of researcher. Arguably, the majority of these studies are theoretically informed, creative, attentive, reflexive, intentional, careful, and pragmatic. This implies that they have been conducted by researchers who view participants with dementia as valued informants and who have taken time to get to know their participants, often designing research for them and with them, rather than just about them. The choice of innovative methods allows researchers to work with the strengths of study participants rather than focus on assessment or identification of deficits. This strengths-based approach has been identified as important in the person-centered care of people with dementia (Kitwood, 1997) but may not yet have been sufficiently emphasized as a desirable approach for research. The role of higher education in dementia studies to improve the quality of dementia care has emphasized the need for both specialist knowledge and skills as well as the development of critical thinking, reflection, and action (Downs, Capstick, Baldwin, Surr, &

Bruce, 2009). This article suggests the need for higher education to also consider its role in training of research students to promote innovation within dementia research.

Although researchers chose innovative methods, challenges in research practice were still acknowledged. In general, when working with people with dementia, particular complexities existed around recruitment, ethics and consent processes, and the time and energy demands of the research. Barriers to inclusive research included complicated and rigid ethics processes and from a funding perspective, a lack of acknowledgment of the time required to build and participate in meaningful research interactions involving people with dementia. Perhaps because of these and other challenges, people with more advanced dementia were included as participants in only four of these studies. Further research should continue to promote the development of innovative methods that are also inclusive of this segment of the population.

The ongoing nature of these challenges suggest that if innovative qualitative methods involving people with dementia are to be supported, it will require not just a change in research training but also in the institutional practices that underpin and support social and health research.

## Conclusion

Innovative qualitative methods can be used to support the inclusion of people with dementia in research. Innovative methods such as ethnographic observation, photo elicitation, visual and sensory adaptations to interviews, and participatory techniques have been used to successfully engage people with dementia and to generate rich insights into their thoughts and experiences. According to researchers, innovative methods can enhance inclusion, empower participants, support self-expression, and increase flexibility. The aims and approaches of innovative methods are aligned with a participatory, emancipatory model of qualitative research.

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