

Talking Lines: A Research Protocol Integrating Verbal and Visual Narratives to Understand the Experiences of People Affected by Rarer Forms of Dementia

International Journal of Qualitative Methods

Volume 22: 1–10

© The Author(s) 2023

DOI: 10.1177/16094069231176195

journals.sagepub.com/home/ijq

Paul M. Camic¹ , Sam Rossi-Harries¹ , Emma Harding¹ , Charles R. Harrison¹ ,
Mary Pat Sullivan² , Adetola Grillo² , Emilie V. Brotherhood¹ , and Sebastian J. Crutch¹ 

Abstract

People affected by rarer forms of dementia often have a long and difficult experience obtaining a diagnosis and appropriate support, impacting family, employment and social relationships, quality of life and wellbeing. For this population progressive cognitive symptoms affect skills other than memory and disproportionately occur under the age of 65 years, often resulting in misdiagnosis and lack of appropriate care pathways. The objective of this study will be to better understand the subjective experience of the time period from first noticing symptoms to obtaining a formal diagnosis, through to accessing support, and onward to the present time. Through the concurrent use of line drawings and video-recorded interviews we will collect the stories of people living with different rarer dementias and/or family members who are care partners in Canada and the United Kingdom. Narrative and visual analysis will be used in parallel to methodologically explore how line drawing and verbal discourse interact and inform each other to construct knowledge, and how the use of drawing lines might enrich research interviews and increase accessibility of research participation. This novel research approach may also have implications for clinical interviewing, support services, and public engagement. To the best of our knowledge, this is the first study to retrospectively explore over time the experiences of people affected by rarer forms of dementia from initial symptoms—to diagnosis—to accessing support—to the present, using visual and verbal methodologies.

Keywords

qualitative interview, line drawing, young onset dementia, arts-based research, virtual environments, family caregivers

Rarer Forms of Dementia

Alzheimer's disease and vascular dementia are generally considered older onset dementias (after 65 years) and account for about 60–70% of all dementias. Symptoms for these types of dementia are well documented and in many places of the world, care pathways exist and support is available. Yet even with these better known dementias there are many people for whom care is limited or non-existent (Giebel, 2020). Other lesser known types of dementia have different symptom profiles, often non-memory led, that disproportionately affect those under 65. Terms used to describe this population are not always precise and include young onset dementia (YOD), rarer dementia, and early-onset dementia. Harvey et al., (1996)

was one of the first to define rare dementia as having progressive cognitive symptoms other than memory and/or where

¹Dementia Research Centre, Research Department of Neurodegenerative Disease, UCL Queen Square Institute of Neurology, University College London, London, UK

²School of Social Work, Faculty of Education and Professional Studies, Nipissing University, North Bay, Ontario, Canada

Corresponding Author:

Emma Harding, Dementia Research Centre, Research Department of Neurodegenerative Disease, UCL Queen Square Institute of Neurology, University College London, 8-11 Queen Square, London WC1E 6BT, UK. Email: emma.harding@ucl.ac.uk



Creative Commons CC BY: This article is distributed under the terms of the Creative Commons Attribution 4.0 License (<https://creativecommons.org/licenses/by/4.0/>) which permits any use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (<https://us.sagepub.com/en-us/nam/open-access-at-sage>).

onset occurs before 65 years. More recently [Hendriks et al., \(2022\)](#) estimates an overall global age-standardised incidence rate of 11.0 per 100 000 population in the age range of 30–64 years, corresponding to 310 000 new cases annually worldwide. London based [Rare Dementia Support \(RDS, n.d.\)](#) reports “between 5 to 15% of people living with a dementia receive a diagnosis of rare, inherited or young onset dementia”, and [Hendriks et al., \(2021\)](#) estimates age standard prevalence of 31.8 per 100 000 in the United States for YOAD.

Non-memory-led dementias include conditions initially affecting behaviour (e.g. behavioural variant frontotemporal dementia [FTD] and genetic variant familial FTD (FFTD)), language (primary progressive aphasia [PPA]), vision (e.g. posterior cortical atrophy [PCA]). Other types include familial variant Alzheimer’s disease (FAD), and young onset Alzheimer’s disease [YOAD], the latter with a reported significantly higher level of depression, anxiety and euphoria than in late-onset AD, ([Gumus et al., 2021](#)), and “where neuropsychiatric symptom profiles of YOAD differ from late-onset AD cross-sectionally but also display significant differences in progression” (p. 213).

People living with rarer and younger onset dementia face a gamut of problems and challenges. Many are still working age at the time of diagnosis and may still have parenting responsibilities, and be in the role of care provider for older family members. Financial changes brought about by reduction or loss of employment are often not made up by state benefits due to not meeting age or disability qualification requirements ([Cartwright et al., 2021](#)). Obtaining an accurate diagnosis and finding appropriate care and support can be stymied by the dearth of information and knowledge about rarer forms of dementia in healthcare and social services ([Millenaar et al., 2016](#); [Roberts et al., 2023](#); [Woolley et al., 2011](#)). The challenges can be profound and have deleterious effects on the lives of people living with rarer dementias (PLwRD) and their care-partners (family members and close friends).

Line Creation in Prehistory and Contemporary Use in Cognitive Screening, Therapeutic Interventions and in Qualitative Research

The representation of human experience through visual forms of creation is truly ancient. Typically, we think of storied depictions of animals and hunting in the cave paintings of our upper palaeolithic ancestors in western Europe as being the first examples of human artmaking ([Bar-Yosef, 2002](#)), but these naturalistic representations are predated by more primary, abstract and symbolic creative behaviours which can be traced back to prehistoric Africa. Some of the earliest known human patterns include lines which run in parallel, form curves, zigzags and criss-cross designs ([Morris-Kay, 2010](#)) and line-making in various forms is considered a primary

component for many central developments of human experience throughout the world (particularly relating to communication and connecting with others) such as language and script, visual art, musical notation and wayfinding ([Ingold, 2016](#)). The ubiquitous nature of line production in everyday life continues to the present day, and most people of adult age are familiar with processes such as doodling, diagramming, or making a hand-drawn map.

Line drawing is a multicomponent process involving personal, social, behavioural, visuo-spatial and motor interactions amongst others. In the context of dementia, it has commonly served a diagnostic or clinical function; screening for those with cognitive impairments through observation of inaccurate or distorted construction of drawings such as clock faces ([Souillard-Mandar et al., 2016](#)) or intersecting shapes. Line drawings are also proposed to differentiate between different dementias ([Trojano & Gainotti, 2016](#)) and one small study also found a selective inability in a person living with “probable” Alzheimer’s disease to draw horizontal lines, whilst the ability to draw oblique and vertical lines was spared ([Grossi et al., 1998](#)). There is little doubt that dementias affecting different brain regions lead to challenges with the construction of drawings, but drawing has also become an important facet of nonpharmacological approaches to dementia care and support, and there is growing evidence to support a range of art forms being used with different populations and age groups in community, clinical, hospital and residential settings ([Clift & Camic, 2016](#)). [McEvoy and Bellas \(2017\)](#) have used drawing as a reflective tool for carers of people living with dementia and found it a helpful tool for carers “to access unspoken thoughts and emotions and improve their understanding of non-verbal interaction” (p. 46). Leisure-based art activities have been used as a source of respite and identity building for carers ([Hunt et al., 2018](#)) and there have been advances with the use of art therapy with people living with dementia in both western and eastern care and research settings ([Wang & Li, 2016](#)). Drawing has frequently been used as a tool in art therapy to build resilience and cope with adversity ([Hass-Cohen et al., 2018](#)), but there have also been calls for more neurologically informed, evidence-based practices when using art therapy with dementia populations ([Guseva, 2019](#)). Likewise, it should also not be assumed that lines or drawings are used or understood in the same way by different cultures and efforts should be made to understand the implications of creative research practices for indigenous populations and people from different cultures accessing dementia services around the world ([Hammond et al., 2018](#); [Kaimal & Arslanbek, 2020](#)).

Line drawings can express both the concrete and the imaginary and provide interconnected ways of orienting knowledge about lived experience ([Ashton, 2014](#)). Increasingly, drawing has been used in qualitative research interviews with recommendations that combining visual and verbal modalities might creatively address real-world research challenges ([Brailas, 2020](#)) such as offering ways to amplify

marginalised voices or reveal aspects of social connectedness (Simon et al., 2022). Some studies have used visual analysis to comprehend how people might understand illness through drawing (Guillemin, 2004) and methods such as timeline mapping have been used to see how the creation of visual timelines might inform verbal semi structured interviewing (Kolar et al., 2015). Dialogic drawing methods have been explored with young children, using thematic analysis to interpret visual schema, dialog, and embodied behaviours (Ruscoe, 2022). Drawing has also been used by social researchers as part of theoretical and methodological development. Ellis et al., (2012), used drawings prior to research interviews to reframe and restructure questions, which also helped participants recall past events and identify central ideas of their experience. Causey (2017) has also suggested the importance of ethnographic researchers “learning to see by drawing what they see” (p. 12) and not depending solely on photographs to depict settings and participants. To the best of our knowledge, this will be the first piece of qualitative research to use the abstract concept of line drawing to represent experiences over time in order to solicit conversation about diagnosis and support in the context of dementia, a method which may be applicable in other health research and engagement settings.

Study Objectives

Embedded within a larger international research study that is investigating different approaches to support people affected by rarer types of dementia (Brotherhood et al., 2020), this protocol specifically explores how visual and verbal narrative inquiry can be methodologically developed to help understand what occurred across the time period from initial appearance of symptoms to the present (interview) day. This is particularly relevant considering the accounts of many people who report their symptoms and concerns being dismissed by healthcare professionals, doubted by relatives and friends, and questioned by employers (SCIE, n.d.). Yet, encouragingly, the use of peer support for this population has been increasing (Sullivan et al., 2022). Following Harrison’s and others contributions to using drawing with people living with rare dementia (PLwRD), care-partners, healthcare researchers, and the general public (Crutch et al., 2018; Harrison, n. d., Harrison, 2018), the following research questions were developed to guide the study:

1. Is it possible to make use of visual representation in a way that illuminates the process of seeking and getting support?
2. How do the lines and verbal accounts inform, contradict, explain, and interact with each other?
3. What does TL add to our understanding of the experience of support seeking?
4. How to people respond to the Talking Lines (TL) process (e.g. what do the participants think and feel

about drawing and being asked questions about their drawings?), and

5. How can the TL process be improved?

Pilot Work

The protocol was developed over a period of several years with conceptual, material, and methodological aspects being field tested in different formats within support, research and public engagement environments. Experimental artistic exercises, such as still life painting, were initially used to capture artistic production in four people living with different diagnoses of dementia and four healthy controls (Harrison et al., 2019), which stimulated interest in the possibilities for artistic representations to communicate facets of the individual creative experience, and the experience of neurodegenerative disease. Building on this work and motivated by conversations with PLwRD in support settings, creative invitations were simplified to solicit the generation of around 500 single painted lines using a brush with yellow paint on grey canvas (Harrison, 2019). Contributions of both patient and citizen researchers helped to develop line-based art activities in research and public engagement settings (Crutch et al., 2018) and line painting ‘in the lab’ formed part of a study investigating altered visual and haptic verticality perception in posterior cortical atrophy and Alzheimer’s disease (Day et al., 2022). Learning about the accessibility of line-based art activities has been expanded through the observation of the physiological, perceptual, and experiential components of line creation using whole-body motion capture data, Empatica E4 wristbands and participant responses to these exercises. Further line drawing exercises using blue pencils on paper were piloted in a series of nationwide (UK) public engagement activities, inviting participation and conversation around methods of assessment and experiences of dementia diagnosis and support (Testing Situations, Harrison, n. d.). The line drawing exercises refined through these activities will form the basis of three ‘practice questions’ for the present study:

- please draw a straight line (control)
- please draw any line that you would like to (expression)
- please draw a line describing from when you woke up today to the present moment [online interview] OR draw a line describing your journey today from home to where you are now (orientation)

Methodology

Line Drawings

Both line drawings and interviews will be used to solicit information. After exploring several approaches to visual analysis (see introduction), a decision was made not to stipulate in advance a predetermined analytic approach for the drawings. We are aware there is some risk in this, yet a

consensus does not exist in the literature on how best to approach visual analysis of line drawings created during the course of research. Within the field of art therapy, for example, there are multiple theoretical perspectives to guide analysis of artwork produced as part of therapy (e.g. [Case & Dalley, 2014](#)) but these theoretical positions (e.g. psychoanalytic, existential, humanistic) have not formed the basis for the present study and are not relevant to our aims. We are nonetheless considering approaches to connect both verbal and visual narrative analysis techniques in our research. Experiments with quantitative pictorial analysis of line drawings has been attempted by looking at both stylistic content and visual features ([Hurtut et al., 2008](#)), but we expect the openness of the line-drawing invitation in our research alongside the possibilities for multiple interpretation of the instructions to thwart efforts to categorise or ‘measure’ the lines. Our open-ended approach has been conceived of by design and not by default. At this point the research team is keen to explore the idiosyncrasies of the drawings and the individual participant approaches to the methodology. Nevertheless, we expect that there will be some consistency and repetition amongst the lines and we will be curious to see if there are commonalities between the lines produced by the participants and the language used to describe them in the transcripts.

The line drawings in our research will capture a series of isolated periods over time and attempts have previously been made by qualitative researchers to explore how to approach the analysis of visual narratives in consecutive panels through ‘peak’ moments in storytelling ([Cohn & Kutas, 2015](#)). Similarly, theories have been proposed to understand how people comprehend visual narratives from sensory and perceptual perspectives ([Loschky et al., 2020](#)). Whilst these research areas have primarily related to preformulated picture-stories, comic-book drawings or film scenes – and not to self-constructed narratives by research participants – they may offer some entry points to consider the dynamic construction of key events in the line drawings, whether there have been dementia related challenges in the construction of the drawings and also how we consider intention as it relates to what has been produced and what has been talked about. There is evidence of the benefits of online video conferencing software for qualitative research ([Archibald et al., 2019](#)) and we will also be interested in how this method might influence relational aspects for the researchers and participants and the effect of the virtual environment in the pacing and production of drawings.

Narrative Analysis

A narrative approach, drawing primarily on theory outlined by [Riessman \(2008\)](#), will be used to analyse the interview transcripts. Narrative analysis is a cross-disciplinary qualitative approach centred on the ordinary everyday practice of storytelling. Narrative approaches can incorporate realist, postmodern and constructionist epistemologies ([Reissman,](#)

[2008](#)) and are linked by an assumption that individuals organise their interpretations and accounts of their experience of the world into the form of narratives ([Murray & Sargeant, 2011](#)). [Riessman \(2008\)](#) encourages narrative analysts to look beyond the content of the narratives and at “how and why incidents are storied”. This involves thinking about to whom, and for what purpose, a story is told, why events might be ordered in a certain way and what cultural resources are being drawn on. Consequently, the act of storytelling is rendered as not only descriptive but productive; individuals use narrative techniques (such as character, plot and genre) to bestow their experiences with meaning and construct their own identities ([Murray, 2021](#)). Another strength of the approach is in its ability incorporate, into analysis, the way context might contribute to the storytelling process (e.g. what the interviewer might represent to a participant and how that might impact the story they are telling), elements of their performance (e.g. who is given direct speech) and the ways a narrative might also invoke, or locate itself in resistance to, broader cultural narratives around a certain subject. Another key element of narrative epistemology is the concept of the double hermeneutic, defined as “a research process constituted by the interplay of an interpretive thematization (of a given cultural phenomenon) and an interpretive self-reflection that invokes the researcher’s rhetorical (or creative) imagination” ([Ginev, 1998](#), p. 264).

Narrative analysis was chosen for the Talking Lines data (1) because it should provide scope to analyse the way PLwRD and carers, often with a unique support journey, incorporate broader cultural narratives around support, illness and independence into their own experiences, and (2) because the choice of line drawings, as well as our focus on three distinct time periods from when symptoms first appear to the present, are likely to lead to individuals providing a chronological account well suited to the approach.

Data Collection and Analysis

Drawing on [Tanner et al., \(2022\)](#) an analysis plan for working narratively with a large number of transcripts, whilst employing the full scope of [Riessman’s \(2008\)](#) theory, has been developed. This will involve creating a key observations document with headings and prompts under four headings: Context (where and with whom a participant is interviewed, how this might impact their telling), Themes (key plot points, characters and themes within the story), Performance (how the story is constructed, identities and selves being performed throughout, cultural narratives invoked) and Development (how the story is broken up, the coherence of the narrative, how is the story ordered in such a way as to develop meaning). Once key observations have been recorded for all transcripts, a coding framework with recurring narratives and higher order narrative categories will be produced. This will act as a first set of results and as a framework with which it will be possible to

do closer inspection of a smaller number of transcripts within the sample.

The study will focus on three segments of time that occurring over a number of years:

- (1) the time period from initial symptoms, “when you noticed something was wrong”, to being diagnosed,
- (2) from diagnosis until self-identified support was received, and
- (3) from first obtaining support to the present time.

Sample, Settings and Recruitment

Sample

People living with a rarer form of dementia, care-partners and bereaved care-partners will be invited to participate. There are no general exclusion criteria or exclusionary medications for this study. The inclusion criteria are as follows:

1. Minimum age of 18 years old
2. Can understand and speak English or Welsh
3. Has the capacity to consent independently
4. Residing in the community and not in residential care or hospital
5. Access to the internet by computer, tablet or smartphone that has a camera.

As a recent systematic analysis highlighted, sample size determination is a contested area within qualitative health research with researchers offering multiple and sometimes conflicting rationales (Vasileiou et al., 2018). This array of sample size justifications, whilst contributing to robust academic debate, can also be seen as a landmine littered field of perplexing recommendations. Concepts such as generalisation, validity, and reliability, more associated with quantitative methods, but used by some qualitative researchers, likely do not help sample size decision making. Sample size determination by analytic strategy with a focus on type of themes and categories (e.g. Morse, 2015), while important, seems too prescriptive and disconnected from epistemology. Malterud et al., (2021) introduced the concept of “information power” as a pragmatic approach where more detailed information provided by the sample, the smaller the needed sample size. Their approach places an important role on the value of theory as one aspect in determining the information power of the sample, with specified theoretical frameworks suggesting smaller sample sizes and no or little theoretical underpinnings suggesting larger samples.

One of the recommendations from Vasileiou et al.’s (2018) systematic review called on researchers to increase transparency by considering data adequacy and data sufficiency in determining sample size. Considering these recommendations and the quality criteria suggested by Andrews (2021) for narrative analysis, it has been clear in planning the present

study that we needed to reflect about multiple factors in determining sample size. These include access to the population (people living with different rarer dementias and family members), context (living at home in different countries), the research aims and questions, the methodology (narrative analysis and a novel visual narrative analysis), the ontological and epistemological underpinnings of the methodology (social constructionism), and the multiple audiences who might be interested in the outputs (type of journal(s), researchers, clinicians). Concepts such as ‘small’ or ‘large’ sample size were inadequate guidelines and provide insufficient justification. After multiple discussions and reviewing different approaches it was decided that the following aspects of the study were important and would be considered in sample size decisions:

1. Include PLwRD, family care-partners, and bereaved family members based on relational theories of care and support (e.g. Nolan et al., 2004) and Eriksen et al.’s, (2016) conceptualisation of “living a meaningful life in relational changes” (p. 363) across changes brought on by dementia.
2. Through purposive (including theoretical and maximum variation) sampling (Ames et al., 2019, p. 3), include people affected by different rarer types of dementia that share challenges in obtaining diagnosis, care and support including PLwRD, current family care-partners and bereaved family members. The rarer forms of dementia we are including within this project are those that are part of the larger study (Brotherhood et al., 2020) and include familial Alzheimer’s disease (FAD), behavioural variant frontotemporal dementia (bvFTD), primary progressive aphasia (PPA), posterior cortical atrophy (PCA), Lewy body dementia (LBD), and young-onset Alzheimer’s disease (YOAD) and reside in the United Kingdom or Canada.
3. Based on these criteria, it is anticipated requiring 20–30 participants to complete a first stage thematic narrative analysis (Riessman, 2008; Tanner et al., 2022) of a larger sample in order to (1) develop a visual glossary of drawings (Harrison, 2019) together with verbal narratives that meet data adequacy and sufficiency criteria (Vasileiou et al., 2018) as assessed by researchers (AG, EH, MPS, CH, PC).
4. A second stage narrative analysis (Tanner et al., 2022) will require selecting 4–5 completed interviews from the initial interview pool of 20–30 participants for a more in-depth analysis. This selection will be informed by the above criteria and determined by research team consensus (SHR, CH, EH, PC).

Setting and Recruitment Strategy

Participants will be interviewed in their place of residence or other location that they choose. All interviews will occur via Go-to-Meeting, a secure and encrypted on-line platform.

Participants residing in the United Kingdom will be recruited from *Rare Dementia Support* (RDS, n.d.), an organisation with over 5000 UK and international members. Members will be contacted through newsletters and email invitations. Canadian participants will be recruited by researchers from Nipissing University through virtual posters and emails to healthcare professionals, dementia-related charities and public presentations and workshops.

Talking Lines Protocol

Talking Lines is seen as an integrated methodological approach for research interviewing that can be completed in-person or virtually, online. The Supplemental Material contains full details of the protocol. It is also being developed for considered use in other settings where information about a person's lived experiences related to dementia is needed, such as dementia charities, clinical settings, and residential care. In developing Talking Lines the research team has given careful consideration that it be made accessible to a wide audience including researchers of different disciplines, charity workers and clinical staff, and those directly affected by dementia. We are envisioning, for example, as part of a first visit interview with a residential care facility, Talking Lines could conceivably replace or augment current interviews. Likewise, during a neurology specialist appointment when there has been a long history of confusing and perplexing symptoms, our pilot work has shown that Talking Lines may help to clarify what those symptoms have been and when they occurred. It is designed to be used with a person living with any type of dementia, singularly, or with a family member, keeping in mind that some types of dementia may make line drawing more difficult (e.g. LBD, PCA).

Online interviews will be conducted and recorded using the *GoToMeeting* (GtM), an encrypted video-conferencing platform. In-person interviews will use a non-intrusive 360-degree style video camera or wearable body camera to record the drawing activity and the interview.

After consent is obtained and a meeting time is agreed, for virtual meetings, a materials pack (contents are described in the protocol) will be sent beforehand. Ahead of the meeting participants will be informed that whenever possible, there needs to be privacy, a quiet environment, and access to a surface upon which to draw. The interviews will be semi-structured with a protocol stipulating prompts for the line drawings, but including opportunities for the interviewer to ask more about specific elements of the drawings or experiences described. The protocol is divided into three sections. The first three questions are introductory and allow participants to get a feel for using the drawing implement and for the interviewer to get a sense how clear the questions are and whether revisions or rewording is necessary. Questions 4–6 pertain to the immediate aims of the research (from when symptoms first developed to diagnosis, from diagnosis to first receiving support, and from first support to the present). The

final section involves questions about a typical day (using drawing then discussion) followed by questions about how participants perceived the Talking Lines interview (use of drawing, level of difficulty, clarity of questions, general reactions). Questions 1–6 will be video recorded where possible and where consent to do so was obtained. Most interviews will be conducted one-on-one, though in some cases participants will be interviewed together. During these interviews both participants will be given the same interview prompts to do either concurrently or sequentially as they chose.

Ethical Considerations

The study has been approved by ethics committees at University College London (8545/004: Rare Dementia Support (RDS) Impact Study) and Nipissing University (10233: Rare Dementia Support Impact Study). Consent will be obtained through telephone or video interviews as agreed through our ethics approval and previously-published study protocol (Brotherhood et al., 2020). For informed consent to be obtained, there must be some form of clear affirmative action (positive opt-in); this cannot be inferred from silence, pre-ticked boxes or inactivity. In addition, we will adhere to Para. 26 (Declaration of Helsinki) which indicates that where obtaining written consent cannot be expressed in writing, non-written informed consent must be formally documented and witnessed. To achieve this, we will record the informed consent provided via telephone recordings and/or virtual face-to-face consent procedures via a secure and encrypted video platform (e.g. GoToMeeting) as outlined in Brotherhood et al., (2020). Ongoing determination relating to a participant's capacity to consent will be carried out in accordance with the *Mental Capacity Act (MCA, 2005)* and MCA Code of Practice (Department of Constitutional Affairs, 2007). In Canada, the consent process is set out in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS, 2018). Where a safeguarding concern is raised or identified in the United Kingdom we will follow the organisation's safeguarding policy and in Canada, guidance will be accessed from the relevant provincial or territorial adult protection agency. The need for further investigation or escalation will be managed in accordance with the safeguarding policy and in line with the Making Safeguarding Personal principles <https://www.local.gov.uk/msp-toolkit>.

In addition to obtaining ethical approval, consideration of how participants respond to the Talking Lines protocol during the interview is essential. The interviewer will need to be aware of any difficulties the task may be creating. This might include problems holding the drawing implement, difficulties with vision, not fully understanding a question, becoming distressed during any part of the interview, and the impact of the interview after it is concluded. Sensitivity to the experiences of participants during the interview in order to safeguard their wellbeing and to assess if Talking Lines is a safe and ethical methodological tool are essential components of this

research. We are also aware that some people may wish to end the interview at any time and others may need a break for a few minutes or to schedule a second meeting to complete Talking Lines. Support for any participant that may become upset/distraught due to the interview process will be provided by staff at our two collaborating service organisations in Canada and in the United Kingdom.

Rigour, Quality Assessment and Reflective Practice

To encourage meaningful reflective practice, core researchers have been and will continue to participate in monthly meetings to discuss all aspects of the study; these meetings are recorded and transcribed and stored on a secure university data storage portal. Three researchers will conduct interviews (AG, EH, SRH). At least two researchers will read and discuss each transcript (SRH, EH, CH, PC) and these four will also view and discuss the line drawings, whilst EB and SC provide critical questioning and review. To help facilitate our understanding of how best to incorporate line drawings in the analysis, a visual glossary of lines will be developed based on the lines drawn by participants. Microsoft Word's word-processing software, using formatting features of margin comments, in-text formatting, bold, italic, coloured text and different bracket styles, will be used for coding, theme development and analytic decisions (Macdonald et al., 2023). While the Standards for Reporting Qualitative Research is often cited as a guide to structure analyses and report results (O'Brien et al., 2014), we will also use an approach specific to narrative analysis (Andrews, 2021) that uses 10 quality indicators: truthfulness, trustworthiness, critical reflexivity, scholarship and accessibility, ethical sensitivity, co-construction of meaning, attention to the untold, awareness of temporal fluidity, multi-layered stories, contextualisation of the research (pp. 363–364) assessed by four researchers.

Discussion

The use of storytelling, narrative interviewing and narrative analysis are well-known tools in qualitative research. What is far less known is *how* line drawings might also methodologically become part of qualitative interviews and what contributions they might add to research interviewing. As noted in the introduction, drawing has been part of *homo sapiens* evolution for thousands of years. Lines depict journeys, emotions, stories, and exist in their own right but also require language to help understand, explain and interpret them. Likewise, there is also the possibility of a line being used to inform and guide its creator to help them tell their stories, and this may be particularly relevant/helpful/insightful for those affected by rarer forms of dementia which are characterised by atypical symptoms and typically a younger age of onset, causing significant disruption in individual and family life. In the present research we are proposing that the line is drawn first, before the verbal interchange most

commonly associated with research interviewing. The line becomes the foundation for the story, it does not replace it but we wonder how it might anchor stories and help participants consider those moments over time that were orientating, complicating, evaluative and resolving moments (Riessman, 2008). We also wonder how this dual approach of visual and verbal data collection will affect our own research practices and how line drawing might be used to document researchers' experiences and observations (Causey, 2021). We will be asking people to draw a line as we observe them either in person or via video conferencing; how people approach this task and their ability and interest to engage, and what it might contribute to qualitative methods within dementia research are also key areas to discover.

Acknowledgements

We would like to thank Rare Dementia Support (<https://www.raredementiasupport.org/>) and the many people with rarer forms of dementia and their care-partners for helping to shape this research. Additional thanks to our research funders for their generous support and anonymous grant reviewers for their encouragement to include visual approaches to research in this population. The Dementia Research Centre, University College London is supported by Alzheimer's Research UK, Brain Research UK, the Wolfson Foundation and the National Institute for Health Research University College London Hospitals Biomedical Research Centre.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.







Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work is part of the Rare Dementia Support Impact Project (The impact of multicomponent support groups for those living with rare dementias, (ES/S010467/1)) and is funded jointly by Economic and Social Research Council, part of UK Research and Innovation, and the National Institute for Health Research (UK). The views expressed are those of the authors and not necessarily those of the ESRC, UKRI, the NIHR or the Department of Health and Social Care. Rare Dementia Support is generously supported by the National Brain Appeal (<https://www.nationalbrainappeal.org/>). Lead investigator S. J. Crutch and co-investigators: J. Stott, P. M. Camic, G. Windle, R. Tudor-Edwards, Z. Hoare, M.P. Sullivan and R. McKee-Jackson.

Ethical Approval

The study has been approved by ethics committees at University College London (8545/004: Rare Dementia Support (RDS) Impact Study) and Nipissing University (10,233: Rare Dementia Support Impact Study).

ORCID iDs

Emilie V. Brotherhood  <https://orcid.org/0000-0002-6244-7735>
 Paul M. Camic  <https://orcid.org/0000-0002-4444-6544>
 Sebastian J. Crutch  <https://orcid.org/0000-0002-4160-0139>
 Adetola Grillo  <https://orcid.org/0000-0003-1045-0606>
 Emma Harding  <https://orcid.org/0000-0001-9675-2335>
 Charlie Harrison  <https://orcid.org/0000-0001-8372-7675>
 Sam Rossi-Harries  <https://orcid.org/0000-0003-3384-865X>
 Mary Pat Sullivan  <https://orcid.org/0000-0001-9514-0783>

Supplemental Material

Supplemental material for this article is available online and consists of the detailed protocol that will be used to guide the study.

References

- Ames, H., Glenton, C., & Lewin, S. (2019). Purposive sampling in a qualitative evidence synthesis: A worked example from a synthesis on parental perceptions of vaccination communication. *BMC Medical Research Methodology*, *19*(1), 26. <https://doi.org/10.1186/s12874-019-0665-4>
- Andrews, M. (2021). Quality indicators in narrative research. *Qualitative Research in Psychology*, *18*(3), 353–368. <https://doi.org/10.1080/14780887.2020.1769241>
- Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., & Lawless, M. (2019). Using Zoom videoconferencing for qualitative data collection: Perceptions and experiences of researchers and participants. *International Journal of Qualitative Methods*, *18*, 160940691987459. <https://doi.org/10.1177/1609406919874596>
- Ashton, A. (2014). Drawing on the “lived experience”: An investigation of perception, ideation and praxis. *Art and Design Review*, *02*(03), 46–61. <https://doi.org/10.4236/adr.2014.23007>
- Bar-Yosef, O. (2002). The upper paleolithic revolution. *Annual Review of Anthropology*, *31*(1), 363–393. <http://www.jstor.org/stable/4132885>
- Brailas, A. (2020). Using drawings in qualitative interviews: An introduction to the practice. *The Qualitative Report*, *25*(12), 4447–4460. <https://doi.org/10.46743/2160-3715/2020.4585>
- Brotherhood, E. V., Stott, J., Windle, G., Barker, S., Culley, S., Harding, E., Camic, P. M., Caufield, M., Ezeofor, V., Hoare, Z., McKee-Jackson, R., Roberts, J., Sharp, R., Suarez-Gonzalez, A., Sullivan, M. P., Tudor Edwards, R., Walton, J., Waddington, C., Winrow, E., & Crutch, S. J. (2020). Protocol for the rare dementia support impact study: RDS impact. *International Journal of Geriatric Psychiatry*, *35*(8), 833–841. <https://doi.org/10.1002/gps.5253>
- Cartwright, A. V., Stoner, C. R., Pione, R. D., & Spector, A. (2021). The experiences of those affected by parental young onset dementia: A qualitative systematic literature review. *Dementia*, *20*(7), 2618–2639. <https://doi.org/10.1177/1471301220988231>
- Case, C., & Dalley, T. (2014). *The handbook of art therapy*. Routledge.
- Causey, A. (2017). *Drawing as an ethnographic method*. University of Toronto Press.
- Causey, A. (2021). Under observation: Line drawing as an investigative method in focused ethnography. In P. M. Camic (Ed.), *Qualitative research in psychology: Expanding perspective in methodology and design* (2nd ed.). American Psychological Association.
- Clift, S., & Camic, P. M. (Eds.), (2016). *Oxford textbook of creative arts, health and wellbeing: International perspectives on practice, policy and research*. Oxford University Press.
- Cohn, N., & Kutas, M. (2015). Getting a cue before getting a clue: Event-related potentials to inference in visual narrative comprehension. *Neuropsychologia*, *77*, 267–278. <https://doi.org/10.1016/j.neuropsychologia.2015.08.026>
- Crutch, S., Yong, K. X. X., Peters, A., Ocal, D., Kaski, D., Gonzalez, A. S., Ryan, N. S., Ball, S., Harrison, C. R., Murphy, C., Hulme, P., Phillips, I., Hulme, G., Brown, A., Brown, L., Riley, P., Ramsey, L., Woods, A., & Day, B. (2018). Contributions of patient and citizen researchers to ‘Am I the right way up?’ study of balance in posterior cortical atrophy and typical Alzheimer’s disease. *Dementia*, *17*(8), 1011–1022. <https://doi.org/10.1177/1471301218789296>
- Day, B. L., Ocal, D., Peters, A., Bancroft, M. J., Cash, D., Kaski, D., Crutch, S. J., & Yong, K. X. X. (2022). Altered visual and haptic verticality perception in posterior cortical atrophy and Alzheimer’s disease. *The Journal of Physiology*, *600*(2), 373–391. <https://doi.org/10.1113/JP282289>
- Department of Constitutional Affairs. (2007). The mental capacity act code of practice. <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>
- Ellis, J. L., Hetherington, R., Lovell, M. A., McConaghy, J., & Viczko, M. (2012). Draw me a picture, tell me a story: Evoking memory and supporting analysis through pre-Interview drawing activities. *Alberta Journal of Educational Research*, *58*(4), 488–508. <https://doi.org/10.11575/ajer.v58i4.55541>
- Eriksen, S., Helvik, A. S., Juvet, L. K., Skovdahl, K., Førsund, L. H., & Grov, E. K. (2016). The experience of relations in persons with dementia: A systematic meta-synthesis. *Dementia and Geriatric Cognitive Disorders*, *42*(5–6), 342–368. <https://doi.org/10.1159/000452404>
- Giebel, C. (2020). Current dementia care: What are the difficulties and how can we advance care globally? *BMC Health Services Research*, *20*(1), 414–423. <https://doi.org/10.1186/s12913-020-05307-1>
- Ginev, D. (1998). Rhetoric and double hermeneutics in the human sciences. *Human Studies*, *21*(3), 259–271. <https://doi.org/10.1023/A:1005327608803>
- Grossi, D., Fragassi, N. A., Giani, E., & Trojano, L. (1998). The selective inability to draw horizontal lines: A peculiar constructional disorder. *Journal of Neurology, Neurosurgery, and Psychiatry*, *64*(6), 795–798. <https://doi.org/10.1136/jnnp.64.6.795>, <https://jnnp.bmj.com/content/64/6/795>
- Guillemin, M. (2004). Understanding illness: Using drawings as a research method. *Qualitative Health Research*, *14*(2), 272–289. <https://doi.org/10.1177/1049732303260445>
- Gumus, M., Multani, N., Mack, M. L., & Tartaglia, M. C., Alzheimer’s Disease Neuroimaging Initiative. (2021). Progression

- of neuropsychiatric symptoms in young-onset versus late-onset Alzheimer's disease. *GeroScience*, 43(1), 213–223. <https://doi.org/10.1007/s11357-020-00304-y>
- Guseva, E. (2019). Art therapy in dementia care: Toward neurologically informed, evidence-based practice. *Art Therapy*, 36(1), 46–49. <https://doi.org/10.1080/07421656.2019.1564613>
- Hammond, C., Gifford, W., Thomas, R., Rabaa, S., Thomas, O., & Domecq, M.-C. (2018). Arts-based research methods with indigenous peoples: An international scoping review. *AlterNative: An International Journal of Indigenous Peoples*, 14(3), 260–276. <https://doi.org/10.1177/1177180118796870>
- Harrison, C. R., Created Out of Mind team. (2018). The lines are open: An artist's experience of working with dementia research. *Dementia*, 17(6), 755–762. <https://doi.org/10.1177/1471301217734097>
- Harrison, C. R., Carton, A. M., Brotherhood, E. V., Hardy, C. J. D., Cohen, M. H., Warren, J. D., & Crutch, S. J. (2019). Profiles in paint: Contrasting responses to a common artistic exercise by people with different dementias. *Arts & Health*, 11(1), 79–86. <https://doi.org/10.1080/17533015.2017.1402795>
- Harrison, C. R. (n.d.). *Testing Situations*. <https://www.charlesrobertharrison.com/testing-situations-about>
- Harvey, R. J., Roques, P., Fox, N. C., & Rossor, M. N. (1996). Non-Alzheimer dementias in young-patients. *The British Journal of Psychiatry: The Journal of Mental Science*, 168(3), 384–385. <https://doi.org/10.1192/bjp.168.3.384b>
- Hass-Cohen, N., Bokoch, R., Clyde Findlay, J., & Banford Witting, A. (2018). A four-drawing art therapy trauma and resiliency protocol study. *The Arts in Psychotherapy*, 61, 44–56. <https://doi.org/10.1016/j.aip.2018.02.003>
- Hendriks, S., Peetoom, K., Bakker, C., Koopmans, R., van der Flier, W., Papma, J., Verhey, F., Young-onset dementia epidemiology group, du Vugt, M., & Köhler, S. (2022). Global incidence of young-onset dementia: A systematic review and meta-analysis. *Alzheimer's & dementia*, 1–13. <https://doi.org/10.1002/alz.12695>
- Hendriks, S., Peetoom, K., Bakker, C., van der Flier, W. M., Papma, J. M., Koopmans, R., Verhey, F. R. J., de Vugt, M., Köhler, S., Young-Onset Dementia Epidemiology Study Group, Withall, A., Parlevliet, J. L., Uysal-Bozkir, Ö., Gibson, R. C., Neita, S. M., Nielsen, T. R., Salem, L. C., Nyberg, J., Lopes, M. A., Dominguez, J. C., De Guzman, M. F., Egeberg, A., Radford, K., Broe, T., Subramaniam, M., Abdin, E., Bruni, A. C., Di Lorenzo, R., Smith, K., Flicker, L., Mol, M. O., Basta, M., Yu, D., Masika, G., Petersen, M. S., & Ruano, L. (2021). Global prevalence of young-onset dementia: A systematic review and meta-analysis. *JAMA Neurology*, 78(9), 1080–1090. <https://doi.org/10.1001/jamaneurol.2021.2161>
- Hunt, B., Truran, L., & Reynolds, F. (2018). Like a drawing of breath": Leisure-based art-making as a source of respite and identity among older women caring for loved ones with dementia. *Arts & Health*, 10(1), 29–44. <https://doi.org/10.1080/17533015.2016.1247370>
- Hurtut, T., Gousseau, T., Cheriet, F., & Schmitt, F. (2008). Pictorial analysis of line drawings. *Proceedings of the fourth Eurographics conference on computational, aesthetics in graphics, visualization and imaging* (pp. 123–130). <https://dl.acm.org/doi/10.5555/2381333.2381354>
- Ingold, T. (2016). *Lines: A brief history*. Routledge.
- Kaimal, G., Carroll-Haskins, K., Ramakrishnan, A., Magsamen, S., Arslanbek, A., & Herres, J. (2020). Outcomes of visual self-expression in virtual reality on psychosocial well-being with the inclusion of a fragrance stimulus: A pilot mixed-methods study. *Frontiers in Psychology*, 11, 589461. <https://doi.org/10.3389/fpsyg.2020.589461>
- Kolar, K., Ahmad, F., Chan, L., & Erickson, P. G. (2015). Timeline mapping in qualitative interviews: A study of resilience with marginalized groups. *International Journal of Qualitative Methods*, 14(3), 13–32. <https://doi.org/10.1177/160940691501400302>
- Loschky, L. C., Larson, A. M., Smith, T. J., & Magliano, J. P. (2020). The scene perception & event comprehension theory (SPECT) applied to visual narratives. *Topics in Cognitive Science*, 12(1), 311–351. <https://doi.org/10.1111/tops.12455>
- Macdonald, M. E., Siedlikowski, S., Liu, K., & Carnevale, F. A. (2023). Introducing SAMMSA, a Five-Step Method for producing 'quality' qualitative analysis. *Qualitative Health Research*, 33(4), 334–344. <https://doi.org/10.1177/10497323231154482>
- Malterud, K., Siersma, V., & Guassora, A. D. (2021). Information power: Sample content and size in qualitative studies. In P. M. Camic (Ed.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (2nd ed.). American Psychological Association.
- McEvoy, P., & Bellass, S. (2017). Using drawings as a reflective tool to enhance communication in dementia care. *Nursing Standard (Royal College of Nursing (Great Britain): 1987)*, 31(19), 46–52. <https://doi.org/10.7748/ns.2017.e10460>
- Mental Capacity Act. (2005). <https://www.legislation.gov.uk/ukpga/2005/9/contents>
- Millenaar, J. K., Bakker, C., Koopmans, R. T., Verhey, F. R., Kurz, A., & de Vugt, M. E. (2016). The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: A systematic review. *International Journal of Geriatric Psychiatry*, 31(12), 1261–1276. <https://doi.org/10.1002/gps.4502>
- Morriss-Kay, G. M. (2010). The evolution of human artistic creativity. *Journal of Anatomy*, 216(2), 158–176. <https://doi.org/10.1111/j.1469-7580.2009.01160.x>
- Morse, J. M. (2015). Analytic strategies and sample size. *Qualitative Health Research*, 25(10), 1317–1318. <https://doi.org/10.1177/1049732315602867>
- Murray, M. (2021). Some ways of doing narrative research. In P. M. Camic (Ed.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (2nd ed.). American Psychological Association.
- Murray, M., & Sargeant, S. (2011). Narrative psychology. In D. Harper, & A. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: An introduction for students and practitioners* (pp. 163–175). Wiley.

- Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond person-centred care: A new vision for gerontological nursing. *Journal of Clinical Nursing*, *13*(s1), 45–53. <https://doi.org/10.1111/j.1365-2702.2004.00926.x>
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine: Journal of the Association of American Medical Colleges*, *89*(9), 1245–1251. <https://doi.org/10.1097/ACM.0000000000000388>
- Rare Dementia Support. (n.d.). <https://www.raredementiasupport.org/what-is-rare-dementia/>
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage.
- Roberts, J., Windle, J., Story, A., Brotherhood, E., Camic, P. M., Crutch, S. J., Stott, J., Sullivan, M. P., & Grillo, A. (2023). *Dementia in rural settings: A scoping review exploring the personal experiences of people with dementia and their carers*. Ageing & Society. <https://doi.org/10.1017/S0144686X2300003X>
- Ruscoe, A. (2022). Dialogic drawing: A method for researching abstract phenomenon in early childhood. *Video Journal of Education and Pedagogy*, *7*(1), 1–22. <https://doi.org/10.1163/23644583-bja10036>
- SCIE. (n.d.). *Young onset dementia: Key issues*. Social Care Institute for Excellence. <https://www.scie.org.uk/dementia/symptoms/young-onset/key-issues.asp>
- Simon, G. L., Wee, B., Chatti, D., & Anderson, E. (2022). Drawing on knowledge: Visual narrative analysis for critical environment and development research. *Environment and Planning E: Nature and Space*, *5*(1), 293–317. <https://doi.org/10.1177/2514848620975340>
- Souillard-Mandar, W., Davis, R., Rudin, C., Au, R., Libon, D. J., Swenson, R., Price, C. C., Lamar, M., & Penney, D. L. (2016). Learning classification models of cognitive conditions from subtle behaviors in the digital clock drawing test. *Machine Learning*, *102*(3), 393–441. <https://doi.org/10.1007/s10994-015-5529-5>
- Sullivan, M. P., Williams, V., Grillo, A., McKee-Jackson, R., Camic, P. M., Windle, G., Stott, J., Brotherhood, E., & Crutch, S. J., Rare Dementia Support RDS research team. (2022). Peer support for people living with rare or young onset dementia: An integrative review. *Dementia*, *21*(8), 2700–2726. <https://doi.org/10.1177/14713012221126368>
- Tanner, D., Ray, M., & Ward, L. (2022). *When it comes to carers, you've got to be grateful that you've got a carer coming': Older people's narratives of self-funding social care in England* (pp. 1–22). Ageing & Society. <https://doi.org/10.1017/S0144686X22000691>
- TCPS. (2018). *Tri-council policy statement: Ethical conduct for research involving humans*. https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html
- Trojano, L., & Gainotti, G. (2016). Drawing disorders in Alzheimer's disease and other forms of dementia. *Journal of Alzheimer's Disease: JAD*, *53*(1), 31–52. <https://doi.org/10.3233/JAD-160009>
- Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: Systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, *18*(1), 148–218. <https://doi.org/10.1186/s12874-018-0594-7>
- Wang, Q.-Y., & Li, D.-M. (2016). Advances in art therapy for patients with dementia. *Chinese Nursing Research*, *3*(3), 105–108. <https://doi.org/10.1016/j.cnre.2016.06.011>
- Woolley, J. D., Khan, B. K., Murthy, N. K., Miller, B. L., & Rankin, K. P. (2011). The diagnostic challenge of psychiatric symptoms in neurodegenerative disease: Rates of and risk factors for prior psychiatric diagnosis in patients with early neurodegenerative disease. *The Journal of Clinical Psychiatry*, *72*(2), 126–133. <https://doi.org/10.4088/JCP.10m06382oli>