



Understanding the personhood of Deaf people with dementia: Methodological issues

Alys Young^{*}, Emma Ferguson-Coleman, John Keady

School of Nursing, Midwifery and Social Work, University of Manchester, UK

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ABSTRACT

This article concerns Deaf people in the United Kingdom, who use sign language, who have a formal diagnosis of dementia and who have participated in interviews in British Sign Language (BSL) about their experience of living with dementia. We address the methodological challenges involved in enabling culturally meaningful participation in circumstances where the non-verbal is not equivalent to the non-linguistic. We demonstrate the use of interpretative narrative representation of data for purposes of cultural brokering. We explore the contribution of Deaf people's experiences and the analysis of their visual, spatial narratives to debates about personhood and the embodied self in dementia studies. Finally, we consider the significance of the situational as cultural in relation to holistic interpretation of narrative.

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Introduction

Dementia research which is concerned with care and support has witnessed a revolution in the past 20 years. A focus on the condition has given way to a focus on the person, variously expressed as personhood, the self, and the citizen (Bartlett & O'Connor, 2010; Cadell & Clare, 2011; Downs, 1997; Kitwood, 1997). The environment in which the person is living with dementia has become as significant as the individualized experience with the recent focus on dementia-friendly neighborhoods (Keady et al., 2012). The resources and history a person brings to their lived experience of dementia is recognized as a key mediator of how it affects their everyday life (e.g. Frazer, Oyeboode, & Cleary, 2011). If we accept, from a symbolic interactionist perspective (Blumer, 1969; Spradley, 1979), that meaning is socially and linguistically produced through the interactions of self and others, then the meaning of dementia cannot be understood without reference to language, social context, interaction

and the self. Similarly if we understand identity(ies) as something that is situated (Hughes, 2001) and that we perform (Kontos & Nagle, 2006), not just something that is intrinsic to us (Sabat, Fath, Moghaddam, & Harre, 1999), then context and relational behavior(s) are vital to how our identity(ies) are both manifest and formed.

These approaches have underpinned a new raft of scholarship which is uncovering what it is *to live* with dementia (e.g. Hubbard, Cook, Tester, & Downs, 2002; Hydén & Örluv, 2009). The voices of those who experience dementia are beginning to influence how the outsiders to the experience understand it (Page & Keady, 2010). The dementia user movement is slowly and surely starting to influence the policy and practice agenda (Dementia Action Alliance (DAA), 2012; Keady et al., 2012). Dementia is becoming seen as individualized, socially constructed, contextualized and *of* the society around all of us, rather than a disease "in" the person.

However, this revolution is largely taking place in the majority world. Seen from the perspectives of those who for whatever reasons (language, culture, ethnicity, disability) occupy a minority and/or minoritized position, many of these revolutions are 'for them not for us'. Studies addressing culturally-embedded understandings of what it is to have dementia are few

^{*} Corresponding author at: University of Manchester, School of Nursing, Midwifery and Social Work, Jean McFarlane Building, Oxford Road, Manchester M139PL UK. Tel.: +44 161 306 7747.

E-mail address: alys.young@manchester.ac.uk (A. Young).

and far between focusing on, for example, care networks and preferences for support that are coherent with cultural norms and priorities (e.g. La Fontaine, Ahuja, Bradbury, Phillips, & Oyeboode, 2007; Nijjar, 2012). Yet dementia is likely disproportionately to affect some ethnic groups in the UK, for example, in comparison to others (APPG, 2013, p.18). Services to support the individual with dementia and their care partners implicitly assume a majority (e.g. English, hearing speaking) baseline, against which further adaptations have to be made. Cultural norms of care networks, care partners, coping strategies, assumptions and preferences are beginning to be investigated (e.g. “Dementia does not discriminate”, APPG, 2013). However the risk always remains in studying the ‘other’, the ‘exception’ and the ‘difference’. By contrast, the emphasis on personhood entails the experience of dementia for that individual in context, including what they bring to this event in the narrative of their lives, and retaining the right to be seen for themselves (“My name is not dementia”, Alzheimer’s Society, 2010a, 2010b). From that point of view there is no ‘other’, there simply ‘is’.

These considerations formed the backdrop to a study in which we set out to have conversations, in the UK, with Deaf people who had a formal diagnosis of dementia in the form of narrative interviews (see below). By Deaf we mean members of the Deaf community for whom being Deaf is a cultural affiliation not a disability (Ladd, 2003). Deaf people use a signed language such as BSL (British Sign Language) which is not a visual version of a spoken language but grammatically separate (Sutton-Spence & Woll, 1999). A distinct and recorded culture is associated with language use (Ladd, 2003) in the same way as we might talk about French culture or Polish culture, hence the use of the capitalized ‘D’ to distinguish Deaf people (the cultural-linguistic minority) from the larger population of Deaf people who might lose their hearing as part of the aging process or have been spoken language users all of their lives (Young & Hunt, 2011).

This is a community whose awareness about and knowledge of dementia lags far behind the majority of their hearing counterparts, in part because of how little information about dementia is available in BSL for the general public (Allan, Stapeleton, & McLean, 2001). This is not the only reason but linguistic access is a significant pre-condition for the acquisition of knowledge (Ferguson-Coleman, Young, & Keady, 2014). The interview study drawn on in this article was one of three designed to explore different aspects of enabling earlier identification of dementia amongst Deaf people (Young et al., 2013). It was designed to contribute evidence towards culturally meaningful dementia care and support services with, by and for Deaf people. In depth interviews, each lasting an average of two hours were undertaken involving four Deaf people with a formal diagnosis of dementia and their care partners ($n = 5$) on two occasions. The decision to interview twice enabled further aspects of experience to be explored and previous content to be revisited and preliminary interpretations checked out.

This evidence base from Deaf people themselves is important because it is easy to make grand claims about the likely effects of dementia for Deaf people, based on what we might know of barriers to diagnosis, service access and support in general from other studies not concerned with dementia (e.g. Alexander, Ladd, & Powell, 2012; Fellingner, Holzinger, & Pollard, 2012; Reeves, Kokoruwe, Dobbins, & Newton, 2003). These have shown that both under- and over- diagnosis is likely to

occur because of the inability of clinicians to communicate directly with Deaf people, there is a lack of culturally and linguistically appropriate screening/diagnostic instruments, and Deaf people experience poor access to health prevention and promotion services in general (Signhealth, 2014).

We sought instead to engage directly with Deaf people who had dementia (and their care partners) to tell us what it was like to live with dementia as a Deaf person, their experiences, preferences, intentions and reflections. In this way previously hidden “voices” would be recorded on their own terms and these would teach us about dementia from a Deaf person’s world view. Without such evidence building directly from Deaf people rather than by inference or assumed experienced, Deaf people’s opportunities to create and control the discourse about their lives is lessened.

Furthermore our intention was not simply to document experiences particular to the Deaf community but also to gain from Deaf people an enhanced understanding of the meaning of dementia in general. It has been remarked that Deaf people(s) are “a visual variety of the human race” (Bahan, 2008); part of humanity’s extensive diversity (Bauman & Murray, 2010; Ladd, 2003). Our failure to recognize Deaf people in this way is a failure to be open to part of a shared humanity that affects all of us and our capacity to be and appreciate what it is to be human. Looking at dementia with Deaf people unlocks that further possibility and extends everyone’s understanding. In this respect, the study is not about “them”, it is about “us”.

In generating data we treated interviews as a form of discourse between signers (‘speakers’) rather than as questions to which answers were offered (Mishler, 1991). Furthermore, the context in which this discourse was occurring was recognized as significant for its interpretation and its influence on how the narrative might be shaped (Mishler, 1991; Riessman, 1993). Interviewer and interviewees were all Deaf sign language users who identified themselves as culturally Deaf people, communication was direct (there was no interpreter present) and therefore in many respects all parties shared common cultural and linguistic points of reference. However in other aspects there was no shared experience; the interviewer did not have dementia, she was not a carer for someone with dementia and there were other disparities of age, gender and background also present in context. This circumstance shapes the first methodological challenge we address below namely: *how to enable culturally meaningful participation in circumstances of diminished mental capacity and whether being Deaf was influential in this process?*

In terms of data analysis, the interviews were video recorded in BSL and we took a narrative analysis approach (McCormack, 2002; Riessman, 1993). Narrative analysis notoriously can imply a variety of standpoints depending on theoretical and disciplinary background (Riessman & Quinney, 2005; Young & Temple, 2014, Ch 6). In this study, after Riessman (1993, 2008) we were interested in examining not just the content to which a narrative refers but also the manner in which it is constructed; how events are storied, temporal sequencing, and lexical choices, and other characteristics of the language employed. Such an approach has an additional dimension when the language used is an entirely visual one whose meanings are created and conveyed in four dimensions (Stokoe, 1960; Sacks, 1989); the usual three spatial dimensions with the addition of time. Also whilst research in dementia has become increasingly

interested in the non-verbal within studies of communication and expression of personhood (e.g. Kontos, 2004; Ward & Campbell, 2013), in the case of our data 'non-verbal' is not an adequate enough description of a visual language in which the absence of sound/speech is normative. This formed the second aspect of the methodological challenges we seek to explore in this paper: *what are the implications of analyzing data in a narrative form when the non-verbal is not the non-linguistic?*

As a means of addressing these two issues (above) we offer two specific examples of data analysis. We choose to present them as "storied stories" (McCormack, 2002). That is to say the narrative analysis itself is represented as a story told by the researcher to the reader. We do this for three principal reasons. First, a key challenge we face in the presentation of these data is that to understand their significance requires a degree of cultural familiarity with the history, context and everyday lives of Deaf people to appreciate the meanings and their resonances present in both the 'what' and the 'how' of Deaf people's narratives. As most readers are unlikely to have this, a third person narrative voice enables these gaps to be filled whilst 'telling' the story. Second, this paper is written in a two dimensional language that is different from the entirely visual language of the original narratives. Talking 'about' and describing language whilst using a different one is one means of showing how space, shape and movement were used linguistically in the original form of the data whilst simultaneously pointing out the discontinuity between source and representation (Stone & West, 2012; Young & Ackerman, 2001). Third, the interpretations of the data have involved cross-language and cross-cultural processes (see Temple & Young, 2004). Data were collected in BSL, analyzed in BSL and are being presented in English to a largely non-culturally Deaf readership. Therefore we wanted to ensure that some of the implications of such processes of cultural and linguistic transformation remained explicit and visible in how the data are represented as part of the transparency and validity of our approach to analysis. These considerations therefore formed the third major issue we highlight in this paper: *the role of storied stories as a means of cultural brokering between generated narrative and its interpreted significance.*

In what follows we present two 'storied' narratives as illustrative of the methodological issues we discuss below as well as demonstrative of our approach to data presentation and its underlying theoretical approach.

Enabling culturally meaningful participation and supporting capacity

It is a well-recognized paradox that in order to gain insight into the perceptions, conceptualizations and, by inference, socially constructed meanings of experience(s) all parties must be capable of some form of *interactional* communication. This is particularly challenging in the face of depleted resources to communicate intent, reflect on shared understandings, narrativise the self or others, or simply to find the words that are needed (Cadell & Clare, 2011). In our study with Deaf people who used BSL there were additional considerations which overlay this previously recognized concern in qualitative studies with people with communication restrictions.

Fundamentally, we had no idea of how dementia might affect Deaf people's signed language; there is little previously recorded narrative data (as opposed to question/answer test

data). It was nonetheless likely to have two aspects. First, characteristic changes in how something was signed, including the use of space, location of communication, hand shapes and movement. These might be regarded as the visual grammatical equivalents of the range of changes in syntax, grammar and complexity recorded in hearing people's communication. Second specific language choices in terms of vocabulary and expressions, which might be similar to deletions in available vocabulary and the potential to find alternatives or repair and support missing words recorded in hearing people's language. Furthermore, there might be both positive resources available in a visual-spatial-gestural language unavailable in a spoken language as well as significant losses.

A further consideration was mediated communication which is a life-long experience for Deaf people for whom the opportunities to interact directly are usually confined to other Deaf people or the few hearing people who sign well. Sign language interpreters, the written word, text communication, summaries by others on behalf of the Deaf person are facts of everyday life in many Deaf people's interactions with the hearing world including research participation. A great deal of research has been carried out by hearing people which concerns Deaf people where it has been assumed that the use of sign language interpreters are an acceptable and necessary means of data collection, including in studies which have used ethnographic, phenomenological and grounded theory approaches. Whilst some writers have problematised the effects of mediated communication and translation on epistemology and qualitative analysis (Stone & West, 2012; Temple & Young, 2004; Young & Temple, 2014 Chs. 6 and 7), the vast majority do not regard it as noteworthy. Dementia can create many challenges in following conversations, participating in interactions and grasping key ideas. Using an interpreted means of data collection would not only add to the potential challenges for participants but more fundamentally would deprioritize their own, preferred and strongest language. Symbolically and practically it would add to the invisibility of the language of thought and witnessed record which befalls many Deaf people's histories (Young & Ackerman, 2001).

In response to these considerations data collection was led by Author (Ferguson-Coleman) who is a culturally Deaf BSL user with a professional background in mental health advocacy although was new to research. Her position in the Deaf community enabled successful recruitment of potential participants and their care partners through community-based networks. In fact this route was far more successful than through clinical services although both were endorsed and received ethical approval through the National Research Ethics Service (England). Word of mouth/sign of hand and trust of her background and history and the team she was part of enabled access. Her linguistic abilities to modify language and communication to scaffold participation and to identify and understand features of someone's signing which might be idiosyncratic, or non-standard uses of grammatical structures, were absolutely central to the flow of the conversation, quality of data collection and subsequent analysis.

The exchanges between the researcher, the Deaf person with dementia and their family carers were filmed in order to capture for purposes of analysis the nuances of meaning, use of visual space and interpersonal interactions as well as the semantic content of the exchanges. In all cases personal and direct consent was taken in BSL from the person with dementia

if they were assessed to have the mental capacity to consent. This consent was, however, viewed as a process, not a one off decision and kept under review throughout the course of data collection with the researcher revisiting the participant's understanding of what was occurring and why throughout the dialog. In other instances, assent was regarded as sufficient provided that the family carers were present also.

From participants' point of view, being able to place the researcher within a cultural landscape that was meaningful (What school did you go to? Who are your parents? Which is your local Deaf club?) was vital to trust (Jones & Pullen, 1992). This trust was not just of the moment in the sense of feeling confident to talk about personal issues to another Deaf person without having to justify or explain the perspective they had. It also had a collective dimension too. Trust that the central involvement of Deaf researcher would in some way guarantee that experiences offered and recorded would be used in a way that would benefit the whole Deaf community in the future despite knowing that any future benefits in service improvement and support would be too late for them. All of our participants in some way expressed this belief and motivation – “it is not for me it is for us”. Deaf communities around the world have been described from an anthropological perspective as collective cultures, rather than individualistic cultures (Emery, 2011; Ladd, 2003; Mindess, 2006). Values are held in trust for the whole rather than the self, responsibility for others within the community is key motivation and common good remains a foundational concept.

The following data extract illustrates the significance of careful attention to the signed language of the person with dementia without which their ability not just to participate but to *frame and lead* a key topic in their experience of dementia would be lost. It foregrounds the central relationship between identity and language for Deaf people and the impact of dementia on the sense of self expressed through and about sign language. It would have been missed without direct communication and without attention to the culturally situated history of this person by someone who could recognize and respond to it as an equal. Some features of this story have been changed in order to protect identity.

We re-present the data in storied form to enable the simultaneous commentary of cultural observation and explanation to be built in so that those outside of/unfamiliar with the context can appreciate the significance of the signed language resource that was retained and used to good effect by ‘Harold’.

Knowing from the inside: Harold's Story.

When we met Harold he was in his 80s. A proud member of the Deaf community all his life he had been brought up in the community and passed on its language and culture to his own Deaf and hearing children. We met him at home with his grown up children whose approach to his care and support was to keep him at the heart of the family, still being dad, still contributing to the vibrant life of the family and the wider Deaf community. He was not so much cared “for” as cared “with”. He was very keen to support the research project contributing all he could about how he felt now, living with dementia. From his point of view, his involvement was ‘for us’, the wider community of Deaf people and those Deaf people who would come after him and face dementia, he knew it was not ‘for him’.

Like many people in the hearing world, Harold had times when he self-consciously knew he had dementia and could for

a short time stand outside his own condition, consider what it had done to him and reflect on the person he was now and the person he had been. One such moment came during our second visit to the family. We have chosen to record it here both to illustrate the vivid dimensions of how his moment of reflection is communicated through the unique resources of a visual-spatial language (BSL), and to caution how easily such a profound expression of identity could be missed if not seen with *Deaf eyes*. First it is important to understand a specific feature of sign language grammar before explaining how Harold used it.

BSL like all signed languages throughout the world, make use of multi-channel signs. These are complex utterances which combine at one and the same time a characteristic mouth pattern and facial expression, a specific gesture located in space and/or on the body and a precise movement. When produced together they augment and extend the semantic content of what someone is saying by layering it with resonances which are inferred from the multi-channel sign. Notoriously impossible to translate, they are a fleeting complex expression in BSL that might require three or four sentences in English to render its meaning precisely. There are common characteristic sets of multi-channel signs which reoccur to indicate, for example, “something that was once present and was expected to be seen but is now missing”. Other multi-channel signs are coined in the moment spontaneously and for specific purpose to express a multi-layered meaning in one fleeting and deft movement. As quick as one might click ones fingers, the multi-channel sign is there then gone, but it is powerful and precise. It was also what Harold used to open a window and allow us in to his awareness of how dementia was affecting him and more importantly his identity.

Sat in his favorite chair, he was telling me about the lessening of his sign language, his hands making the shape and movement to indicate someone signing. But then he broke eye contact with us, looked at his hands and looked back at me – holding my gaze. His shift in eye contact had told me he was observing his own expression and this “thing called signing” had become objectified as he asked me to look too. His hands were both the expression and the object of that expression – seeing sign language as *of himself* (produced through his body) and *about himself* (he could comment on his own language). He signed “disappeared”. Then he made one of his hands flat and horizontal and slowly let it fall over the front of his upper body in the middle of his chest, whilst on his face his eyes were downcast and his mouth made an oval ‘o’ shape whilst gently exhaling air. That was the multi-channel sign, produced in a second and easily missed but layered with a profound insight.

The middle of the upper body in BSL when combined with a handshape which moves vertically, is the site of the most common expressions concerning “role”, “personality”, “self”, “confidence” and “being”. A downward movement, in some instances, indicates loss or decrease but any potential ambiguity was more clearly communicated as an intended meaning of lessening and/or loss because of the simultaneous mouth pattern. The oval ‘o’ shape is commonly used to indicate something small or becoming smaller particularly when combined with breath exhaling, as if a balloon were deflating. (By contrast breath inhaling commonly indicates acquisition and growth).

In one brief expression Harold had told me that he was referring to his language, his sign language, that was a fundamental part of his being, and that he knew this was slipping

away from him and that this was a cause of deep sadness and despondency. Dementia has “got him” he was losing his battle to retain *his* language.

From a cultural point of view, sign language use is a primary marker of cultural affiliation. Being deaf is not visible to others without an external referent and for the Deaf community this is sign language. In Harold's life time he has seen the wider world make a transition from assuming BSL is a form of pantomime or visual English to an appreciation of its independent and complex linguistic status. He has seen the Deaf community cease to hide their language, or be concerned about the stigma it might attract, and become instead proud and highly visible people within wider society. Signing is absolutely core to his identity and being. Its loss and his conscious awareness of it slowly being carried away as if on a breeze over which he has no control, was deeply moving to observe.

However it was witnessed within the signing environment of this interview where all participants shared a common language and cultural background. In another context, the complexity of Harold's expression might have been identified as non-linguistic and it was very quick. Yet Harold was making his views known, expressing his personhood and firmly asking for it to be recognized as a contribution to our understanding of Deaf people's experiences of dementia. He shared his story with resilience. The signed interview was his opportunity to do so.

Analyzing data when the non-verbal is not the non-linguistic

Initially, we had situated the analysis of the interview data within the framework of interpretative phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009). This was because we had at first sought to identify themes and concepts which were generated from within the perspective of the participants, rather than imposing topic areas we might wish to investigate. Also IPA is good at exposing culturally distinguished concepts through the attention paid to the terms in which experience is described as well the ways in which it is portrayed. It is an approach which has been used extensively in previous qualitative studies with people with dementia (e.g. Clare, 2003; Clare, Rowlands, & Quinn, 2008) and has yielded many context-specific insights such as those associated with women who live alone and have dementia (Frazer et al., 2011).

Initially, therefore, the recordings in BSL were watched and re-watched by the researcher who had first collected the data and a set of thematic codes developed. A second member of the team who was a BSL user also sampled data segments and potential codes in order, through dialog with the first, to reach a consensus on the final coding framework to be employed. Advances in sort and retrieve software such as QSR Nvivo now enable the coding of visual (including sign language) data without the need for translation or transposition to the written text (Young & Temple, 2014, Chapter 7). However in starting to analyze data in this way the limitation of a strict IPA approach for our kind of data become clear. IPA relies predominantly on close reading of and interpretive engagement with *the text*. Even given that in our case the text could be regarded as a visual one, and thematic codes nonetheless applied, a central problem remained. Much of what we might wish to code was situationally produced features of interaction that did not constitute “talk”.

Attention to *situationally generated significance* has long been recognized in work that encourages the analysis of the environment as interactional space (Lofland & Lofland, 1984). Its structuring and people's roles within it are regarded as meaningful in their own right as well as generators of meaning through interpersonal interaction (Spradley, 1979). Furthermore, this focus on the situational and contextual was of particular importance in a study involving Deaf people because of the ways in which Deaf culture gives predominance to the visual environment in the structuring of communication.

In Deaf culture, language, the visual, the linguistic and the environmental are not as easily separable entities as in hearing cultures because the visual is the medium of language (not sound or the written text) and language moves (quite literally) in the environment through the spatial and temporal aspects of how language is produced (Sacks, 1989; Stokoe, 1960). Consequently the physical environment has to be arranged to facilitate language and communication far more deliberately than in hearing worlds and the visual is a pre-condition for language.

These environmental and visual preferences are increasingly referred to as “DeafSpace” (Gallaudet University, 2013). For example, Deaf people have to be able to see each other to communicate; this influences preferred arrangements of furniture and color and texture of walls in the home which form the background to interact in a visual language. Sitting/standing in a circle is more usual in interactions involving multiple people in order to be able to judge when to contribute and see who is talking. Adequate light, reflective surfaces and reverberant materials connect the individual to the environment and enable the calling of attention and noticing of presence (through vibration, changes in light and movement). Consequently how the situational experiences of Deaf participants demonstrate cultural connection, support communication and may or may not be modified to support the needs of a Deaf person with dementia, is a vital component of data analysis.

The non-verbal, situational and environmental has also been recognized in mainstream dementia research studies from the point of view of the embodied self (Cadell & Clare, 2011; Hubbard et al., 2002; Hughes, 2001; Kontos, 2004; Ward & Campbell, 2013). A key debate in considering the experience of the dementia is whether on the one hand the person is fundamentally defined through the psychological abilities of thought, reason, memory, reflection and consciousness; hence when dementia limits these so is the self eradicated. Or on the other hand whether the person is defined by what Hughes (2001) terms the self-embodied-agent. That is to say the self is unknowable without situation in context and furthermore the ability to influence, express and interpret the social world is not confined to properties of the mind. The body may continue to have agency (to do, intend, witness, and respond) despite decreases in cognitive and linguistic powers through dementia. As Kontos (2004) states: “... selfhood is tantamount to the existential expressiveness of the body that emerges from our active and responsive propensity towards the world” (p. 837).

A focus on the embodied self has led to an emerging body of work on the non-verbal as situated and embodied communication amongst people with dementia (Hubbard et al., 2002; Ward & Campbell, 2013). However much of the discussion in the dementia literature, whilst recognizing the non-verbal as communicative, nonetheless equates non-verbal with non-linguistic. To study the non-verbal is to study behaviors, facial

expressions and gestures from which communicative intent and response might be derived but which are not language in a formal sense.

However, studying the narratives of Deaf people with dementia transgresses some of these divisions. The non-verbal is language. For example, facial expression is an integral feature of signed languages with differences in shapes and expressions made on the face precisely contributing to the meaning of an utterance from a grammatical point of view. For instance, eyebrows raised or lowered indicate the difference between rhetorical and non-rhetorical questions. Variations on how much one puffs one's cheeks can calibrate the size or volume of the object or person being referred to.

Furthermore, there are uses of the body which are *culturally* conventionalized to such an extent that they can communicate specific intent and meaning. In this respect eyes are the most common example. For instance their movement from left to right in someone with whom you are conversing lets you know that a person is crossing your path behind you. Making one's eyes wider can signal "be careful someone is watching our conversation" simultaneously to having the conversation. Looking away signals disengagement or lack of interest, not because it is a non-verbal marker of indifference but because quite literally no language can be perceived. Eye gaze also has specific grammatical properties in signed languages such as marking plurals in some instances.

In our data we observed many, many instances of the retention of grammatical features of signed language which involve conventionalized uses of facial expression, eye gaze, space and movement even if the ability to form syntactically complex signed utterances had been diminished or was no longer present. These features are *of the language* not in addition or separate to it. Thus understanding eye gaze in our data required an understanding of how it is used within the grammar of signed languages. We also treated non-verbal features of our participants' interviews as living artifacts of deeply culturally-embedded rules of social interaction *which had been retained* and were fundamental to participants' expression of agency. This is qualitatively different from recording non-verbal communications and interactions amongst hearing people with dementia who have not experienced a lifetime of using the visual-spatial medium as the linguistic medium. It is also more complex than the identification of single gestures which might be regarded as culturally indicative such as those observed by Kontos (2004) amongst orthodox Jewish people with dementia. If language in its entirety is gestural, in the sense of using space, time, vision and movement, then culture resides in the entirety of expression in that medium not in a single item that might use that medium.

These differences and the significance of the cultural-embeddedness of non-verbal language is exemplified in the following example, in which deliberate failure to look at something was the strongest expression this person mustered to convey her lived experience with dementia. She was determined that we understood her and trusted that the researcher would understand the cultural inferences of how she used eye gaze and not simply mistake it for a form of inferred communication. This was deliberate. Once again, we render the data as re-presented narrative with simultaneous cultural explication in order to broker between the reader and text, the inter-cultural significance of this dementia story.

Living with red cord: Maggie's story

When we met Maggie she was in her late 70s and had been a BSL user all her life. The Deaf community was the place she felt she belonged. Now she has dementia and lives alone in sheltered accommodation. She is the only Deaf person in the complex of flats. Carers visit her twice a day to make sure she has her medication and in the corner of the room hangs the red cord.

But to Maggie they are not just carers; she is quite particular in pointing out they are "hearing carers". I ask her about them and in one breath she tells me they are "nice" and in the next with very demonstrative signing: DOOR-FLASH-ME-WALK-OPEN-DOOR-SEE-SHUT DOOR HARD. She clearly does not appreciate having to answer the door to hearing parties who cannot sign. The flashing doorbell that has been a part of her life always, still takes her to the door, but when she opens it there are now people who cannot sign, who cannot communicate with her and yet she still must open the door. Where has her native language gone? Why does the flashing doorbell no longer bring signing friends?

We sit down and I ask her about the red cord. It hangs in the corner of the room as it does for every resident of the sheltered housing complex. RED-CORD-THERE-WHAT-FOR? I ask, pointing to the exact location over and beyond her right shoulder. But she does not look. She does not follow my finger with her gaze as Deaf people usually do when asked a question like that. Instead she looks away from me and from the red cord and looks downwards. Without a shared eye gaze, our interaction ceases. She is telling me with her glance that this subject is closed. She is not going to discuss the red cord with me. To her it was not a source of security, something that could be pulled to attract the help she needed. No, it was just another way in which hearing people with whom she has nothing in common, with whom she cannot communicate, turn up on her doorstep. No reassurance there, only more frustration. In this non-verbal, fully linguistic response, Maggie is saying to me: "RED-CORD-THERE-WHAT-FOR?"

Discussion

Directly engaging Deaf people in narrative interviews about their experience of dementia challenges and expands our understanding of some emergent concerns in the mainstream (non-Deaf) research literature about dementia and the self. It does this because the base-line assumptions in the majority literature from which interpretations are made and theories emerge are, in the case of sign language users, inverted or modified.

For example, the study of the role of non-verbal communication, its potential and contribution to the continued recognition of the agency and personhood of someone with dementia would usually begin from the perspective of the non-verbal as an auxiliary, modified or additional channel of communication. It is one that can become more important and facilitative as mental capacity declines and the usual repertoires of language and interactional skills are lessened. For Deaf people, the non-verbal, visual, spatial world is one that has been occupied all of their lives and signed language uses space, movement, location, handshape and the body in highly precise ways. Therefore, the implications of dementia for these communicative resources, rather than these communicative alternatives is a key concern and one, as we have demonstrated, too easily missed and

misunderstood without direct sign language user to sign language user interaction.

The embodied self as retaining agency and demonstrating personhood is also a significant theme in raft of dementia literature that has highlighted its importance in meeting the needs and maximizing the capacity of people living with dementia. However, for Deaf people the embodied self is obvious and central throughout their whole lives because it is through the body that language is formed and identity is performed (the signing person, not the person who uses sign language). For Deaf people, there is a far more extensive elision of the physicality of the self with the perceiving, communicating and performative self (Davis, 1995; Merleau-Ponty, 1962) than is usually the case with hearing people. Spoken language might also require the use of the body (mouth and organs of articulation) but such use is devoid of the four dimensional spatial (and temporal) relationships required of the signing body. These spatial relationships mean that language as it is produced can also be observed by the producer becoming, in some instances, both subject and object of the utterance, as we saw in Harold's story. He simultaneously watched his language deteriorate whilst telling us it was happening and asking us to look all at the same time and within the same utterance.

Such effects of visual, spatial language sit well with narrative analysis concern with sequence and consequence (Riessman & Quinney, 2005) but it is different. The narrative is not just a linear one in which we might connect elements and intentions on how it is put together at different points. Signed languages have the capacity to produce multi-layered effects and meanings, playing with observation and the observed, the subject and object, the intention and its commentary simultaneously because of its multi-dimensional nature and its site of production: the body in time and space (Nelson, 2006; Rayman, 1999; Young & Temple, 2014, Ch6).

Consequently as we have also demonstrated, the situational and contextual elements of where the narrative is produced are important on how it is produced (e.g. Maggie's resistance to looking at the red cord). Whilst context, situation and environment are an increasing concern in the dementia literature for how they enable or deny the performance of the self (e.g. Ward & Campbell, 2013) in relation to Deaf people there is an additional element. The situational is cultural and linguistic too in that the arrangement of the physical environment is vital to the ability to communicate and understand in a visual-spatial language. Failure to tune in to how the environment enables language for Deaf people is a powerful denial of potential for a Deaf person with dementia.

Finally, we would point out that in writing this article there is a resultant discontinuity between the four dimensional experience of data generation and the two dimensional experience of data presentation. This is deliberate. Symbolically it mirrors how the Deaf person with dementia, whose personhood remains present and active through the medium of their sign language, is largely unseen without recognition of the visual as linguistic and the situational as cultural.

Conclusion

The data generously shared with us by the four Deaf people with dementia and their 5 care partners on two occasions has yielded many insights which will contribute to future analyses.

Sadly two of our participants passed away after this study was completed. However, their desire to ensure that their contribution was "not for me but for us" is honored in a series of dissemination events with the Deaf community in which we are sharing the insights of this paper and many more from the study yet to be published in order to invite challenge, reinforcement, discussion and action by other Deaf people for Deaf people.

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