

## Review

# Everyday conversation in dementia: a review of the literature to inform research and practice

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### Abstract

*Background:* There has been increasing interest in dementia care in recent years, including how practitioners, service providers and society in general can help individuals to live well with the condition. An important aspect to this is provision of advice to ensure conversation partners effectively support the person with dementia in conversation.

*Aims:* To provide a descriptive review of the literature examining everyday conversation in dementia in order to inform practice and research.

*Methods & Procedures:* This review used a method specifically developed for reviewing conversation analytic and related literature. A range of databases were searched using key words and explicitly described inclusion criteria leading to a final corpus of 50 titles. Using this qualitative methodology, each paper was examined and data extracted. The contribution of each of these is described and the implications for practice and research are outlined.

*Main Contribution:* This review examined studies into conversation in Alzheimer's disease, vascular dementia and Lewy body dementia, grouping these into: early influential studies; work drawing on positioning theory; studies using social and linguistic approaches; collaborative storytelling; formulaic language; studies specifically using conversation analysis; and conversation as a target for individualized therapy. In addition, more recent work examining primary progressive aphasia and behavioural variant frontotemporal dementia was explored. Overall, this review indicates that research examining conversation in natural settings provides a rich source of data to explore not just the challenges within conversation for those taking part, but also the skills retained by the person with dementia. An important aspect of this understanding is the notion that these skills relate not only to information exchange but also aspects of social interaction. The role of others in scaffolding the conversation abilities of the person with dementia and the potential of this for developing interventions are discussed.

*Conclusions & Implications:* The review indicates that interventions targeting conversation in dementia are often advocated in the literature but currently such approaches remain to be systematically evaluated. In addition, many of the important insights arising from these studies have yet to inform multidisciplinary dementia care practice.

*Keywords:* conversation, dementia, narrative, review.

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**What this paper adds***What is already known on the subject?*

There is an increasing interest globally in providing effective support for people with dementia and their family members. An important aspect to this consists of those interventions aimed at enhancing conversation in everyday life. Currently there are few reviews examining everyday conversation in dementia. Literature examining this area can be found in diverse fields and journals, meaning it can be difficult for the researcher or practitioner to gain an overview of work in this area.

*What this paper adds*

The review aims to identify, organize and translate systematically what is currently known about everyday conversation in dementia into a useable resource to inform practitioners and researchers of all disciplines. This study, therefore, provides a descriptive review of the literature to date, including how this currently impacts on dementia care and makes recommendations for future practice and research. Research examining conversation in natural settings provides a rich source of data to explore not just the challenges within conversation for those taking part, but also the skills retained by the person with dementia. These skills relate to information exchange and aspects of social interaction. Conversation partners have a crucial role in scaffolding the conversation abilities of the person with dementia. There is potential for developing interventions around conversation, however, dementia care has so far not exploited such approaches in research or practice.

**Introduction**

Dementia is a syndrome caused by a variety of conditions that affect the brain leading to problems with memory, language, understanding and judgment (Alzheimer's Society 2015). These conditions include Alzheimer's disease, vascular dementia, Lewy body dementia and frontotemporal dementia. Alzheimer's Disease International (2012) estimate that 36 million people in the world are living with dementia with a projected increase in 2030 to 66 million. These figures have led to an increasing focus on dementia in recent years, with the national and international policy context developing rapidly. For example, in England, the National Dementia Strategy (Department of Health 2009) set out specific recommendations from the government for the National Health Service (NHS), local government and others to improve dementia care, linked to a specific commissioning agenda. Within the strategy there were three overarching themes: raising awareness and understanding; early diagnosis and support; and living well with dementia. Similar plans and strategies are present in many other countries including France, Norway, United States, Australia, South Korea and Japan (Nakanishi and Nakahima 2014, Pot *et al.* 2013).

An important aspect to living well with dementia is the appropriate management of communication difficulties in everyday life. However, whilst much has been written about communication in dementia, the evidence on which this is based is not always explicit. For example, Young *et al.* (2011) note that 'the vast majority of advice and most of the communication tools or training programmes currently available make no explicit link to any theoretical framework' (1007) with an absence of any underpinning communication theory or empirical

basis and a writer/trainer perspective. Research into the study of naturally occurring conversation may go some way to address this gap. Importantly this field of research explores not only the communicative abilities and difficulties of the person with dementia within a given social context, but also the influence of the conversation partner (Hamilton 2008a). A variety of methods have been used to study natural conversation in-depth including conversation analysis (Hamilton 1994), systemic functional linguistics (Müller and Wilson 2008) and narrative analysis (Ramanathan 1994). These methods have much in common including: (1) audio recording, or more latterly video recording, of conversation, (2) detailed exploration of interaction as it sequentially occurs in context and (3) observations arising from the data, rather than predefined hypotheses guiding the analysis, i.e., analysis is data driven.

Whilst there has been interest in whether such in-depth study of conversation could be developed into interventions (Chatwin 2014, Kindell *et al.* 2013, Perkins *et al.* 1997, Taylor *et al.* 2014), to date, dementia care has not exploited this potential as has occurred in the field of aphasia following stroke (Simmons-Mackie *et al.* 2014). Moreover, access to specialist communication services for people with dementia is often restricted compared with other adult populations with acquired neurological conditions (see Royal College of Speech and Language Therapists 2014 for a discussion of this issue in the UK). The study of conversation not only provides an opportunity to explore the changing needs of people with dementia in conversation, but also, crucially, how others can adapt to these changes. This helps deliver interventions that are empirically grounded in the experiences of people with dementia and their family

members, that have a clear theoretical framework and that can be tailored to individual need. In addition, person-centred approaches underpin the work of all disciplines in dementia care and the social environment is a crucial aspect to such philosophies (Brooker 2007). This means the study of everyday conversation is of interest to all members of the multidisciplinary team when providing care and support. However, mapping results across studies of conversation in dementia to inform this work can be challenging due to the diversity of conversation practices studied, variability in methods used and differing emphases from linguistic, psychological and sociological perspectives. There are also methodological challenges with over-generalizing from work in this field as most studies report from qualitative case study work where individual experience is described in-depth and is highly contextualized.

More generally, it has been suggested that knowledge from studies exploring conversation analysis and related approaches has often remained within the academic literature and has not been adequately translated into healthcare policy, education and practice and a significant aspect of this has been the low number of reviews in this area (Parry and Land 2013). This current review explores the literature examining conversation in dementia. The primary aim of the review is to identify, organize and translate systematically what is currently known about everyday conversation in dementia into a useable resource to inform practitioners and researchers of all disciplines (Parry and Land 2013). Objectives of this review include: ascertaining knowledge to inform the field; identifying areas that require further exploration; and comparing and positioning this literature within current dementia care practice and research.

### **Methods: search and review strategy**

The review was guided by a method specifically developed for systematically reviewing and synthesizing conversation analytic and related literature (Parry and Land 2013). Parry and Land (2013) argue that research of this nature does not neatly fit into either of the categories of quantitative or qualitative methods and this means that tools currently available are not adequately suited to the review of conversation studies. For example, conversation data and findings are not numerical, making quantitative review and synthesis impossible. In addition, whilst this literature shares much more with qualitative study, Parry and Land argue that the nature of evidence from conversation studies is different from other qualitative work. Results are descriptive, contextualized and specific in nature and this is in contrast to qualitative work that investigates meanings, views and understandings using interpretive analysis. Reviews of the latter

qualitative work often aim to further interpret and generate new theory (Barnett-Page and Thomas 2009).

Parry and Land (2013), therefore, examined various approaches and from this developed a step-by-step review method suited to the field of conversation analytic and related discursive research. The method shares important aspects with other approaches to avoid reviewer bias, including a comprehensive, formalized and transparent method to search, sift through the literature and extract data. There are, however, a number of differences. For example, inclusion and exclusion criteria are explicitly written to restrict the review only to the study of naturally occurring talk where audio or video recording has allowed for repeated and detailed viewing. In this way, the review method allows for a variety of research methods but filters out studies that do not conform to important pillars of quality for conversation research. This would, for example, exclude studies that use observation and written data collection only. Parry and Land's method also preserves the descriptive nature of conversation research and aggregates findings by describing, summarizing and grouping findings into logical categories to draw out the implications for the review rather than attempting to use interpretive processes to generate new meaning. This review is the first in dementia studies to use this method.

In order to develop a broad understanding of the field and the potential contribution of all disciplines and approaches, this review was not confined solely to studies using conversation analysis or to a particular type of dementia. The following eligibility criteria were agreed by the review team (who are all authors of this paper):

- Studies must examine everyday conversation occurring in an environment familiar to the person with dementia, e.g., own home, residential home, day centre using:
- Conversation analysis or other methods where the analysis is predominantly qualitative and conforms to the following:
  - Data collection uses audio or video recording of conversation.
  - Detailed analysis arises from the data rather than guided by prior hypotheses or constrained by predefined systems of coding.
  - Involves analysis across turns between at least two speakers.
  - Involves presentation of conversation samples in findings/results.
  - The focus of study is on conversation itself and the part both parties play to develop the conversation or the narrative within it.
  - Conversation develops in a naturalistic manner and allows the person with dementia to

take an active part in developing the encounter.

- Conversations could be with family, volunteers, paid carers or researchers.
- Studies are reported in English examining monolingual conversations.<sup>1</sup>
- Papers must be published within peer-reviewed journals and book chapters.

The initial stages of this review were undertaken by the first author. Exploratory searches were used to develop an appropriate search strategy, considering particular databases, search terms and search fields. As well as searching the literature about everyday conversation in dementia, it became clear during this step that supporting people with dementia to tell stories about their lives, within conversation, also represented an overlapping body of literature important to dementia care and, therefore, conversational story telling in dementia was also explored. The following two areas were searched:

- Everyday conversation in dementia—using the search terms ‘conversation\* OR discourse AND dementia OR primary progressive aphasia’.
- Conversational storytelling in dementia—using the search terms ‘conversation\* AND story\* OR narrative AND dementia’.

The following databases were searched: Medline, Amed, PsycINFO, Social policy and practice, Books@Ovid, PsycBooks, ASSIA, Web of Science, CINAHAL. References within papers were explored and the journal ‘Dementia: The International Journal of Social Research and Practice’ was searched using ‘conversation’ as a key term. The first search area led to the retrieval of 1312 titles. Following inspection of each title and abstract 87 publications were retrieved for detailed inspection with 38 titles remaining after this process was complete. The second search area led to the retrieval of 1778 titles and abstracts, 18 publications were retrieved in full, with a final nine remaining in the review. This exercise was carried out in October 2014 for studies from 1990 to this date (obtaining 47 titles). This search was then updated in March 2016 (locating a further three studies). This review, therefore, consists of 50 titles. Templates were specifically designed in order to extract data and after reading each paper, these were completed in detail; this included aspect(s) of conversation studied, setting, participants, approach used, number of examples, depth of analysis and reviewers notes.

The results were explored and discussed by all the authors in order to collate, group and synthesize the data. In this way the outcomes of the review were exam-

ined and compared with the wider dementia literature to draw together the implications for practice and further research. There were potentially numerous ways to organize the literature review, with a variety of overlapping areas. The diversity of the conversation practices described meant that grouping studies by particular conversation practices was not appropriate. Most research studies in this review examined conversations where memory difficulties were prominent, including those studies that explored specific diagnoses such as Alzheimer’s disease, vascular dementia and Lewy body dementia, or where due to the nature of the difficulties described memory problems were a central feature of the condition. Less prevalent is work around rarer dementias that initially present with changes in language, personality and behaviour, rather than memory, including those in frontotemporal dementia. This review has, therefore, been organized into two broad sections: the first focusing on studies of Alzheimer’s disease, vascular dementia and Lewy body dementia; the second focusing on frontotemporal dementia. Table 1 outlines these studies and the areas under which they have been further grouped arising from the focus of the study, methods used and historical contributions to the field. In keeping with the philosophical and methodological underpinnings of these studies and the reporting approach advocated by Parry and Land (2013), the results are now described followed by discussion of the implications from this review for a variety of informed stakeholders.

### **Review findings: conversation in Alzheimer’s disease, vascular dementia and Lewy body dementia**

#### *Early influential studies in dementia communication*

Hamilton (1994) and Shakespeare (1998) used methods drawn from conversation analysis and ethnomethodology to analyse conversation skills, thus presenting a move away from the focus on language functioning that had been dominant at the time (Appell *et al.* 1982). Hamilton (1994) recorded herself in a care home talking to Elsie, a woman with Alzheimer’s disease, over a four-year period to illustrate the decline in Elsie’s ability to formulate her talk clearly for the listener. For example, Elsie’s use of pronouns without a clear reference increased and her ability to notice and self-repair conversational trouble decreased. Despite this, Elsie retained the mechanical aspects of turn-taking, with automatic speech appearing more resistant to change. With time, Hamilton noted her own increasing responsibility to facilitate the conversation and that she did not always indicate when she had not understood Elsie; arguing, in these instances, she

Table 1. Studies Reviewed

| <b>Conversation in Alzheimer's disease, vascular dementia and Lewy body dementia</b> |  |
|--|--|
| Early influential studies in dementia communication                                  | Hamilton (1994), Shakespeare (1998)  |
| Work drawing on positioning theory   | Purves (2010), Sabat (1991a, 1991b, 2001)  |
| Social and linguistic approaches to conversation                                     | Guendouzi and Müller (2006), Guendouzi and Pate (2014), Hydén (2014), Mok and Müller (2013), Müller (2003), Müller and Guendouzi (2005), Müller and Mok (2012, 2014)                     |
| Studies specifically using conversation analysis                                     | Chatwin (2014), Jansson (2016), Jansson and Plejert (2014), Jones (2015), Kitzinger and Jones (2007), Lindholm (2008, 2014, 2015), Müller and Wilson (2008), Wilson <i>et al.</i> (2007) |
| Conversation as a target for individualized therapy                                  | Ekström <i>et al.</i> (2015), Perkins <i>et al.</i> (1997, 1998), Spilkin and Bethlehem (2003), Whitworth <i>et al.</i> (1999)   |
| Collaborative storytelling in dementia   | Davis and Maclagan (2014), Hamilton (2008b), Hydén (2011, 2013), Hydén and Orulv (2009), Hydén <i>et al.</i> (2012), Ramanathan (1994, 1995)   |
| Formulaic language   | Guendouzi and Müller (2001), Wray (2010, 2014)   |
| <b>Conversation in frontotemporal dementia</b>                                       |  |
| Conversation in primary progressive aphasia  | Kindell <i>et al.</i> (2013), Simmons-Mackie and Damico (1997)   |
| Conversation in behavioural variant frontotemporal dementia                          | Joaquin (2010a, 2010b), Mikesell (2009, 2010a, 2010b, 2014), Smith (2010), Torrisi (2010)  |

chose not to highlight Elsie's conversational difficulties but instead acted to preserve 'face' (Goffman 1967).

Shakespeare (1998) used audiotaped conversations with people with 'confusion' talking in a clinic situation with the researcher and at home with family to distinguish different abilities in conversation, labelling these as 'minimally active', 'moderately active' and 'very active' confused speakers. Shakespeare was interested in how confused speakers were assigned less-than-full membership within society and how such issues were displayed in talk. She, for example, describes that 'ordinary members' when talking to someone identified with confusion may 'take license to do some unusual things in conversation—engage in test questions, interrupt, present bizarre formulations and so on' (215). Thus the difficulties faced by people with confusion are not only those arising from their cognitive difficulties but also arising from the actions of others (Shakespeare 1998).

*Work drawing on positioning theory*

The beliefs and behaviours of others towards the person with dementia have also been highlighted in other work, exploring the social construction of the self within conversation. When talking with 'Dr M' who had Alzheimer's disease, Sabat (1991a, 1991b) found it helpful to give her time to organize her thoughts to find words (Sabat 1991b), and paraphrase and check for understanding using 'indirect repair' (Sabat 1991a). Sabat's contribution lies in the link he made between the need for mutual cooperation in conversation in Alzheimer's disease to the social constructionist work of Harré (1983, 1991), in particular that the communicative scaffolding provided by the conversation partner allows for the social construction and projection of the 'self' into social situ-

ations (Sabat 1991a). The 'self' is, therefore, a product of joint enterprise, rather than residing in the brain of the person with dementia. Sabat (2001) further explores the relevance of 'positioning theory' (Davies and Harré 1990, Harré and Van Langenhove 1999) to interactions with those with Alzheimer's disease. Positioning refers to 'the discursive process whereby people are located in conversations as observably and subjectively coherent participants in jointly produced storylines' (Davies and Harré 1990: 37). Sabat (2001) argues that malignant positioning occurs when others come to see the person with Alzheimer's disease negatively in terms of their deficits alone, rather than their positive attributes and fail to foster their social abilities, potentially leading to a range of depersonalized interactions (Sabat 2001).

A more recent study by Purves (2010) explores positioning in everyday talk at home, in a family where the mother had Alzheimer's disease. Family members attempted to support the woman's competence in conversation and negotiate those changes that dementia had brought, e.g., to maintain her role as expert cook, despite others now doing most of the cooking. In this family, depersonalizing interactions did not occur, but the author acknowledges each family unit is different with values influenced by different historical and cultural milieu, in this case a Japanese-Canadian context.

*Social and linguistic approaches to conversation*

Returning to a more linguistic focus, Müller (2003) uses an extract of conversation, taken in a care home to illustrate the various elements at play that extend far beyond the person with dementia's language competence into a collaborative system distributed across both speakers and the environment. Müller and Guendouzi (2005) demonstrate that despite significant problems

with memory and fluctuations in intelligibility, skills in conversation were present in the two participants they studied. This included turn-taking and attempts to repair sources of trouble in the conversation and, whilst topic shifts were abrupt, these contributed to the conversation moving forward. Müller and Guendouzi argue that different 'extensions' of memory are at play in conversation, so for example, memory to hold the perception of an utterance long enough to decode it, turn-exchange length memory for memory within two or three turns, conversation length memory that enables reference to things already established in the conversation and longer term memory referring to events that stretch back over the person's life. Guendouzi and Müller (2006) use data from four individuals with dementia to illustrate different approaches to study communication in dementia, highlighting the strength of interactional data.

Müller and Mok (2012) use systemic functional linguistics to examine conversations between two women with dementia living in care and two visiting speech pathology students and demonstrate that the women took an active part in the conversation, using their cultural and social knowledge to make sense of their visitors within the interaction, despite their memory difficulties. Although the students appeared passive, e.g., tolerating very long pauses in the conversation, their behaviour allowed the women time to direct the conversation. In another study, Mok and Müller (2013) examine conversation in a residential facility between five pairs of people with dementia, with the researcher present as a participant observer. Analysis illustrates a range of mostly successful interactions and the authors argue for the importance of facilitating such casual conversation in care settings.

In further analysis of their earlier work, Müller and Mok (2014) argue that cognition in dementia is often regarded as a static and context free retention and recall of information, for example, having information in a test situation; their data, however, illustrates the dynamic skills of seeking out and attempting to make sense of the situation at hand, demonstrated in the moments of conversation they studied. They argue that this contextually situated and co-constructed view of cognition has been ignored in research. An expanded view of cognition is also given by Hydén (2014) who uses video to analyse two women with dementia cooking with two staff members at a day centre. Despite significant dementia, the two women played an active part in the activity because of the support provided by the staff, including breaking down the activity into manageable steps, appropriate verbal instructions, physical prompting and the layout of objects in the immediate environment. Hydén (2014) argues that in order to fully understand cognition and communication in dementia, a move away from a fo-

cus solely on the person with dementia's cognitive skills is needed to one that focuses on other contextual resources, including the cognitive resources of others and physical prompts in the environment: 'the cognitive and communicative ecosystem' (116).

Guendouzi and Pate (2014) use extracts from conversations recorded in a care home with a researcher to demonstrate how 'F' (with advanced dementia) used a variety of resources to participate in the conversation: using agreements, minimal responses, formulaic comments and remarks that held a general, rather than a specific meaning within the conversation. They argue there could be alternative explanations for these findings. On the one hand, this represented 'F's' ability to use her retained socially acquired communicative behaviours to compensate for her difficulties. However, an alternative explanation could be that many of her responses also demonstrated an inability to inhibit semantically related information in her thinking and responses. Thus, her conversational behaviour may be the 'result of an interaction between both cognitive deficits and interactional resources' (142). Guendouzi and Pate also discuss the problematic nature of using the word 'strategy' to describe such conversation behaviours because of the assumption that this represents a deliberate act, when in all likelihood in 'F's' case, this is non-volitional behaviour.

#### *Collaborative storytelling in dementia*

As described within the methods section, an overlapping body of literature important to dementia care practice represents those studies that examine the collaborative nature of autobiographical narratives in conversations between people with dementia, their family members and others. Ramanathan (1994) illustrates that Tina, with mild to moderate Alzheimer's disease, produced extended narratives with the researcher at home; however, in the same activity with her husband, her responses lacked this extended response. Her husband tended to use event-specific prompts to elicit particular storylines, thus deciding the topic and at times talking for her. Ramanathan argues Tina's husband had overcompensated for her difficulties, perhaps arising out of a desire to help her maintain such memories. However, when talking to the same researcher at the day centre, Tina required more scaffolding within the conversation, with greater evidence of incoherence and egocentricity in her speech (Ramanathan 1995). These two studies illustrate variability in the skills of the person with dementia in terms of both audience and setting and Ramanathan (1995) maintains the need to pay attention to these contextual factors.

Hamilton (2008b) revisits her earlier conversations with Elsie (described earlier in this review) noting that

Elsie had more advanced dementia than others described in the literature. Elsie tended not to talk a great deal about the past and of the 204 clauses that did refer to past events, only 27% were part of narratives. The rest were in the form of 'narrative traces', or 'out of the blue' utterances within talk about the present, that contained past verb tense constructions, indicating this part of talk was about a past event. However, Elsie, it was shown, had difficulty creating important anchors of the story-world to help her listener fully understand such narrative traces, e.g., who or what was there in the story, when and where was it and what happened. Hamilton argues that whilst a listener might not be sure exactly what is being communicated on a semantic level by an individual with advanced dementia and may only have access to generic meaning, they may use cues from the talk, nonverbal behaviours and the environment to draw inferences about these narrative traces and, therefore, identity. This means identity work through talk is still possible even at this late stage.

Hydén and Örvulv (2009) examined instances of a woman, Martha, with advanced Alzheimer's disease who lived in a care facility, telling the same story (getting her driving licence), on three different occasions with different audiences. When telling her friend, Catherine, who also had dementia, the story had a repetitive quality. However, with staff there was less repetition because of the way they supported aspects of the story within the conversation. Martha used direct reported speech (the dialogue in the story), paralinguistic features such as tone of voice, gesture and body contact to give the story a dramatizing or performative aspect. Hydén *et al.* (2012) return to this data to illustrate the active and attentive part that listener's play within storytelling interactions, including the use of continuers ('mmm', 'yeah'), news-marks ('you don't say!') and formulations (summing up the gist of what has been said or requesting a clarification). Hydén and Örvulv (2009) and Hydén *et al.* (2012) argue that conversational storytelling is a socially rewarding activity and it is not the temporal order, or details of the story that is important but the moral point or 'evaluation' because this illustrates aspects of identity.

Hydén (2011, 2013) demonstrates how family carers provide 'narrative scaffolding' to help the person with dementia tell their story. Remembering together, for Oswald, a man with dementia and Linda, his wife, was a way to support their identity and commitment to each other as a couple (Hydén 2011). Hydén (2013) additionally demonstrates the embodied nature of the story telling, for example, how Oswald used gestures to convey parts of the story, because his linguistic and memory difficulties made it hard for him to use verbal means. Hydén (2013) makes the case for video recording and analysis to be a standard methodology when research-

ing narrative activities, in order to examine embodied behaviour.

Davis and Maclagan (2014) studied an extensive longitudinal corpus of conversation with Maureen Littlejohn, a woman with dementia living in care, talking to students and researchers. Whilst initially it was difficult to see any issues with Maureen's talk, analysis over time indicated her favourite stories seemed to be slipping into the conversation more and, in later datasets, were repeated within the same conversation. These were not pure perseverations, as the format and details changed each time. Listener feedback was important to encourage Maureen, particularly the use of emotive/evaluative responses, e.g., 'that's good'. Formulaic language and extenders ('and so on', 'and stuff like that') also helped Maureen take part in conversation.

### *Formulaic language*

Use of formulaic language in those with dementia within conversation is a recurring theme in the literature. Formulaic sequences have been defined as: 'a sequence, continuous or discontinuous, of words or other meaning elements, which is or appears to be, prefabricated: that is, stored and retrieved whole from memory at the time of use, rather than being subject to generation of analysis by the language grammar' (Wray 1999: 214). A number of authors have raised the importance of this for people with dementia. For example, formulaic language was noted to be important for Maureen Littlejohn (Davis and Maclagan 2014) and 'ready-made language' was noted in Elsie's conversations (Hamilton 1994). Guendouzi and Müller (2001) described that certain well used phrases frequently cropped up in 'F's' conversation and, in contrast to other talk, these sequences stood out because of their greater intelligibility.

Wray (2010) observed Joan, a renowned opera singer with dementia, delivering a weekend singing workshop. For Joan, the workshop format was highly familiar so she understood the requirements of the task. Success was also attributed to her retained musical skills, ability to use gesture to convey ideas, the sensitive support from her co-trainer and her use of formulaic utterances, which were appropriate in this context. Wray (2014) argues that formulaic language is used in normal conversation and when processing demands rise, such prefabricated sequences can be relied upon to increase capacity for production and comprehension; in Alzheimer's disease reduced cognitive processing can lead to an increased reliance on such formulaic sequences.

### *Studies specifically using conversation analysis*

Some studies have specifically used conversation analysis or methods very closely adapted from this approach.

Kitzinger and Jones (2007) demonstrate that 'May', a woman with Alzheimer's disease, retained many skills whilst making telephone calls to her family, including routine aspects of call openings, recognition of speakers, use of greetings and 'how are you' sequences. However, May's memory problems become evident as calls progress. Jones (2015) further analyses May's telephone calls over a two-year period. She notes how May's episodic memory problems led to particular difficulties when her family ask questions relating to recent events. May does, however, use her conversation skills to 'answer without knowing' and by doing this she was able to take her turn despite being unable to remember the particular information required (Jones 2015: 14).

Studies have explored how people with dementia use laughter within conversation to deal with communication difficulties. Lindholm (2008) analysed videotaped interaction in a day centre during an informal quiz to argue that participant's use of laughter was a compensatory strategy displaying aspects of competence, e.g., signalling awareness of word finding problems and maintaining the flow of conversation. In another study 'M', a man with probable Alzheimer's disease, was shown to use laughter to demonstrate communicative success after trouble in the conversation and as an instruction to mark parts of his talk as important to the young researcher listening to him (Wilson *et al.* 2007). This latter aspect also had a function in reinforcing 'M's' identity as an older man giving advice to one younger and this aspect, along with M's significant linguistic difficulties, are explored further in a related paper, in this instance using systemic functional linguistics (Müller and Wilson 2008).

Lindholm (2014) looks at how difficulties with comprehension are displayed by people with dementia attending a day centre and how staff attempt to repair such issues. Both abilities and disabilities with understanding are shown to be as much a collective production as they are a consequence of the person with dementia's cognitive abilities alone. Lindholm (2015) examines confabulation, or false beliefs, in the conversation of a man with dementia in a daycare centre, noting that responses to this by others formed a continuum. At one end, responses attempted to encourage the man to rethink his contribution to the conversation or distance the listener from the false belief in some way. At the opposite end, responses confirmed the man's confabulatory view of the world. Confabulation, it is argued, provides a tool to help the person with dementia engage in conversation and promote positive identity; attention to such interactional behaviours could form an important part of life story approaches.

Jansson and Plejert (2014) discuss interaction between three care workers when showering three residents with dementia. Whilst all the residents protest they do

not want their hair to be washed, two of the workers perform this task in a more step-by-step and negotiated manner, taking account of the resident's wishes and discomfort. These conversations are characterized by greater rapport, less argument and reduced threats to face. Jansson (2016) examines how praise is given by staff in residential care to encourage residents to engage in care activities, including how this contrasts with normal conversation practices, highlighting the institutional nature of such interactions.

Chatwin (2014) argues that whilst general issues of interaction have been explored in care homes, micro-interaction analysis is missing from the field and that this detail is required to fully understand the issues at hand and provide appropriate training programmes for staff. He argues for the use of conversation analysis using an extract of conversation from 'Ted' talking to two care workers. This illustrates how the care workers attempts to reassure Ted may appear to him as random topic changes, causing misalignment in the conversation between them all (Chatwin 2014).

#### *Conversation as a potential target for individualized intervention*

Some studies have more directly focused on the therapeutic potential of conversation approaches to inform intervention. Perkins *et al.* (1997) audiotaped and analysed conversations between individuals with Alzheimer's disease and Lewy body dementia in conversation at home with their family carers (without researchers present) and from this developed a clinical resource to examine interaction: Conversation Analysis Profile for People with Cognitive Impairments (CAP-PCI). This was followed by a paper arguing that conversation analysis is well placed to contribute to dementia care as it has high validity for therapeutic interventions because it provides analysis at the level that intervention is ultimately targeting: everyday talk (Perkins *et al.* 1998). The authors emphasize the collaborative nature of conversation and that a person's ability to produce meaningful talk is not just a function of cognitive ability but also interactionally produced. Analysis of conversation, therefore, gives a profile of skills and difficulties that can be used to derive individually targeted education and advice. Perkins *et al.* (1998) present data to illustrate a range of issues, such as allowing time to respond in turn taking, different approaches to repairing trouble in the conversation and their associated consequences (e.g. pursuing a repair or 'passing over it'; 43) and the challenges in managing topics and topic shifts due to memory difficulties in dementia. Interviews in the CAPPCI explore carers perceptions of conversation difficulties alongside the strategies they use to manage them (Perkins *et al.* 1997) with a later publication



examining this further in Lewy body dementia (Whitworth *et al.* 1999).

Conversation methodologies may have potential to explore interaction using other therapy approaches including life story work and augmentative and alternative communication devices. For example, conversation analysis has been used to study interaction before and after training (a one-hour workshop) between a man with dementia and his daughter talking using a life story memory book made by the researchers (Spilkin and Bethlehem 2003). Following training the father took a more active part in the encounter. Spilkin and Bethlehem (2003) caution that advice around such life story resources is required, as the format of the book may encourage behaviours such as labelling and listing of materials, rather than more open interaction. In a similar vein, Ekström *et al.* (2015) video recorded a woman with Alzheimer's disease talking with her husband at home with and without a tablet computer containing a personalized communication book, made by a speech and language therapist. Whilst the activity offered possibilities to encourage interaction, the format was not without difficulties including the tendency for the use of questions where the answer was already known.

### **Review findings: conversation in frontotemporal dementia**

#### *Conversation in primary progressive aphasia*

The literature search revealed one study examining everyday conversation in semantic dementia (Kindell *et al.* 2013) and another where one of the two participants studied was living with non-fluent primary progressive aphasia (Simmons-Mackie and Damico 1997). Kindell *et al.* (2013) describe how Doug, a man with semantic dementia, had a repeated practice of acting out scenes within conversation using direct reported speech, changes in vocal pitch and loudness, body posture and facial expression. This enabled Doug to take part in conversation and the listener to gain at least some meaning from him, despite significant linguistic difficulties. Doug's wife Karina spoke about her ability to 'get the general gist of what's going on' and the need to prioritize the flow of the interaction, as much as the information content.

Kindell *et al.* (2013) drew on earlier work by Simmons-Mackie and Damico (1997) who videotaped two women at home and at the clinic, one (referred to as 'N.N.') experiencing non-fluent primary progressive aphasia. By studying the videotapes alongside other ethnographic data, a qualitative cycle of analysis was used in order to derive a data-driven definition of compensatory strategies: 'a new or expanded communicative behaviour, often spontaneously acquired and systemat-

ically employed, to overcome a communication barrier in an effort to meet both transactional and interactional communicative goals' (Simmons-Mackie and Damico 1997: 770). For example, N.N. had traditional compensatory strategies such as a word book she had been taught to use, however, she also used other less conscious practices such as gestures to regulate the conversation flow and words such as 'nice', 'really' and 'wonderful' to take a turn but then shift the burden of conversation back to the other speaker. This definition, therefore, moves away from compensations seen solely as consciously learnt practices, to include those spontaneously acquired over time, such as doing more of something, e.g., gestures, or using the skills the individual has available in new ways.

#### *Conversation in behavioural variant frontotemporal dementia*

With respect to behavioural variant frontotemporal dementia all the studies located arose from work undertaken in Los Angeles, USA, by the Social Relations in Frontotemporal Dementia Research Group. This multidisciplinary research draws expertise from applied linguistics, social anthropology and neurology. This group used conversation analysis and ethnography, focusing on data gathered in naturally occurring settings to study interaction and behaviour. Whilst work from this group is reported by them as the study of behavioural variant frontotemporal dementia, further examination of these publications for this review revealed that some participants also had previous diagnoses of progressive language disorders. For example, Kelly, described as having 'disinhibited frontotemporal dementia', also had a prior diagnosis of semantic dementia, although the language disorder was reported not to be problematic in interactions (Mikesell 2010a). Kelly is described as egocentric in conversation, with a lack of impulse control and perseverative conversation (particularly checking her medication) (Mikesell 2010a, Torrisi 2010). In addition, within conversation Kelly showed a 'breakdown in social regulation' (Torrisi 2010: 28) with a tendency to turn the topic of conversation towards her own concerns, rather than the orientation of her conversation partner. Kelly's verbal, embodied and emotional reactions were sometimes at odds with the situation and those around her, e.g., displaying indifference when others within the interaction showed upset or surprise.

With respect to behavioural variant frontotemporal dementia, Mikesell (2009) analyses the conversation of SD, a man in his 70s, described as exhibiting the 'apathetic variant of frontotemporal dementia' (138). SD had few problems with isolated question and answer turns. However, extended sequences reveal difficulties with initiation and elaboration of topics and frequent use of 'minimal responses', e.g., 'mm' and 'I don't know'

which, when placed within these larger sequences, could be inappropriate or contradictory. Those talking to SD provided scaffolding to include and sustain his involvement, such as narrowing questions when a lack of information was forthcoming, with yes/no questions forming an important aspect to this (Mikesell 2009).

In examining repetitional responses, Mikesell (2010b) argues that, despite the often used description of 'echolalia' in behavioural variant frontotemporal dementia, the responses provided by 'Steve' and 'Romeo' were not meaningless repetitions, but had a function in the conversation allowing the individual to participate and respond. In some instances, the repeat was modulated in some way and this, along with embodied responses, indicated the person's awareness that they were being directed like a child. Given that people with frontotemporal dementia are potentially faced with a greater proportion of directives (to initiate and regulate behaviour), Mikesell (2010b) argues that the high rate of repetition in their talk may arise, not solely out of brain changes, but may also reflect the context of care.

Returning to her original data, Mikesell (2014) examines how understanding was demonstrated with different levels of evidence within the interaction of three participants with frontotemporal dementia: Steve, Romeo and Kelly. Mikesell (2014) illustrates instances where individuals seemed to understand as evidenced by a verbal response that involved processing or reformulating the talk of another. However, when required to demonstrate this understanding, by an embodied response in the interaction, such as following an instruction, this was not forthcoming. Much like her earlier work with expression, Mikesell demonstrates that the issue is not so much with turn-by-turn understanding but with understanding the 'over-arching agenda of the entire sequence' (173) and it is at this level that the cognitive planning and integration breaks down.

Joaquin (2010a) demonstrates how certain interactional features (directives, 'let's/we' framed sequences, initiation–response–evaluation sequences) used to guide the behaviour of the person with behavioural variant frontotemporal dementia, were like parent–child interactions. Such verbal assistance led to a diminished status, despite evidence in some cases that competency was missed and, therefore, this was not always necessary. In another publication Joaquin (2010b) argues that the social rules learnt from childhood through to early adulthood, become lost in frontotemporal dementia, arising out of damage to the prefrontal cortex.

Smith (2010) makes the case to study the complexities of behaviours in situ in frontotemporal dementia and presents conversations from Louise and Vera talking to family, researchers and strangers. Conversation partners were shown to facilitate and normalize any issues within the interaction in a variety of ways: deliberately

bringing Louise and Vera into the conversation; rephrasing their talk to help understanding; and if the interaction involved inappropriate remarks to a third party by the person with dementia (in these data to strangers in a shop), conversation partners worked to smooth over this breach. Vera's interaction style could sometimes appear as insensitive, often arising from her tendency to move the topic on to herself within the conversation. Smith argues that whilst this 'person-specific bias' (65) in talk appears on the surface as self-centred, this might be due to participants relying on personal knowledge to engage in action, simply because they no longer have access to other forms of experience.

## Discussion

The studies in this review illustrate that conversation data are a rich source of information for research and practice illustrating both the challenges and skills of people with dementia within everyday interaction. The collaborative nature of conversation is demonstrated; it is clear that the behaviour of others can scaffold the conversation abilities of the person with dementia and this in turn, has the potential to support their well-being and identity. This literature review outlines a broader view of communication than is often presented in the biomedical literature or general discussions of communication in dementia. Simmons-Mackie and Damico (1997) draw on the work of Brown and Yule (1983) to highlight that the goal of conversation is not solely to convey meaning, or transaction; rather, conversation also has an important interactive function. Thus, interaction has a social function that enables being together in the moment and a number of authors in this review highlight the importance of this (e.g., Hamilton 1994, Hydén *et al.* 2012, Müller and Mok 2014). Whilst the distinction between transaction and interaction may be commonly applied in practice in aphasia, this notion has yet to fully inform debates about conversation in dementia and may be particularly useful for those working with people with advanced dementia who appear to retain many skills in terms of interaction, even when their ability with transaction is declining (Hamilton 1994). For example, those focusing on transaction may notice the difficulties a person with dementia has in giving specific information at a given time, as evidenced in the interactions between May and her relatives when they ask her about recent events (Jones 2015). In contrast, others focusing on interactional abilities may see other skills discussed in this review, including turn taking, eye contact, and embodied behaviour (Hamilton 1994, Hydén *et al.* 2012, Kindell *et al.* 2013, Müller and Mok 2014) and feel that the individual effectively engages in other ways. This distinction delivers important concepts to dementia practitioners to describe

how connecting with people with dementia does not have to rest solely upon the transfer of information. In terms of support, activities and care, focusing on interactive abilities provides important ways to enhance social connections.

Across these studies data are used to illustrate people with dementia drawing on a variety of abilities in order to take part in conversation. For example, in spite of significant cognitive challenges and in some cases advanced dementia, skills are evident in turn-taking (Hamilton 1994, Mikesell 2009), routine sequences (Kitzinger and Jones 2007), enactment (Kindell *et al.* 2013), attempts at repair (Müller and Guendouzi 2005), attempts to make sense of other speakers (Müller and Mok 2012, 2014), the use of laughter to display competency (Lindholm 2008, Wilson *et al.* 2007) and the use of formulaic language (Davis and Maclagan 2014, Hamilton 1994, Wray 2010). Whilst some authors have used the word 'strategy' to reflect certain recurring positive conversation practices used by people with dementia (Jones 2015, Kindell *et al.* 2013, Lindholm 2008, Simmons-Mackie and Damico 1997), albeit with a reworked definition, others have questioned whether 'strategy' is the right term given this implies deliberate behaviour (Guendouzi and Pate 2014). Aside from this debate about terminology, actively facilitating such unique behaviours within conversation lies at the heart of person-centred dementia practice, with current approaches in the field explicitly aiming to foster abilities within the social environment (Brooker 2007, Sabat 2008). It is argued that such behaviours are likely to be highly individualized and therapy will be more fruitful if it begins with understanding an individual's current conversation practices and builds on those (Kindell *et al.* 2013, Simmons-Mackie and Damico 1997).

The studies reviewed here deliver a representation of cognition as dynamic and co-constructed that might appeal to those seeking to facilitate skills through provision of appropriate support in the social and physical environment. For example, Müller and Mok (2014) attempt to place cognition in an everyday context, described as the 'dynamic seeking out of learning and joint construction of understanding' (80). In addition, the notion of the cognitive and communicative ecosystem discussed by Hydén (2014) gives researchers and practitioners a way to consider how cues to thought, communication and action are distributed not just in the communication of others but also in the physical environment. There are parallels in the work of Smith (2010), Mikesell (2010b) and Joaquin (2010a), who demonstrate the potential that conversation analysis has to uncover the perspective of the person with frontotemporal dementia, including situated displays of interpersonal awareness. This provides an expanded concept of awareness, which focuses not only on having awareness in decontextual-

ized test situations but includes how awareness might be displayed in everyday settings with others.

Whilst the analysis of conversation may highlight skills not observed on cognitive testing, the literature also illustrates how conversation and particularly talk of a less supportive nature can expose the difficulties of those with dementia and the consequences of this. A number of authors have discussed such issues, relating this to the work of Goffman on 'face', i.e., an individual's sense of dignity or self-image within interactions (Goffman 1967). Goffman argues that, in social situations individuals cooperate using a variety of strategies to maintain each other's face during interaction, thus avoiding the negative emotions associated with actions that lead to a loss of face (Goffman 1967). Hamilton (1994) reports how she did not always highlight Elsie's difficulties, choosing to let these go to preserve face. Perkins *et al.* (1998) argue that repairing trouble in conversation is a delicate business for family carers as exposing memory failure can be seen as a face-threatening act. Guendouzi and Pate (2014) argue that in conversation generally speakers choose their words to 'attend to the psychosocial dimensions of interpersonal communication' (124). These studies, therefore, illuminate that breakdown in the conversation does not just disrupt meaning, this breakdown also threatens to expose a lack of competence on the part of the person with dementia and this, in turn, has social consequences, including placing the individual's positive identity at stake at that point in the interaction.

#### *Future directions: issues requiring further attention*

Despite the insights provided by research into conversation in dementia, there remain a number of gaps that require attention. The conversation literature displays the complexities of cognition in conversation and the integration of multiple cognitive domains (language, memory, executive function etc.). A range of cognitive processes and functions are discussed in these studies, for example: semantics (Guendouzi and Pate 2014, Kindell *et al.* 2013), episodic memory (Jones 2015), short and long term memory (Müller and Guendouzi 2005), intelligibility (Müller 2003, Müller and Guendouzi 2005) and executive function (Mikesell 2009). The literature, therefore, presents a vast range of communication skills and difficulties across individuals with dementia. This heterogeneity challenges the often unitary descriptions of communication in dementia and presents as a challenge in the delivery of communication training. This review has separated out studies into Alzheimer's disease, vascular dementia and Lewy body dementia on the one hand, and those into frontotemporal dementia and primary progressive aphasia on the other, highlighting areas of overlap but

also some differences. This has emphasized the role of memory in conversation in the former group (e.g., Jones 2015, Lindholm 2015, Müller and Guendouzi 2005). In contrast, studies into frontotemporal dementia show the effects of executive dysfunction, illustrating conversation is planned, not just in a turn-by-turn manner but in a broader sequence (Mikesell 2009, 2014) and the challenges at play when talk is not appropriate to the current social context (Smith 2010).

The range of skills on display may explain some of the issues that on the surface appear contradictory. For example, Mikesell (2009) illustrates that when a lack of information was forthcoming yes/no questions were important to encourage the person to engage. However, Ramanathan (1994) argues that open-ended questions were important to allow the person with dementia to take a more active part in the conversation. Whilst there may be general principles of communication in dementia care, particular conversation practices and strategies may also be highly individualized. This arises from features unique to the individual, the type of dementia, the stage of the condition and the different scaffolding provided in the conversation by others. Training programmes around communication often provide generic advice and there is a challenge in tailoring such advice to the individual concerned (Young *et al.* 2011). Moreover, this advice is typically focused on features arising from memory problems inherent in more common dementias such as Alzheimer's disease. This review indicates that, in particular, the conversation needs of those with rarer or less typical patterns of dementia may not be met through such generic programmes.

The conversation literature acknowledges the cognitive changes present in dementia but moves beyond this to examine the psycho-social context. However, few studies have made links to the broader psycho-social dementia care literature, apart from the occasional mention of the work of Kitwood (1997). Moreover, although many authors recommend their methods for further research, individualized assessment or to generate appropriate training for carers, concrete clinical applications are lacking. At times, the literature appears to lie in parallel rather than inform dementia practice. There are also potential points of conflict with current therapeutic approaches. The work on co-construction of conversational narratives has much to inform life story approaches in dementia care. For example, Hydén and Örülv (2009) argue that performance of the narrative in conversation is more important than remembering specific 'facts' about oneself, e.g., marriage, children etc. However, in life story work currently popular in clinical practice, the use of certain tools to explore life stories may focus on such factual information (Kindell *et al.* 2014). Further research would, therefore, benefit from particular attention to the study of performed

and embodied identity in conversation using video data (Hydén 2013, Hydén and Örülv 2009) and how different life story formats potentially impact on interaction (Ekström *et al.* 2015, Spilkin and Bethlehem 2003).

Studies specifically exploring face-to-face everyday conversation between people with dementia and their family members, that do not involve researchers taking part in such conversations, are surprisingly rare (e.g., Kindell *et al.* 2013, Perkins *et al.* 1998, Purves 2010, Ramanathan 1994, Spilkin and Bethlehem 2003). Using conversation approaches within intervention as part of individualized programmes at home is often advocated and appears to offer potential but as yet, with the exception of the single case study of Spilkin and Bethlehem (2003), remains largely untested. Communication problems have been linked to carer burden (Savundranayagam *et al.* 2008) and it is rarely acknowledged within the conversation literature that family carers may have their own needs within an interaction beyond facilitating the person with dementia's communication. In some studies, both family carer and researcher interaction is present in the data and there are reports that there may be some differences. Mikesell (2010a), for example, reports that a variety of strategies were used by others to manage Kelly's perseverative responses in conversation, but her husband was quicker to move through the sequence of strategies than the ethnographer, perhaps reflecting his greater familiarity with her needs. Smith (2010) illustrates that in some instances, family carers showed irritation or frustration during interactions. He briefly explores issues such as 'investment' in the interaction (e.g., getting a memory 'correct') or having a third party present to support the situation but does not explore such issues in depth. It seems probable that, for example, an inappropriate comment to a stranger within an interaction is likely to be felt very differently by a daughter, as opposed to a paid carer or a researcher in that situation and this may, in turn, affect the interaction.

There is also evidence from the qualitative dementia literature examining relationships that married couples may have different ways of working as a couple in the face of dementia and particular issues with intra-couple interaction are highlighted in this work (Hellström *et al.* 2007, Keady and Nolan 2003). Following their synthesis of qualitative research examining family relationships in dementia, La Fontaine and Oyeboode (2014) argue for the need to explore both positive and negative themes in this area; for example, those families 'working apart' or feeling 'disconnectedness' and direct observation of interaction is an important aspect to this. Overall, therefore, there is a need for research to directly examine interactions between the person with dementia and their family members at home and examine how this sits

within the broader context of their lives and the ways they face dementia within their relationships.

In addition, providing support to both people with dementia and their relatives is at the heart of community dementia practice; however, this is not without its challenges. Other qualitative research has highlighted that tensions may exist between the needs or perspective of the spouse and the person with dementia (O'Connor 2007, O'Shaughnessy *et al.* 2010). Wray (2014) explores the dilemma faced by family carers in their response in conversation to increasing use of formulaic language in dementia. She argues that if carers assume this increase represents normal language, then the consequence might be to view the person as impolite and for the carer to feel offended and respond accordingly. Conversely, to treat the language as abnormal 'is to challenge the person's capacity to behave like a human being and this might change the ground rules for how the person is treated' (279). Wray (2014) goes on to argue for empathy-training that helps carers to understand what functions the formulaic language is having for the person with dementia within the interaction. Shakespeare (1998) discusses issues with respect to different carer strategies for repair of confused talk, in that certain ways of responding, even those which are helpful, orientate to less-than-full membership because, in normal conversation, such practices typically do not occur. Conversation-based research has the potential to tease out the complexities and dilemmas within such situated experience precisely because such research places equal focus on the part each party plays in the conversation (Perkins *et al.* 1998). However, the literature has yet to fully exploit this opportunity. In addition, examining how communication strategies change as the dementia progresses, using a longitudinal research design would seem a logical and important methodological development.

## Conclusions

This review has provided an overview of the diverse literature relating to conversation in dementia and made recommendations for future research and practice. Conducting a conversation can pose challenges to people with dementia and their everyday conversation partners. At the same time, conversation can also reveal unique skills and competences that people with dementia have retained or have spontaneously developed in response to the cognitive changes associated with dementia, as well as skills employed by conversation partners to scaffold such abilities. Insights from the analysis of conversation can have therapeutic implications, not just for improving conversation, but also for supporting well-being, identity and relationships. Interventions around conversation, therefore, could potentially form an important

part of helping people with dementia and their family members to adapt and live well with dementia. Overall, this review indicates that the study of conversation in dementia and associated interventions to support interaction at home, presents as worthy of further research.

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## Note

1. This review excluded research involving multilingual conversations. A range of publications explore such interactions and further work to review this particular area would benefit the field.

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