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**Combining music and life story to enhance participation in family interaction in semantic dementia: Findings from a longitudinal case study**

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| Journal:         | <i>Qualitative Research</i>  |
| Manuscript ID    | Draft  |
| Manuscript Type: | Standard Article   |
| Keywords:        | dementia, frontotemporal dementia, semantic dementia, conversation, narrative, intervention, interaction   |
| Abstract:        | Semantic dementia is a rarer dementia, classified under frontotemporal dementia and primary progressive aphasia. Communication interventions in this condition have most often focussed on strategies to improve word retrieval. Less evident are studies examining conversation at home and interventions aiming to enhance participation in family life. Presented here is a case study of a family living with semantic dementia. Conversation analysis and narrative analysis allowed for detailed assessment of need and the design of an individually tailored life story intervention to facilitate interaction between them: a co-produced life story music DVD. This provided the family with a resource that allowed the person with semantic dementia to display areas of retained competence and enhanced participation in interaction in a way that was not typically present in everyday conversation. It is argued that fostering greater opportunities for such in-the-moment connections is an important goal for intervention. |
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9 **Combining music and life story to enhance participation in family interaction in**  
10 **semantic dementia: Findings from a longitudinal case study**  
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15 **Introduction**  
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17 Dementia is a syndrome that is caused by a range of conditions that affect the brain.  
18 Such conditions include Alzheimer's disease and vascular disease as well as less  
19 common dementias, such as frontotemporal dementia (Alzheimer's Society, 2015).  
20 Frontotemporal dementia is thought to account for between 5-10% of all cases of  
21 dementia (Alzheimer's Disease International, 2009) and is a common cause of younger  
22 onset dementia (Onyike and Diehl-Schmid, 2013). Semantic dementia is one of the  
23 subtypes of frontotemporal dementia and presents with progressive communication  
24 difficulties arising out of changes to semantic memory (Neary et al., 1998; Gorno-  
25 Tempini et al., 2011). As semantic dementia presents with a prominent language  
26 disorder the condition may be classified, particularly within the North American and  
27 Australian literature, as the semantic variant of primary progressive aphasia (Gorno-  
28 Tempini et al., 2011).  
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46 Expressive speech in semantic dementia is described as fluent with word finding  
47 difficulties, semantic paraphasias and an increasing lack of content words as the disease  
48 progresses (Hodges and Patterson, 2007; Kertesz et al., 2010). In this condition the  
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9 changes with semantic memory are regarded as a central conceptual deficit. This is an  
10 important point because it is not just difficulties accessing knowledge that is thought to  
11 lead to symptoms, but loss of the knowledge itself. For this reason, people present with  
12 difficulties understanding and using words; however, the symptoms extend beyond  
13 words and this affects recognition and understanding of all other stimuli, including  
14 objects, faces, sounds, smells, touch and tastes (Bozeat et al., 2000; Luzzi et al., 2007).  
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16 In contrast to Alzheimer's disease, visuospatial skills in semantic dementia are  
17 relatively well preserved and, although episodic memory does become impaired with  
18 time, difficulties are often described in retrieving remote, rather than recent day-to-day,  
19 memories (Hodges and Patterson, 2007).  
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33 To date, studies examining communication in semantic dementia have largely focussed  
34 on the language disorder seen on cognitive testing, most commonly exploring the  
35 conceptual difficulties evident at a single word level in both expression and  
36 comprehension (Hoffman and Lambon Ralph, 2011; Author C and others, 2010). A  
37 smaller range of studies have examined connected speech and aspects of discourse  
38 (Sajjadi et al., 2012; Garrard and Forsyth, 2010). However, there are very few studies  
39 examining everyday conversation at home and the challenges this provides for the  
40 person with semantic dementia and their family members (but see Author A and others,  
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9 2003) or exploring others ways in which the person with semantic dementia participates  
10 in everyday family life.  
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15 The International Classification of Functioning, Disability and Health Framework (ICF)  
16 (World Health Organization, 2001) provides a useful framework to explore how  
17 interventions may potentially target different areas in semantic dementia, thus  
18 delivering contrasting outcomes in terms of brain structures, brain functions and,  
19 alternatively, activities and participation in daily life. Interventions aiming to change  
20 brain structures or chemistry through medication to arrest or slow down the disease  
21 process are not available currently in semantic dementia. The most common focus to  
22 intervention in the literature is direct therapy tasks with the person with semantic  
23 dementia to improve brain function, specifically language function, with practice of  
24 target words to improve word retrieval (Savage et al., 2014). Whilst reviews of these  
25 methods have shown improvement in treated words compared to non-treated words  
26 within the experimental design, debate remains about issues of maintenance and  
27 generalizability to everyday conversation (Carthery-Goulart et al., 2013; Jokel et al.,  
28 2014). Less evident are studies focussing on activities and participation in daily life, for  
29 example, studies exploring dyadic interventions to enhance communication with family  
30 members (but see Cartwright and Elliott, 2009; Wong et al., 2009).  
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9 There is also a lack of guidance in the literature or in clinical guidelines as to if, or how,  
10 therapies used across the general field of dementia care can be applied to semantic  
11 dementia. Common interventions include reminiscence, life story work and  
12 communication skills training (Eggenberger et al., 2013; McKeown et al., 2006;  
13 Westerhof et al., 2010). However, as yet, such interventions have not been explored in  
14 semantic dementia. Moreover, it has been noted that the different presentation of recent  
15 and long term memory difficulties in semantic dementia may mean that reminiscence  
16 and life story work may not be appropriate or may need to be modified, as in the case  
17 study presented in this paper, for those living with this specific condition  
18 (Frontotemporal Dementia Toolkit, 2014; Author A and others, 2003).  
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33 To help commence a psychosocial evidence-base in semantic dementia, the following  
34 case study of Sarah [person with semantic dementia], Reg [husband] and Harriet  
35 [couple's daughter] will outline how a life story music DVD was developed by the first  
36 author alongside the family to enhance the participation of Sarah in family interactions.  
37 The intervention and the associated outcomes are described, including an exploration of  
38 the resulting in-the-moment family connections.  
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## 51 **Study Methods**

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9 Sarah and Reg (64 and 66 years old, respectively) were both retired and had been  
10 married for 43 years. They had one daughter, Harriet and two grandchildren, who lived  
11 locally and offered considerable support. Sarah had been diagnosed with semantic  
12 dementia four years before this research took place. A community psychiatric nurse  
13 visited regularly and a care package provided a designated support worker to take Sarah  
14 out shopping and to social clubs a number of times in the week. Sarah was aware that  
15 she had dementia and would make reference to her condition using this word and  
16 recognized that there had been changes in her memory and talking. Reg reported that  
17 Sarah's personality and behaviour had also changed and that their lives were now  
18 heavily built around the routines that Sarah had developed since the onset of semantic  
19 dementia. One of the problematic issues for them both was that Sarah was experiencing  
20 recurring headaches and would ask Reg for pain relief every few minutes, even if she  
21 had just taken her tablets.  
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40 Participants were visited at home by the first author over an 18 month period, with 20  
41 visits made in total. A case study design (Yin, 2009) used a mixed methods approach  
42 with the following aims: i) to gain in-depth insight into the everyday experiences of  
43 Sarah, Reg and Harriet around interaction; ii) to use this knowledge to plan and deliver  
44 an individually tailored intervention to enhance interaction in the home situation; iii) to  
45 explore the effects of the intervention on interaction and participation.  
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9 In the initial stages semi-structured interviews explored the participants' lives both  
10 before and now living with semantic dementia, with 11 hours and 7 minutes of  
11 interviews audio-recorded and transcribed in full. This was analysed using thematic  
12 narrative analysis (Riessman, 2008). Author B and others (2003) advise that at its  
13 simplest level 'narrative research and analysis is about asking for people's stories,  
14 listening and making sense of them and establishing how individual stories are part of a  
15 wider 'storied' narrative of people's lives' (p.331). This approach was used to  
16 understand the interrelationship between identity, self and the social world for Sarah,  
17 now living with semantic dementia and her family members (Williams and Keady,  
18 2008). Conversation at home was explored directly through analysis of video data taken  
19 of everyday conversations and analysed using conversation analysis (Hutchy and  
20 Woofitt, 2008). Conversation analysis analyses the part that both parties play in order to  
21 jointly negotiate the meaning within a given communicative context (Schegloff, 2003)  
22 and, therefore, offers an ideal method to explore the natural communicative behaviours  
23 of both the person with semantic dementia and their family members (Perkins et al.,  
24 1998). Participants were given a small video camera and asked to record natural  
25 conversation at home. They were free to choose where and when they recorded and the  
26 topic(s) of conversation. Researchers were not present when recordings were made. The  
27 aim was therefore to record a sample of everyday interaction at home including the  
28 challenges and skills for all participants. An initial 127 minutes and 49 seconds of video  
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9 were recorded and analysed. At a later stage, the effects of the life story music DVD on  
10 Sarah's wellbeing and interaction with family members were also explored; this will be  
11 described later in this paper.  
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17 The study was approved by a National Health Service Registered Ethics Committee and  
18 was also approved by the research governance department at the National Health  
19 Service local organisation where the research took place. Names and some  
20 contextual/biographical information have been changed in order to maintain  
21 confidentiality.  
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### 31 **Pre-intervention Assessment**

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33 Assessment indicated that whilst there were significant challenges in interaction due to  
34 Sarah's semantic dementia, Reg had a good understanding of how to manage her  
35 communication needs and he displayed a remarkable level of patience, with a number of  
36 strategies to help them both cope. Conversation analysis revealed a reduced repertoire  
37 of topics of conversation with the same topics often recurring in Sarah's talk. In  
38 addition Sarah was observed to repeatedly use certain questions and statements,  
39 particularly about the routine of the day. Reg reported that, at times, Sarah lacked  
40 appropriate emotional responses in conversation. He also conveyed that a lack of  
41 conversation in the household was an issue because outside of those recurring themes  
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9 identified, Sarah did not initiate interaction and trying to encourage her to participate in  
10 conversation could be difficult. Reg's attempts to engage Sarah in conversation could at  
11 times be met with minimal acknowledgements from her, e.g. 'mm' or 'oh' as Extract 1  
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15 now illustrates.

### 16 17 18 19 20 **Extract 1 - Minimal responses**

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22 In this extract Sarah and Reg are waiting for the support worker and Reg is trying to  
23 encourage Sarah to participate in the conversation. There are five instances of minimal  
24 responses (lines indicated with an arrow) from Sarah, i.e. monosyllabic responses, low  
25 in volume and accompanied by a lack of eye contact. There are only two other  
26 responses from Sarah (lines 008 and 021), where she looks to Reg, addresses his  
27 question briefly but she does not elaborate on her response. Overall, Sarah's responses  
28 convey minimal participation in the interaction. Please see Appendix for transcription  
29 symbols.  
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42           001 R     Suzanne will fetch us out take  
43           002           us out maybe somewhere for a meal an ride  
44           003           round for you you can say you've been out  
45           004           then (2.0) alright  
46 →       005 S     mmm °yeah° ((no eye contact))  
47           006 R     now you didn't sleep very well last night  
48           007           did you  
49           008 S     I don't know ((looks at Reg))  
50           009 R     you was up and down all night long saying  
51           010           that you couldn't sleep

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9 → 011 S mmm ((no eye contact))  
10 012 R I thought you probably would've wanted to  
11 013 stop in bed a bit longer this morning  
12 → 014 S [mmm] ((no eye contact))  
13 015 R [but] you was up at half past seven and I  
14 016 thought you might have wanted to have a  
15 017 little sleep but you seemed to be awake  
16 018 again now  
17  
18 → 019 S mm ((no eye contact))  
19 020 R do you feel tired  
20 021 S not now ((looks at Reg))  
21 022 R but seeing that you was up and down all  
22 023 through the night and you didn't sleep at  
23 024 all you said  
24 → 025 S mmm ((no eye contact))  
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28  
29 Since assessment of the family's everyday lives indicated that Reg had adapted well to  
30 changes in Sarah's conversation abilities, it was felt that advice about communication  
31 techniques was not necessary. However, Sarah's limited involvement in everyday  
32 interactions at home suggested that further opportunities for participation were  
33 indicated. This, therefore, raised the question of whether activities such as life story  
34 work could contribute to facilitating such occasions for enhanced and biographically-  
35 orientated social interaction and participation within everyday family life.  
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#### 46 **The Intervention: Life Story Music DVD**

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48 Sarah already had a printed and bound life story book and whilst the book was reported  
49 to have been useful at an earlier stage to encourage communication, it was now limited  
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9 as an aid to enhance conversation because Sarah had difficulty recognising many of the  
10 people and places portrayed in the photographs and remembering the events concerned,  
11 even with verbal explanation and prompting. This is consistent with reports of  
12 associative agnosia affecting understanding of faces and places, along with evidence of  
13 long term memory difficulties in semantic dementia (Hodges and Patterson, 2007).  
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21 Interviews with the family described that Sarah had a long standing interest in music  
22 and singing and that she still retained many of these abilities. This indicated that  
23 exploring music within life story work might be more successful and so the decision  
24 was made to make a life story music DVD with Sarah and her family. Together with  
25 Sarah, Reg and Harriet the first author compiled a list of songs that were meaningful to  
26 Sarah, either in the past or the present. These songs were played to her using either an  
27 audio or video clip of the particular artist, thus identifying the songs she particularly  
28 liked. Following this, video footage was recorded at home with Sarah singing with her  
29 family using these clips. Also recorded was a member of the family introducing each  
30 song, e.g. *'We've chosen this song because we know you love RED'* to introduce Chris  
31 De Burgh singing 'The Lady in Red'. Clips were uploaded into a popular DVD  
32 programme maker, including: family members introducing the artists and stating why  
33 the song was meaningful, various artists singing and footage of family members singing  
34 with Sarah. The videos were then organized appropriately with relevant title lines added  
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9 on screen, e.g. the title of the DVD as an introduction (Thank You for the Music),  
10 family members' names when they appeared on screen and linking title slides to give  
11 flow to the DVD, e.g. '*and now for us all singing...(song name)*'. Where possible  
12 atypical words were spelt with a regular spelling, e.g. the popular English singer 'Cilla'  
13 (Black) was spelt '*Silla*' on screen, to help Sarah read as she was experiencing surface  
14 dyslexia and so had difficulty reading words with irregular spellings. Finally, a credits  
15 slide listed the names of the family members who took part. The video was shown to  
16 Sarah on two occasions to pilot and refine the format, once on a laptop computer and  
17 once on the screen of her television and alterations were made as appropriate. This  
18 included:  
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31 • Ensuring labels of family names appeared on screen throughout. This reduced  
32 Sarah saying '*who's that?*' as had been the case during piloting the video when  
33 names were not present.  
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37 • Altering the order of songs – the song 'I like a nice cup of tea' was initially first,  
38 however, this led to Sarah requesting tea from Reg even if she had just had a cup  
39 and this was, therefore, placed at the end.  
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44 • Ensuring all lyrics of songs appeared at the bottom of the screen, at the request  
45 of the family so they could all sing along more easily.  
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49 • A particular song was omitted as this made Sarah's daughter upset as it  
50 reminded her of how her mum used to be prior to her dementia.  
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9 A final DVD was given with a cover using stills from the recording session and an  
10 explanation of life story work on the reverse. The DVD was 40 minutes long. Copies  
11 were given to Sarah and Reg and another to Harriet and her family.  
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### 16 17 **Outcomes of the Intervention**

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19 In terms of exploring the effects of the intervention, the aim was to understand how the  
20 life story process and the life story music DVD contributed to Sarah's social interaction  
21 and participation with family members and to her well-being in the here and now. Video  
22 and audio recordings of the session making the DVD and the two sessions with Sarah  
23 and Reg watching the piloted and final versions were analysed (82 minutes of video  
24 data and an additional 40 minutes of audio data). The principles of conversation  
25 analysis guided this process and the video and audio were examined in their entirety  
26 with salient recurring features noted. Collections were then made of these recurring  
27 features using transcriptions of the data including speaking and singing and these were  
28 subjected to further detailed analysis focusing on how the life story music DVD  
29 impacted on Sarah's well-being and participation in interaction (see below). In order to  
30 capture aspects of the interaction for analysis, transcription of relevant body movements  
31 was included and photographs were added to further display embodied aspects  
32 (particularly where description of parts of the scene would not convey the whole scene).  
33 This data driven method was used to analyse recurring features, or moments in the data.  
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9 This method, therefore, draws from conversation analysis (Hutchby and Wooffitt, 2008)  
10 but also has overlaps with micro analytical approaches using video to explore the effects  
11 of music therapy (Wosch and Wigram, 2007). This approach allowed for a qualitative  
12 comparison between the recurring features during conversation with those during  
13 singing. Analysis revealed three recurring patterns, or outcomes, in the data that could  
14 then be broken down further into specific behaviours:  
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22 **1. Distraction from Distress**

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24 **2. Facilitating Interaction**

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26 a. In response to the lyrics  
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28 b. Making up own lyrics  
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30 c. Embodied and emotional connections  
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32 d. Interaction arising from the video process or watching the DVD  
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36 **3. Performance and Identity**

- 37  
38 a. Embellishments and over-singing  
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40 b. Embodied performance  
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42 c. Reaction from her audience.  
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46 These results will be presented and extracts from the video data used to further illustrate  
47 issues. In the following extracts bold type is used for singing and standard type for  
48 talking. Behaviours occurring simultaneously are bracketed, as is standard in  
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9 conversation analysis. Still photographs taken from the video have been used to  
10 illustrate important nonverbal aspects to the data.  
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### 13 14 15 *Area 1 - Distraction from Distress* 16

17 Engaging Sarah in song distracted her from her recurring worries about her headaches  
18 and requests for pain relief. This provided the foundations for enhanced participation in  
19 interaction. The effects of this distraction were particularly dramatic during the session  
20 making the DVD. On this occasion Sarah was initially in bed, with her family present in  
21 the lounge. Reg asked her to get out of bed, as he thought it might distract her, but she  
22 looked in pain and it seemed as though filming might have to be postponed. Video  
23 footage, however, revealed the transformative nature of the music and interaction within  
24 the first minute. At the start of the recording Sarah complains about her headache. There  
25 is no eye contact with Harriet who is sitting next to her; Sarah eyes are shut and she is  
26 looking ill whilst rubbing her head. However, as the music plays (Lady in Red, Chris de  
27 Burgh) she opens her eyes, looks at the artist on the laptop screen and then to the  
28 researcher, beginning to attend to the music (18 seconds). Sarah begins to move to the  
29 music and smile (23 seconds), make eye contact with Harriet (28 seconds) and start to  
30 sing (33 seconds). At 54 seconds, she appears happy and engaged in the song as  
31 evidenced by her voice, face and body movements. This level of engagement continues  
32 throughout this song. During this visit Sarah did not ask for headache tablets while the  
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9 music was playing but when the music stopped, she started to complain about her head  
10 and ask for tablets. At a later visit Sarah was again repeatedly asking for pain relief in  
11 the first hour (during normal conversation), rarely going more than five minutes  
12 between requests. However, whilst watching the 40 minutes of the completed DVD she  
13 did not request any tablets. The DVD did not eliminate all repetitive behaviours, as  
14 Sarah often still asked for food, cups of tea and chewing gum. It would seem, therefore,  
15 that music appeared to lift her mood and distract her from her worries about her head,  
16 rather than reduce all such behaviours.  
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### 28 *Area 2 - Facilitating Interaction*

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30 There were a number of ways that the DVD facilitated interaction including: a) In  
31 response to the lyrics; b) Sarah making up her own lyrics; c) Giving rise to embodied  
32 emotional connections; d) Interaction arising from the video process or watching the  
33 DVD:  
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#### 42 **a) In response to the lyrics**

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44 The following extract illustrates that Sarah did not just sing the lyrics of the songs, at an  
45 automatic or perhaps 'over-learnt' manner; she often processed the meaning and used  
46 these words as a vehicle to interact with others:  
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## Extract 2 - Interaction arising from lyrics

Here Harriet and Sarah are singing to a Tina Turner song, 'Simply the Best' (M = music).

001 M [tear us apart]  
 002 H [tear us apart]  
 003 S ((looks at H)) no [no no] no chance no chance  
 004 H [no no]  
 005 M **baby I would rather be [dead]**  
 006 S [dead] no no we don't  
 007 want to die yet do we

In response to the lyric '*tear us apart*,' Sarah looks to Harriet in line 003 and expresses her disagreement with that possibility: '*no*' and '*no chance*'. Harriet also expresses '*no*' as they look at each other. Following the lyric '*I would rather be dead*' Sarah says to Harriet '*we don't want to die yet do we?*' The result is both affectionate and humorous.

### b) Making up own lyrics

Sarah would sometimes make up her own lyrics, singing in tune and in time to the music, but with her own words. For example, with Tina Turner's 'Simply the Best', at a point where only the music is playing, Sarah sings her own lyrics to Harriet '*ah ah I love you any time of day I can't stay awake I love you so oh oh oh.*'

### c) Embodied and emotional connections

Connections between family members were not just verbal but also embodied. The Cilla Black song, 'You are my World', is Sarah and Reg's engagement song that Sarah sung to Reg on the night they got engaged at a family party. Sarah no longer remembers this association with the song but does still remember many of the lyrics and its distinctive tempo. On the two occasions Sarah is video recorded listening to this song, Sarah is seen to reach for Reg's hand when she sings '*my arms reach out to you for love*' thus demonstrating an embodied connection with him, as extracts 3 and 4 illustrate. The behaviours observed on both videos are remarkably similar, with Sarah and Reg holding hands while Sarah sings.

### Extract 3 - Embodied connection - engagement song 1

This example is from the session making the DVD.

001 M [So my arms reach out to you for love]  
 002 S [So my arms reach out to you for love]  
 003 [ ((reaches over to Reg takes his hand)) ]  
 004 R [ ((takes Sarah's hand, smiling)) ]



002 – 'reach out to you'



002 - 004 – '... for love.'

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9 **Extract 4 - Embodied connection - engagement song 2**

10 This example is from a later session watching the DVD, as before Sarah reaches over to  
11 Reg, who is sitting next to her, taking his hand.  
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15 001 M [So my arms reach out to you for love]  
16 002 S [So my arms reach out to you for love]  
17 003 [((reaches over to Reg takes his hand))]  
18 004 R [((looks at Sarah, takes her hand)) ]  
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46 Sarah also makes embodied and emotional connections with Harriet, for example, when  
47 making the DVD she places her cheek to Harriet's when singing about dancing 'cheek  
48 to cheek' and at the end of this song (Lady in Red) there is a particularly poignant  
49 exchange between them both, as illustrated in extract 5:  
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**Extract 5 - Emotional connection**

001 M my lady in [red]  
002 S ↑ [re:] e:ed  
003 H I love you ((leans in joint eye contact))  
004 S I love you darlin' I love you so: much

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9 **d) Interaction arising from making or watching the DVD**

10 Sarah regularly commented on the video, or about seeing herself and her family on  
11 screen, e.g. *'I love red [reading off screen] I do, I do love it'; 'my baby girl' [Harriet on*  
12 *screen]*. She often seemed surprised and delighted to see her family on television. When  
13 watching the DVD Sarah often asked *'who's put me on telly Reg?'* with amazement, but  
14 was unable to retain any explanation as to why the DVD had been made. It was decided  
15 with Reg that saying it was because she had a good voice was the most easily  
16 understandable and helpful for her, as it reinforced a positive aspect of her retained  
17 identity.  
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31 ***Area 3 - Performance and Identity***

32 With regard to being 'a singer', it was clear during interviews that this was an extremely  
33 important and distinct part to Sarah's identity that she still retained, as she explained  
34 when watching the DVD: *'you've not been a singer really have you Reg, I've always*  
35 *been a singer, I remember when I was a child when me mum was her'*. The video also  
36 illustrates that Sarah does not just sing, she is seen to perform with the following  
37 aspects contributing to this sense of performance.  
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48 **a) Embellishments and 'over-singing'**  
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There are numerous examples of Sarah creatively embellishing her performance by adding extra notes, pitch rises and falls and singing extra items such as ‘*oh yeah*’ as a professional performer might do, as illustrated in extract 6.

### Extract 6 – Embellishment

In the following example Sarah is watching the DVD and singing to Roy Orbison’s ‘Pretty Woman.’

|     |   |   |
|-----|---|---|
| 001 | M | <b>I don't believe you you're not the truth</b>                               |
| 002 | S | <b>no</b> (( <i>point - in time</i> )) <b>no</b> (( <i>point - in time</i> )) |
| 003 | M | <b>No one could look as good</b> [as you]                                     |
| 004 | S | [as you]  |
| 005 | S | go  |
| 006 | M | <b>mercy</b>  |
| 007 | S | yeah  |

Here we see Sarah adding in extra embellishments such as two well timed ‘*no*’s’ (002) accompanied with emphatic ‘points’. In line 005 she adds ‘*go*’ before Orbison sings his distinctive ‘*mercy*’ to which Sarah responds ‘*yeah*’ in line 007.

#### b) Embodied performance

Across the data Sarah is observed to move along to the music. These movements seem less about communicating to others but more about her natural and unintended response to the music, as extract 7 demonstrates.

**Extract 7 - Embodied performance**

Here when singing to ‘Simply the Best’ with Harriet, Sarah holds out her hands much as a singer would do when performing (see photo and lines 003-004)

001 M [better than all the rest ]  
 002 H [better than [all the rest ]  
 003 S [all the rest ]  
 004 [((S holds out two palms)) ]



003-004 – ‘all the rest’

**c) Reaction from ‘her audience’**

Sarah’s sense of performance is added to by the reaction of those around her. She is centre stage when singing, both when making and when watching DVD. Those present look to Sarah and comment positively about her singing and encourage her to perform as extract 8 shows.

**Extract 8 - Audience reaction**

At a rather flamboyant end to ‘the Lady in Red,’ Reg comments positively on Sarah’s performance (003):

001 M     **my lady in** [red]  
 002 S                     ↑ [re:] e:e: ed  
 003 R     well done Sarah beautiful that

In other instances family members clap her performance. When watching herself on screen Sarah also indicates approval by clapping. In this way there is evidence of Sarah ‘reliving the moment’ with approval of her own performance abilities.

### Summary of Outcomes

Prior to the introduction of the life story music DVD, Sarah’s participation in interactions with her family members through conversation was generally limited. She initiated little, and her responses were often minimal, as seen in Extract 1. When Sarah used questions or initiated topics these were typically drawn from a limited repertoire of utterances and topics of conversation. The introduction of the life story music DVD provided Sarah and her family with a resource which allowed Sarah to display areas of retained competence (such as singing and performing for an audience). The use of this resource resulted in the enhanced participation of Sarah in interactions with her family members. When using the music DVD, Sarah’s well-being also appeared to improve, as seen in the reduction of her complaints about her headaches.



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9 Engaging with familiar and meaningful music had the power to enhance Sarah's  
10 participation and involvement with her family both verbally and nonverbally in a way  
11 that was not typically present in everyday conversation. For example, in-the-moment  
12 analysis of the video data sees Sarah take an active part in both the process of making  
13 the DVD and in her reactions when watching it, with playful, humorous and emotional  
14 connections with family members displayed. Sarah is thus centre stage when singing, in  
15 contrast to conversation, where she can often take a more passive role. Sarah was able  
16 to display her identity as a competent singer through song and embodied performance.  
17 In this way the intervention was able to enhance Sarah's abilities and participation  
18 within interaction in a way that by-passed her difficulties with language and  
19 conversation skills.  
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35 Sarah and her family reported that they were very happy with the DVD and that it had  
36 been shown to others visiting the house including Reg's relatives, their neighbour, the  
37 community nurse and their support worker. They had developed a family joke teasing  
38 each other about who was the best singer. The process had led to other activities with  
39 their son-in-law making Sarah another DVD with another set of favourite songs. Harriet  
40 in particular, however, reported that whilst it was lovely to see her mum happy,  
41 sometimes when making the DVD, it also made her sad as it reminded her of how her  
42 mum used to be in the past and she compared this to how she was now, saying:  
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*'sometimes happy memories can also make you sad'*. Reg reported a similar feeling, though perhaps to a lesser extent. A telephone call from Reg, six months after they had received the DVD, revealed that they still enjoyed watching it together, with Reg reporting *'I'm surprised it's not worn out, the amount of times she's seen it'*.

### **Discussion**

The intervention outlined in this case study illustrates the way life story work can be used to enhance interaction between an individual with semantic dementia and members of her family. An important aspect to this work involved tailoring the intervention to the specific needs of the person with semantic dementia. In this case whilst a life story book had been of use in the earlier stages of Sarah's condition, changes in her ability to recognize faces and in her long term memory limited current use to encourage conversation. Music and song, in contrast, was demonstrated to provide an opportunity for in-the-moment connections with her family and opportunities to display her positive identity as a singer. The format allowed Sarah to participate in interaction in a way that exploited her retained skills. The data demonstrate not just a range of verbal connections but embodied and emotional connections, including love, joy and humour. Author A and others (2003) argue that professional outcomes from life story work may be very different from the outcomes that family members value. For example, whilst professionals may focus on reducing negative behaviour or fostering certain abilities,

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9 simply 'having fun' together might be highly valued by family members struggling to  
10 cope with dementia in their lives. At times it is easy for professionals to forget that  
11 dementia may, for some families, reduce the choices they have at their disposal to  
12 engage in positive experiences together as a family and this is where appropriately  
13 tailored life story work may offer potential. Watching the DVD allowed Sarah an  
14 opportunity to relive the moment and interact with her family. Reg indicated later that  
15 Sarah often enjoyed watching the DVD even after the intervention had been completed.  
16 As such it can be seen that the intervention had a continuing effect over the longer term,  
17 not in terms of a continuous change in functional abilities, but rather as a resource  
18 which provided recurring opportunities to foster positive interaction and participation.  
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33 A heightened liking for music, described as 'musicophilia', has been noted to be  
34 particularly common in frontotemporal dementia (Fletcher et al., 2013). This has  
35 implications for diagnosis as well as for broader understanding of the neurobiology of  
36 music within the human brain (Hailstone et al., 2009; Weinstein et al., 2011; Warren et  
37 al., 2011). In some reports excessive listening to music has been displayed as a problem  
38 behaviour (Boeve and Geda, 2001). The literature, however, lacks any detailed  
39 exploration of the benefits of music from the perspective of the person with semantic  
40 dementia or their family. For example, whilst music therapy has been explored in  
41 dementia generally (McDermott et al., 2013; 2014), less attention has been paid to this  
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9 as an intervention in frontotemporal dementia. Ridder and Aldridge (2005), however,  
10 describe how Mrs F, with advanced frontotemporal dementia, enjoyed singing familiar  
11 songs and a reduction in heart rate and antipsychotic medication was noted over the four  
12 week programme. In a later report, Ridder et al. (2009) explore various measures to  
13 develop a research protocol for music therapy in frontotemporal dementia.  
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21 This study demonstrates that the singing of familiar tunes can be used as a vehicle to  
22 provide opportunities for positive interaction and participation at home in semantic  
23 dementia. Sarah's case illustrates the effects on interaction in detail and the positive  
24 benefit this has to Sarah in deploying retained abilities, displaying competence and  
25 showing aspects of her identity (for example, as a singer and also as a loving wife and  
26 mother). Moreover, the case demonstrates that music facilitates a different range of  
27 interactional skills compared to everyday conversation and evidences the reports in  
28 interviews that music has a special effect on Sarah's well-being. For example, singing  
29 allows the playful and creative aspects of Sarah's identity to be displayed and this is in  
30 contrast to observations of conversation, both before and after the intervention, where  
31 she is often relatively passive. The embellishments and over-singing that Sarah uses  
32 intensifies her sense of performance. Musical embellishments were also reported in a  
33 case study of a harpsichord player with semantic dementia and it is argued that such  
34 behaviours indicate that these musical skills are not merely being retrieved and played  
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9 out in a rote manner from long term memory but show innovation in musical delivery  
10 (Weinstein et al., 2011). This would also appear to be the case for Sarah as  
11 demonstrated by her performance skills, creativity with singing and her ability to  
12 process the words of the song and use this as a vehicle to interact with those around her.  
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19 Hailstone et al. (2009) argue that the relative sparing of musical knowledge may  
20 contribute to musicophilia in people with frontotemporal dementia. This raises the  
21 question as to whether such behaviours may, in part, be an adaptive response on the part  
22 of the person with semantic dementia, where the individual uses the skills they still have  
23 at their disposal to engage in activities that provide them with pleasure, i.e. repeatedly  
24 listening to music. Such observations have important implications for interventions. For  
25 example, a study of the practice of speech and language therapists working with people  
26 with semantic dementia reported that one of the founding principles of their work was a  
27 focus on ability and the promotion of this, rather than a focus on disability in therapy  
28 (Author A and others, 2003). This approach drew on the principles of person-centred  
29 dementia care practice (Brooker, 2007). Sarah's case study illustrates that  
30 communication interventions may build on abilities outside of language to provide  
31 appropriate opportunities to contribute to interactional and emotional connections with  
32 family members. Importantly, in this case study singing was not just a solitary pleasure  
33 for Sarah but an activity that could engage others.  
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9 The biographical nature of the intervention enabled longstanding aspects of Sarah's  
10 identity to be displayed within interaction, including behaviours of a performative  
11 nature. Performance is an area where the data intersect narrative analysis, conversation  
12 analysis and elements of performance studies with certain recurring behaviours from  
13 Sarah that can be viewed and analysed 'as performance' (Schechner, 2013, p.168). This  
14 performance observed in the present, was also often compared with elements of the  
15 past. For example, when observing her current behaviour when singing, Sarah's family  
16 talked about her long standing love of singing and recalled stories of her singing  
17 abilities from her childhood through to her adult life. The interplay between how the  
18 present performance is positioned against the past is an important aspect of performance  
19 analysis within the fields of both narrative inquiry (Riessman, 2008; Phoenix et al.,  
20 2010) and performance studies (Schechner, 2013). Phoenix et al. (2010) argue that  
21 performance analysis is an attractive method because it can 'explicitly illuminate how  
22 the researcher shapes and is shaped by the research process' (p.7). This is an important  
23 point for an intervention study because the explicit aim here was to shape interactional  
24 and participatory behaviour. The life story work, however, also presented some  
25 challenges to family members. Sarah's performance reminded her family of how she  
26 used to be. As Schechner (2013) notes 'performances mark identities, bend time,  
27 reshape and adorn the body and tell stories' (p.28) and Sarah's performance, it could be  
28 argued, was in some ways an autobiographical performance in the present but also from  
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9 the past. Her family, as the audience, were aware this was only a moment and not a  
10 lasting performance and this also brought them some sadness.  
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15 There is no evidence that the music DVD had wider effects on Sarah's interaction or  
16 well-being when it was not being used. For example, the video data shows that, once the  
17 music had stopped, Sarah returned to complaints about her headache. Similarly there is  
18 no evidence that the conversations between Sarah and her family differed in any ways  
19 which could be attributable to the use of the music DVD. However, this lack of  
20 generalisation should not detract from the in-the-moment effects on interaction and  
21 emotion evident in the data when the music DVD was being used. Thompson (2009)  
22 notes that in the search for the 'effects' of performance in terms of social utility, applied  
23 theatre is in danger of forgetting the 'affect' of performance at the time and this is a  
24 problem faced too by dementia care. It can be extremely difficult for families to engage  
25 individuals with advancing semantic dementia in activity or conversation of any kind.  
26 However, the achievement and creativity seen within such in-the-moment exchanges, as  
27 discussed here, can be too easily forgotten when a lack of 'effect' in the long term is  
28 noted. Dementia care would benefit from greater attention to such issues. Providing  
29 families with ways to exploit these in-the-moment opportunities within everyday  
30 interaction and experience emotions such as joy, fun, love and laughter seems an  
31 important goal for intervention. As Reg indicated in his telephone call six months after  
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9 the intervention had been completed, Sarah watched the DVD on many occasions. This  
10 recurring opportunity for the family members to engage in this way illustrates a  
11 particular kind of long term outcome; the life story music DVD gave them a resource  
12 they could use to facilitate connections and enhance Sarah's well-being and her  
13 participation in family life.  
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### 21 **Conclusion**

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24 This case study moved away from the focus evident in the literature on language  
25 function in semantic dementia to an intervention to enhance participation in life  
26 situations. Specifically, the life story work with Sarah aimed to foster participation in  
27 interaction at home, through manipulating opportunities in the environment. In this way,  
28 participation was the primary goal and so evaluating this had to be the relevant outcome  
29 measure, as demonstrated here through in-the-moment effects in interaction. Changes in  
30 behaviour and brain functions after the activity has finished, whilst welcome, are not  
31 necessary for the goals of the intervention to be achieved. Separating out these aspects  
32 is a crucial aspect to delivering person-centred care and interventions in dementia. This  
33 encourages practice and care to value such in-the-moment connections and seek to  
34 foster greater opportunities for these to occur in the daily lives of those living with  
35 semantic dementia and their family members.  
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### Appendix - Transcription Symbols

| Symbols | Explanation   |
|---------|---|
| [       | A large left-hand bracket links overlapping utterances or non-verbal actions at the point where the overlap begins.                         |
| ]       | A large right-hand bracket marks where overlapping utterances/simultaneous non-verbal actions stop overlapping.                             |
| e.g.    | 01 PR how have you been since I last saw [you]<br>02 AM [not ] so good  |
| (0.6)   | Silences are marked in seconds and tenths of seconds, i.e. (0.6) is six tenths of a second; (1.2) is one second and two tenths of a second. |
| (.)     | A full stop in single brackets indicates an interval of tenth of a second or less in the stream of talk.                                    |
| oh:     | A colon indicates an extension of the sound or syllable it follows (more colons prolong the stretch).                                       |

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11 ↑↓            Marked rising and falling shifts in intonation are indicated by upward  
12                    and downward pointing arrows immediately *prior* to the rise or fall.  
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18 stress            Underlining indicates emphasis.  
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22 °no°            Degree signs indicate talk which is *quieter* than surrounding talk.  
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26 ((*nods*))            Double brackets represent a gloss or description of some non-verbal  
27                    aspect of the talk  
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33 **Bold**            Bold type in this report indicates singing,  
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