

## Combining music and life story work to enhance participation in family interaction in semantic dementia: a longitudinal study of one family's experience.

KINDELL, J., WILKINSON, R., SAGE, Karen <<http://orcid.org/0000-0002-7365-5177>> and KEADY, J.

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/16155/>

---

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

### Published version

KINDELL, J., WILKINSON, R., SAGE, Karen and KEADY, J. (2018). Combining music and life story work to enhance participation in family interaction in semantic dementia: a longitudinal study of one family's experience. *Arts and health : an international journal for research, policy and practice*, 10 (2), 165-180.

---

### Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>



**Combining music and life story to enhance participation in family interaction in semantic dementia: A longitudinal study of one family's experience**

Journal:	<i>Arts &amp; Health</i>
Manuscript ID	RAHE-2017-0002.R1
Manuscript Type:	Research or Policy Paper
Keywords:	Music < Art Forms, interaction, intervention, life story, semantic dementia

SCHOLARONE™  
Manuscripts

View Only

1  
2  
3 **Combining music and life story to enhance participation in family interaction in**  
4  
5 **semantic dementia: A longitudinal study of one family's experience**  
6  
7

8  
9 **Abstract**

10  
11 **Background:** Semantic dementia is a rarer dementia, classified as a type of frontotemporal  
12 dementia and a variant of primary progressive aphasia. Studies examining conversation at  
13 home in this condition and interventions aiming to enhance participation in family life  
14 present as gaps in the research literature.  
15  
16

17  
18 **Methods:** Working with one family on a longitudinal basis, this study used conversation  
19 analysis and narrative analysis to provide a detailed assessment of communication needs.  
20 This information was then used to design an individually tailored life story intervention to  
21 facilitate family interaction: a co-produced life story music DVD.  
22  
23

24  
25 **Results:** This intervention offered the family a resource that allowed the person with  
26 semantic dementia to display areas of retained competence and enhanced participation in  
27 interaction in a way that was not typically present in everyday conversation.  
28  
29

30  
31 **Conclusions:** It is argued that fostering greater opportunities for such in-the-moment  
32 connections is an important goal for intervention, particularly when language may be  
33 significantly compromised.  
34  
35

36  
37 **Key words:** semantic dementia; life story; music; interaction; intervention  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## Background

Dementia is caused by a number of diseases that affect the brain, each giving rise to a range of cognitive and behavioural symptoms. The most common types of dementia include Alzheimer's disease, vascular dementia and Lewy Body dementia (Alzheimer's Disease International, 2009, 2014). Frontotemporal dementia is a less common dementia, thought to account for between 5-10% of all cases of dementia, however, it represents a significant cause of younger onset dementia (Alzheimer's Disease International, 2009). Semantic dementia is one of the subtypes of frontotemporal dementia and presents with progressive communication difficulties arising out of changes to semantic memory (Gorno-Tempini et al., 2011; Neary et al., 1998). As semantic dementia presents with a prominent language disorder the condition may be classified, particularly within the North American and Australian literature, as the semantic variant of primary progressive aphasia (Gorno-Tempini, et al., 2011). In contrast to Alzheimer's disease, recent memory is initially well preserved in semantic dementia and, although episodic memory does become impaired with time, difficulties are described in retrieving long term memories (Hodges & Patterson, 2007).

To date, studies examining communication in semantic dementia have largely focussed on the language disorder evident during cognitive testing, with expressive speech described as fluent with difficulties in word retrieval (Hodges & Patterson, 2007). A smaller range of studies have examined connected speech and discourse (Garrard & Forsyth, 2010; Sajjadi, Patterson, Tomek, & Nestor, 2012). However, there are very few studies examining the effects of semantic dementia on everyday communication at home (but see authors, 2013).

The International Classification of Functioning (ICF), Disability and Health (WHO, 2001) provides a bio-psycho-social framework to conceptualise interventions for all conditions

1  
2  
3 targeting different levels: body structures, functions, everyday activities and participation in  
4 life situations. For example, semantic dementia damages body structures (i.e. brain cells)  
5 causing difficulties with particular functions (i.e. cognitive functions, such as language  
6 skills). In addition, this gives rise to limitations in executing everyday activities, such as  
7 conversation and participation in family life. Currently, medication is not available to treat  
8 the underlying disease affecting brain cells in semantic dementia and interventions have most  
9 often focused on improving language functions, including practice tasks to enhance word  
10 retrieval (Jokel et al., 2014). Less prevalent is an exploration of those interventions that  
11 target everyday activities in semantic dementia including conversation and participation in  
12 social life.  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26

27 Across dementia care a number of activities are used to enhance social interaction including  
28 reminiscence, life story work and use of the arts (McKeown, Clarke, & Repper, 2006;  
29 Westerhof, Bohlmeijer, & Webster, 2010; Beard, 2012). However, there is a lack of guidance  
30 as to how these can be applied to semantic dementia. In particular, the reported difficulties  
31 with long memory in semantic dementia may mean that interventions that rely heavily on  
32 such memories, including reminiscence and life story work, may not be appropriate or may  
33 need to be modified, as in the study that shortly follows, for those living with this condition  
34 (Frontotemporal Dementia Toolkit, 2014; authors, 2014a). This raises the question as to  
35 whether approaches that rely less on these particular cognitive processes may be beneficial  
36 for some individuals with semantic dementia. For example, the use of musical activities and  
37 singing has been explored in dementia in general, with particular positive effects noted on  
38 engagement and interaction (Camic, Williams, & Meeten, 2011; Särkämö et al., 2014).  
39 Interestingly, an heightened liking for music, described as 'musicophilia', is particularly  
40 common in frontotemporal dementia (Fletcher, Downey, Witoonpanich, & Warren, 2013). In  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 some reports excessive listening to music has been displayed as problematic behaviour  
4  
5 (Boeve & Geda, 2001). The literature, however, has lacked any detailed exploration about the  
6  
7 benefits of music from the perspective of the person with semantic dementia or how this  
8  
9 could be used for the purposes of intervention. That said, Ridder and Aldridge (2005), have  
10  
11 previously described how Mrs F, who lived with advanced frontotemporal dementia, enjoyed  
12  
13 singing familiar songs over a four week structured music programme; this activity was noted  
14  
15 to reduce her heart rate and prescription of antipsychotic medication.  
16  
17  
18  
19

20  
21 To help commence a psychosocial evidence-base, the following study will outline how a life  
22  
23 story music DVD was developed over time by the first author with a family living with  
24  
25 semantic dementia in order to enhance participation in interaction at home. The intervention  
26  
27 and the associated outcomes are described, including an exploration of the resulting in-the-  
28  
29 moment family connections using conversation analysis.  
30  
31  
32  
33

### 34 **Research Approach and Methodology**

35  
36 A case study design (Yin, 2009) was used with one family living with semantic dementia  
37  
38 utilising a mixed methods approach with both narrative analysis and conversation analysis.  
39  
40 The aims were: i) to gain in-depth insight into the everyday experiences of family members  
41  
42 around interaction; ii) to use this knowledge to plan and deliver an individually tailored  
43  
44 intervention to enhance interaction in the home situation; iii) to explore the effects of the  
45  
46 intervention on interaction and participation. The study was approved by a National Health  
47  
48 Service UK Registered Ethics Committee designated to review research involving those who  
49  
50 may lack capacity to consent and was also approved by the research governance department  
51  
52 at the National Health Service local organisation where the research took place. Names and  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 some contextual/biographical information have been changed in order to maintain  
4 confidentiality in the following description of this family.  
5  
6  
7  
8

9  
10 Sarah and Reg (64 and 66 years old, respectively) were both retired and had been married for  
11 43 years. They had one daughter, Harriet, who lived locally and offered considerable support.  
12 Sarah had been diagnosed with semantic dementia four years before this research took place.  
13 She was aware that she had 'dementia', making reference to her condition using this word  
14 and recognised that there had been changes in her memory and talking. Reg reported that  
15 Sarah's personality and behaviour had also changed. One of the problematic issues for them  
16 both was that Sarah was experiencing recurring headaches and would ask Reg for pain relief  
17 every few minutes, even if she had just taken her analgesic tablets. The family were visited at  
18 home by the first author over an 18 month period, with 20 visits made in total.  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31

32 During early encounters, structured and semi-structured interviews explored participant's  
33 lives both before - and now living with - semantic dementia, with 11 hours and 7 minutes of  
34 interviews audio-recorded and transcribed in full. This was analysed using thematic narrative  
35 analysis (Riessman, 2008). Williams and Keady (2008) advise that at its simplest level  
36 'narrative research and analysis is about asking for people's stories, listening and making  
37 sense of them and establishing how individual stories are part of a wider 'storied' narrative of  
38 people's lives' (p.331). This approach was used to understand the interrelationship between  
39 identity, self and the social world for Sarah, now living with semantic dementia and her  
40 family members (Williams & Keady, 2008). This information, for example, helped reveal  
41 how life had changed since the onset of semantic dementia but also to understand  
42 longstanding aspects of Sarah's interests and identity in order to plan the intervention which  
43 is the focus of this paper.  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

Conversation at home was explored directly through analysis of video data recording everyday conversations and analysed using conversation analysis (Hutchy & Woofitt, 2008). Conversation analysis analyses the part that both parties play within a given communicative context and **has been used in a number of studies** to explore the natural communicative behaviours of both the person with dementia and their family members (Authors, 2016; Perkins, Whitworth, & Lesser, 1998). **The method is data driven and not constrained by prior theory or systems of coding and, therefore, allows anything within the data to be of interest** (Hutchy & Woofitt, 2008). Participants were given a small video camera (Cannon Legria FS200) and asked to record conversation at home without researchers present, **with Reg taking charge of operating the camera**. They were free to choose where and when they recorded and the topic(s) of conversation. The aim was, therefore, to record a sample of everyday interaction at home including the challenges and skills for all participants.

An initial 127 minutes and 49 seconds of video were recorded and analysed, **with conversations ranging from 6:44 minutes to 20:07 minutes and recorded at all times of the day from 11:32 am to 19:11pm**. Analysis followed the approach described by Hutchy and Woofitt (2008) in order to generate an understanding of recurring practices within the conversation data: i) highlight and make a collections of examples of a particular practice within the data; ii) analyse and describe one particular practice in detail; iii) return to the data to see if other instances of the practice can be analysed and described in this way. Therefore, **all the video data was watched on two occasions by author (01) with detailed notes made to gain an overall impression and to note any recurring features**. This analysis was then discussed with authors (02 and 04) and **41:25 minutes were identified for further analysis that illustrated these features**. This was transcribed in detail by author (01), with both verbal and



1  
2  
3 nonverbal behaviour transcribed using the conventions of conversation analysis for video  
4 data (Jefferson, 2005). The transcriptions and the associated video data were then viewed by  
5 authors (01, 02 and 04) together to further analyse the data. At a later stage, this method was  
6 also used to explore the effects of the intervention on family interactions; this will be  
7 described later in this paper.  
8  
9  
10  
11  
12

### 13 14 15 16 **Pre-intervention Assessment**

17  
18 **Initial** assessment indicated that whilst there were significant challenges in interaction due to  
19 Sarah's dementia, Reg had a good understanding of how to manage her communication  
20 needs, displaying a remarkable level of patience and a number of strategies to help them  
21 cope. Conversation analysis revealed a reduced repertoire of topics of conversation, with the  
22 same topics recurring in Sarah's talk, as well as repeated use of certain questions and  
23 statements, particularly about the routine of the day. Reg reported that, at times, Sarah lacked  
24 appropriate emotional responses in conversation. In addition, a poverty of conversation in the  
25 household was an issue because outside of those identified recurring themes, Sarah did not  
26 initiate interaction and trying to encourage her to participate in conversation could be  
27 difficult. Reg's attempts to engage Sarah in conversation could at times be met with minimal  
28 acknowledgements from her, e.g. 'mm' or 'oh' as Extract 1 now illustrates.  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44

#### 45 *Extract 1 - Minimal responses*

46  
47 In this extract, Sarah and Reg are waiting for the support worker and Reg is trying to  
48 encourage Sarah to participate in the conversation. There are five instances of minimal  
49 responses (lines indicated with an arrow) from Sarah, i.e. monosyllabic responses, low in  
50 volume and accompanied by a lack of eye contact. There are only two other responses from  
51 Sarah (lines 008 and 021), where she looks to Reg, addresses his question briefly but she does  
52  
53  
54  
55  
56  
57  
58  
59  
60

not elaborate further. Sarah's responses convey minimal participation in the interaction.

Please see Appendix for transcription symbols.

001 R Suzanne will fetch us out take  
 002 us out maybe somewhere for a meal an ride  
 003 round for you you can say you've been out  
 004 then (2.0) alright  
 → 005 S mmm °yeah° ((no eye contact))  
 006 R now you didn't sleep very well last night did  
 007 you  
 008 S I don't know ((looks at Reg))  
 009 R you was up and down all night long saying  
 010 that you couldn't sleep  
 → 011 S mmm ((no eye contact))  
 012 R I thought you probably would've wanted to  
 013 stop in bed a bit longer this morning  
 → 014 S [mmm] ((no eye contact))  
 015 R [but] you was up at half past seven and I  
 016 thought you might have wanted to have a  
 017 little sleep but you seemed to be awake again  
 018 now  
 → 019 S m ((no eye contact))  
 020 R do you feel tired  
 021 S not now ((looks at Reg))  
 022 R but seeing that you was up and down all  
 023 through the night and you didn't sleep at all  
 024 you said  
 → 025 S mmm ((no eye contact))

Since assessment indicated that Reg had adapted well to the changes in Sarah's conversation abilities, advice about communication techniques was not necessary. However, Sarah's limited involvement in interactions at home was a concern and this raised the question of whether activities such as life story work could provide enhanced opportunities for participation within everyday family life.

### **The Intervention: Life Story Music DVD**

Sarah already had a printed life story book and it was reported that the book was useful at an earlier stage to encourage communication. However, it was now limited as an aid to conversation because Sarah had difficulty recognising many of the people and places

1  
2  
3 portrayed in the photographs and remembering the events concerned. This is consistent with  
4 reports of associative agnosia affecting understanding of faces and places, along with  
5 evidence of long term memory difficulties in semantic dementia (Hodges & Patterson, 2007).  
6  
7  
8  
9

10  
11 **Narrative** interviews with the family identified that Sarah had a long-standing interest in  
12 music and singing and that she still retained many of these abilities. This indicated that  
13 exploring music within life story work might be more successful and so the decision was  
14 made to make a life story music DVD. Together with Sarah, Reg and Harriet the first author  
15 compiled a list of songs that were meaningful to Sarah, either in the past or the present. These  
16 songs were played to her using either an audio or video clip of the particular artist, thus  
17 identifying the songs she particularly liked. Following this, video footage was recorded at  
18 home with Sarah singing with her family using these clips. Also recorded was a member of  
19 the family introducing each song, e.g. *'We've chosen this song because we know you love*  
20 *RED'* to introduce Chris De Burgh singing 'The Lady in Red'. Clips were uploaded into a  
21 popular DVD programme maker, including: family members introducing the artists and  
22 stating why the song was meaningful, various artists singing and footage of family members  
23 singing with Sarah. The videos were then organised appropriately with relevant title lines  
24 added on screen, e.g. the title of the DVD as an introduction (Thank You for the Music),  
25 family member's names when they appeared on screen and linking title slides to give flow to  
26 the DVD, e.g. *'and now for us all singing...(song name)'*. Care was taken to ensure that  
27 videos were of a similar volume with fading used to slowly fade in and fade out tracks.  
28 Where possible atypical words were spelt with a regular spelling, e.g. the popular English  
29 singer 'Cilla' (Black) was spelt '*Silla*' on screen, to help Sarah read as her acquired dyslexia  
30 meant she had difficulty reading words with irregular spellings. Finally, a credits slide listed  
31 the names of those who took part. The video was shown to Sarah on two occasions to pilot  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 and refine the format, once on a laptop computer and once on the screen of her television and  
4  
5 alterations were made as appropriate. This included:

- 6  
7 • Ensuring labels of family names appeared on screen throughout (this reduced Sarah  
8 saying ‘*who’s that?*’).
- 9  
10 • Altering the order of songs – the song ‘I like a nice cup of tea’ was initially first,  
11  
12 however, this led to Sarah requesting tea from Reg even if she had just had a cup and  
13  
14 this was, therefore, placed at the end.
- 15  
16 • Ensuring all song lyrics appeared on screen too, at the request of the family so they  
17  
18 could sing along more easily.
- 19  
20 • A particular song was omitted as this made Sarah’s daughter upset as it reminded her  
21  
22 of how her mum used to be prior to her dementia.
- 23  
24  
25  
26  
27  
28  
29

30 A final DVD was given with a cover using stills from the recording session and an  
31  
32 explanation of life story work on the reverse. The DVD was 40 minutes long. Copies were  
33  
34 given to Sarah and Reg and another to Harriet.

### 35 36 37 38 **Outcomes of the Intervention**

39  
40 In terms of exploring the effects of the intervention, the aim was to understand how the life  
41  
42 story process and the music DVD resource contributed to Sarah’s participation in social  
43  
44 interaction with family members. Video and audio recordings were made of the session  
45  
46 making the DVD (recorded in the late afternoon) and the two sessions with Sarah and Reg  
47  
48 watching the piloted and final versions (recorded over two mornings) giving 82 minutes of  
49  
50 video data and an additional 40 minutes of audio data. In these instances the video camera  
51  
52 was operated by the researcher filming in the lounge area. The principles of conversation  
53  
54 analysis guided the analysis of the data as described earlier. Firstly, the video and audio were  
55  
56  
57  
58  
59  
60

1  
2  
3 examined in entirety by author (01) on two occasions with salient recurring features noted.  
4  
5 Extracts of the data were then viewed and discussed with authors (02, 04). A collection of  
6  
7 specific examples of recurring practices within interaction was then made with detailed  
8  
9 transcriptions of the data including speaking, singing and nonverbal behaviours. These  
10  
11 examples were viewed and discussed by authors (01, 02, 03) and these were subjected to  
12  
13 further detailed analysis focusing on how the life story music DVD impacted on Sarah's  
14  
15 behaviour and participation in interaction (see below).  
16  
17  
18  
19

20  
21 This data driven method was used to analyse recurring interactional behaviours, or moments  
22  
23 in the data as required by conversation analysis (Hutchby & Wooffitt, 2008). The method  
24  
25 used has some overlap with micro analytical approaches using video to explore the in-the-  
26  
27 moment effects of music therapy, where detailed analysis of both verbal and nonverbal  
28  
29 behaviour derived from observation in context has been used (Wosch & Wigram, 2007).  
30  
31 Application of conversation analysis, however, allowed for a qualitative comparison between  
32  
33 the recurring practices during conversation, with those during the intervention, in order to  
34  
35 explore in detail how the intervention influenced participation in interaction. Analysis  
36  
37 revealed three recurring patterns in the data that could then be broken down further into  
38  
39 specific interactional practices:  
40  
41  
42  
43  
44

- 45 1. Distraction from Distress
- 46
- 47 2. Facilitating Interaction
- 48
- 49 a. In response to the lyrics
- 50
- 51 b. Making up own lyrics
- 52
- 53 c. Embodied and emotional connections
- 54
- 55
- 56 3. Performance and Identity
- 57
- 58
- 59
- 60

- a. Embellishments and over-singing
- b. Embodied performance
- c. Reaction from her audience.

These findings will be presented and extracts from the video data used to further illustrate issues. In the following extracts bold type is used for singing and standard type for talking. Behaviours occurring simultaneously are bracketed, as is standard in conversation analysis. Still photographs taken from the video have been used to illustrate important nonverbal aspects to the data.

#### ***Pattern 1 - Distraction from Distress***

Engaging Sarah in song distracted her from her recurring worries about her headaches and requests for pain relief, providing a foundation for enhanced participation in interaction. The effects of this distraction were particularly dramatic during the session making the DVD when Sarah was initially in bed, with her family present in the lounge. Reg asked Sarah to join the family, as he thought it might help her, but she looked in pain and it seemed as though filming might have to be postponed. Video footage, however, revealed the transformative nature of the music within the first minute. At the start of the recording Sarah complains about her headache. There is no eye contact with Harriet who is sitting next to her; Sarah eyes are shut and she is looking ill whilst rubbing her head. However, as the music plays (Lady in Red, Chris de Burgh) she opens her eyes, looks at the artist on the laptop screen and then to the researcher, beginning to attend to the music (18 seconds). Sarah begins to move to the music and smile (23 seconds), make eye contact with Harriet (28 seconds) and start to sing (33 seconds). At 54 seconds, she appears happy and engaged in the song as evidenced by her voice, face and body movements. This level of engagement continues

throughout this song. During this visit Sarah did not request pain relief while the music was playing but when the music stopped, she started to complain about her head and ask for tablets. At a later visit Sarah was again repeatedly asking for tablets in the first hour (during normal conversation), rarely going more than five minutes between requests. However, whilst watching the 40 minutes of the DVD she did not request any tablets. The DVD did not eliminate all repetitive behaviours, as Sarah often still asked for food, cups of tea and chewing gum. It would seem, therefore, that music appeared to lift her mood and distract her from her worries about her head, rather than reduce all such behaviours.

### ***Pattern 2 - Facilitating Interaction***

There were a number of ways that the DVD facilitated interaction including: a) In response to the lyrics; b) Sarah making up her own lyrics; c) Giving rise to embodied emotional connections:

#### *a) In response to the lyrics*

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

#### *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	<b>baby I would rather be [dead]</b>
006	S	[dead] no no we don't
007		want to die yet do we

1  
2  
3  
4  
5 Thus, in response to the lyric *'tear us apart,'* Sarah looks to Harriet in line 003 and expresses  
6 her disagreement with that possibility: *'no'* and *'no chance'* and in response to *'I would*  
7 *rather be dead'* (005) Sarah says to Harriet *'we don't want to die yet do we?'* The result is  
8 both affectionate and humorous.  
9  
10  
11  
12

13  
14  
15  
16 *b) Making up own lyrics*  
17

18 Sarah would sometimes make up her own lyrics, singing in tune and in time to the music, but  
19 with her own words. For example, with Tina Turner's *'Simply the Best'*, at a point where  
20 only the music is playing, Sarah sings her own lyrics to Harriet *'ah ah I love you any time of*  
21 *day I can't stay awake I love you so oh oh oh.'*  
22  
23  
24  
25  
26  
27

28  
29  
30 *c) Embodied and emotional connections*  
31

32 Connections between family members were not just verbal but also embodied, **evident by the**  
33 **coordinated use of touch, body posture and eye gaze used spontaneously by both participants**  
34 **within the context.** The Cilla Black song, *'You are my World'*, is Sarah and Reg's  
35 engagement song. Sarah no longer remembers this association but does still remember many  
36 of the lyrics and its distinctive tempo. On the two occasions Sarah is video recorded listening  
37 to this song, Sarah is seen to **look to Reg and reach for his hand** when she sings *'my arms*  
38 *reach out to you for love'*. **Reg leans towards Sarah, holds her hand and smiles as she sings.**  
39 **This further demonstrates the embodied connection between them,** as extracts 3 and 4  
40 illustrate, with the behaviours observed on both videos remarkably similar.  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53

54 *Extract 3 - Embodied connection - engagement song 1*  
55

56 This example is from the session making the DVD.  
57  
58  
59  
60



1  
2  
3 001 M [So my arms reach out to you for love]  
4 002 S [So my arms reach out to you for love]  
5  
6 003 [ ((reaches over to Reg takes his hand)) ]  
7 004 R [ ((takes Sarah's hand, smiling)) ]  
8  
9



20  
21 002 – “reach out to you”  
22



23  
24 002 - 004 – “... for love.”  
25

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

27 This example is from a later session watching the DVD, as before Sarah reaches over to Reg,  
28 who is sitting next to her (this time on the other side and further away) taking his hand.  
29  
30  
31  
32  
33

34 001 M [So my arms reach out to you for love]  
35 002 S [So my arms reach out to you for love]  
36  
37 003 [ ((reaches over to Reg takes his hand)) ]  
38 004 R [ ((looks at Sarah, takes her hand)) ]  
39



50  
51 002 – “reach out to you”  
52



53  
54 002 - 004 – “... for love.”  
55

56 Sarah also makes embodied and emotional connections with Harriet, for example, **she smiles**  
57 **and leans towards Harriet, placing** her cheek to Harriet's when singing about dancing 'cheek  
58  
59  
60

to cheek' and at the end of this song (Lady in Red) there is a particularly poignant exchange between them both, as illustrated in extract 5:

*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

***Pattern 3 - Performance and Identity***

It was clear during interviews that being 'a singer' was an extremely important and distinct part to Sarah's identity that she still retained, as she explained when watching the DVD: 'you've not been a singer really have you Reg, I've always been a singer, I remember when I was a child when me mum was here'. When watching the DVD Sarah often asked 'who's put me on telly Reg?' with amazement, but was unable to retain any explanation as to why the DVD had been made. It was decided with Reg that saying it was because she had a good voice was the most easily understandable and helpful for her, as it reinforced this positive aspect of her retained identity. The video also illustrates that Sarah does not just sing, she is seen to perform with the following aspects contributing to this sense of performance.

*a) Embellishments and 'over-singing'*

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*





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 watching the 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**

Initial assessment revealed that Sarah’s participation in interactions with her family members during conversation was generally limited. As described earlier, she initiated little, and her responses were often minimal with questions and topics drawn from a limited repertoire. The introduction of the life story music DVD provided Sarah and her family with a resource

1  
2  
3 which distracted her from her worries and complaints about her headaches and facilitated  
4  
5 interaction.  
6  
7

8  
9  
10 **Analysis reveals that** engaging with familiar and meaningful music had the power to enhance  
11 Sarah's participation and involvement with her family both verbally and nonverbally in a way  
12 that was not typically present in everyday conversation. For example, in-the-moment analysis  
13 of the video data sees Sarah take an active part in both the process of making the DVD and in  
14 her reactions when watching it, with playful, humorous and emotional connections with  
15 family members displayed. Sarah is thus fully engaged when singing, in contrast to  
16 conversation, where she can often take a more passive role. **The resource allowed** Sarah to  
17 use areas of retained competence in singing and embodied performance to display her  
18 identity as a singer **and this resulted in positive reactions from her family.**  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31

32 Sarah and her family reported that were very happy with the DVD and that it had been shown  
33 to others visiting the house including Reg's relatives, their neighbour, the community nurse  
34 and their support worker. They had developed a family joke teasing each other about who  
35 was the best singer. The process had led to other activities with their son-in-law making  
36 Sarah another DVD with another set of favourite songs. Harriet in particular, however,  
37 reported that whilst it was lovely to see her mum happy, sometimes when making the DVD, it  
38 also made her sad as it reminded her of how her mum used to be in the past and she compared  
39 this to how she was now, saying: *'sometimes happy memories can also make you sad'*. Reg  
40 reported a similar feeling, though perhaps to a lesser extent. A telephone call from Reg, six  
41 months after they had received the DVD, revealed that they still enjoyed watching it together,  
42 with Reg reporting *'I'm surprised it's not worn out, the amount of times she's seen it'*.  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## Discussion

This study demonstrates that the **life story music DVD intervention acted as** a vehicle to provide opportunities for positive interaction and participation at home in semantic dementia.

**Analysis** illustrates the effects on interaction in detail and the positive benefit this has to Sarah in deploying retained abilities, displaying competence and showing aspects of her identity, for example, as a singer and also as a loving wife and mother. Moreover, the case demonstrates that music facilitates a different range of interactional skills compared to everyday conversation and evidences the reports in interviews that music has a special effect on Sarah's well-being. For instance, singing allows the playful and creative aspects of Sarah's identity to be displayed and this is in contrast to observations of conversation, both before and after the intervention, where she is often relatively passive. The embellishments and over-singing that Sarah uses intensifies her sense of performance. Musical embellishments were also reported in a case study of a harpsichord player with semantic dementia with the authors arguing that such behaviours indicate that these musical skills are not merely being retrieved whole from long term memory (Weinstein et al., 2011). This would also appear to be the case for Sarah as demonstrated by her performance skills, creativity with singing and her ability to process the words of the song and use this as a vehicle to interact with those around her.

Hailstone, Omar, and Warren (2009) **found that in a woman with semantic dementia, musical knowledge was disproportionately preserved in comparison to other modalities of knowledge, suggesting that this** may contribute to musicophilia in people with frontotemporal dementia.

Areas of retained skill may have implications for interventions; for example, a study of the practice of speech and language therapists working with people with semantic dementia reported that one of the founding principles of their work was a focus on ability and its

1  
2  
3 promotion, rather than a focus on disability in therapy (authors, 2015). Sarah's case study  
4  
5 illustrates that communication interventions may build on abilities outside of language to  
6  
7 provide appropriate opportunities to contribute to interactional and emotional connections  
8  
9 with family members. Importantly, in this case study, singing was not just a solitary pleasure  
10  
11 for Sarah, but an activity that could engage others.  
12

13  
14  
15  
16 The data demonstrates not just a range of verbal connections, but embodied and emotional  
17  
18 connections including love, joy and humour. Authors (2014b) argue that professional  
19  
20 outcomes from life story work may be very different from the outcomes that family members  
21  
22 value. For example, whilst professionals may focus on reducing negative behaviour or  
23  
24 fostering certain abilities, simply 'having fun together' might be highly valued by family  
25  
26 members. This is where appropriately tailored life story work may offer potential as watching  
27  
28 the biographically-centred DVD allowed Sarah an opportunity to relive-the-moment and  
29  
30 interact with her family. Reg later reported that Sarah often enjoyed watching the DVD, even  
31  
32 after the intervention had been completed.  
33  
34  
35

36  
37  
38 The biographical nature of the intervention enabled longstanding aspects of Sarah's identity  
39  
40 to be displayed within interaction, including behaviours of a performative nature. **Kontos**  
41  
42 **(2005) has outlined a notion of embodied selfhood for dementia care to capture the idea that**  
43  
44 **fundamental aspects of selfhood are manifested in the way the body moves and behaves. The**  
45  
46 **data here is consistent with this notion with Sarah automatically moving her body and**  
47  
48 **performing to the music as she has always done. The intervention, therefore, actively**  
49  
50 **provides an opportunity for Sarah to express her identity with her body.** This performance  
51  
52 observed in the present, was also often compared with elements of the past. For example,  
53  
54 when observing her current behaviour when singing **or watching the video data**, Sarah's  
55  
56  
57  
58  
59  
60

1  
2  
3 family talked about her long-standing love of singing and recalled stories of her singing  
4  
5 abilities from her childhood through to her adult life. However, reminding them of how she  
6  
7 used to be presented some challenges for her family, particularly her daughter. As Schechner  
8  
9 (2013) notes ‘performances mark identities, bend time, reshape and adorn the body and tell  
10  
11 stories’ (p.28) and Sarah’s performance, it could be argued, was in some ways an  
12  
13 autobiographical performance in the present but also from the past. Her family, as the  
14  
15 audience, were aware this was only a momentary, and not a lasting, performance and this also  
16  
17 brought them some sadness.  
18  
19

20  
21  
22  
23 There is no evidence that the music DVD had wider or longer term effects on Sarah’s  
24  
25 interaction, or behaviour, when it was not being used. For example, the video data shows that  
26  
27 once the music had stopped, Sarah returned to complaints about her headache. Similarly,  
28  
29 there is no evidence that the conversations between Sarah and her family differed in any ways  
30  
31 which could be attributable to the use of the music DVD. However, this lack of generalisation  
32  
33 should not detract from the in-the-moment effects on interaction and emotion evident in the  
34  
35 data when the life story music DVD was being used. Moreover, the goal of this intervention,  
36  
37 following the framework of the ICF (WHO, 2001), was to enhance participation in  
38  
39 interaction and this, therefore, should be the primary focus for examining outcomes. A recent  
40  
41 review of music-based therapeutic interventions found a lack of demonstrated long term  
42  
43 effects on behaviour, cognition, quality of life and emotional well-being, with effects on  
44  
45 social behaviour particularly difficult to demonstrate (van der Steen et al., 2017). However,  
46  
47 commenting on a lack of long term benefit, McDermott, Crellin, Ridder, & Orrell (2013)  
48  
49 have argued for studies to re-define realistic and clinically relevant goals, including  
50  
51 temporary effects on quality of life. Similarly, a focus on engagement and in-the-moment  
52  
53 effects has been advocated in other studies using the arts (MacPherson, et al., 2009; Camic, et  
54  
55  
56  
57  
58  
59  
60



1  
2  
3 al., 2011). Within theatre studies, Thompson (2009) notes that in the search for the ‘effects’  
4  
5 of performance in terms of social utility, applied theatre is in danger of forgetting the ‘affect’  
6  
7 of performance at the time and this is a problem faced too by dementia care. It can be  
8  
9 extremely difficult for families to engage individuals with advancing semantic dementia in  
10  
11 activity or conversation of any kind. However, the achievement and creativity seen within  
12  
13 such in-the-moment exchanges, as discussed here, can be too easily overlooked when a lack  
14  
15 of ‘effect’ in the long term is noted. Dementia care would benefit from greater attention to  
16  
17 such issues.  
18  
19

## 20 21 22 23 **Conclusion**

24  
25 This case study moved away from the focus in the literature on improving language function  
26  
27 in semantic dementia to an intervention to enhance participation in life situations using a life  
28  
29 story music DVD at home. Using the ICF framework (WHO, 2001), enhanced participation  
30  
31 in interaction was the primary goal of the intervention and evaluating this was, therefore, the  
32  
33 relevant outcome measure, as demonstrated here through in-the-moment effects within  
34  
35 interaction, analysed using conversation analysis. Changes in behaviour and brain functions  
36  
37 after the activity has finished, whilst welcome, are not necessary for the goals of the  
38  
39 intervention to be achieved. Separating out these aspects is a crucial aspect to delivering  
40  
41 person-centred care and interventions in dementia. This encourages practice and care to value  
42  
43 such in-the-moment connections and seek to foster greater opportunities for these to occur in  
44  
45 the daily lives of those living with semantic dementia and their family members.  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## References

Authors (2016)

Authors (2015)

Authors (2014a)

Authors (2014b)

Authors (2013)

Alzheimer's Disease International. (2009). *World Alzheimer's report: The global prevalence of dementia*. London: Alzheimer's Disease International.

Alzheimer's Disease International. (2014). *World Alzheimer's report: Dementia and risk reduction*. London: Alzheimer's Disease International.

Beard, R. L. (2012) Art therapies and dementia care: A systematic review. *Dementia* 11(5), 633-656. doi: 10.1177/1471301211421090

Boeve, B. F., & Geda, Y. E. (2001). Polka music and semantic dementia. *Neurology*, 57, 1485.

Camic, P. M., Williams, C. M. & Meeten, F. (2011). Does a 'singing together group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*, 12(2), 157-176. doi: 10.1177/1471301211422761

Fletcher, P. D., Downey, L. E., Witoonpanich, P., & Warren, J. D. (2013). The brain basis of musicophilia: Evidence from frontotemporal lobar degeneration. *Frontiers in Psychology*, 4, 1-8. doi: 10.3389/fpsyg.2013.00347

Frontotemporal Dementia Toolkit. (2014) Retrieved from Eastern Cognitive Disorders Clinic: <http://ecdc.org.au/>

Garrard, P., & Forsyth, R. (2010). Abnormal discourse in semantic dementia: A data-driven approach. *Neurocase*, 16, 520-528. doi: 10.1080/13554791003785901

- 1  
2  
3 Gorno-Tempini, M. L., Hillis, A. E., Weintraub, S., Kertesz, A., Mendez, M., Cappa, S. F., . .  
4  
5 . Grossman, M. (2011). Classification of primary progressive aphasia and its variants.  
6  
7 *Neurology*, 76, 1006-1014. doi: 10.1212/WNL.0b013e31821103e6  
8  
9  
10 Hailstone, J. C., Omar, R., & Warren, J. (2009) Relatively preserved knowledge of music in  
11  
12 semantic dementia. *Journal of Neurology Neurosurgery and Psychiatry*, 80, 808-809.  
13  
14 doi:10.1136/jnnp.2008.153130  
15  
16 Hodges, J. R., & Patterson, K. (2007). Semantic dementia: A unique clinicopathological  
17  
18 syndrome. *Lancet Neurol*, 6, 1004-1014. doi: 10.1016/S1474-4422(07)70266-1  
19  
20  
21 Hutchby, I., & Wooffitt, R. (2008). *Conversation analysis*. Cambridge: Polity Press.  
22  
23 Jefferson, G. (2005). Glossary of transcript symbols with an introduction. In G. Lerner (Ed.),  
24  
25 *Conversation Analysis: Studies from the First Generation* (pp. 13-31). Amsterdam:  
26  
27 John Benjamins.  
28  
29  
30 Jokel, R., Graham, N., Leonard, C., & Rochon, E. (2014) Word retrieval therapies in primary  
31  
32 progressive aphasia. *Aphasiology*, 28, 1038–1068.  
33  
34 doi: 10.1080/02687038.2014.899306  
35  
36 **Kontos, P. C. (2005). Embodied selfhood in Alzheimer's disease: Rethinking person-centred**  
37  
38 **care. *Dementia*, 4, 553-570.**  
39  
40  
41 MacPherson, S., Bird, M., Anderson, K., Davis, T., & Blair, A. (2009). An art gallery access  
42  
43 programme for people with dementia: You do it for the moment. *Aging & Mental*  
44  
45 *Health*, 13, 744-752.  
46  
47  
48 McDermott, O., Crellin, N., Ridder, H. M., & Orrell, M. (2013). Music therapy in dementia:  
49  
50 A narrative synthesis systematic review. *International Journal of Geriatric*  
51  
52 *Psychiatry*, 28, 781-794. doi: 10.1002/gps.3895  
53  
54  
55 McKeown, J., Clarke, A., & Repper, J. (2006). Life story work in health and social care:  
56  
57 systematic literature review. *Journal of Advanced Nursing*, 55, 237 – 247.  
58  
59  
60

- 1  
2  
3 doi: 10.1111/j.1365-2648.2006.03897.x  
4  
5 Neary, D., Snowden, J. S., Gustafson, L., Passant, U., Stuss, D., Black, S., . . . Benson, D. F.  
6  
7 (1998). Frontotemporal lobar degeneration: A consensus on clinical diagnostic  
8  
9 criteria. *Neurology*, *51*, 1546-1554.  
10  
11 Perkins, L., Whitworth, A., & Lesser, R. (1998). Conversing in dementia: A conversation  
12  
13 analytic approach. *J Neurolinguistics*, *11*, 33-55.  
14  
15 Ridder, H. M., & David Aldridge, D. (2005). Individual music therapy with persons with  
16  
17 frontotemporal dementia. *Nordic Journal of Music Therapy*, *14*, 91-106.  
18  
19 doi: 10.1080/08098130509478132  
20  
21  
22 Riessman, C. K. (2008). *Narrative methods for the human sciences*. Thousand Oaks, CA:  
23  
24 Sage Publications.  
25  
26  
27 Sajjadi, S. A., Patterson, K., Tomek, M., & Nestor, P. J. (2012). Abnormalities of connected  
28  
29 speech in semantic dementia vs Alzheimer's disease. *Aphasiology*, *26*, 847-866.  
30  
31 doi: 10.1080/02687038.2012.654933  
32  
33  
34 Särkämö, T., Tervaniemi, M., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K. &  
35  
36 Rantanen, P. (2014) Cognitive, emotional, and social benefits of regular musical  
37  
38 activities in early dementia: A randomized controlled study. *The Gerontologist*,  
39  
40 *54*(634-650). doi:10.1093/geront/gnt100  
41  
42  
43 Schechner, R. (2013). *Performance studies: An introduction*. London: Routledge.  
44  
45 Thompson, J. (2009). *Performance affects: Applied theatre and the end of effect*.  
46  
47 Basingstoke: Palgrave MacMillan.  
48  
49 van der Steen, J. T., van Soest-Poortvliet, M. C., van der Wouden, J. C., Bruinsma, M. S.,  
50  
51 Scholten, R. J. P. M., & Vink, A. C. (2017). Music-based therapeutic interventions for  
52  
53 people with dementia. *Cochrane Database of Systematic Reviews*, Issue 5. Art. No.:  
54  
55 CD003477. doi: 10.1002/14651858.CD003477.pub3.  
56  
57  
58  
59  
60

- 1  
2  
3 Weinstein, J., Koenig, P., Gunawardena, D., McMillan, C., Bonner, M., & Grossman, M.  
4  
5 (2011). Preserved musical semantic memory in semantic dementia. *Archives of*  
6  
7 *Neurology*, 68, 248-250. doi: 10.1001/archneurol.2010.364  
8  
9  
10 Westerhof, G. J., Bohlmeijer, E., & Webster, J. D. (2010). Reminiscence and mental health:  
11  
12 A review of recent progress in theory, research and interventions. *Ageing & Society*,  
13  
14 30, 697-721. doi:10.1017/S0144686X09990328  
15  
16 Williams, S., & Keady, J. (2008). Narrative research and analysis. In R. Watson, H.  
17  
18 McKenna, S. Cowman & J. Keady (Eds.), *Nursing research designs and methods*.  
19  
20 Philadelphia, PA: Churchill Livingstone Elsevier.  
21  
22  
23 World Health Organization. (2001). *International Classification of Functioning, Disability*  
24  
25 *and Health*. Geneva: WHO.  
26  
27  
28 Wosch, T., & Wigram, T. (Eds.). (2007). *Microanalysis in music therapy: Methods,*  
29  
30 *techniques and applications for clinicians, researchers, educators and students*.  
31  
32 London: Jessica Kingsley.  
33  
34 Yin, R. K. (2009). *Case study research: Design and methods*. Thousand Oaks, CA: Sage  
35  
36 Publications.  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 **Appendix - Transcription Symbols**  
4

5 **Symbols**      **Explanation**  
6  
7  
8  
9  
10 [              A large left-hand bracket links overlapping utterances or non-verbal  
11  
12 [              actions at the point where the overlap begins.  
13  
14  
15  
16 ]              A large right-hand bracket marks where overlapping  
17  
18 ]              utterances/simultaneous non-verbal actions stop overlapping.  
19  
20  
21  
22  
23 (0.6)          Silences are marked in seconds and tenths of seconds, i.e. (0.6) is six tenths of  
24  
25 a second; (1.2) is one second and two tenths of a second.  
26  
27  
28  
29  
30 oh:            A colon indicates an extension of the sound or syllable it follows (more colons  
31  
32 prolong the stretch).  
33  
34  
35  
36  
37 ↑↓            Marked rising and falling shifts in intonation are indicated by upward and  
38  
39 downward pointing arrows immediately *prior* to the rise or fall.  
40  
41  
42  
43 stress       Underlining indicates emphasis.  
44  
45  
46  
47 °no°          Degree signs indicate talk which is *quieter* than surrounding talk.  
48  
49  
50  
51  
52 ((*nods*))      Double brackets represent a gloss or description of some non-verbal aspect of  
53  
54 the talk  
55  
56  
57  
58  
59  
60

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

**Bold** Bold type in this report indicates singing,

For Peer Review Only