

Music in Dementia Care: Increased Understanding Through Mixed Research Methods

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ABSTRACT

Over the past decade there has been an increased interest in the wide variety of issues involved in the care of individuals with dementia. One particular area of research is the effect of music on those with dementia, commonly studied through the perspectives of neuroscience and (the more applied) music therapy. There is, however, a black box common to both these fields: music is seen as an input and its effect as a simple output. In treating the human (brain) as merely an object to stimulate with music or sound, the socio-cultural context of musical interaction is omitted from the analysis. This article discusses the employment of mixed research methods adapted specifically to explore the use of music in dementia care and to open this black box. In particular, this article explores the use of ethnographic participant observations and semi-structured interviews with individuals with dementia, their families/carers and (volunteer) staff of *Singing for the Brain* (SFTB) in a British town. The article concludes with a discussion of the preliminary themes generated by this mixed-methods approach (such as the importance of 'relationships'), and the importance of examining music as a 'catalyst' in building relationships. Although the issues examined in this article are specific to dementia, similar sensitive issues may be found in research on health and other creative (therapeutic) activities for people with dementia.

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INTRODUCTION

The ‘greying’ of many industrialized countries, and subsequent rise in illnesses prevalent among the elderly, is leading to a growing interest in dementia care. One consequence of this is an increased interest in creative therapeutic approaches, such as music therapy, to care for individuals with dementia. A variety of professionals, including music therapists, musicians and former music teachers, are involved in an assortment of therapeutic music activities in care homes, daily care centres and community centres.

The dominant methodology to study the effect of music on dementia is based on the medical and neuroscience model, in which music is seen as a stimulus for the brain (Baird and Samson, 2009; Crystal, *et al.*, 1989; Cuddy and Duffin, 2005; Norberg, *et al.* 1986). Although scientifically robust, the sociocultural context of the music listening experience (which is itself linked to the individual and musical histories) is often left out of the analysis. A more sociological approach would seek to address this limitation by looking in depth at individual experience with music in dementia care.

A key concern related to such studies, however, is the inherent difficulty in approaching those suffering from dementia to obtain data, particularly as dementia progressively destroys the cognitive functions. There are debates and ethical issues associated with conducting social research with people with dementia. The difficulties and challenges in eliciting the data from people with dementia, particularly those who are in advanced stage of dementia, have been discussed by Proctor (2001) and Reid *et al.* (2001). Consequently, in the study of dementia care, the caregiver’s perspective is often emphasized rather than that of the patient (Reid, *et al.*, 2001). Acknowledging this issue, Reid, *et al.* (2001, p. 378) have also suggested that although there is a “mushrooming of personal narratives that are attributed to individuals with dementia”, the precise nature of their authorships is uncertain. A similar phenomenon can be seen in the growing media interest in music in dementia care, which has been quite influential in raising the profile of these personal narratives. On the one hand, these narratives become powerful tools to showcase the power of music in dementia care, which leads to increased funding for charities to launch music activities in this area (BBC TWO, 2009; ITV, 2010). On the other hand we are still lacking a detailed and careful study of how one can obtain reliable and valid data from people with dementia and make use of such data to understand the role of music in relation to their everyday lives (and those of their carers).

This article will present a research programme aimed at exactly that: exploring how music can be used to support the everyday lives of people with dementia, particularly those who are cared for by their partners and family at home. I have chosen the community-based singing activity *Singing for the Brain* (SFTB) run by the *Alzheimer’s Society* (a UK charity) as a research site. Most of the members with dementia in SFTB are cared for in their own homes and participate in activities along with their regular carers (partner, family members or sometimes hired professionals).

In this article, I discuss the mixed methods I have used to explore the meaning of music in dementia care: (extended) participant observation, an ethnographic study of the music and care world in Watertown, UK and interview research with the members of and participants in SFTB.¹ These research methods obviously try not to regard music as merely a ‘stimulus’ designed to obtain measurable effects; rather I aim to explore the more nuanced meaning of music in everyday dementia care. To do this, I focus on the music-elicitation strategies I have used in interviewing individuals with dementia and their carers, and discuss preliminary evidence that supports the utility and efficacy of these methods in advancing this unexplored area. The important preliminary evidence drawn from these mixed methods is that music does not work as a simple stimulus but as a catalyst for building relationships. Furthermore, these research methods illuminate how SFTB itself is an important meeting place for people with dementia, their carers and volunteers to build a local support network.

PAST AND ALTERNATIVE APPROACHES TO UNDERSTANDING MUSIC IN DEMENTIA CARE

THE MEDICAL MODEL AND ITS APPLICATIONS: A BLACK BOX

As the number of people suffering from dementia increases,² there is increased interest in applying interventions through non-pharmacological therapy in care situations to improve the quality of life for individuals with dementia.³ In particular, music use with people with dementia has grown rapidly over the last decade (Watanabe, *et al.*, 2005). This interest comes from a number of disciplines and practices including neuroscience⁴ (DeKosky, *et al.*, 2001; Geroldi, *et al.*, 2000), nursing (Gotell, *et al.*, 2002; Kneafsey, 1997), environmental design (Topo and Östlund, 2009) and music therapy⁵ (Aldridge, 2000; Goodall and Eters, 2005; Lou, 2001; Raglio and Gianelli, 2009; Ridder, 2003). Two of the most visible disciplines in this area are neuroscience, on the one hand, and music therapy and more general (therapeutic) music activities for those with dementia, on the other.

In the neuroscientific approach, the study of music’s effects on the brain and vice-versa is a long-standing research area (Hodges, 2000). Discussions in this field have tended to focus on the “mechanics” of how music works on the brain, for instance how music can be a stimulus for memories (Baird and Samson, 2009; Crystal, *et al.*, 1989; Cuddy and Duffin, 2005; Norberg, *et al.*, 1986), the relationship between music and language (Koger and Brotons, 2000; Ruiz and Montanés, 2005) and behavioural management (Choi, *et al.*, 2009; Goodall and Eters, 2005; Raglio, *et al.*, 2008; Suzuki, *et al.*, 2004; Winckel, *et al.*, 2004). In neuroscientific models, quantitative methods are used to ‘prove’ the effectiveness of these “mechanics”, most

¹ The names of places and individuals have been changed to protect their privacy.

² According to a recent report by Luengo-Fernandez, *et al.*, “in the United Kingdom (UK), a previous study estimated that 683,597 people suffered from dementia in 2005, with the total forecasted to increase to 940,110 by 2021 and 1,735,087 by 2051” (2010, p. 10).

³ Dementia is a significant loss of cognitive ability, most prevalent in the geriatric population.

⁴ Neuroscience here refers to the study of the brain and nervous system as related to music and sound stimuli.

⁵ Music therapy is an established health profession particularly in the West (e.g., the U.S., several European countries and Australia) where music is used to support the physical, emotional, cognitive and social needs of individuals.

commonly statistics from randomized controlled trials (*e.g.*, Haas and Brandes, 2009; Miller, *et al.*, 2000).

In more applied fields like music therapy (based on the clinical application of the aforementioned 'medical' model of understanding music and health), music is often discussed as a possible medium to enhance verbal/non-verbal communication (Koger and Brotons, 2000) and, as in neuroscience, access memories (Cuddy and Duffin, 2005; Ridder, 2003) or manage agitated behaviour (Raglio, *et al.*, 2008; Ridder, 2003; Vink, 2000; Vink, *et al.*, 2004). The latter is also a growing concern in nursing (Lou, 2001; Sung and Chang, 2005; Wall and Duffy, 2010). The social aspects of music in dementia care have also been discussed as a means of building interactive relationships (Simpson, 2000) or facilitating the relationship between care-receivers and care-givers (Clair, 2000; Clair, 2002). To summarize, music therapy for individuals with dementia focuses on communication, memory, behavioural management and facilitating interactive relationship with therapists and carers. Music is seen as a tool to achieve those goals, and the outcomes of music sessions are measured either quantitatively (*e.g.*, Cuddy and Duffin, 2005; Vink, *et al.*, 2004) or qualitatively (*e.g.*, Clair, 1996; Simpson, 2000). Hence, in both the neuroscience and music therapy models, music is used instrumentally as an isolated material for making change. Like a pharmaceutical drug, its effect is administered and measured in a specific, predefined way. In other words, goals and hypotheses are defined prior to an intervention, and the effect of music is measured in terms of whether and/or how many of the predetermined goals have been achieved. In both cases, the embedded social and cultural dimensions of musical activity are absent. Indeed, the situational *experience* of music by people with dementia is difficult to generalize along the lines of these simple causal models.

In the UK, as well as other Western countries, the past decade has witnessed an increase among local community organizations and institutional groups in organizing and facilitating musical activities for members of older generations, including for individuals with some form of dementia (Bannan and Montogemery-Smith, 2008; Music for Life, 2010; Sing for Your Life, 2010). These activities are designed for people who have been diagnosed with dementia to different degrees, and who can participate in structured social activities with the assistance of their carers. Neither discussions of music as a stimulus to the *individual* brain from a neuroscientific viewpoint (Sherratt, *et al.*, 2004), nor measures of the outcome benefits of music (activities) for clients (Clair, 2002; Ridder, 2003; Vink, *et al.*, 2004), are sufficient to explain or understand the meaning of such activities. In short, what is missing is the in-depth study of the meaning of musical activity in the *everyday contexts* of the lives of individuals with dementia. I believe that this closer examination can greatly inform our understanding of the benefits of community-oriented musical activities in dementia care.

CAPTURING MUSIC-IN-ACTION: SOCIAL CONTEXTS OF MUSIC USE

In music therapy there is an additional school of thought which considers the meaning of music and therapeutic meaning in its socio-cultural context; this can be

seen, for example, in the recent emphasis on ‘community’ in music therapy (Ansdell, 1997; Stige, 2002). In this case, music is seen as ‘process’:

Music is not an object, a ‘thing’, but a set of processes that inevitably involves people. Music is an inherently social process. (Shepherd and Wicke, 1997 cited in Ansdell, 1997, p. 37)

In order to capture the “social process” as seen in music-in-action, music therapists conduct ethnographic studies such as participant observation in community music therapy activities; they then analyze their data to locate emergent themes that shed light on the meanings of the music-in-action (Stige, 2002; Stige, *et al.*, 2010).

By “music-in-action”, I refer to an approach in recent music sociology that has shown how music is embedded in social activities and behaviours in everyday life, rather than being an isolated activity (cf. Bergh, 2010; DeNora, 2000; Hennion, 2007). Innovative work on music and health (*e.g.*, Batt-Rawden, 2007; Batt-Rawden, *et al.*, 2007; DeNora, 2006) looks in particular at the role of music in *health promotion*.⁶ For example, Batt-Rawden (2007) examined music listening as a lay health promotion practice in the lives of men and women with long-term illness, using multiple interviews with informants over a period of time. The study showed that health promotion practices through music can be self-administered and do not necessarily have to be provided by health professionals (*e.g.*, music therapists). In both community music therapy and music sociology approaches to health, music is not seen as a stimulus or isolated activity to cure disease or disability; rather, the researcher (or therapist) explores the situated meanings of musical activity through a longer-term ethnographic process and in-depth interviews.

Both ethnographic research (*e.g.*, Kontos and Naglie, 2006; Reed-Danahay, 2001) and interview-based studies (*e.g.*, Proctor, 2001; Reid, *et al.*, 2001) have been used to investigate the experience of individuals with dementia. In fact, Proctor (2001) notes that participatory research and attempts to present the subjective experience of people with dementia challenge the dominant medical model and research methodologies in this area. Similarly, grounded theory approaches have been employed to analyze the accumulated ethnographic and interview data in music sociology (Batt-Rawden, 2007; Bergh, 2010), music therapy (Amir, 2005), studies of health issues and nursing (Glaser and Strauss, 1977; Schreiber and Stern, 2001), as well as the study of Alzheimer’s caregivers (Orona, 1997). Grounded theory refers to analytical techniques that allow themes (and new theories) to emerge from (often rich ethnographic) data, rather than defining the themes of interest prior to beginning analysis. In this way, grounded theory approaches do not preclude important issues and findings that are not necessarily known or obvious to the researcher before the research takes place. By applying a grounded theory framework, the socio-cultural contexts of the informants’ experiences are illuminated, thus adding to the experimental studies discussed above (*e.g.*, in neuroscience study, music therapy). In particular, Charmaz (2006) describes grounded theory as a good fit with intensive

⁶ Health promotion is defined as “the process of enabling people to increase control over their health and its determinants and thereby improve their health” by the [World Health Organization](#)’s 2005 [Bangkok Charter for Health Promotion in a Globalized World](#) (World Health Organization 2005).

qualitative interviewing, as both methods are open-ended yet directed, both shaping and emergent, and paced while also unrestricted.

The studies cited here indicate the promise of ethnographically-minded research aimed at investigating and understanding how music can help dementia care, and overcome the isolated focus prevalent in more overtly medical work, namely, 'music as a stimulus and its effect as a measurable outcome'. Hence, I have decided to implement a research program using ethnographic and interview research methods to shed light on the experiences of individuals with dementia who participate in locally-situated music practices.

BACKGROUND TO THE RESEARCH STUDY

Prior to the research discussed here, I conducted in-depth interview research with 30 elderly people about their musical orientations in everyday life in Japan (Hara, 2007). As many of the music (therapeutic) activities provided in nursing homes and day care centres were group-oriented rather than individual-focused, I was interested in exploring how those group-oriented music activities were received by individuals in relation to their own past history and previous musical orientations in everyday life. My past experience made me aware of the vital importance of building significant rapport before conducting one-on-one interviews, particularly given the risk of raising sensitive issues when speaking about music in the everyday lives of my informants.

As a result of these considerations, I chose *Singing for the Brain* (SFTB) in Watertown, in the Southwest UK, as my research site. SFTB is a singing-based musical activity program for individuals with dementia and their carers in a community setting. I decided to utilize participant observation as the core method of collecting data, supplemented by semi-structured interviews and recordings, as well as ethnography of the local music and care world in the town (taking advantage of my residency there). One of the key reasons for doing participant observation was that interviewing informants with dementia would be difficult and not sufficient as the sole method of data collection. It was very important not only to build rapport with them and their carers but also to observe their reactions and involvements during the musical activity. Using a mixed-methods approach, I set out to investigate the meaning of music and musical activities in relation to their everyday life experiences, and used grounded theory to analyze the collected data. In what follows, I provide a detailed background to my research program in order to evidence one possible alternative approach to understanding music in the social context of dementia care.

INFORMANT POPULATION

SFTB is a therapeutic and social activity for people with dementia and their carers. SFTB is one of many activities run by the UK *Alzheimer's Society*.⁷ It was first organised by the [Alzheimer's Society West Berkshire Branch](#). The Watertown group was started in 2007 by a former music teacher who was also one of the committee

⁷ The *Alzheimer's Society* is a membership organisation that works to improve the quality of life for people affected by dementia in England, Wales and Northern Ireland.

members of the local *Alzheimer's Society* branch, and she is still leading the group. The number of participants varies from session to session, but approximately 10 care-receivers, 10 carers⁸ and 10 volunteers attend.⁹ The majority of the members with dementia are cared for by their family members at home and join the SFTB singing sessions with these family members. The singing sessions are carefully planned by the facilitator and a few volunteers in order to cater for their target audience, and take place every week during the school term. The members (care-receivers) are in various stages of dementia. In some cases, they've joined SFTB after they and their carers found difficulties continuing singing in their previous choirs. In other cases, the family of the member with dementia happened upon SFTB through a local doctor or *Alzheimer's Society*. The length of time members have participated in SFTB also varies, from a few months to three years, but the majority of members participate in on a regular weekly basis. The age of the members with dementia also varies from late 60s to mid 80s. Their carers range from similar ages (*e.g.*, partners), to two daughters (in-law), and several volunteer members. The majority of the volunteer members (including the facilitator) have been participating in SFTB since its inception, which was two years before the beginning of my involvement. Most of the volunteers are in their late 60s and 70s, and began volunteering with the group after their own retirement.

ACCESS

Right after I moved to the UK from Japan to pursue my doctoral studies in sociology, I was introduced to the SFTB facilitator, who happened to be a long-time friend of the facilitator of SFTB, Watertown. I visited the music session and decided to work with them as a weekly volunteer because the group was looking for a volunteer, and I thought that working as a volunteer would help me learn more about the group and build the rapport with other members. I ultimately decided to choose the group as my research site because: (1) SFTB was easily accessible, and (2) I began working as a weekly volunteer with another local music group working with people with disabilities, and I thought that working with these two group simultaneously would enable me to build a robust understanding of the wider music and care world in Watertown, and, thus, help me to better understand my informants' everyday lives.

After eight months of volunteering, I announced my wish to conduct research with the group. In a letter to the group I explained my research plan and my background as a music facilitator for older people in Japan. At the bottom of the letter, I included a field (which could be torn from the rest of the letter) for each member to express permission in three areas of my research plan: (1) participation in an interview, (2) the taking of photographs, and (3) the audio recording of weekly singing sessions. I also asked each member to provide their names, addresses and phone number for me

⁸ By "carers", I refer to family members of the members who have dementia as well as hired professional carers.

⁹ One of SFTB's goals is to give carers a 'break' from their daily caring work so that they can enjoy a pleasant afternoon out with others. Therefore, all of the preparation for the activity is done by the volunteers, including preparing and cleaning up the venue, preparing the tea and biscuits and administrative work. The group tries to keep a ratio of 1:1:1 (Carers: Care-receivers: Volunteers).

to contact them later. I asked each person to return these permissions and contact information to me only after they understood my research plan.

I then contacted my informants, using the information they had provided as well as face-to-face interactions in the weekly music sessions, to 'book' them for the interview. For the members with dementia, I contacted their carers and asked them if I could interview them together (carers and care-receivers). 35 members (all the members who were actively involved in the group at the time of my involvement) gave me permission to take photographs and record the active singing sessions. Everyone agreed to participate in an interview, save one volunteer. With this permission in hand, I recorded and took photographs during the singing sessions for two terms. I also interviewed seven volunteers (including the facilitator), two charity (*Alzheimer's Society*) representatives, nine carers and seven care-receivers.¹⁰ Because this study deals with a vulnerable group of people, I have changed all their names and related identifiable information. (Further details about obtaining informed and ethical consent are given below.)

In the following three sections, I will focus in more depth on each of my main research methods: participant observation and ethnography, interviewing and interviewing with music-elicitation.

ETHNOGRAPHIC STUDY OF THE MUSIC AND CARE WORLDS

Before I started collecting data from SFTB, I had worked as a weekly volunteer with the group for eight months, as well as with another group in Watertown called *Sounding Out* (a music project involving people with learning disabilities) for the same period of time. At SFTB, I prepared and cleaned the venue, served tea and biscuits to the members, joined in singing and chatted with the members to make the whole group as welcoming and comfortable as possible for the members with dementia and their carers. The weekly sessions took place in a local community centre from 2.30-3.30 p.m. The other volunteers and I started to prepare the chairs and tea table from 1.30 p.m, so I spoke with them while setting up and cleaned up the venue with other volunteers afterwards.

Since I had personal caring experience with my own grandmother who had dementia, as well as five years career experience in running the music activities in nursing home and day care centres in Japan, I did not experience any difficulties joining the group. I enjoyed meeting volunteers with similar interests and spending what I experienced as pleasant afternoons in group singing sessions. Some of the songs sung in the singing session were new to me because of my Japanese upbringing, but I quickly learned how to sing those songs.

With the other music group, *Sounding Out*, I worked also as a volunteer for the weekly session. With them, I often played instruments (mainly piano) and supported making songs with people with learning difficulties. Since I also had experience working musically with people with learning difficulties in Japan, I found joining this

¹⁰ The reason that there are nine carers for seven patients is that two of the carers are friends of the care receivers who also look after him/her when the care receivers' partner and main carer is not present.

activity very enjoyable as well. Gradually, attending the two groups became part of my weekly routine.

Despite my past experience working professionally in this capacity in Japan, I undertook several training programs on volunteering with older people and vulnerable populations run by the University of Exeter, *Age Concern* (a local charity working with older people) and the local council during this period of volunteering. I did this to ensure that I understood the specific situations and regulations governing such work in the UK.

PARTICIPANT OBSERVATION

After spending eight months as a volunteer with SFTP, I started collecting data as a participant observer (which was supported by the recording of sessions and taking photographs). Practical difficulties of taking notes during the “covert observation” have already been discussed in social research (cf. Bryman, 2008, p. 405). Although everyone there knew that I was also a researcher, I continued being involved as a volunteer as before and deliberately tried not to show my ‘researcher’ pose to session participants. I also tried to avoid interrupting or influencing the sessions in any way. For example, I placed my audio recorder behind my chair so as to be invisible to most participants; I did not want anyone to become self-conscious about their singing being recorded. As soon as I left each session, I wrote down several key points from my reflections in the session. When arriving home, I updated these memos, and continued writing detailed fieldnotes while listening to the session recordings carefully and referring to the session plans given to me by the facilitator. I also made notes about strategies for future sessions, *e.g.*, what/who to look at more carefully. Before I went to each subsequent session, I read all previous fieldnotes to refresh my memory. During the sessions, I tried to sit close to the participants about whom I was interested in knowing more, or sat in a chair where I could observe them clearly. To date, I have observed 12 sessions in this way over six months. After this intense six month period of data collection, I stayed in the field for another year, participating in both SFTB and *Sounding Out* as an occasional volunteer.

Through this long-term involvement with both SFTB and *Sounding Out*, I came to know people working in the music and care world and discovered the connections and overlaps between individuals working with different music (or care) groups. This helped me to gain an understanding of how the music community and music and care community were closely linked to each other in Watertown. In other words, the long-term active involvement helped me understand the local music activities more holistically, to trace relationships between the different music care groups, and discover the local hidden music activities (Finnegan, 2007) which are shown in the figure on the next page (*e.g.* *Acoustic Cafe*, *Park Club*, *Linking Voices* and *Silver Song Clubs*). The figure below also illustrates the relationship of SFTB to the larger music and care world in Watertown:

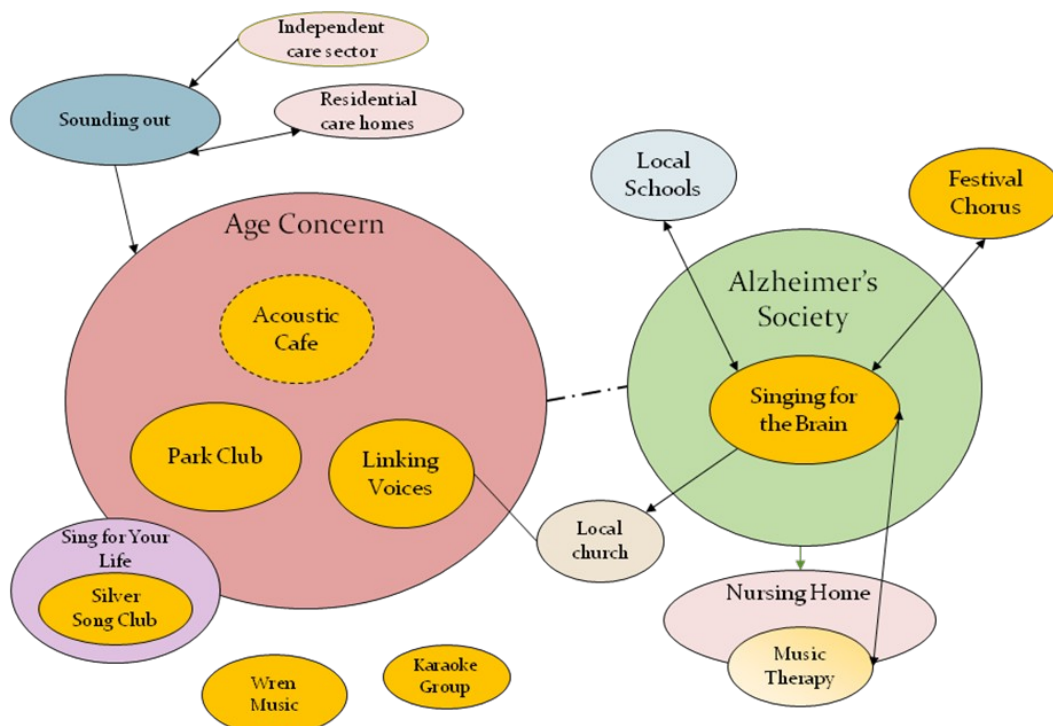


Figure 1: Watertown music and care network

Being temporarily local also gave me access to further pertinent data. I often went to music concerts that some of the members of SFTB and *Sounding Out* took part in, and kept myself informed about activities run by charities and attended such events as much as possible. I often ‘bumped into’ members of SFTB in town, which helped me to get a sense of what their daily lives were like. This ongoing data collection became a part of my daily life just by living locally and being involved with these activities and events, as well as participating in the weekly sessions. More importantly, these multiple involvements helped me to situate myself both as a researcher and as a volunteer in the field in order to experience and explore the meaning of the music in action *with* the other group members (*i.e.*, my informants).

INTERVIEWING

I conducted my formal interview research over the same six month rigorous data collection period. Before conducting each interview, I obtained formal signed consent from my informants, and explained that they could choose to withdraw this consent anytime they wished. The interviews were semi-structured with different sets of questions prepared for different categories of informants: the facilitator, charity representatives, carers, care-receivers and volunteers. By using semi-structured interviews I was able to let the informants ‘take charge’ and lead me through their views and experiences of music use; this active approach to interviewing was of key importance in order to learn more about how music connects with their everyday lives, rather than leading my informants to see music as a static and isolated ‘input’. As Denzin (2009) notes, data collection through interviews is an interactive activity which depends significantly on the variable personal and situational properties of the interaction between interviewers and informants. I also asked more spontaneous questions to further investigate themes and topics expressed by interviewees. Before

each interview, I read through all of the fieldnotes relevant to each interviewee, making notes of any particular episodes that I wanted to discuss in addition to my prepared interview protocol. I also used these fieldnotes to remind myself of events from SFTB sessions that I could discuss with them to help improve our rapport during the interview. In this way, my continuous involvement as a volunteer prepared me for the interviews, most notably with the carers and care-receivers. For carers and care-receivers, their experiences of caring or having dementia is a very sensitive issue, and it may be difficult for them to discuss (and be understood) by someone who only has limited time available to share with them. The mutual trust I had built up over time was necessary for me as well as for the informants to feel comfortable when talking about the sessions and their own experiences with music and dementia more generally. Moreover, since it was often difficult to make sense of the words of my informants with dementia, and their moods could alter quickly and become agitated, the longer-term observation was helpful in understanding the meaning of specific habits and the overall character of care-receivers.

I chose to interview the volunteers (including the facilitator) first because they were local and easily accessed (partly because I was one of them), and because I hoped to shed light on the group from an organizing point of view and to examine any shared values behind the organization and its volunteers. These beginning interviews were resourceful in many ways, and also helped me to prepare the interviews with the members with dementia and their carers. Some of the volunteers shared notable episodes from the singing sessions that had escaped my notice. The majority of the volunteers, who each had been involved with the group for a longer period than myself, knew the members with dementia when they first joined the group and could speak to their involvements in the singing session with their carers in earlier stages of dementia. I did not refer to these interviews when interviewing the informants with dementia and their carers. However, the knowledge gained through interviewing the volunteers prepared me to direct my interviews with my informants with dementia and their carers, for example, by reassuring the data in subtle ways and by enabling me to use these later interviews to further develop the themes that arose in the data from fieldnotes and interviews with the volunteers (rather than starting from scratch in later interviews).

When scheduling the interviews with carers and care-receivers, I tried to observe their situations and conditions in the weekly sessions and make plans for the interview accordingly so as not to make it a burden for them. As I described above, I also consulted with the carers as to when and where it would be appropriate to conduct the interview. In one instance, the interview was cancelled due to the sudden worsening of a care-receiver's condition; in this case, his carer contacted me. There were instances when care-receivers' conditions deteriorated largely from the time I first asked them to participate in the interview research. In those cases, I depended on carers' decision and advice as to whether the interview should be carried out or cancelled, and when and where the interview would take place. The aim of the interview was explained to carer and care-receivers when I obtained signed consent from them, and the interviews were conducted in the present of both carers and care-

receivers. With the members who were in later stage of dementia I employed the carers' assistance in explaining and signing the consent form. With these individuals, I was not sure if they even recognized me during the interview, despite the fact that we had met once a week for more than a year during weekly sessions. However, none of the care-receivers, in spite of their limited cognitive responses, looked uncomfortable with my presence or me chatting with them and their carers. In the singing sessions up to this point and after, I tried to sit next to carers and care-receivers, partly to fulfil my role as volunteer (to be of help as needed), and partly to build rapport with them and observe their involvement in the singing sessions. On this weekly basis, I often chatted with them about music and their daily lives. Therefore, although the interviews took place in different places such as their homes, these interviews became smooth 'extensions' of these informal 'chats' in the singing sessions rather than uptight, formal interviews.

In the next sections, I will discuss the specific techniques and strategies I used during the interviews with members with dementia and their carers, and some of the possible opportunities and forms of understanding these enabled.

THE MUSIC ELICITATION INTERVIEW

MUSICKING AS A POSSIBLE RESOURCE TO ELICIT INFORMATION IN THE INTERVIEW

In this section, I discuss how active music making can become a resource for eliciting information during interviews with my informants, including those with dementia and their carers. To emphasize the active musical involvement that takes place in many ways, I will use the term "musicking", an action and performance oriented concept developed by Small (1998). It expands the meaning of music making as follows:

To music is to take part, in any capacity, in a musical performance, whether by performing, by listening, by rehearsing or practicing, by providing material for performance (what is called composing), or by dancing. (Small, 1998, p. 9)

The concept of "musicking" in this paper implies informants' active musical engagement during the interview, ranging from singing and humming to listening to others' singing.

Below is an excerpt of an interview with Michael and Laura, which took place at a local café. Laura has dementia, and Michael is Laura's husband and carer.

Q: How do you find this activity? How do you like it?

Michael: Well, everything...the friendship. And Laura always feels better afterwards... the singing... you know.

Laura: I sing well.

Q: Yes, you sing well! I heard you sing at home, too?

Laura: I was in on the radio.

Q: You were on the radio?

Laura: I was.

Michael: Yes. Yes, we sing at home as well.

Laura: I sing very well.

As in the above interview excerpt, Laura, who has dementia, often says, “I sing very well” when someone is talking about music generally. Being able to sing well builds her self-confidence in the moment, and that is how she presents herself during the singing sessions and interview. Regarding her comment, “I was on the radio”, I assume that she was referring to the radio program which featured a SFTB session a few weeks before the interview. As the interview with Laura and Michael proceeded, I asked them about their musical background, and they told me how they both had been active in various music groups and choirs before Laura began exhibiting signs of dementia. In the interview snippet below, we explore these activities further, as well as their involvement with SFTB:

Q: How do you feel after singing? How do you feel when you sing?

Laura: I am not singing.

Michael: How do you feel afterwards?

Laura: I feel fine...

Q: How do you find singing in the group? Is it different than when you sing alone?

Laura: [Starts singing] *Just walking in the rain, get soaking wet...*

Michael: Well, actually, I used to belong to a singing group, a men's singing group, you know. I used to be in the church choir. So I've always sung with other people.

Q: I see... So, it's part of you to sing with people. Has being involved with this activity made any changes in your life?

Michael: What, the singing?

Q: Yes, Singing for the Brain.

Michael: Yeah, it's something to look forward to every Tuesday, you know that you are gonna enjoy it. Yeah. We enjoy it.

Laura: What?

Michael: Singing...

Laura: I love singing, and they told me that I have the best voice.

Q: Yes, and you know all the songs, right?

Laura: Yeah.

As we can see in this second excerpt with Michael and Laura, Laura, the care-receiver, sang during the interview, responding to my question and conversation between Michael and I. She did not answer my question, “How do you find singing in the group? Is it different than when you sing alone?”; instead, she sang the tune “Just walking in the rain”, which is one of the standard songs often sung in the SFTB sessions and seems to be one of her favourite tunes as well (she often sang the tune during the sessions). Later in the interview, as shown above, she answered, prompted by Michael, “I love singing, and they told me that I have the best voice.” Before this

comment, she kept saying “I sing well”; however, she then commented that “they told me...” which possibly means that she was aware of the context of my question. Moreover, her comment on this issue was true because in the SFTB sessions her participation was frequently very spontaneous and energetic as she often even got up and danced with the music by herself and the other session members and volunteers always told her how well she sang during the session.

This interview made me aware that singing or other kinds of music-related activity may help elicit data in the interview. At the same time, it made me realize that the setting and situation are crucial to the interview, especially when one of the interviewees has dementia. In these cases, the setting should be somewhere the interviewee can sing and, equally importantly, should be somewhere the carer feels comfortable about any spontaneous incident (such as spontaneous singing by the care-receiver). After this interview I tried to choose the location of the interview more carefully. Luckily, all the other informants (carers and care-receivers) were happy to conduct the interview in their homes or in the nursing homes where the care-receivers lived.

In other research, music listening has been used as a tool during interviews to elicit information about how music is used, heard and judged by the informants (Allett, 2010; Anderson, 2005), and, similarly, auditory stimuli have been used to evoke autobiographical recall for people with dementia (Foster and Valentine, 2001). These studies, however, used recordings as input and did not engage in interactive singing or any other music-related activities in the interviews.

Based on my experiences when working with people in care situations (Hara, 2007), I was aware that interviewing individuals with dementia can be very challenging, even in a secure environment, with regards to exploring what they ‘really’ think. There are two main reasons that this is the case. First, musical taste is frequently ‘performed’ (*i.e.*, as individuals attempt to present themselves in a certain way) (Hennion, 2007). This is also the case during interviews; often informants do not expose their personal musical preferences, but instead prefer to give ‘correct’ answers, for instance by claiming that they like songs that others (in their peer group) enjoy (Koizumi, 2002) or songs that are regarded as ‘appropriate’ for their generational image (Hara, 2007). This strategy may apply to individuals with dementia as well. Second, communication is particularly difficult overall with individuals in the later stages of dementia because of their limited cognitive abilities.

I therefore decided that music could be a useful research resource in my interviews. Laura often sang spontaneously during the singing sessions and knew the words of the songs very well; therefore, she did not need to refer to songbooks in the interview. However, for other members who were more shy or reserved, I brought the songbook (if appropriate) that they usually sing with to the interview to refer to or sing with if needed. In this way, I sought to explore the meaning of music and music making in their lives *with* the informants, by recreating a situation similar to the SFTB sessions. I sometimes went through the songbook in the interview as we talked about their favourite tunes, and sometimes sang or hummed tunes together. Some carers took

the initiative in singing songs in the book with their care-receivers, which led to a mini-singing session with me as an audience or as an accompanying singer. Using the songbook and singing in the interviews helped me understand the meanings of music and singing for these individuals.

MUSIC AS CREATING THE SOCIAL CONTEXT OF MEMORY

The interview excerpt below comes from the beginning part of an interview with Hannah (a carer) and Simon (a care-receiver). In this case, I used the songbook for the interview. Hannah and Simon had been regular members of SFTB for more than a year and half. The interview took place at their house a few weeks after they decided to stop coming to the SFTB sessions due to Simon's advanced symptoms of Alzheimer's. I showed Hannah and Simon the songbook from SFTB, and put it in the middle of Hannah, Simon and myself.

Q: How did you enjoy the SFTB sessions? How do you like singing?

Simon: I usually enjoy it. The music especially. Sometimes throwing events different organization of things. Relationships, friendships.¹¹

Q: Ahhh....

Hannah: Yes, it does with relationships and friendships. Yes Simon, you are right. It does, we do enjoy going. To begin with, we absolutely loved it because Simon was quite able to... we could dance those silly dances. Couldn't we darling? The *Lambeth Walk*, and then hands, knees and boopsy daisy. We would 'pop' up and do these things very happily. Jessica [the facilitator] had a lot of lovely songs we knew well. You took our book of songs to Jessica, didn't you Simon?

Simon: Yes.

Hannah: Yes. Songs for travellers, Jessica took some of them out for you, because they were your favourite songs and put them in her book.

Q: Really?

Hannah: That was so nice. So we...

Simon: I gave her a book.

Hannah: Yes, we did.

Simon: Lots of pages

Hannah: Yes, we gave her a lot of pages from it, she was very glad to have it, so even when we stop going, people will still be singing your favourite songs.

Q: Which one is that?

Hannah: Lots of them. Lots of them, weren't there Simon? We like "*When Irish eyes are smiling*", [Hannah started singing the beginning], would you like to sing with me darling? Help me?

Simon: [yawns] Don't care too much thanks...

¹¹ Simon's comments were murmured in the truncated sentences throughout the interview.

Hannah: Just a little bit... Mariko and I will sing...you just join in. [Hannah looks up the song in the songbook. Hannah and I begin singing, and Simon joins in in the middle of the song...]

The whole interview was as relaxed as it could be, with Simon lying down on the bed and Hannah and I sitting beside him in their house. As the transcript excerpt above shows, I used music in the interview, mainly singing and referring to tunes from the SFTB session (the songbook was in front of Simon and Hannah, who referred to it occasionally throughout the interview). Although Simon was not as talkative as Hannah during the interview, he sometimes complemented and echoed Hannah's words with shorter words. The songbook I brought with me became a resource for developing the conversation. Having the songbook there reminded Hannah and Simon that they had brought their songbook to Jessica (the facilitator), and gave her "lots of pages" (Simon), which also evoked a nice feeling: even though they were no longer singing with the group, other group members were continuing to sing their favourite songs.

Every time Hannah (and I) sang or hummed the tunes (Hannah and I tried to make it as gentle as possible not to overwhelm Simon but still maintain a lively atmosphere), Simon joined in the singing in the middle of each song. Even though he was not up for singing with us in the beginning, as he told Hannah above, "Don't care too much thanks", he did indeed join in singing once Hannah (and I) started singing the tune from SFTB. DeNora (2000, p. 79) discusses musical entrainment as the use of music to regulate physiological states (*e.g.*, heart rate), behaviour (*e.g.*, blinking, jumping and sleeping) or temporal parameters of moods and feelings. Here, Simon's behaviour was in part musically entrained by our singing despite his initial reluctance. Afterwards, as the quote below shows, he joined in with the singing whenever Hannah (occasionally with me) started singing, without showing any hesitation. I believe it would have been difficult for him to sing without our initiative. Additionally, after singing each song, Hannah reflected upon the particular feelings and memories elicited by the singing. The excerpt below shows one such instance of this:

Hannah: Wanna sing one more? From the book? We've got a book here. [She looks through the song book.] How about that *I'll be your sweetheart*? We all know this...we sang this on Valentine's Day. *I will be your sweetheart*. [Hannah starts singing, Mariko joins in, then Simon joins.]

Hannah: Thank you, I should hold you to that. I don't need to hold you to that Simon, 59 years we have been married.

Hannah and Q: [laughs]

Hannah: Long time.

Q: 59.

Q: Yes. Did you use this song when he proposed?

Hannah: I think that is a Valentine's Day song. I think that's it. [laughs] I can't remember the actual proposal. I can't remember when we suddenly decided to actually get married.

Hannah responded to the lyrics of *I'll be your sweetheart* by saying, "I should hold on to that", and the interview (which was rather more like a conversation) developed further, as they discussed the time they first met during the war, their married life, their children and so on. In fact, although neither Hannah nor Simon mentioned a specific association or memory with this song (*I'll be your sweetheart*), one of the volunteers, Rosie, mentioned a touching moment involving this song during an earlier SFTB singing session:

When Hannah and Simon first started to come, we sang that (*I'll be your sweetheart*) once, and they both looked at one another and they both put their arms around another and Hannah started to cry...and it was so moving for them. Of course you know, she doesn't get much back from Simon. Obviously they have been together a long time; she adores him still but she doesn't get back the same as she gives. Because he can't do that... he is different person than he used to be, you know, now. He follows her around the house and she can't have any time on her own. At that moment, it was really moving...

As described by Rosie above, in an earlier singing session, Hannah and Simon responded directly to the singing of the tune (*I'll be your sweetheart*) by looking at each other, and Hannah was moved to tears. As Rosie notes, their life as a couple has changed due to the onset of Simon's Alzheimer's disease. It seems as if singing this familiar tune may have created an enjoyable moment that reminded them of their previous life and reconnected their relationship as a couple once again. If so, a similar phenomenon may have happened in the previous interview as prompted by the same tune (*I'll be your sweetheart*), which led Hannah to become suddenly eloquent in talking to me about their married life.

After singing these tunes, an intimacy also developed between Hannah, myself and (possibly) with Simon by singing together, which made it easier for Hannah and I to talk about their personal matters: family, the experiences and difficulties of their daily caring life, etc. This way, their intimate stories around music came out more naturally in the interview setting, requiring much less intentional prompting from me. The songbook itself, and SFTB song repertoires collected in the songbook, provided resources for the interview, triggering our singing. Talking about music and singing also provided a comfortable social context for eliciting memories for the informants. We also performed and improvised the interview using the repertoires from SFTB as engines for our activity. In other words, these repertoires were known to the informants and me, and we also shared the common experience of having sung these songs in the SFTB sessions. Therefore, the SFTB repertoires worked as an 'engine' that helped to move the interviews forward and expand their depth. Put otherwise, the musicking forged by using these repertoires during the interview shaped the direction of the interview and supported its flow.

As the interview with Hannah and Simon continued, the topic of conversation turned to their family life, and Hannah began talking about how Simon used to sing 'funny' songs he learned from his students (Simon had been a teacher) which made Hannah and their children laugh:

Hannah: (...) that Devon one. The children used to fall out laughing when he sang in the car about blackbird. Can you remember how that one goes? [Hannah starts singing.]

Simon: [Explains that they sing this song after football matches when changing out of their football gear/outfits].¹²

Hannah: where be..[initiates song]

Simon: [sings accurately, remembering lyrics, Hannah joins.] Where be that blackbird to? I know where 'e be! 'e be in yon wurzel bush, And I be a'ter 'e! And 'e sees I, And I sees 'e, And 'e knows I be a'ter 'e, With a ruddy girt stick, I'll clobber 'e, Blackbird! I'll 'ave 'e!

[laughter]

Hannah: very naughty.

Q: What is this song about?

Hannah: Very naughty song... children fall about...

Simon: [inaudible]

Hannah: ...just about an old farmer using rather poor language about seeing a blackbird up the tree, he's there with a gun, and he is gonna shoot it. [laughs] That's all there is to it [laughs]

Q: [laughs]

Hannah: It is a silly thing. [To Simon] Well you still remember that! Good for you!!

This song they sang was called *Blackbird*, originally sung by a group called the *Wurzels* from Devon where they spent most of their life. In this case, we did not have the lyrics of this song with us in the interview; it was sung spontaneously as the conversation flowed. Afterwards, the interview continued with Hannah and Simon talking about music they liked. They told me they had a wide range of collections of classical music, and that Mozart and Beethoven were Simon's favourites. Both of them also expressed that Simon prefers Chopin's piano pieces at the moment because they are "gentle" (Hannah). At the time I visited them, they were facing the sudden deterioration of Simon's condition. They had stopped joining SFTB, which was their only regular social activity, a few weeks before the interview. Their daily lives had to be changed as well as the music Simon could listen to. However, within this limitation, they continued to enjoy listening to music in everyday life, music that did not overwhelm Simon such as gentle music (Chopin's piano pieces). Hannah also read Simon's favourite poems to him.

Music became a fulcrum of the interview with Hannah and Simon. In the beginning, the interview was initiated by the repertoires and songbook from SFTB, but later the conversation flowed without these explicit devices. Throughout, music was an anchor for the conversation. In this way, I could elicit data about their lives, the time they first met, their married life, their life with their children, their life after retirement and changes in their lives due to Simon's Alzheimer's disease without focusing on these topics too much. Rather, these data were evoked in relation to music,

¹² Simon mumbled intermittently so it was impossible to transcribe his words precisely. Therefore, instead of transcribing precisely, the author paraphrased his words.

sometimes through reflecting on the transformation of their musical life (as music has been deeply embedded in the lives of Simon and Hannah). Seen in this way, music-elicitation is an active and naturalistic way to access deep and musically entrenched memories woven into the fabric of one's life.

MUSIC AS A 'LIFE BUOY' IN INTERVIEWING INDIVIDUALS WITH DEMENTIA

Although it can be difficult to understand or interpret the experiences that individuals with dementia have related to music and musical activities, we cannot simply leave them behind in our research and analysis. I believe that it is not respectful to continue running music activities for this population based on presumptions of the benefits of these activities without attempting to learn more about the experiences of participants with dementia.

Indeed, in my study described here, the interviews with these individuals were always challenging. I tried to listen very carefully to their words, their responses to my questions, as well as their comments in and outside of the interview. I tried not to interpret their words literally, in the context of my own worldview, but rather understand the worlds of my informants and what their responses and words mean in their worlds. As a result, I sometimes became lost in their worlds or in my attempts to understand their worlds, and, as a consequence, occasionally felt that the interviews were taken over by these individuals. As an interviewer, I sometimes feared for my 'objective' independence, and my 'distant' role as a scientist concerned with selecting the right questions and finding out the correct answers. However, rather than fear for the validity of the data being collected I took comfort from the importance of this process of reflection for understanding and correctly analyzing the data being collected.

The communication process with individuals with dementia is necessarily a two-way process (Goldsmith, 1996); so too is the process of interviewing individuals with dementia. As Reid (2001, p. 379) argues, the person seeking to "hear the voice" of the other must be conscious of the normative expectations he or she brings to encounter. When working in the field, my normative expectations (*i.e.*, my presumptions about the levels of possible communication with people as well as the levels and varieties of musical engagement by people with dementia) were continuously challenged. For example, I came to realize rather quickly that I could not just passively 'listen' to my informants with dementia; rather, I had to be proactive in relating to and communicating with these individuals. This process of relating and communicating took different forms in various situations (*e.g.*, 'interviewer', 'ethnographer' or 'volunteer') during the ethnographic study and interviews.

Put simply, music was the agent that enabled me in those various situations to relate to and communicate with my informants. Music took a variety of shapes, including the SFTB repertoires I had already shared with my informants in the singing sessions, our own singing activities, and even just talking about music in their everyday lives

(past and present). Seen together, music worked as a ‘lifebuoy’ of sorts for me in communicating and relating to my informants with dementia, particularly when I felt lost in my attempts to understand their worlds. As I searched for a direction and an entry point to their experiences, music helped to invoke new actions and topics between us, which frequently resulted in redirecting our conversation and interview. Although the informants and I may both be ‘lost at sea’, as it were, the role of music as lifebuoy worked literally to give us ‘something to hold onto’ as we bobbed our way through the currents and changing winds.

CONCLUSION: MIXED METHODS TO EXPLORE MUSIC IN DEMENTIA CARE

In this article, I have discussed my own mixed methods approach to investigate the meaning of music in dementia care: an ethnographic study of the music and care world in Watertown, participant observation in singing sessions, and interviews with the members of the group *Singing for the Brain*. Using a grounded-theory approach to begin analyzing the fieldnotes and interview transcripts, I identified two preliminary themes across the data: relationships (as Simon mentioned in the first interview excerpt above) and support network.

To elaborate further, music seems to become a catalyst that activates the ‘relationships’ between care-receivers and carers, for example, as joining together in song (a song that they have sung together before) reminds both parties of their personal histories together and pre-illness relationship. Although these moments of connection are temporary, they seem to aid carers in maintaining the quality of caring beyond the singing activities by helping them to focus on their relationships before and outside of the dementia. Moreover, the SFTB sessions not only provide a pleasant afternoon of singing, but also many forms of information on other musical and creative activities and events targeted at dementia care, events to support carers, chances to take part in training sessions for volunteers and fundraising events in the music and care world. The SFTB staff also visit the members with dementia and their carers who are no longer able to join in singing sessions (then sharing these updates with current SFTB group members), and facilitate contact with the *Alzheimer’s Society* as needed. In this way, SFTB becomes an important node in a larger ‘support network’ for individuals with dementia and their carers. Given the significant loss of social life and involvement (e.g., community choirs, sports teams) suffered by many care-receivers and their carers, SFTB is frequently the only social involvement where these individuals can meet people who are in the same situation as well as volunteers who provide support in and outside of SFTB. In short, music works as a ‘catalyst’ in strengthening the relationships between carers and care-receivers while, at the same time, the SFTB singing activities also ‘catalyse’ local volunteers (together with the carers) to develop a wider ‘support network’ for local people with dementia and their carers.

It would have been difficult, if not impossible, to isolate these key themes without situating the SFTB sessions in a wider ethnographic study of the Watertown music and care world. By investigating the music and care world as an active agent (cf.

Latour, 2005), I could trace the connections between various groups to explore how various connections in this world are 'activated' to support people with dementia and their carers. The combined research focus on longer-term participation observation also helped me to build mutual trust with carers and care-receivers by learning the favourite songs and activities of each member and, in tandem, details about the condition of their daily lives as well as their past and current musical lives. These deeply individual observations then formed a robust and vital background for each individual interview.

This article has shown that the gap between seeing music as an input, and its effect as a simple output (which is prevalent in the study of music in dementia care), can be filled by mixed methods designed to explore the meaning of music-making in the *everyday lives* of people with dementia and their carers. The preliminary evidence, as discussed here, suggest that music's (nuanced) affect can be investigated by seeing music as a 'catalyst' for building relationships as well as connecting people and various groups. And, equally importantly, music plays a vital role as a 'lifebuoy' in the data collection process by providing a means to access thought and experience related to music activities.

Individuals with dementia become 'alive' again when music allows them to reconnect with others, as well as themselves. The mixed methods discussed here propose one innovative way to capture these essences of music-in-action in dementia care. Further empirical work on this theme should see sociology, music therapy, medicine and neuroscience working together to explore the potential and discrete outcomes of music use in everyday dementia care.

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