

We'll Meet Again:
Music in Dementia Care

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Abstract

The aim of this study was to explore how musicking (a term denoting any music related activity, see Small 1998, p. 9) could be used locally to support people with dementia and their caregivers in a sustainable manner. The data for the study came primarily from a group known as “*Song Birds*”, a community-based volunteer music group working with people with dementia and their caregivers in the south of England.

Participant observation was combined with interviews and an extensive ethnographic study of the music and care world surrounding the group. The data was explored using a grounded theory approach investigating three time phases, “preparation for the events”, “during the events” and “in-between and after the events”. The main findings related to the lay crafting of the events and the emergence of pathways between “music and care nodes” in a local, social network.

The preparatory physical and social crafting of *Song Birds* events created a transitional time and place that guided the participants from everyday life into their collective musicking. This crafting was essential to the success of the musicking and produced inclusive activities that considered the different capabilities of **all** participants. As a result of these carefully crafted events, dementia identities were temporarily displaced and relationships were transformed. The musical repertoire was an important resource in this crafting and evolved according to the participants’ changing situations.

The positive musical benefits and affordances (see DeNora 2000) from such weekly events could be transferred into participants’ everyday lives through multiple music and care groups and the pathways that connected those groups which constituted a “music and care world”. Such musically fostered networks helped generate a virtuous cycle that maintained the music group as a sustainable activity. As dementia care was a long-term

activity, such sustainability was important to the on-going community support for people affected by dementia. Community musicking thus allowed people affected by dementia, their relatives and friends to remain together.

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Chapter 1. Introduction

Responding to the “greying” of industrialized countries and subsequent increased interest in creative therapeutic approaches to cater for individuals with dementia, this thesis explores the use of music in dementia care particularly in local settings.

Specifically I use data I collected from “*Song Birds*” (SB)¹, a local music group for people with dementia and their caregivers in the south west region of the UK. The group is run by a former music teacher and several other volunteers, and is one of the services provided by a UK charity, *Dementia Support Group*². I explore how music can be integrated into everyday life in a sustainable manner in order to improve the lives of people with dementia and their caregivers with attention to the symptoms and progressive nature of the illness. In this chapter, I will discuss the background of the topic, the awakening of my interest in the topic and a brief description of the symptoms of dementia. This will be followed by an outline of the thesis.

1.1 Background: My interest in music in dementia care

My grandmother was involved with the local Catholic Church in Kobe, particularly with its music side, as a church organist and active choir member for about forty years of her life until the relocation due to the Great Hanshin Earthquake³ in 1995. Her life was

¹ Anonymized name

² Anonymized name

³ The Great Hanshin earthquake occurred on Tuesday, January 17, 1995 in the southern part of Hyōgo Prefecture, Japan. It measured 6.8 on the moment magnitude scale. It is estimated that 6,434 people lost their lives; about 4,600 of them were from Kobe.

filled with music but after the relocation to Okayama prefecture (where her husband originally came from) she lost her musical involvements.

During this time, my grandmother developed dementia and it became difficult for the two of them to continue the life they were used to living. They relocated to Kobe again, but this time to a residential care home. They brought my grandmother's small organ to their own room in the care home and often played it there. While my grandmother's cognitive ability declined to the extent that she was no longer able to recognize me and other family members, her ability to play the organ remained. Once family members and I and staff at the residential care home realized that she had retained her musical ability, we started encouraging her to play the organ. She could play the tunes she used to play at church, folk tunes, school songs and several classical pieces perfectly by ear. Although she had difficulty communicating with others, once it came to music she could respond to other people's requests and transpose the key according to the voice range of others if they were singing with her tunes. One time I saw her playing her own arrangement of all these tunes while looking at her own diary. She looked as if she was connecting with her past by playing the tunes that triggered the memory from the past. At this point I realised that musical engagements have the potential to trigger and connect with long-term memories.

I also thought she looked calmer and more concentrated when she was either playing the organ or singing. It seemed music helped to calm the often tense atmosphere between my grandparents caused by my grandmother's ongoing confusion and lack of orientation due to dementia. My grandfather and grandmother also joined the group music sessions in the residential care home, where residents came together and sang familiar tunes from the past with keyboard accompaniment. As the residential care

home was new and few programmes were arranged, I also started facilitating the group music session there as well⁴. Participants seemed to enjoy themselves, though their participation was low key – no large gestures for example. These group music sessions allowed my grandparents to be present with other residents outside meal times. My grandmother sometimes played the organ during or after the music sessions and started to be recognized as a pianist in the care home. Ironically, my grandmother recovered her socio-musical life albeit in a different environment (not church but in the residential care home) because of her dementia.

These private observations and the remembrance of my grandmother made me realize the potential of music-making in dementia care. Her preserved, accurate memories of music (its melody and lyrics) and retained ability to play and sing these tunes most certainly helped her to be social, or rather to be with others in a way not pressurizing but rather pleasant and fun, which was otherwise difficult considering her limited cognitive ability. The cognitive and physical functions of the residents of the care home were varied. However, while singing and participating in the music session, these differences were invisible and everyone seemed to be drawn together. Music seemed to help to lessen boundaries between people with different cognitive/physical abilities.

⁴ I continued working as a music facilitator in the same residential care home as well as in the local day care centre in Japan until 2008 when I started my PhD at Exeter University. These practical experiences led me to conduct ethnographic research on the musical orientations of older people in Japan, to investigate music in the everyday lives of older people, and in particular to examine group music sessions in day care centres or residential care homes (Hara 2007).

These two points convinced me that music use in dementia care especially in its social aspect was worth pursuing further.

1.2 Dementia as a major global issue in the 21st century

First of all, what is dementia? How does it affect people? According to a WHO Report (2012, p.7), Dementia is "a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement", and Alzheimer's disease is the most common form of dementia and possibly contributes to 60–70% of cases.

Generally, the symptoms of dementia are classified into two categories (Sturdy et al. 2012):

- Behavioural symptoms: agitation, aggression, wandering, sleep disturbance, inappropriate eating behaviour and inappropriate sexual behaviour.
- Psychiatric/psychological symptoms: depression, apathy, anxiety, delusions, hallucinations, paranoid ideas, reduplications and misidentifications.

The combinations and levels of these symptoms vary according to the person as well as the stage of dementia (Hughes et al. 2006). According to Hardman (2009), the first sign of dementia is usually short-term memory loss: difficulties in remembering words and people's names. People may start having difficulties with everyday tasks such as driving and cooking. Familiar surroundings start to become unfamiliar, which make people frustrated and unfocused. This can also lead to people wandering off from their homes to search for things that are familiar to them. Because of the short-term memory loss, people may have to stop engaging in the cultural and sports activities they used to participate in and tend to withdraw from others, which leads to isolation of themselves

and their partners from the community. As dementia progresses, people gradually lose the abilities required to take care of themselves: eating, taking showers and dressing. They may also suffer from sleep disturbance, hallucination and delusions. Their confusion and difficulties in identifying familiar surroundings progress and additional psychological symptoms become more articulated: depressions, anxiety, agitation, paranoia, and aggression. Some of these symptoms depending on the person can also cause personality changes, turning normally happy, peaceful people into angry, hostile ones, unable to control their emotions (Hardman 2009; Hughes et al. 2006). At the late stage of dementia, people usually become totally dependent on others for their everyday life care. People may be confined to bed, unable to control urination, incapable of swallowing, and lose their abilities to communicate (Hardman 2009; Mace & Rabins 2006).

The latest WHO report (2012) has described the massive rise in dementia and appealed for the need for greater public awareness and better support programmes in all countries. Dementia is found not only in rich countries, where it has become a major public health issue, but also in poor and middle-income countries. The projections suggest continued growth as populations will be ageing rapidly in the coming decades⁵:

The total number of people with dementia worldwide in 2010 is estimated at 35.6 million and is projected nearly to double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. The total number of new cases of dementia each year worldwide is nearly 7.7 million, implying one new case every four seconds (World Health Organization & Alzheimer's Disease International 2012, p.2).

⁵ In the United Kingdom alone, with the massive increase over 40 years it is also 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 (Luengo-Fernandez et al. 2010).

Anti-psychotic drugs have been used to manage the agitated behaviour especially when there is a risk of harming self or others. However, Banerjee (2009) warns that these antipsychotic drugs appear to have only a limited positive effect in treating these symptoms, and can instead cause significant harm to people with dementia. According to Banerjee (2009, p.5), “among the 180,000 people with dementia treated with antipsychotic medication across the country each year, negative effects directly attributable to the use of antipsychotic medication at this level could equate to an additional 1800 deaths and an additional 1620 cerebrovascular adverse events, around half of which may be severe, per year”. Because of these situations, there is an urgent need to develop non-pharmacological methods in order to treat the behavioural and psychological symptoms of dementia as an alternative to this antipsychotic medication (Banerjee 2009; Sturdy et al. 2012).

A number of activities and therapies have been deployed as useful means to manage such symptoms, enhance moods and also to improve the quality of life of people with dementia albeit within the limitations imposed by dementia. It is therefore useful to discuss these activities and therapies briefly. For instance, reminiscence therapy is a group oriented activity where people are encouraged to discuss their past experiences or events using photos and music (Woods et al. 1996) while life review therapy is usually conducted on a one-to-one basis to encourage evaluating memories and past events (Haight et al. 2003). These are both aimed at enhancing moods and cognitive and behavioural functioning. Social and diversional activities are often implemented in residential care homes and day care centres in order to encourage interaction and enjoyment such as physical exercise sessions, quizzes, sing-alongs, bingo and cooking (Pulsford 1997). Among such activities and therapy, music is often recognized as a low-cost, simple tool with minimal risk to people who are cared for (Witzke et al. 2008).

In fact music has been used in a variety of contexts in dementia care ranging from informal sing-alongs (Pulsford 1997), structured group singing activities (Bannan & Montgomery-Smith 2008; Bungay et al. 2010), reminiscence therapy where music acts as an aid (Woods et al. 1996) to individual music therapy sessions (Clair 2008). Singing and background music have also been used as useful aids to enhance quality of caring (Dennis 2011; Götell 2003; Götell et al. 2009). I will discuss these in detail in the following chapter.

1.3 Outline of the thesis

Combining my interests based on personal experiences as described earlier and the urgent need to develop non-pharmacological methods in dementia care, responding to the increasing number of people suffering from dementia worldwide, I was particularly interested in investigating the use of music in dementia care in local settings. This form of care aims to support people with dementia who are cared for by their own family members at home and their family caregivers. A key focus for this was to explore how music can be integrated and adapted to the everyday lives of people affected by dementia including caregivers and their friends, in ways that support them in a sustainable manner. It is important to stress that the findings are specific to the UK context although I believe that the emergent themes can also contribute to increasing understanding on the local use of music in different contexts. The emergence of the research question will be further discussed in the following chapter while reviewing the literature.

My thesis consists of 10 chapters. The following chapter reviews the studies related to local music use in dementia care while identifying any problematic issues in this field. I will discuss the methods of my inquiry in chapter 3. The field site chosen for the project

is a community music activity for people with dementia and their caregivers called “*Song Birds*” (SB), which will be described in chapter 3 as well. The findings of this detailed research will be discussed from chapter 4 to chapter 8, where I take the reader through a SB session, focussing on three temporal phases of the event – before, during and after. Chapter 4 describes the material and social crafting of the weekly SB sessions *before* the musical events start. In chapter 5, the musical crafting and the process of collaborative aesthetic crafting *during* the musical events is the topic of examination. Linked to this focus, I discuss the repertoire of the musical events in chapter 6. In an interlude (chapter 7), I describe the humour and joyfulness of the musical events and this leads into Chapter 8 where I discuss the development of musical benefits and affordances *in-between and after* the events, thus highlighting the integration of SB into participants’ everyday life. Chapter 9 situates SB in the context of the wider community and shows how SB musically fosters the pathways between various groups by functioning as a “safe” node allowing local people with dementia and their caregivers to move from one node to another. My conclusion in chapter 10 will summarize key issues in this extensive field of music and dementia.

Chapter 2. Literature Review

This chapter will summarize the core issues and research related to the local use of music in dementia care. I will start by examining the literature on dementia care with a focus on its community support which is most relevant to this thesis. This will be followed by a review of sociological research on music and health that addresses the use of music as an active health resource of social life. As the chosen field site uses collective singing as its primary vehicle, I will also discuss recent research on collective musicking, collective singing as a means for health and the social significance of musicking. Lastly, the literature on the use of music in dementia care will be reviewed; here there is a cause for concern as I will show. Following this, I will consider the issues that have emerged in the use of music in dementia care.

2.1 Dementia care

2.1.1 Care giving and dementia care

Despite the often difficult symptoms that were described in the previous chapter, a number of dementia care theories and related literature suggest that it is possible for people with dementia to live *well* and with dignity, given appropriate care and support from care-givers (both family and professional). For instance, the World Health Organization & Alzheimer's Disease International recommend the following in order to support physical and mental functioning and the wellbeing of people with dementia for as long as possible: "1) social engagement and recreational activities, 2) cognitive stimulation and rehabilitation where appropriate, 3) physiological support, including the identification and management of co-morbid symptoms such as pain and delirium, 4) environments that are both safe and stimulating and 5) recognition of behavioural and

psychological change and potential causes” (2012, p.53). Obviously, the symptoms of dementia cause distress not only to the person with dementia and but also to their care-givers, who are in most cases their family members and friends. In fact, the peculiar symptoms of dementia are the main factors which increase the caregivers’ burden (Hirono et al. 1998) and cause significant strain through the emotional and physical pressures that those who provide most of the care experience.

The distressing features of dementia have been discussed in the scholarly and professional literature. For instance, Sweeting & Gilhooly (1997) described how “social death”⁶ may occur before biological death among elderly people with dementia. Their exploratory study examined the caregiving relatives of people with dementia. They observe that care giving relatives think of the death of their family members with dementia as “a blessing”, perceiving them as “already dead”. The authors suggest that this way of perceiving people with dementia may provide a kind of coping strategy, allowing caregivers to detach emotionally and thus decreasing the probability of “burn out” (Sweeting & Gilhooly 1997) especially since dementia caring is often a long-term activity which can last up to about 10 years (Alzheimer’s Society 2011; Stibich 2008). Thus there is a time gap between social and biological death and the process of

⁶ Sweeting and Gilhooly (1997) referred to two definitions of “social death”. One of them was by Sudnow (1967, p.74) who discussed social death as a “point at which socially relevant attributes of the patient begin permanently to cease to be operative as conditions for treating him, and when he is essentially regarded as already dead”. The other is by Kastenbaum (1969, p.15; 1977, p.31): “a situation in which there is absence of those behaviours which we would expect to be directed towards a living person and the presence of behaviours we would expect when dealing with a deceased or non-existent person”. I will use the latter definition as it highlights the loss of connections between a person with dementia and others due to the absence of expected behaviour (or responses) of a person with dementia.

caregivers' emotional agonies and distress during these years are often referred to as the "long goodbye" (Harrison 2010), "the never ending funeral" or "a slow unravelling of the self"(Beard et al. 2007, p.227).

The experience of caregiving is also affected by the negative public perceptions of dementia. IMPACT (Important Perspectives on Alzheimer's Care and Treatment),⁷ for example, found that Alzheimer's disease was ranked second of 10 diseases that people would be most fearful of developing in the future. The stigma associated with dementia leads to delay in diagnoses as people are afraid to learn that they or a loved one have the disease (Vernooij - Dassen et al. 2005). Such stigma and discrimination can extend to family caregivers: individuals may regard the symptoms of people with dementia as evidence of neglect and may attempt to avoid social interactions with people with dementia and their family members (World Health Organization & Alzheimer's Disease International 2012).

In order to help support family caregivers and enable them to continue their caregiving roles as long as possible, sustainable support is indispensable both for people with dementia and their caregivers. A number of studies and practical guides provide information about dementia and give actual instructions for family members in caring for people with dementia (Mace & Rabins 2006) as well as for the professionals in supporting family members (Doka 2010)⁸. Support in the UK includes information to

⁷ <http://www.alz.co.uk/impact-study>

⁸ Doka (2010), for instance, emphasizes the importance of assisting family members to cope with their loss both prior and following the death of the person with dementia, and suggests the following strategies; 1) providing information about dementia, 2) helping them with their emotional issues related to loss, 3) helping them to recognize and respond to changes and 4) preparing them for the future.

aid understanding, skills to assist in caring, respite care for caregivers, financial support, various therapeutic activities and care services (Age UK 2012; Alzheimer's Society 2011; World Health Organization & Alzheimer's Disease International 2012). Two major charities in the UK working with people with dementia and their caregivers provide very detailed information about available services and useful information on dementia care. Local branches of these charities provide hands-on support for local people with dementia and their caregivers. They also raise public awareness of dementia through events and the media to improve understanding and decrease stigmatizing so as to help reduce the barriers to accessing and using services (Age UK 2012; Alzheimer's Society 2012).

One problem is that those services are not distributed equally. In fact, the frequency and availability of the therapeutic activities given to people with dementia in residential care institutions often depend on the values and beliefs among staff members; do they for instance value providing therapeutic activities for people with dementia (Pulsford 1997)? Similarly, available therapeutic services in the community also sometimes rely on the interests and values of local geriatric psychiatrists⁹. Considering all the symptoms of dementia, briefly described in the previous chapter, and the “convenience” of consolidating dementia care, especially in institutions where resources may be limited, quality of care can easily be spoiled with the possibilities of infantilization, neglect or downright abuse of people with dementia (BBC News 2011; BBC News 2012b; Mirror News 2012). Thus, values and attitudes of care-givers and professionals (e.g., what they value and how they regard people with dementia) matter with regard to the availability

⁹ Personal communication with Hemsley Svetlana, a local geriatrist in Oxford, UK after her talk on dementia (Hemsley 2012).

of therapeutic services as well as in terms of maintaining the quality of care. A response to these problems has been articulated by Kitwood who argues that caring for many people in a care home in the interests of “efficiency” spoils the dignity of the person. By contrast, Kitwood has proposed a “person-centred” approach (1997; 2012) that has influenced recent dementia care perspectives and debates, and merits a closer investigation.

2.1.2 Humanization of dementia in dementia care

“Person-Centred Care” is a moral philosophy of care developed by Tom Kitwood. This aims to ensure the respect and maintenance of each “personhood” (each person's individuality) as core to the design of care for people with dementia. It also suggests that psychosocial factors play an important role in maintaining quality of life of people with dementia (Kitwood 1997). According to Kitwood (1997), what is contrasted with this person-centre care is “malignant” (1997, p.46) social psychology as it generates a social environment which diminishes the “personhood” of those people experiencing the environment. He also points out the strong tendency to excluding people with dementia, partly because of the influence of ageism. One of the causes of the dehumanization of people with dementia is a defensive reaction; a response to anxieties held in part at an unconscious level; being with people with dementia may give us some terrifying anticipation of how we might become (Kitwood 1997). These views are echoed by several informants as I will discuss more in detail in chapter eight. Deguchi (2011) also points out that a strong feeling of avoidance towards dementia among the public, so called “dementia phobia”, may also come from “competency supremacy”, a term that refers to our tendency to judge individuals based on their skills in relation to tasks. The principal solution for this dehumanization of people with dementia is not about

changing people with dementia or managing their behaviour, instead it is about “moving beyond our own anxieties and defences, so that true meeting can occur, and life-giving relationships can grow” (Kitwood 2012, p.90). Therefore, it is important to work with the lived experience of people with dementia that emphasised communication and relationships as a way of combating such dehumanization (Brooker 2006).

The importance of this sea-change has been succinctly summarized by Brooker (2006) as below:

Person-centred care was part of a wider movement during the last decades of the 20th century that recognised that people with dementia could benefit from psychological approaches, that they had human rights and that they posed a challenge to dehumanising care practice which had not been seen previously. Person-centred care has come to encompass all these elements in a short-hand phrase for what is now considered to be good quality care for people with dementia (p.15).

This philosophy of person-centred care has been influential ever since, having been applied in the practices of dementia care worldwide (Beard et al. 2007; Bradford Dementia Group 2001; Brooker 2006; Hayes & Povey 2011; Kotai-Ewers 2000; Morley et al. 2010; Sturdy et al. 2012). For instance, in the leading nursing magazine in the UK, “Nursing Standard”, Sturdy et al (2012) discuss how good practices by nurses, care home staff and multi-professional teams in care homes are vital, and highlights that “getting to know clients through biographical/life story approaches and person-centred assessment is fundamental to good care and can offer clues to the person's behaviours, motivations and priorities” (2012, p.6). Person-centred care is also increasingly applied around the world particularly in the rapidly ageing countries (World Health Organization & Alzheimer’s Disease International 2012). Additionally, Sabat (1994) points out that the victim-oriented perspectives on people bring negative influences on the social

environment around people with dementia. For example, negative stereotypes can motivate people with dementia to withdraw from various social situations, which leads to the increase of their isolation and their dependence upon family and formal caregivers (Scholl & Sabat 2008). Thus it is important to free people with dementia from the threat of such stereotypes by calling attention to the person's valued intact attributes and helping them to restore their feeling of self-worth (Scholl & Sabat 2008), which echoes the idea of person-centred care. Similarly, Beard et al (2007) criticizes the normative victimization of people with dementia and their relatives, which views them as objects of illness or victims of dreaded disease. Instead, using the data gathered from surveys with people with dementia, they discuss how people with dementia and their caregivers are actively managing dementia in their everyday lives by implementing coping strategies and personal adaptations, engaging in concrete activities (e.g., jigsaw puzzles, reading poetry, exercises and listening to music), environmental adaptation, re-evaluating self-expectations and avoiding troublesome situations. Through the study, Beard et al (2007, p.234) emphasizes the need for "additional reframing of dementia or reframing to incorporate an empowered identity" to challenge normative victimization and the social disadvantage of the biomedical reductionism of dementia.

The biomedical reductionism of dementia, which indeed only focuses on the "deficit" and "loss" of identity, memory and even self, is also criticized by Iguchi (2007) as "one-directional and static". Thus professionals who give care and support to people with dementia may need to free themselves from such static perspectives. A necessary ingredient in this is communication and relationship, as Kitwood (1997) originally emphasized, by involving people with dementia in the caring process. This needs to take into consideration the view that dementia is also a social process and that people with dementia are participants in this process rather than mere objects of illness (Beard et al.

2007). This process around dementia can also lead to a “social death” that occurs a long time before their biological death, “a situation in which there is an absence of behaviours we would expect to be directed toward a living person, and the presence of behaviours we would expect when dealing with a deceased or non-existent person ” as Kastenbaum put it (1969, p.15; 1977, p.31). Therefore, listening and becoming involved in subjective experiences of people with dementia and their family helps to highlight the multifaceted experiences around dementia (Iguchi 2007; Reid et al. 2001) as people with dementia and their caregivers often have unique insights into their own condition and life (Iguchi 2007; Latour 2005; World Health Organization & Alzheimer’s Disease International 2012). Their voices can obviously contribute to reframing the view of dementia and thus challenges the static biomedical reductionism of dementia, as Beard et al (2007) argues, for instance by being involved in formulating the actual policies, plans, laws and services that relate to them (World Health Organization & Alzheimer’s Disease International 2012).

A recent Japanese study on dementia care provides further insight into the need to craft suitable social environments for dementia care, which also contributes to further advances in person-centred and humanizing dementia movements as discussed above. Nishikawa (2007) discusses how dementia caring can rely on the dynamics of various relationships and networks, considering the common environments of dementia care settings where a number of people with dementia co-exist with the support of professionals. Nishikawa (2007) explains how care that emerges accidentally from the dynamics of relationships can transform the social environment of dementia caring. He uses an example from his clinical practice involving a person with dementia whose mood was transformed through the dynamics of a social environment, in this case on-going interaction in a dining room:

It is not that someone gave special care to her. Instead small pieces of care – fragmented greetings from me, staff, family, other residents, and the dining room filled with the nice smell of dinner, cutlery shining softly reflecting the light on tables, soft chairs relaxing the tensions of legs, were gradually assembled together around her and somehow calmed her. There was no need of skillful persuasion or performance (2007, pp.123–124)¹⁰.

Nishikawa (2007) emphasizes the importance of respecting such moments of assembled care and refers to it as “patching care”, because it is a patchwork of subtle interplays, relationships and networks, which repositions the person and thus has the potential to transform both the situation and the condition. According to Nishikawa (2007), the intensity of one-to-one caring is avoided; furthermore, the boundaries between those who are giving care and the one who is receiving care are blurred in the environment where “patching care” occurs. This work reminds us of the potential for developing alternative caring by collaborating with others (other staff members, professionals, members with dementia and their family members) to craft a social environment that leads to improved dementia caring. What follows touches on the issue of how community support is indispensable in maintaining a certain quality of life for people with dementia and their caregivers.

2.1.3 Community support

Because dementia and dementia care can stretch to more than ten years, the long-term care starts as soon as dementia is diagnosed and continues through the end stages of dementia, which also includes the bereavement care for caregivers as the bereavement process may start earlier due to the nature of dementia as discussed earlier (World Health Organization & Alzheimer’s Disease International 2012; Doka 2010). The

¹⁰ My translation.

increasing numbers of people suffering from dementia obviously raises the number of people who are cared for by their family members at home. Therefore, community service is central in maintaining quality of life of people with dementia and their caregivers living in the community, at the same time helping the smooth transition towards the end of life care, whether this is through a residential care home or a continued care at home. This suggests that such support functions should benefit people living in the community according to their needs as much as possible. Another important community service for people living in the community is a respite type of care, which gives a short term break for family care-givers while a person with dementia is taken care of by temporary care-givers or stays in institutions for a short time. The respite care is recognized as an important care service to maintain the well-being of care-givers (Abramson 2009; Caserta et al. 1987).

One issue is whether such community support and services reach people's needs. Allocation of such community support and services may become challenging as such people (who are cared for at home) can be scattered in the community unlike people with dementia who are residing in care homes or hospitals. In fact, there seems to be a barrier in accessing those services for people with dementia and their caregivers. For instance, Brodaty (2005) discusses how many caregivers did not use support services although caregivers of people with dementia felt significantly distressed and they require a variety of services. One of the major reasons of the barrier is the lack of awareness among physicians about available services, perceived needs and delays in referring for community services (Brodaty et al. 2005; Bruce & Paterson 2000; Fortinsky 1998). Therefore, better links and networks between physicians and available community services (=care pathways) in the community are indispensable to cater for as many people as possible. The importance of these community networks is stressed by

Sawanobori (2012), who suggests that only people nearby can help when needed, in order not to isolate people with dementia. He also emphasizes the importance of strong networks between professionals (e.g. medicine and care), and suggests that such strong local networks allow people with dementia and their caregivers to keep on living in the local community not as “patients” or “service users” but as “citizens” (Sawanobori 2012). This view is reinforced by Kurita (2012), who similarly states that people with dementia can continue to live in the same community if they remain part of the active network and have access to support from people in the community. Kurita further explains that “such community does not merely mean geographical or special space, but the world that people created by assembling the wisdom to survive. The world keeps evolving with the wisdom of people”¹¹ (Kurita 2012, p.11).

If we perceive of community not as a static but an evolving entity based on people’s efforts and initiatives as Kurita claims, community support can also be seen as a form of continual care that emerges from the active networks of people’s initiatives and knowledge, and not a combination of time-limited and isolated services. Therefore, what is necessary for sustainable actions to support people with dementia and their caregivers in the community from their diagnosis to the bereavement is an active, evolving network of people (e.g. professionals, volunteers, friends and family) and their knowledge of the local community. A focus on assemblages of care, knowledge and networks resonates with the idea of patchwork care discussed earlier. I will therefore focus my investigations on forms of sustainable care within the network and I will explore how the dynamics of care can transform “conditions”. This will in turn lead to a

¹¹ My translation.

focus on music in this context and help to define the particular perspective I take on music for dementia care.

2.2 Sociological approaches to music and health

The key concern of my thesis is to explore how music can be used in everyday care situations to support people with dementia in the community. In what follows, I will review how research that focuses on music and health has developed over the years and the current state of the field. This will be followed by a more specific discussion on collective music making, a key perspective linked to my fieldwork.

Small (1998) highlighted music as an inherently social process, and suggested a very interesting concept “musicking” that focuses on the processes of people participating with musical performances in various ways in music studies:

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 (1998, p.9).

The idea of musicking is crucial as it encompasses music’s broad social dimension. It is also important as it suspends any exclusive aesthetic judgements of the art work that arise solely from musical texts and gives equal value to various form of participation in musical performances (e.g. selling tickets, rehearsing, carrying instruments) (Nakamura 2011). Such an ecological model of music related activities highlights how music(king) is “*never alone, never abstract*” (Ansdell 2010, p.168) but part of a social ecology. By this, I mean musicking is not isolated from the layers of relationships and phenomena that interact and influence each other in social situations. This also resonates with the earlier music related sociology work by Becker (1992) which highlighted the social processes that occur behind the scenes of an art work’s production. At the same time,

the concept of “musicking” leaves room for a broader range of musical engagement in everyday life, which includes any possible form of “taking part” in musical activity, for example, humming songs while walking or dancing with someone when sitting down. I will return to this point in chapter five.

Music can also be a self-care/health resource in everyday life. Recent studies in psychology and sociology have focused on the use of music to manage emotions and corporeal states. For instance, Sloboda & O'Neill (2001) conducted psychological experiments to discover how music listening affects emotional states of the self, and how people consciously manage their emotions by listening to particular music pieces. Bull (2000; 2007) also discusses individuals' use of personal stereos/MP3 players as a strategy to maintain their own space in a busy urban life. Using ethnography and in-depth interviews, DeNora (2000) explores the use of music in detail, particularly how people use music in their everyday life as a “technology of the self”. When discussing music as a technology of the self, DeNora refers to the use of music for the self-regulation of emotions and corporeal states:

(...) music is an accomplice in attaining, enhancing and maintaining desired states of feeling and bodily energy (such as relaxation); it is a vehicle they use to move out of dispreferred states (such as stress or fatigue). It is a resource for modulating and structuring the parameters of aesthetic agency (2000, p.53).

This concept (technology of the self) covers the use of music from the obvious to the subtle, unconscious level to manage all sorts of actions in everyday life. It ranges from the music used as a prosthetic technology that enhances bodily movements (e.g. aerobics class) through the deliberate choice of background music to produce an intimate atmosphere, to the use of music in presenting desired roles to others (DeNora 2000).

Another important development in our understanding of music in relation to its situated environment is the concept of “affordances” in music research. The concept of “affordance” was introduced by the psychologist Gibson (1977). He defined affordances as all "action possibilities" that are latent in the environment, objectively measurable and independent of the individual's ability to recognize them, but always in relation to the actor and therefore dependent on their capabilities. DeNora has developed this concept further in relation to music and care of the self, and emphasized the discursiveness of musical affordance and its dependency on the process of appropriation (2000; 2003):

Music’s role as a resource for configuring emotional and embodied agency is not one that can be predetermined (because it is a resource that must be appropriated by music consumers). Music is not an objective ‘force’ or a ‘stimulus’, but it is real in its effects and its specific properties provide mechanisms for achieving those effects (DeNora 2000, p.107).

In this way music can lend itself to various effects, depending on how it is coupled with other objects, practices, people, and interpretations; music is, in other words, a resource, which may then produce a sense of wellness as discussed by Batt-Rawden (2007). For instance, the combination of a song with a particular location may afford people who suffer from memory issues strong reminiscences and a sense of coherency where actors can regain a sense of control.

These studies and sociological concepts highlight music as an ecological phenomenon that actors themselves “latch on to” (DeNora 2000, p.85-7) in relation to other resources (Bergh 2010; Hagen 2012). These perspectives also open up further possibilities to investigate how people use music in everyday situations and not only when they participate in formal concerts or listen to music, but also in more personal settings. Patterns of latching on to music should not be presumed by the researchers as Hennion (2001) has pointed out; rather they need to be observed and described at their level of

operation. This is once again where ethnographic studies are useful in order to follow actors in and out of various situations where they draw music into their social practices (Martin 2006).

To that end, as I will describe in the chapters that follow, I employ the musical affordance concept and the concept of the “musical event” (DeNora 2003) in order to closely examine how actors use music in relation to a variety of other materials, practices and people. According to DeNora (2003, pp.49–50), the musical event looks at a specific act of engagement with music based on three time phases; “before the event”, “during the event” and “after the event”. Important factors to consider “before the event” are the preconditions of the musical events, conventions and biographical association. “During the event” includes five components; 1) actor(s), 2) music, 3) acts of engagement with the music, 4) local conditions of point 3, and 5) the environment. The outcome is examined in terms of what happens “after the event”; how or if any changes are recognized and what the engagement with the music afforded. Thus, the musical event model facilitates the exploration of music as it comes to be meaningful to the actors who engage with it and as music is linked to other things (e.g., preconditions, actors’ own engagement, local condition and environment) (DeNora 2003).

So far, I have reviewed recent musical studies and concepts as well as methodological models that are useful when doing a close examination of how music is used by actors in everyday life. These developments are utilized and further developed in current studies and practices on the use of music for health promotion.

Before I look at this in detail it will be useful to achieve some terminological clarifications, in particular the meaning of the term “health”. The common sense understanding of health is often binary; one is either healthy or ill, thus health is seen

simply as the absence of disease or illness. However, recent studies in music and health adopt a broader view of health (Batt-Rawden 2007; DeNora 2007; Skånland 2012). A very useful perspective to support this view of health is developed by Antonovsky (1987), who suggests that we view disease and health as a continuum of “health/dis-ease” rather than seeing them as separated states. This perspective includes the “Sense of Coherence” framework (Antonovsky 1987, p.19), which consists of three components; comprehensibility, manageability, and meaningfulness. Experiencing such senses of coherence is a key to cope with challenges in life which in turn enables people to maintain their health. With such perspectives, therefore, people can make use of their own and available resources within the environment to regain a sense of coherence. This leads them towards the healthy state in the continuum, albeit with any limitations imposed by disability and illness (e.g., dementia). This view of health as relational, as emerging from environmental affordances and relations, resonates with recent developments in disability studies such as Freund’s (2001) perspective on the importance of well-crafted social-spatial environments as mediators of the bodily experience of disability.

Music has also been discussed as a mediator, a useful resource for regaining the sense of coherence and for promoting the maintenance of one’s own health. For instance, when further developing the concept music as technology of self, DeNora (2007) discusses music as a structuring resource for self-care, self-stability, something that affects how one perceives one’s own health. Ruud (2008) further highlights music as an everyday technology of health, by suggesting that music activities can manage and/or prevent discomforts, such as asthma, depression and sadness, and provide comfort. These perspectives are useful in my study as they shift the focus from the role of music as a “cure” or a “treatment” of a disease to more social and discursive roles in health

promotion. I will address this further when I review the literature on the use of music in dementia care later.

In the field of music and health, there are three studies that have applied these concepts when investigating the use of music in everyday life. First, Batt-Rawden (2005; 2007; 2008) conducted a study using a participatory design of “mix CDs” with people who had long-term illnesses. In her work, Batt-Rawden helped participants learn about how to use music for self-care, self-construction and self-monitoring, and how to activate these functions through listening to the custom designed CDs in their everyday life. Similarly, second, Skanland (2012) researched the use of MP3-players in everyday life as a technology of health among adults; here MP3-players became a means for regulating affection and managing stress among her informants. Third, I have also discussed how elderly informants were aware of music’s effects on regulating their emotions, in other words, music as a technology of self by using music consciously in their everyday life through their own music devices (radio, tape/CD/record players) (Hara 2007). These elderly informants were also aware of the use of different music in public and private places in order to act/perform the appropriate elderly person’s roles, which was an important surviving skill in the social life in the nursing home. As Batt-Rawden & DeNora (2005) discuss, such mundane musicking, in other words, “lay” therapeutic practices are incorporated in other tasks in everyday life. This to some extent challenges the music therapy orthodoxy as it emphasizes a high degree of professionalism and it is oriented towards pre-set goals in a situation where music is used for health purposes.

All these concepts, methodological models and lay therapeutic studies are important tools in my thesis because they bring new perspectives to the literature on the use of music in dementia care. The prevalent perspective in music and dementia care regards

music as a temporal stimulus that can be isolated from its context, thus music is seen as functional tools to care for people with dementia simply because certain parts of the brain can still respond to sound stimuli/music (Miller et al. 2000; Panksepp & Bernatzky 2002). However, the sociological approaches to music and health reviewed here can shed some light on additional aspects of the use of music in dementia care as I will discuss in detail in my findings. The literature discussed above suggests to me that music works for people with dementia not simply because music is a stimulus to particular parts of the brain, but rather that any remaining functionality of their brain is a part of the multiple resources (which in my research also includes music) that are assembled with and without the help of a third person. As a result, music can lend itself to various effects and affects in dementia care: regulating emotions, enhancing memory retrieval, regaining one's confidence and/or enabling bodily capacity. This aspect of music use in dementia care will be explored in chapter five.

The concepts reviewed above, "music as a technology of self" and "musical affordance", also help us to highlight how people with dementia are active actors who latch on to music in relation to other resources by themselves, rather than being passive and/or captive clients who are the target of musical interventions and as a result show "effects" that are measured based on a pre-given hypothesis.

2.3 Permeability between musical events and everyday health musicking

This increased focus on how people use music in everyday situations has also stimulated a development in the practical field of music and health: how aesthetic experiences in organised musical events can permeate into people's everyday lives.

For instance, in her discussion of her community music therapy practice in South Africa, Pavlicevic (2004, p.42) suggests that music therapists cannot separate the "outside" and

the "inside" (of music therapy practice) as distinct spaces, thus cannot close door to everyday life. She argues that "life and therapy work are inseparable, in the special, temporal or mental state" (Pavlicevic, 2004, p. 42). Stige (2012) divides the rituals of musicking developed for mobilization of health resources into two categories. One is "interaction rituals" (Collins 2004 in Stige 2012) where shared mood is established and emotional transforming occurs through collaborative music making. The other is "individualized rituals" in which people listen to music through portable personal stereo to manage the challenges of people's everyday lives. Stige (2012) then emphasizes avoiding the polarization of these rituals by viewing them as isolated events. Instead we should seek to explore them as elements in broader ecologies.

Several studies have touched on ecological aspects of organized musical events (e.g. music therapy sessions and music activities) by situating them in broader ecologies in the context of everyday life. Swallow (1987) has discussed the carry-over effects of group-oriented music therapy for people with Parkinson's disease; the improvements in patients' movement last only about 24 hours. However, he points out the possibilities of prolonging the effect by consciously reminding people of the musical associations (Swallow 1987). Similarly, Aasgaard discussed how pleasurable moments of song activities in paediatric oncology settings can be prolonged with their potential for "providing good memories and creating pleasurable expectations" (2002, p.203). Thus, music activities allow participants to add "colour" to their present lives by keeping their creativity or imagination alive in between the music activities (Aasgaard 2002). Thus the regularity of music activities is beneficial in terms of providing a regular framework (Hara 2011a). This point is echoed by two studies. Stige (2012) also emphasizes the importance of repeated music making "in order to renew the emotional bonds that musicking can create" (2012, p.191) because the emotional energy and sense of

community generated in collaborative music making lasts for some time, but gradually vanishes. Similarly Bergh (2010) also argues the importance of regularity of music workshops for conflict transformation in order to be embedded in participants' everyday lives.

Additionally, there are studies that have explored the link between collaborative musical events and everyday health musicking from the opposite direction. For instance, as mentioned earlier Batt-Rawden (2005; 2007; 2008) taught the participants about music's potential use in self-care, self-construction and self-monitoring, and how to activate these functions of music through listening to the participatory designed CD in their everyday life. At the end of the study, Batt-Rawden (2007) invited her informants to a socio-cultural event where people casually talked and introduced songs they had chosen for their own participatory design CDs with friendly and welcoming surroundings. There, the informants formed an informal network with the potential to lead on into further musical pathways. Meanwhile, using in-depth interview research with elderly people who live in residential care homes, I have pointed out the importance of learning about the everyday lay musical practices of the participants when facilitating a communal music activity (Hara 2007). Such studies on linking and exploring the relation between everyday health musicking and collective musicking occasions (Batt-Rawden 2007; Hara 2007) lead us to realise the importance of understanding varieties of musicking that are in seemingly different arenas as part of a coherent ecology. Such investigating into the "lay craft" of everyday health musicking can also bring new insights into the organized musical events as discussed by DeNora (2007):

By considering the often hidden lay-therapeutic functions music serves in everyday life, it is possible to return to music's use in hospital and therapeutic

settings with new eyes, focusing on the role of the client/patient and what they bring to the music (therapeutic) event- their 'lay' craft. From there, it is also possible to see the craft of the music therapist or health-musician with new eyes as they seek to activate latent health-musicking skills in those with whom they work (DeNora 2007, p.284).

Highlighting the individual lay craft of music as health resources in everyday life can enhance our understanding of the collaborative crafting of aesthetic encounters as it takes place between music therapists or health-musicians and participants in the collective musicking. How is it possible to “collaborate” in crafting music and aesthetics among people with different cognitive/physical abilities? What techniques and skills are necessarily to enact such collaboration? Chapter five in my thesis will highlight such collaborative crafting of aesthetics among participants in SB, while chapter eight and nine will discuss its relation with participants’ lay craft of music as health resources in everyday life.

It is also useful to review more practice-based studies that highlight the permeation of aesthetic creations through different boundaries. Allison (2008), an ethnomusicologist, for instance, chose a song-writing group in a Jewish nursing home as a central site of her ethnographic study and investigated how a song created in the group started to be sung in different places and at times for different purposes. For instance, one song which was created in a unit of the nursing home spread among residents and staff at the whole home, while other songs written in response to a psalm study were performed when a new synagogue opened in the nursing home. In this way, songs created in a small group in the nursing home travelled and developed across different physical places. This song creation thus worked as a means for the residents to transcend the daily confines of their nursing home by drawing on the experience of their entire lives, and thus reach other social worlds (Allison 2008).

Aasgaard (1999; 2000; 2002; 2004) also conducted similar studies on song creations within a paediatric oncology ward. He provided a very detailed description and analysis of how the serial singing of songs in multiple contexts allowed one ill child to make, take and play new roles, which led to her stepping out of the role of a sick person in various social environments beyond her room in the hospital (Aasgaard 2000). Similarly to Allison's study, Aasgaard's example from the world of community music therapy also shows how aesthetic experiences of a song can travel and develop across spatial boundaries and how such developments can contribute to expanding the life world of a person who at that point is classified as "ill" (Aasgaard 2002).

Throughout his work based on data from the children's hospital, Aasgaard (1999; 2000; 2002; 2004) emphasizes the importance of a dual approach where individually directed music therapy is combined with another form of musical engagement focused on the person's environment. This dual focus is necessary, as Aasgaard suggests, because individual music therapy can otherwise end up working in a vacuum. Similar to more recent community music therapy approaches (e.g., Numata 2010; Powell 2004; Procter 2004; Zharinova-Sanderson 2004), Aasgaard's way of working as a music therapist challenges the orthodoxy of traditional music therapy. First, it "challenge(s) any belief that the 'important things' (in music therapy) go on solely within music therapy sessions and within predetermined, enclosed areas of music therapy activities" (Aasgaard 2002, p.217). Secondly, this (e.g. entertaining people in an open space) is deemed inappropriate by some music therapists outside community music therapy (Aasgaard 2004; Procter 2004). For instance, Magee (2002, p.182), argues that music therapists should establish clear boundaries so as not to mix up two musical settings; one is recreational activity where music is used for pleasure and enjoyment, the other is a music therapy session where clients express more difficult emotional responses. This

raises another crucial question; are such professional boundaries (e.g. recreation versus therapy) an obstacle for someone to continue and further develop the aesthetic experiences from such activities in other parts of their lives? Instead it is more useful to apply Ansdell and DeNora's (2012) suggestion to look at the use of music as self-therapy in everyday life as a part of a continuum that crosses into more organized music therapy practices in mental health settings. They also suggest that we rethink professionalism through examples of community music therapy practices that highlight "permeable borders between experiences, activities and roles" (Ansdell & DeNora 2012, p.109). We therefore need to ask ourselves, how can permeable borders be cultivated in local settings? How do they encourage the movement and development of grounded aesthetics across various boundaries? How does such permeation help to maintain the quality of life of local people with dementia and their caregivers? A core part of my thesis (chapters seven and eight) will explore these questions.

2.4 Understanding collective musicking

Because the field site I chose ("*Song Birds*") was a group-oriented singing activity that involved people with dementia, their caregivers and local volunteers, it has been useful to review studies related to such collective singing/musicking. In the following section, two points will be highlighted. First, health benefits of singing will be explored as the activity (SB) is aimed at enhancing and maintaining quality of life of people with dementia and their caregivers. Secondly, bearing in mind that the lack of social

engagement is pointed out as a common problem among participants with dementia and their caregivers of SB¹², the social significance of musicking will be reviewed.

2.4.1 Singing for health

In the UK, the health benefits of singing have received considerable attention over the last decade, and a number of charities working with elderly people have been starting singing groups in the community. Along with this trend, surveys as well as qualitative studies have attempted to explore the benefits of singing for health promotion: positive effects, physical relaxation, sense of bonding and motivation, increased self-esteem and self-confidence, reduction of stress (Clift et al. 2008), focused attention, deep breathing, social solidarity, cognitive stimulation and regular commitment (Clift & Hancox 2010), improved mood (Unwin et al. 2002), positive self-image and enhanced sense of belonging for high school students (Hylton 1981), emotional release, especially for women (Sandgren 2009) and enhanced immune functions (Stacy et al. 2002). Skingley (2011) points out the cost-effectiveness of group singing in maintaining the health of people in later life. All these discussions of the benefits of singing have to be tempered with caution by more close examination that highlights each individual experience, which will be further discussed in the methods chapter (chapter three).

The social benefits of singing have been discussed widely both within and outside of the UK context, for instance as a means of providing a protected space for self-expression and a context for reframing (Silber 2005); creating potentials for social bonding (Bailey

¹² The characteristic of informants' everyday life and conditions, as important elements to be taken into account in crafting the SB sessions will be further discussed in chapter 4 and 5.

&Davidson 2005; Davidson 2008) and giving opportunities for social empowerment (Davidson 2008). Davidson (2008) also points out how singing may provide holistic benefits (cognitive, emotional, spiritual, social and physical effects) compared to other activities (e.g., physical activity) and that those positive rewards of group singing are independent of formal training or ability. Among the social benefits of singing, the community building aspect has been discussed and applied specifically for older generations who often suffer from social isolation. For example, the participants of a senior choir emphasized how the collaborative efforts involved in singing in a choir had contributed to a sense of co-presence with corresponding changes in mood and an experience of community (Stige 2010). Singing in a choir also helps caregivers, people who are cared for, volunteers and paid caregivers to enhance mutual and informal interactions as people see different/multiple sides of each other while participating in a choir together. As a result increased social networking and support within and across the group was observed (Davidson & Faulkner 2010, p.169). Singing in a choir also has the potential to transform boundaries and conflicts between people that may arise due to differences in values, assumptions and age (Davidson & Faulkner 2010; Davidson & Emberly 2012). It was also recognized by Stige's study (2012) on a senior choir where members felt singing together was the only possibility for survival as a group. All these social benefits of singing have the possibility of aiding people with dementia and their caregivers. This is because group singing can foster bonding and thus delay or prevent the social death which I discussed earlier in this chapter. Singing may also become a part of community support where people with dementia and their caregivers acquire opportunities for further social networks that are inclusive. This may also reframe the view of dementia from static to more multi-faceted among the participants in the community.

2.4.2 Musicking and social significance

As discussed above, the social benefits of **collective** singing seemed to be one of the major contributions to the health benefits of singing. It is therefore important to discuss what is distinctive about singing/musicking that brings social benefits to people as opposed to listening or singing alone. Finnegan (2007[1989]), for instance, documented amateur music-makings and the overlapping world of those in the English town through ethnography with a focus on how people participate in local musical practices from classical orchestra, church choirs, brass bands, amateur operatic societies to amateur (jazz, rock, folk and country) bands. These local music making practices were explained as “music pathways” which Finnegan defined as “habitual routes by which people identified themselves as worthwhile members of society and which they regarded as of somehow deep-seated importance to them as human beings” (2007, p.306). These ideas help us to conceptualize local musical participations as significant “routes” to sociability, more generally drawing people back into the wider community. Finnegan also emphasizes the social functions of music in linking people, giving identity and status, marking out and constituting the rituals of time (2007, p.339). As she puts it:

Far from being the kind of marginal and unstructured activity often suggested by the label ‘leisure’, with its implication of residual items somehow left over from ‘real’ life, these musical practices were upheld not by isolated individuals in an asocial vacuum or by people merely trying to fill in the time to ‘solve’ the ‘problem of leisure’, but through a series of socially recognized pathways which systematically linked into a wide variety of settings and institutions within the city (Finnegan 2007, p.299).

Finnegan’s perspective also helps us to view music making by and with people with dementia and their caregivers not something to “solve” their social problems (e.g. isolation and possible exclusion) but as a valuable activity itself to be linked into further

musical pathways and a variety of resources locally. Although Finnegan's work is crucial in thinking further about the social significance of collective musicking, it still leaves room for a more detailed investigation of personal/private music use and musicking, such as any forms of "taking part" in collective musicking (e.g., humming, moving the mouth, listening, or just being there). As Small (1998) suggests, musicking is an inherently social activity where multiple interlinked relationships can be formed or transformed within their local context, which includes preconditions such as the complexities and conflicts of existing relationships. How can we highlight the ecologies of the relationships that come out of musicking activities?

The sociological concept, "social capital" can shed light on this issue by helping us to highlight the social significance of various forms of musicking. Though several scholars have dealt with the concept of "social capital" (c.f. Putnam 2000; Bourdieu 1986; Berkman & Kawachi 2000), in what follows I will use Putnam's conceptualization which emphasizes connection between people. Putnam's conception of social capital (2000, p.19) emphasizes social networks and the norms of reciprocity and trustworthiness that arise from networks. He distinguishes two forms of social capital; bonding and bridging. Bonding social capital refers to ties between people in similar situations and backgrounds, for instance, similar ages, same religion, same race and similar cultural orientation. Bridging social capital on the other hand refers to the network that brings people in different situations and background together. Putnam (2000) argues that these two types of social capitals strengthen each other and the possessions of such social capital have considerable impact on human well-being.

Can music making contribute to the generation of such social capital? Putnam himself emphasizes the effectiveness of cultural activities, whose main purposes are purely

artistic, in generating social capital (Putnam 2000, p.411). Local art projects have been found to play catalytic roles in generating a range of social, educational and economic benefits within a community health framework (White 2006). The community music therapy literature also highlights music making as a means of generating social capital.¹³ The focus on social capital highlights the importance of participation as a factor in wellbeing and contrasts with the predominant medical, evidence-based framework whose perspective is primarily any easily measured effects of music therapy (Pavlicevic & Ansdell 2004; Stige 2010; Stige & Aarø 2011). For instance, Procter (2007) argues how participants increase possibilities of actions through cultivating reciprocity and trust in and out of these collective aesthetic realization processes. Thus social capital is nurtured as a by-product of collective musicking even if its creation is not an initial goal, and this is in line with Putnam's (2000) suggestion mentioned above. Furthermore, the acquired social capital seems to have positive effects even after the collaborative musicking ceases, as participants of a community music therapy session are seen as more prepared for positive social interactions in-between the sessions (Procter 2007, p.158). Thus acquisition of social capital through collective musicking makes changes in their everyday life as well.

Is music more effective in producing such social capital than other art forms? The answer may be in its malleability that allows micro negotiation in the process of collective musicking and collaborative aesthetic creation. Procter (2007; 2011) suggests that in collective musicking shared musical norms (e.g. the structure of a waltz) afford

¹³ Community Music Therapy, as defined by Ansdell (2002) is “an approach to working musically with people *in context*: acknowledging the social and cultural factors of their health, illness, relationships and musics”.

frameworks “within which to interact, to perceive our interaction, and to add this to our accrued experiences of interactions characterized by trust, reciprocation and enjoyment – in turn preparing us to risk trusting another person another time” (Procter 2011, p.9). This focus on music and collaboration also reminds us that acquisition of social capital in collective musicking requires effort and initiatives. For instance, Osborne et al (2009) and Hara (2007) have both suggested that social identities, such as “mother” or “elderly”, can be imposed in some participatory art and music groups, this then strongly affects their participation and experiences in the group. This can lead to the reinforcement of gender inequality or age stereotyping and should thus be avoided, particularly as people with dementia often have a negative self-image that already oppresses their capabilities as discussed by Scholl and Sabat (2008). Music can also sometimes mark and strengthen ethnic boundaries, as pointed out by Bergh (2010, p.23), therefore one needs to be careful when selecting the repertoire for events where people have different ethnic and cultural backgrounds so as to avoid negative ethnocentrism. Acquisition of social capital through collective musicking can therefore involve a struggle, and is not necessarily the simple outcome of merely participating in the musical event as Daykin (2012) has discussed: Thus it needs careful considerations and crafting so as to reduce social inequalities. There is considerable evidence that suggests that collective musicking is socially significant. However, importantly, planning local music activities by definition highlights an imbalance of power between facilitators who lead the music activities and participants who are initially targeted, in the case of my thesis, people with dementia and their caregivers. Continuous and democratic negotiations are therefore necessary between the participants and facilitators in order to avoid the imposition of inappropriate meanings and structures. Collective musicking using shared musical norms can provide a framework that allows micro negotiations that help to

cultivate trust and reciprocation among participants and facilitators as suggested by Procter. The details of such negotiations will be further explored in chapter five of this thesis.

2.5 Music in dementia care

As previously mentioned, the increase in dementia caused a similar increase in the focus on the non-pharmacological therapy in care situations to improve quality of life for individuals with dementia. In particular, the use of music has grown rapidly over the last 10 years (Watanabe et al. 2005). This interest comes from a number of disciplines and practices including neuroscience¹⁴ (DeKosky et al. 2001; Geroldi et al. 2000), nursing (Gotell et al. 2002; Kneafsey 1997), environmental design (Topo & Östlund 2009) and music therapy (Aldridge 2000; Goodall & Ethers 2005; Lou 2001; Raglio & Gianelli 2009; Ridder 2003). The most active disciplines in this area are neuroscience, music therapy and more general (therapeutic) music activities for those with dementia.

In the neuroscientific approach, the study of music's effects on the brain is a long-standing research area (Hodges 2000). As mentioned briefly earlier in this chapter, 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 & Samson 2009; Crystal et al. 1989; Cuddy & Duffin 2005; Norberg et al. 1986), the relationship between music and language (Koger & Brotons 2000; Ruiz & Montanés 2005) and behavioural management (Choi et al. 2009; Goodall & Ethers 2005; Raglio et al. 2008; Suzuki et al. 2004; Winckel et al. 2004). In neuroscientific models, quantitative methods

¹⁴ Neuroscience here refers to the study of the brain and nervous system as related to music and sound stimuli.

are used to “prove” the effectiveness of these “mechanics”, most commonly statistics from randomized controlled trials (e.g., Haas & Brandes 2009; Miller et al. 2000).

These discourses on music as a stimulus to the brain have been influential in applied practice fields such as music therapy. This is a broad discipline and there exists a wide variety of models according to the fields as well as various schools of thoughts (e.g. medical model, behavioural model and community model) (Aldridge 1996; Bonny 2002; Davis et al. 2008; Nordoff et al. 1977; Pavlicevic & Ansdell 2004; Stige et al. 2010).

While various techniques are applied that range from the receptive approach using recorded music to the more participative such as improvisation and singing. Literature on music therapy in dementia care tells us about the orientation towards medical model in their practices. For instance, in music therapy in dementia care, music is often discussed as a possible medium to enhance verbal/non-verbal communication (Koger & Brotons 2000) and, as in neuroscience, access memories (Cuddy & Duffin 2005; Ridder 2003) or manage agitated behaviour (Raglio et al. 2008; Ridder 2003; Vink 2000; Vink et al. 2009). The latter is also a growing concern in nursing (Lou 2001; Sung & Chang 2005; Wall & 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 caregivers (Clair 2000; Clair 2002). In short, music therapy for individuals with dementia tends to focus on communication, memory, behavioural management and facilitating interactive relationships with therapists and caregivers. Music is seen as a tool to achieve those goals, and the outcomes of music sessions are measured either quantitatively (e.g., Cuddy & Duffin 2005; Vink et al. 2009) or qualitatively (e.g., Clair 1996; Simpson 2000). Goals tend to be chosen according to the assessment of efficiency in music therapy (Bright 1988). For instance, according to

Bright (1988) changes in depression and agitated behaviour are often chosen as goals as they are easy to be rated to show the effectiveness of music therapy.

In both the neuroscientific and music therapy models then, music is often used instrumentally as an isolated material for making very specific changes. Like a pharmaceutical drug, its effect is administered and measured in a specific, predefined way. Goals 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 were achieved. The evidence of the effects of music on the brain for memories, for verbalization and for behaviour management, as discussed above, are certainly important in raising the awareness of the potential benefits of music use in (parts of) dementia care. Functional assessment in music therapy is also important in order to see “how much of the condition is reversible, to plan more effective treatment, more appropriate placement, and to facilitate better relationships between sufferer and family as well as between sufferer and his world” (Bright 1988, p.20). However, I am concerned about the absence of embedded social and cultural dimensions of musicking in the literature that views music simply as a temporal stimulus rather than something that is embedded in everyday life. When this view is prevalent we are unable to learn how music can be integrated into the everyday life of people with dementia, which in turn means that the community support that is required to sustain the clear benefits of music use goes missing. In addition, the situational *experience* of music by people with dementia is difficult to generalize along the lines of simple causal models. In what follows, I will highlight several issues in music in dementia care, which require more careful investigation on the situational experience and the use of music.

For instance 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. This includes activities for individuals with some form of dementia (e.g., Bannan & Montogemery-Smith 2008). 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 caregivers occasionally together with elderly volunteer members who do not have dementia. Positive effects have been reported on such group music therapy sessions; activity disturbance, aggressiveness and anxiety were improved although the effects had diminished 1 month after the project stopped (Svansdottir & Snaedal 2006, p.7). Their effects on depression are also reported (Myskja & Nord 2008). However, there are issues to be highlighted in the very process of music making besides those proved positive effects. 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. 2009), are sufficient enough to explain or understand the meaning of such activities.

For instance, the Japanese music therapist Sakashita (2007; 2008) points out several concerns related to group music therapy sessions taking place inside institutions (day care centres and nursing homes), which is a common form of music (therapy) activity for people with dementia in Japan. One issue is that while music can improve and lighten the atmosphere it can also change the social environment in ways that may actually encourage certain kinds of conflicts among participants. Secondly, there is also a possibility that residents (or day care users) are forced to sing or listen to songs against their will for caring “efficiency” purposes. Lastly, songs used in group music

therapy sessions may rekindle emotions and memories that are not necessarily pleasant for some of the participants if the therapists (or facilitators) do not know the individuals' background and preferences. As some of people with dementia may not be able to express their unpleasant experiences verbally, especially if they are in the late stage of dementia, careful assessment and consideration are important.

It is common to use songs that are familiar to participants from their childhood for such group music therapy sessions; however, the function(s) of such familiar songs should also be carefully investigated. As mentioned above, such familiar songs (or preferred songs) are discussed as a useful means to access memories (Cuddy & Duffin 2005; Ridder 2003), which also helps manage agitated behavior (Sung & Chang 2005). The problematic issue relates to the methodological limitation as Baird and Samson (2009) pointed out in particular is that the effects of music on memory are difficult to be measured without considering the individual musical background. First of all, why are songs that are familiar to people with dementia from their childhood used and considered as significant? Why not songs that they learned or experienced after their adolescence? Tackling these questions, I have in other places discussed how elderly people use music that was learned or heard in their formative years (in their teens to late twenties) as tools for self-care in their everyday lives, rather than songs they learned in their later lives (Hara 2007). Similarly, Minamida (2011) points out people have the most intensive interest in music in their formative years, which is referred to as "rite of passage"(NHK Survey Institute 1982) and "season of music"(Yoshii 1984). Minamida also argues that songs that were familiarized in formative years remain favourites and there is a high possibility that they will be listened to later in life. Moreover, he suggested that this music is strongly embodied, thus carried through life. Additionally,

Ruud has also explained what makes songs from childhood endure and remain important even in the latter stages of life:

When people talk or write about their first musical memories, we often hear stories about parents or grandparents who sang lullabies or played songs. These songs framed or anchored the person in her early memories of “being held” and supported within a trustworthy relationship. The song often creates strong memories of the person behind the song, thus recalling the person as a symbol of trust and faith in life, or letting the song symbolically represent this feeling. Frequently, the song is recalled during frightening situations later in life, helping the person to overcome a difficult task. The feelings of warmth and harmony brought forth by the song are often re-enacted through the song’s performance (Ruud 1998, p.39).

These studies by Hara, Minamida and Ruud support the idea that familiar songs from the participants’ early years are important not only as devices for music (therapy) sessions for people with dementia but also for elderly people generally. The warm, protective feelings that are recalled by these songs, as Ruud (1998) discusses, may be particularly necessary for people who are slowly losing memories and cognitive abilities.

Moreover, people with dementia can often access their long-term memories while having problems with short-term memories, which makes them displaced in time and place (Schillmeier 2008). The familiar songs learned in earlier life work very well as they act as cues to help the process of retrieving such long-term memories (Ridder 2003). Importantly, such a retrieving process is immediate and do not require cognitive processing (Clair 1996). This process, as a result, regulates the “arousal level of the participant towards environmental attention and a state most optimal for entering dialogue” (Ridder 2003, p.280) and also helps the reality orientation by raising “awareness of the place in which they live, of those who love them and care for them,

those with whom they share a home” (Bright 1988, p.34). Such use of familiar songs in group music sessions will be explored in chapter five and six in this thesis.

Another issue in music in dementia care, which is difficult to examine with simple causal models of how music works, is music’s integration into everyday life, in other words, the ecological affordances of music. For instance, Sixsmith and Gibson (2006) and Brummel-Smith (2008) point out the lack of research on the role of music in everyday life of people with dementia (e.g., listening to music, reminiscing about music, musicking with family and community), while there are plenty of studies to show the benefits of musical (therapeutic) interventions. Sixsmith and Gibson (2006) also emphasize the importance of the integration of music use in everyday care:

Professional and informal care-givers need to appreciate their role in facilitating access to music; quick and simple help and encouragement can have a great impact on a person’s quality of life, without making large demands on a carer’s time and resources (2006, p.141).

Several innovative studies have attempted to tackle these issues by integrating music use in everyday care. For instance, Götell et al (2003; 2009) emphasized that background music and a caregiver’s singing during dementia caring in nursing homes bring positive impacts on both caregivers and people with severe dementia to express positive emotions and reduce aggressiveness in people with dementia. This approach of including music-making during caring activities is defined as “music therapeutic caregiving” and Götell and others suggested that this is a simple and inexpensive way to improve the quality of care (Brown et al. 2001; Götell 2003; Götell et al. 2009). Dennis also implemented a similar study in nursing homes and discussed the use of music during the morning care session as “a simple, effective and economical intervention to improve the daily lives and environments for both the carer and the cared for” (2011,

p.36). Such studies are crucial as they show possibilities in terms of music use as an aid to increasing the quality of care outside any formal, therapeutic interventions. Given the increasing number of people now caring for people with dementia in their own home, there is an urgent need to ensure that such researches are transferrable to these settings as well.

However, there are difficulties in integrating music use in everyday life. For instance, due to the temporal quality of music and short-term memory loss of people with dementia, many of the experiences are forgotten soon after the music stops (Sixsmith & Gibson 2006). Odell-Miller (2002) also draws our attention to the fact that the higher levels of engagement shown among participants with dementia in their music therapy sessions only last for approximately half an hour. This affects caregivers' motivation as some of them "struggle to accept that the enjoyable experiences are not retained in a person's memory, and questioned whether there is any point in ensuring that the people take part" (Sweeting & Gilhooly 1997 in Sixsmith and Gibson 2006, p.134). Götell (2003) investigated this issue further through an ethnography study that explores the extended effects of participating in organized group music events in the nursing home. According to Götell (2003), participants with dementia demonstrated enhanced attention span and full vitality directly after the music events. Although they usually forgot that they had participated after 15 minutes, the mood lasted longer, which allowed the staff members to care for them more easily for another several hours or even the rest of the day. Additionally, staff members felt the bonding between themselves and residents with dementia developed in ways to eliminate the boundary between them. This feeling lasted long after the music events end. Additionally, Ridder (2004) emphasizes the importance of close collaboration with the staff to carry over the effects of music therapy sessions to maintain the effects longer. As we have seen earlier,

cultivation of “permeable borders between experiences, activities and roles” (Ansdell & DeNora 2012, p.109) may be necessary to explore how functions of music as a health resource can be maintained in the everyday life of people with dementia. Such investigations, obviously, cannot be pursued with a simple causal model, thus the ethnographic study becomes appropriate.

From the carer’s perspective, one of the most distressing features of dementia care is a loss of connection with partners and loved ones as discussed earlier. How has music been used to help such connections between people with dementia and their family members? Group music therapy sessions have been discussed as a potential means for people in their earlier stage of dementia and their family members to work on their daily stress and enhance understanding with each other without verbal communication (Hanser & Clair 1995; Hanser et al. 2011). Such sessions include a variety of activities from singing, listening to their favourite music and improvisation to song writing. Singing and dancing together with their own family caregivers and others also provide opportunities for people with dementia to reinforce positive emotions towards their family caregivers (Sixsmith & Gibson 2006). Partners’ retained abilities to respond to music bring further supports to caregivers as Bright discusses as below:

In music therapy, the wife was able to enjoy a shared experience of music with her husband despite his advanced dementia. They had met through an amateur musical group and had fallen in love while playing opposite each other in a suburban production of a musical, and he responded strongly to the music from that show. This provided only one small comfort to them both. It caused pain as well, but the wife felt that the joy of seeing her husband once more relating to her as he used to do compensated her for the sense of loss which this response also brought (Bright 1988, p.45).

In this way, music is used as a way to rekindle the relationship between people with dementia and their family members, which has usually been hidden away. Even after

people lose their ability to sing in their late stage of dementia, rhythm activities (e.g. using drums) still remain and act as an effective medium for communication (Clair & Bernstein 1990). Caregivers' singing and listening to recorded music together with care-receivers are also discussed as a means for caregivers themselves to remain a viable part of the life of their partners or family members in the late stage of dementia (Brown et al. 2001; Clair 2002; Clair 2008). Regaining connection through music making also provides "opportunities for family caregivers to recover from the persistent and intensely demanding work of caregiving" (Clair 2008, p.215). All these studies suggest useful ways of integrating music use in everyday dementia care from early stage to late stage. Thus regular music making opportunities can help in maintaining the quality of life of people with dementia and their family members (Hara 2011a), especially because dementia caring can be stretched into the long-term (World Health Organization & Alzheimer's Disease International 2012).

These studies with their focus on music use for social benefits particularly in regaining the feeling of connection between caregivers and their family members with dementia, clearly resonate with the central principle in palliative care: "being there" (Nikura 2010). Although musical interventions in dementia care rely on observable responses and changes (e.g. changes in behaviour, depression and engagement as well as facial, physical responses), such focus on the connection help us to shift our view from "music as a stimulus to see measurable outcomes" to music as a useful means to allow people to be reconnected and to remain together.

2.6 Conclusion: music in dementia care, from temporal stimulus to sustainable action

In this chapter, I began by reviewing the literature on dementia care. I pointed out that sustainable support is indispensable both for people with dementia and their caregivers if both are to act effectively as symptoms progress over the long-term. Next, I reviewed the sociological study of music and health and I focused in particular on the use of music situated in everyday life, especially to manage corporeal states, such as self-care and health. I also reviewed the literature on collective musicking. This included work on singing as a useful means for health and the social significance of collective musicking. I also considered the permeability of aesthetic creations across boundaries. Finally, I have shown how the predominant discourse on music as a stimulus to the brain is influential in the applied fields (e.g., music therapy) of music in dementia care. The limitation of such a perspective was discussed as it leaves room to investigate the situated use of music that is embedded in everyday life. For instance, several issues arising in dementia care were discussed; ethical issues in group music (therapy) sessions, the use of familiar songs from formative years, integration of music use in everyday life and finally music use that allows people to connect with each other throughout the long stretch of life with dementia from its early to late stages. All these issues are very much embedded in the cultural and local contexts; hence the predominant discourse on music as stimulus to the brain is not sufficient to highlight such situated use of music.

Therefore, just as recent music studies focus on the processes of people's musical participation resonates well with the ethnographic study, so too, music use in dementia care also needs ethnographic study to investigate the discursive affordances of music in the whole process of one's cultural life. This will hopefully cut across some of the

dominant discourse on music as a temporal stimulus to brain and highlight instead the potential of music use in dementia as a sustainable action.

In the chapters that follow, I use an ethnographic study of everyday musicking and dementia to highlight music as a useful means for sustainable community support, where continuous care emerges from the networks of people and knowledge developed through music making. The methods of such an ethnographic study will now be discussed in detail in the following chapter.

Chapter 3. Methods

3.1 Introduction

As I discussed in the previous chapter, the dominant methodology used to study the effect of music on dementia was based on medical and neuroscience models, in which music was seen as a stimulus for the brain (e.g., Baird & Samson 2009; Crystal et al. 1989; Cuddy & Duffin 2005; Norberg et al. 1986). Although these methodologies were scientifically robust, the sociocultural context of the musicking experience (which was linked to the individual and their musical histories) was often left out of the analysis. A more sociologically oriented approach would seek to address this limitation by looking in depth at individual experiences with music in dementia care.

A key concern related to sociological studies, however, was the inherent difficulty in approaching those suffering from dementia to obtain data, particularly as dementia progressively destroyed the cognitive functions, both on a practical and ethical level. The difficulties and challenges in eliciting the data from people with dementia, particularly those who were 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 was often emphasized rather than that of the patient (Reid et al. 2001). Acknowledging this issue, Reid et al. (2001, p.378) have suggested that although there is a "mushrooming of personal narratives that are attributed to individuals with dementia", the precise nature of their authorship was uncertain. A similar phenomenon could be observed in the growing media interest in the use of music in dementia care, which has been quite influential in raising the profile of such personal narratives. On the one hand, these narratives become efficient tools to showcase the power of music in dementia care as seen in TV programmes (BBC TWO 2009; ITV 2010), one of which

(ITV 2010) led to increased funding for charities to launch music activities. On the other hand we still lacked detailed and careful methods to obtain reliable and valid data from people with dementia and make use of such data to understand the role of music in relation to the everyday lives of these people and their caregivers.

Given the problems of using interviews as the sole method of data collection in this context due to the regressive cognitive functions of people with dementia, as Goldsmith (1996) discussed, qualitative studies particularly ethnographic studies were often applied in order to shed light on the experience of dementia and dementia care.

Ethnographic studies were qualitative research procedures designed to capture various socio-cultural phenomena and people's lives without imposing the researcher's bias (Brewer 2000). In an ethnographic study, data was often collected through multiple methods, such as participant observation, interviews and surveys. How then have ethnographic studies been utilized in the study of dementia and dementia care? What were the specific methods particularly useful in the ethnographic studies of dementia and dementia care? Several studies have led the way and illustrated some of the different methodological approaches that could be used to address these questions. In one instance, Hubbard et al (2003) conducted an ethnographic study in a care home and observed the meaningful ways people with dementia used non-verbal communicative behaviours in their interactions with other residents. In another in-depth ethnographic study Ericsson et al. (2011) evaluated how seemingly good treatment and positive attitudes of caregivers could be experienced negatively by people with dementia. Long-term ethnographic studies from 8 weeks to 1 year were also useful in exploring issues that were difficult to approach through short-term observations. For example, Kontos (2004) was able closely to explore the selfhood of people with dementia and how it was embodied when they engaged with the surrounding world in the care homes.

This was also utilized by Bassett and Graham (2007), together with in-depth interviews involving people with dementia and their caregivers. The aim was to investigate people's memories and how memories of people with dementia were retrieved in social interactions. Finally, long-term participant observation, which was a common method in ethnographic study, had allowed researchers carefully to explore the meanings of the occupational patterns of people with dementia in residential care homes. For instance Holthe et al. (2007) discovered that the seeming passivity of people with dementia resulted actually from their adaptive strategies to fill expected roles and adapt themselves to the new environment in a care home.

Ethnographic studies were also useful in exploring the meaning of music that emerges in the process of music being appropriated by individual actors (DeNora 2007), given that music was an inherently social process (Small 1998). This enabled us to highlight any situated use of music in everyday life as discussed in chapter 2 (cf. DeNora 2000; DeNora 2003; Frith 1978; Frith 1981; Martin 2006; Willis 1978) .

Bearing all this in mind, I chose to conduct a long-term ethnographic study as it enabled me carefully to understand informants' experience of musicking instead of merely reporting at face value what occurred, which was often the tendency of qualitative research on arts and health as Daykin (2012) suggested. Participatory methods in ethnographic study and its attempts to present the subjective experience of people with dementia challenged the dominant medical model as Proctor (2001) noted. Therefore, the ethnographic study also allowed me to challenge the predominant medical model in music in dementia care.

I chose the community-based singing activity *Song Birds* (SB) run by *Dementia Support Group* in Watertown, UK as my main research site.¹⁵ Most of the members with dementia in SB were cared for in their own homes and participated together with their regular caregivers (partner, family members, or sometimes hired professionals). My research programme was based on long-term participant observation (6 months) of SB as well as interviews with the participants: people with dementia, their caregivers and volunteer members. This involved additional ethnographic research within related local music and care events. The use of complementary methods helped me to improve and extend my understanding of the complex social worlds around informants as Mason (2006) suggested. The multi-methods approach also provided information on multiple dimensions of the phenomena I observed; for instance my participant observation helped me understand what my informants said in interviews as Clare et al. (2008) also pointed out. This multi-method approach was important as the narratives of people with dementia were sometimes not clear or coherent enough to be comprehended in isolation. In order to highlight the potential of music use in dementia as a sustainable action, I allowed myself to move across settings following actors (Latour 2005) rather than restricting myself only to work in a single setting. By following the informants in and out of the weekly SB activities, I could investigate how music got used in various actions in their everyday life (DeNora 2000), how it was imbricated into their social networks (Frith 2003) and how it expanded their social worlds (Aasgaard 1999; Aasgaard 2000; Aasgaard 2002; Allison 2008). Multiple methods were necessary to

¹⁵ Throughout this thesis I have anonymized all names of individuals, organizations and locations. The only exception is "*Song Birds*" itself, as it is a national organization whose branches spread across the UK and could not be identified through this name alone.

approach the discursive affordance of music in dementia care as, for instance, a single method merely to measure effects has been criticized by Ledger & Baker (2007) as not sufficient for investigating the longer-term effects of group music therapy session for people with dementia.

Underestimating the communicative abilities of people with dementia could lead to their exclusion in research. Thus it was important to keep reminding ourselves that “much can be gained from changing our view of the person with dementia from someone to be studied to someone whose perspectives can help us understand AD[Alzheimer’s Disease]” (Cotrell & Schulz 1993, p.210). As I discussed in chapter 2, the person-centred approach suggested by Tom Kitwood has led to a number of studies that engaged with the voices of people who had dementia (e.g., Beard et al. 2007; Cotrell & Schulz 1993; Ericsson et al. 2011; Hellström et al. 2007; Moser 2011). In line with these studies, I have been particularly careful to involve people with dementia in the research process. As Kontos & Naglie (2006) pointed out, positive interactions such as reminding people of past careers or memories could reduce the feeling of “dislocation” experienced by people with dementia. I therefore attempted to do this when the opportunities arose during the fieldwork. One of the main ethical issues in involving people with dementia with the research, however, was their capacity to understand the information given by the researcher as Hellström et al. (2007) pointed out. As dementia was progressive and the cognitive capacities of my informant with dementia changed constantly, ethics became an ongoing process which should be based on non-verbal and behavioural cues and not only verbal language as Hellström et al. (2007) also suggested. My long-term ethnographic studies also allowed me to observe the characteristics and changes of each individual. As a result, I was able carefully to continue negotiating my researcher role in order not to affect the dignity of informants with dementia in a

negative way and at the same time to involve them in the research process as much as possible within their capacities at that moment. Meanwhile, I tried to achieve “maximally informed consent” (Pratt 2002) by making sure to consult with the main gatekeepers, usually their family caregivers as well as the volunteer member who was in charge of admissions of SB and knew the conditions of the informants.

I can now describe in detail the combination of methods I adapted for my study as follows: 1) preparation for the research, 2) description of the main field site, 3) carrying out the research and 4) analysis of the data collected.

3.2 Preparation for the research

Prior to my Ph.D. research I conducted in-depth interview research with 30 elderly people without dementia in Japan about their musical orientations in everyday life (Hara 2007). As many of the music (therapeutic) activities provided in nursing homes and day care centres in Japan were group rather than individual focused, I was interested in exploring how those activities were received by individuals in relation to their own past histories and previous musical orientations. This experience made me aware of the importance of building significant rapport with informants before conducting one-on-one interviews, particularly as sensitive issues might arise. For example, some of the Japanese elderly informants claimed certain songs as their favourites, only to adapt to what they perceived their roles to be in the nursing home (Hara 2007). This could not have been discovered without complete trust in the one-on-one interviews. I was also aware of the challenges of carrying the participatory research as a foreign researcher who was not a native English speaker and who was an Asian, something that was not so common in the

locality of Watertown, UK¹⁶. Pre-fieldwork preparation was important but had to be adjusted depending on the research and research site as Stock (2004) suggested.

As a result of these considerations, I prepared myself accordingly before actually starting to collect data. First, I asked two volunteer respondents (referred to me by my supervisor) to take part in pilot interviews. Both were musically active. This helped me to familiarize myself with interviewing in English. More importantly, it helped me clarify the wording so it was easy to be understood. Thus an initially prepared list of 37 questions (see Appendix 1) was reduced to 27 clearer questions, and the remaining questions were left to emerge from the conversations (see Appendix 2). The pilot study also helped me gain knowledge about local music activities as well as some idea about what local musical participation was common among local upper-middle class, middle aged people.

In addition to this, I worked as a volunteer with two local music groups for 8 months before starting to collect data; SB where I eventually collected the data for my study and “*Sounding-out*” (anonymized name), a local music group involving people with learning difficulties. I felt that working as a volunteer with these two groups would be a good start for my ethnographic study, which would help me to gain a holistic

¹⁶ A brief summary of key demographics is useful for the reader to contextualize the discussion in this chapter: Watertown was a historic town surrounded by countryside in the south west region of the UK. The population was approximately 120 thousand people, of which 18% was of pensionable age (female over 60 and male over 65). Unlike many other towns in the UK, Watertown was not a particularly diverse city; approximately 95% of the population was categorized as “White” (according to official statistics). Additionally, Watertown was within the region with the second highest per capita income in the UK (London being the highest).

understanding of the local infrastructures in terms of music and care opportunities that supported local people with dementia and disabilities before honing in on one organization. As it was common for university volunteers to join and leave the two groups within a period of one to two years, I was sure that my involvement for a similar period would not have any negative repercussions for these groups. At SB, 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 caregivers. This was a common role for volunteers. Since I had long-term personal caring experience with my own grandmother who had dementia, as well as five years' experience in running the music activities in day care /nursing homes in Japan, I did not experience any difficulties when 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 sessions were new to me because of my Japanese background, but I learned how to sing those songs because it was important to reciprocate with the song, as also discussed in ethnographic studies on music of a different culture than the researcher's own (e.g., Seeger 2008). With *Sounding-out* I also worked as a volunteer for their weekly sessions. I often played instruments. Gradually, attending the two groups became part of my weekly routine.

I also undertook several training programs on volunteering with older people and vulnerable populations run by the University of Exeter, by *Elderly Support Group* (a local charity working with older people) and by the local council during this period. This was done to ensure that I understood the specific situations and any regulations governing such work in the U.K. This training was given throughout the two years of

my research through two charities; *Elderly Support Group* and *Dementia Support Group*.

I continued participating in these opportunities as much as I could.

Participating in the actual music making process in these ways was not a new approach; rather it had been applied and discussed as an important part of ethnographic study, especially in the field of ethnomusicology (Seeger 2008; Shelemay 2008; Titon 2008).

The intersubjective involvement with music making as a volunteer member for 8 months before the actual data collection, joining in the “musical way of being-in the world” as Titon (2008, p.32) called it, helped me to get to know people, and to be known by them. More specifically, it helped us to get to know each other without using verbal communication; this was often a difficult task considering the cognitive capacities of people with dementia as well as my initially limited capacities to understand their verbal expressions. The residency, the participation in the music making as a volunteer and the training workshops also helped me to understand the contexts within which music making occurred involving people with dementia and disabilities. They also familiarized me with local idioms, norms and values around the music making. This involvement thus prepared me for real discussions later during the interviews. By that time I had already become “a part of the existing ‘community of speech’, whose norms and values could be so easily displaced or closed off by the externally imposed constraints of interviewing” as discussed by Stock (2004, p.17).

3.2.1 About the main field site (SB) and access

I ultimately chose SB as my main research site for my study, and a more detailed description of this is useful at this point. SB was a therapeutic and social activity for people with dementia and their caregivers and it was one of many activities run by the UK *Dementia Support Group*. The Watertown group was started in 2007 by a former

music teacher, Jessica, who was also one of the committee members of the local *Dementia Support Group* branch. As the facilitator she was responsible both for the practical and artistic aspects of the group. The number of participants varied from session to session, but approximately ten care-receivers, ten caregivers and ten volunteers attended. The majority of the members with dementia were cared for by their family members at home and joined the SB singing sessions with these family members. The singing sessions were carefully planned by the facilitator and a few volunteers in order to cater for their target audience. They took place every week during the school term. The members (care-receivers) were in various stages of dementia. In some cases, they joined SB after they and their caregivers found difficulties in continuing singing in their previous choirs. In other cases, the family of the member with dementia happened upon SB through a local doctor or *Dementia Support Group*. The length of time members participated in SB also varied from a few months to three years, but the majority of members participated on a regular weekly basis. The age of the members with dementia also varied from late 60s to mid-80s. The age of their caregivers ranged from similar ages (e.g., partners) to late 40s and early 50s (two caregivers were daughters [in-law]). The majority of the volunteer members (including the facilitator) had been participating in SB since its inception, which was two years before the beginning of my involvement. Most of the volunteers were in their late 60s and 70s, and began volunteering with the group after their own retirement.

Prior to my research I received the ethical approval from the Ethics Committee at University of Exeter and my research was also approved by the SB's parent charity, *Dementia Support Group*. When I was ready to start the research, Jessica and I had a meeting before the first session of the term when I planned to announce the wish to conduct research in the group. We discussed my plans, what methodologies would be

suitable to the group and agreed on the following areas to ask the participants of SB for their permission:

- 1) Audio-recording of the weekly SB sessions
- 2) Participant observations of the weekly SB sessions
- 3) Taking photos from time to time of the weekly SB sessions
- 4) Interviews with the participants (people with dementia, their caregivers and volunteers) wherever and whenever it would suit them

Jessica was very keen to have the recordings of the SB sessions both for promotion and as a record of the group's activities; thus we also talked about the possibility of making a CD out of my recordings. She was happy for me to study her own group through participant observations but in a non-intrusive way without any obvious action (e.g., sitting outside of the circle to observe). We effectively agreed that I would continue participating in a singing role as I had done for the previous 8 months while taking notes and photos from time to time. With Jessica's request, I wrote a letter to each member of SB, explaining my research plan. In the letter, I also included a part the members could tick if they were interested in participating a brief interview, recorded sessions, and photos taken by me with a section to write their personal details. Through the letter I not only explained to the group about my research but also got an idea about the number of potential informants. Jessica proof read the letter and suggested some changes to improve the English in the letter. For instance, she suggested to change the term "elderly" to "older" explaining that members would not be happy being referred as "elderly" but would not mind "older". Jessica also suggested inserting the logo of the

Dementia Support Group in the letter to emphasise that my research was approved by the parent charity (see Appendix 3).

The next day at the session, Jessica “reintroduced” me to the group and mentioned that I wished to do my research with them. I then explained about my research and my plan to do the interviews, audio-recording and taking photos and handed out the letter to the members. I asked the members to return it only after they understood my research plan. The facilitator prompted laughter by saying, “We can make a CD out of the recordings, and be famous!” The members laughed and clapped their hands. The presentation was informal and humorous and went very smoothly with Jessica’s help. The fact that I was already a familiar member of the group and that the group members had already experienced student researchers the year before seemed to have helped as well. I spent the next two weeks making sure that I had the forms returned by all the members. I depended on caregivers’ decisions whether they would like to cooperate with my study if the care-receivers were in their late-stage of dementia and understanding my research was beyond their capacities. In this way, I continued having the family caregivers involved in the research process to create a safe context for both caregivers and participants with dementia as suggested by Hellström et al. (2007). Several caregivers and volunteers came up to me and asked me when the interview would be. One couple gave me back the sheet in a beautiful envelope and told me that they would be happy to support my research. This process helped me to re-establish myself as someone who was interested in studying about music and care and it was also an important part of my ethical considerations in order not to impose my plan onto each individual in the first place, but rather let them decide whether they wanted to participate in my research project. Ultimately all members who were actively involved in the group at the time gave me permission to take photographs and record the active singing sessions and

everyone except one volunteer agreed to participate in an interview. From then on I recorded all sessions and occasionally photographed them for two terms. I also interviewed seven volunteers (including the facilitator), two representatives from the parent charity (“*Dementia Support Group*”), nine caregivers and seven members with dementia (See Appendix 7 for a list of the informants).

3.3 Carrying out the research

During the spring and summer terms in 2009 I collected data through participant observation and interviews as well as a complementary ethnographic study of the wider music and care world in Watertown. Below, I will discuss this process in detail.

3.3.1 Participant Observation

As Finnegan (2003, p.189) said, “people participate in music in multifarious ways in the different roles they take, the occasion, or their own personal histories-experiences of ‘the same’ text are not necessarily uniform”. I therefore thought that highlighting the varied meanings and experiences of the fairly simple tunes sung in SB sessions would help increase my understanding of the use of music in dementia care. As I discussed in the previous chapter, music was a larger set of resources available in people’s wider environment that allowed actors to access memories and to be connected with each other, thus bringing a sense of coherency. Hence, participant observation was effective as it allowed researchers to observe the patterns and combinations of available resources that affected individual ways of latching on to music. The researcher’s full involvement in the music making was important as musical experiences were corporeal and often multisensory (Finnegan 2003; Frith 1998; Seeger 2008; Shelemay 2008; Titon 2008). Therefore, it was important for me to observe them in action. Particularly, I focused on observing verbal and non-verbal interaction, the ways participants with dementia used

their bodies, the transformation of their engagement when music was introduced and their arousal level, the ways how all the members collaboratively crafted the group singing and its aesthetics using their different levels of cognitive functioning.

As discussed previously in chapter 2, I used DeNora's methodological model, "the Musical Event" (DeNora 2003), which helps ethnographers to observe specific acts of engagement with music based on three time lines; "before the event", "during the event" and "after the event". Every Tuesday during the term period, I arrived at the community centre before 1.30 p.m. where weekly SB sessions occurred, and started preparing the venue while chatting with volunteer members and welcoming participants with dementia and their caregivers, which was my participant observation of "before the events". The music activity started at 2.30, thus my "during the events" observation started at the same time and it continued over an hour until the participants left the venue. My "in-between and after the events"¹⁷ observation was based on my additional ethnographic study on music and care worlds outside of weekly SB sessions as well as the interviews with participants. Findings based on these three lines of observation have developed into my main chapters on findings (chapters 4, 5 and 8).

My participant observation of "before the event" and "during the event" was based on my involvement as a volunteer with SB after I started the formal research programme. Practical difficulties of taking notes during the non-intrusive observation were common in social research (cf. Bryman 2008, p.405). Although everyone there knew that I was also a PhD researcher, I continued being involved as a volunteer as before and

¹⁷ As I observed weekly musical events over the period of 6 months rather than just a single event, I called them "in-between and after the events".

deliberately tried not to focus too much on my “researcher” pose to session participants. This was also a part of my ethical considerations. I 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. However, immediately after each session, I wrote down several key points that seemed poignant and significant from my reflections on the session (e.g., “The way A raises his concentration was very subtle, but I could see that his concentration was raised by reading the lyrics carefully and paying attention to them.”) When I arrived home later, I updated these memos, and continued writing detailed field notes while carefully listening to the session recordings and referring to the session plans that were given to me by the facilitator. The photographs were also useful to refer to as an *aide memoire* when writing field notes and acted as reminders of contexts as Bryman (2008, p.425) also suggested. Afterwards I also made notes about strategies for future sessions, for example what/who to look at more carefully. Before I went to subsequent sessions, I read previous field notes to refresh my memory. During the sessions, I tried to sit close to the participants that I was interested in learning more about or sat in a chair where I could observe them clearly. I also read relevant field notes before each interview and sometimes added pertinent questions to ask each informant to explore their experience of particular musical events more in-depth. The participant observation also allowed me to “set a picture of what people actually do alongside what they say they do” as Stock (2004, p.23) also pointed out in his ethnographic study. In this way, the complementary use of methods was useful to enhance my understanding of the meaning of musicking. Thus my research interests and the direction of further data collection of data were led by the data in keeping with

grounded theory conventions (Charmaz 1995, pp.32–33), something I will return to later. Overall, 12 sessions were observed in this way over six months.

I made use of photos and recordings taken during the weekly sessions in other ways as well. For instance, I brought hard copies of some photos and put them on the admission table in a photo album for the participants to look at. These photos seemed to have become tools for participants to remember past sessions as well as simple devices to generate conversation among the members. One example of these photos is shown below.



Picture 1: A photo from SB sessions

Additional benefits of the audio recordings of the sessions were derived by the creation of several compilation CDs (see Appendix 8 for the song list) with songs from different sessions. Compilation CDs have been used in other studies on music and health. For

instance Batt-Rawden's (2007) "participatory CD design" used the CDs of recorded music as core research tools. Within my study however, the CDs were additional tools to elicit further feedback with all the songs being from the actual SB sessions. The compilation CD was first made for a volunteer to bring to participants who already left SB due to the progress of their illness. They were also given to caregivers and care-receivers in the later stages of my volunteering work (after the interviews were done) which went some way towards thanking the informants for their time, and they were well received.

3.3.2 Interviewing

3.3.2.1 Interview programme

The interviews were conducted in parallel to the participant observation. Before conducting each interview, I obtained formal signed consent from my informants (see Appendix 9) and I explained that they could choose to withdraw this consent anytime they wished, a key ethical issue. The interviews were semi-structured with different sets of questions prepared for different categories of informants: the facilitator, charity representatives, caregivers, care-receivers and volunteers (Appendix 2, 4, 5 and 6).

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 while at the same time ensuring that I covered areas of interest to my research. This approach to interviewing was of key importance in order to learn more about how music connected with their everyday lives, rather than leading my informants to see music as a static and isolated "input". As Denzin (2009) noted, data collection through interviews was an interactive process which depended significantly on the variable personal and situational properties of the interaction between interviewers and informants. I also asked additional questions

to investigate themes and topics brought up by interviewees. Not only did the participant observation help the data elicitation in the interview as discussed earlier, my continuous involvement as a volunteer prepared me for the interviews most notably with the caregivers and care-receivers. For them, their experiences of caring or having dementia were very sensitive issues, and it might have been difficult for them to discuss (and be understood) by someone who only had limited time available to share with them. The mutual trust I had built up over time was necessary for me to create safe contexts (Hellström et al. 2007, p.614) for them to feel comfortable when talking about the sessions and their own experiences with music and dementia more generally. Moreover, since it could be difficult to make immediate sense of the words of my informants with dementia, and since their moods could alter quickly, the total of 14 months of observation was helpful in helping me understand the meaning of specific habits and the overall character of care-receivers.

I interviewed the volunteers, the facilitator as well as two representatives of *Dementia Support Group*, first because I wanted to shed more light on the group from an organizational point of view. After these were done, I interviewed participants with dementia and also their caregivers. The initial interviews had been useful in many ways, and also helped me to prepare for the interviews with the members with dementia and their caregivers. Some of the volunteers shared notable episodes from the sessions that had escaped my notice. The majority of the volunteers, who had been involved with the group longer than myself, knew the members with dementia from when these members first joined the group. They were therefore my “key informants” as Ericsson et al (2011) term them. Thus they could often tell me about members’ involvements in earlier stages of dementia. I did not explicitly refer to these interviews when interviewing the members; however the knowledge gained through interviewing the volunteers prepared me for my

interviews with care receiver/giver informants. I was also able to confirm the data in subtle ways and was able to use these later interviews to further develop the themes that arose in the data from field notes and interviews with the volunteers.

When scheduling interviews with caregivers 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. There were instances when care-receivers' conditions deteriorated considerably from the time I first asked them to participate in the interview research. In those cases, I depended on caregivers' decisions and advice as to whether the interview should be carried out or cancelled, and when and where the interview would take place. In one instance, for example, the interview was cancelled due to the sudden worsening of a care-receiver's condition; in this case, his caregiver contacted me.

The purpose of the interview was explained to the caregivers and care-receivers when I first obtained signed consent from them and the interviews were conducted in the presence of both. As Steeman et al. (2007) suggested, interviewing a person with dementia and his/her caregivers together provided better understanding of the social context of the person with dementia's lived experience and of data triangulation.

Dewing (2002, p.168) also argued, "Maintaining consent is clearly an issue in much of the research with people who have a dementia because of their memory changes". Thus, with the members who were in later stages of dementia I employed the caregivers' 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 with my interviewing them and their caregivers. Hence it could be considered that they consented to participate in the interview through such non-verbal and behavioural cues as Hellström et al. (2007) also discussed. In the singing sessions up to this point and after, 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 more restricted, formal interviews.

Conventional semi-structured interviews may not always be appropriate for people with dementia (Goldsmith 1996), thus alternative approaches could be required. Kitwood (1997) and Muguruma (2012) both suggested observing and paying attention to what people with dementia said in the course of their day-to-day lives. In my case this was achieved through my extended participant observation and the ethnographic study of the wider music and care world outside of SB sessions, which will be discussed later in this chapter. I also developed techniques and strategies during the interviews with members with dementia by using music to involve people with dementia further in the interview process.

3.3.3 Music use as an interview strategy

3.3.3.1 Musicking as a possible resource to elicit information in the interview

In this section I will discuss how active music making, musicking, became a resource for eliciting information during interviews with my informants, including those with dementia and their caregivers in my study. Below is an excerpt of an interview with Michael and Laura, the first I did with a person with dementia and their carer, which took place at a local café and triggered the development of the use of music in the interviews. Laura had dementia, and Michael was Laura’s husband and caregiver.

Interviewer: How do you like [SB]? What do you like about it?

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

Laura: I sing well.

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

Laura: I was on the radio.

Interviewer: You were on the radio?

Laura: I was.

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

Laura: I sing very well.

Laura, who had dementia, often said, “*I sing very well*” when someone was talking about music generally. This clearly built her self-confidence in the moment, and that is how she presented herself during the singing sessions and interview. Regarding her comment, “*I was on the radio*”, she was probably referring to the radio program which featured a SB 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 explored these activities further, as well as their involvement with SB:

Interviewer: 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...

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

Laura: What?

Michael: Singing.

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

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

Laura: Yeah.

As we can see in this second excerpt, Laura sang during the interview, responding to my question and conversation between Michael and me. 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 SB sessions¹⁸ and seemed 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 SB 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.

¹⁸ American popular song (1952).

This interview made me aware that singing or other kinds of music-related activity may help elicit data in the interview. I also realized that the setting and situation were crucial to the interview, especially when one of the interviewees had dementia. In these cases, the setting should be somewhere the interviewee could sing and, equally importantly, should be somewhere the caregiver felt comfortable about any spontaneous incident (such as spontaneous singing by the care-receiver). Fortunately, all the other informants (caregivers and care-receivers) were happy to conduct the interview in their homes or nursing homes.

In other research, music listening has been used as a tool during interviews to elicit information about how music was used, heard and judged by the informants (Allett 2010) and, similarly, auditory stimuli have been used to evoke autobiographical recall for people with dementia (Foster & Valentine 2001). The use of CD listening has been also discussed as a useful tool in conjunction with interviews in the data collection procedure as it acted as an icebreaker, triggered memories and awareness and thus contributed to achieving a qualitatively rich data collection (Batt-Rawden & Aasgaard 2006). These studies, however, used recordings as an “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 could be very challenging, even in a secure environment, with regards to exploring what they “really” think. There are two main reasons that this was the case. First, musical taste was frequently ‘performed’ (i.e., as individuals attempt to present themselves in a certain way) (Hennion 2007). This was also the case during interviews; often informants did not expose their personal musical preferences, but instead preferred to give “correct” answers, for instance by claiming

that they liked songs that others (in their peer group) enjoyed (Koizumi 2002) or songs that were regarded as “appropriate” for their generational image (Hara 2007). This strategy might apply to individuals with dementia as well. Second, communication was particularly difficult with individuals who were 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 and started bringing the SB songbook that they usually sang with to the interview to refer to or sing with if appropriate. 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 SB 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 caregivers took the initiative to sing 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.

3.3.3.2 Creating the social context of memory through music

The interview excerpt below came from the beginning of an interview with Hannah (a caregiver) and Simon (a care-receiver). This was an example of how musicking helped elicit data in an interview. Hannah and Simon had been regular members of SB 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 SB sessions due to Simon’s advanced symptoms of Alzheimer’s. I showed Hannah and Simon the songbook from SB, and put it between us. The whole interview was very relaxed, with Simon lying down on the bed and with Hannah and me sitting beside him in their house. I used music in the interview, mainly singing and referring to tunes from the SB 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 also 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, something that will be discussed more in detail in chapter 8.

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) in the interview, Simon joined in the singing in the middle of each song. DeNora (2000, p.79) discussed 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: You want to sing one more? From the book? Since we got the book here. [She looks through the song book.] How about 'I'll be your sweetheart'? We have that here, because we all know that tune. Do you remember it darling? We had it on Valentine's day. 'I will be your sweetheart..' [Hannah starts singing, Mariko joins in, then Simon joins.]*¹⁹

¹⁹ See Appendix 10 for the lyrics

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 & Interviewer: [laughs]

Hannah: Long time...

Interviewer: 59 years... yes. Did he use this song when he proposed?

Hannah: I think that is a Valentine's day song. I think that's it. (laugh) I can't remember the actual proposal. I can't remember when we suddenly decided that we would actually get married.

After Hannah responded with the lyrics of “*I’ll be your sweetheart*” 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.

Although neither Hannah nor Simon mentioned a specific association or memory with this song, one of the volunteers, Rosie, mentioned a touching moment involving this song during an earlier SB singing session; when Hannah and Simon responded directly to the singing of “*I’ll be your sweetheart*” by looking at each other, and Hannah was moved to tears. Rosie also noted how their life as a couple has changed due to the onset of Simon’s Alzheimer’s disease. 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. A similar phenomenon took place in my interview with them, prompted by the same tune which led Hannah suddenly to become very eloquent in talking to me about their married life. In this way, multiple methods aided each other in collecting rich data; in this case, participant observation at the weekly SB sessions as well as the interview with Rosie helped me to situate what Hannah said and how she might have felt in the interview after singing “*I’ll be your sweetheart*” together with Simon.

After singing these tunes, an intimacy also developed between Hanna, myself and (possibly) Simon by singing together, which made it easier for Hannah and me to talk about their personal matters: family, the experiences and difficulties of their daily caring life and transformation of their musical life due to Simon's dementia. 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 the SB repertoires collected in the songbook, provided resources for the interview by triggering our singing. Talking about music and singing also provided a comfortable social context for eliciting memories for the informants. These repertoires were known to the informants and me, so we shared the common experience of having sung these songs in the SB sessions. Therefore, the SB 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.

Benett and Maas (1988) discuss how music can be used effectively for life review. As the example above shows, the use of musicking also worked as an effective method in life review. In the beginning, the interview was initiated by the repertoires and songbook from SB, 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, 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 was an active and naturalistic way to access deep and musically entrenched memories woven into the fabric of one's life.

3.3.4 Continued ethnographic study of wider music and care worlds

I extended my ethnographic study of SB into the wider music and care world in Watertown during and after the 6-month period of data collection. This was done so that I could gain a better understanding of the local context(s) where various SB participants' everyday life actions and involvements took place. This included my continued involvement as a volunteer with *Sounding-out*, the local music group, participation in music and care related events as well as meetings with participants of SB during the vacation periods. Being temporarily local gave me access to further pertinent data. For instance, I often went to music concerts that some of the members of SB and/or *Sounding-out* took part in, kept myself informed about activities run by charities and attended such events as much as possible. I often "bumped into" members of SB 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 allowed me to penetrate the field more deeply than what just attending the weekly SB sessions would allow (c.f., Stock 2004). For instance, they enabled me to investigate what my informants' everyday life was like apart from their participation in SB, what their musical lives were like before and after the onset of dementia and how weekly participation in SB might have helped their everyday life and the development of musical affordances (from SB sessions) in ways to affect their everyday life positively. The findings of this will be explored more in detail in chapter 8.

Just as Becker (1974) studied the networks that were responsible for producing specific art events and highlighted the overlaps of such networks as “art world”, I also analysed the network of local music and care groups and individual actors in these groups and mapped the interrelations in order to explore various social relationships and the densities and qualities of the links between groups and individual actors (Scott 2000). Thus, I gained a holistic understanding of how local music and care pathways were linked to each other to support local people with dementia and their caregivers (see chapter 9).

After the 6-month period for data collection, I stayed in the field as a volunteer with the two groups (SB and *Sounding-out*) and continued attending the weekly sessions for about one year until relocating to another town in England. Although the level of my engagement was reduced by comparison with the data collection period and the period before that, my extended involvement, which took place alongside my analysis and writing up, allowed me to do additional participant observation when needed. This will be discussed in the following section.

In this way my data collection was triangulated through 1) participant observation of the weekly SB sessions; 2) interviews and 3) the extended ethnographic study of wider music and care worlds. The data gathered from the participant observation was written down as field notes that I did after the singing sessions, often aided by photos and audio recordings. This data was corroborated and further explored through the interviews with informants (i.e. the care-givers, care-receivers, volunteers and charity representatives), thus multiple perspectives, including mine, were compiled. The additional extended ethnographic study helped to contextualize the data from the participant observation and

the interviews and also helped to further explore the connections and the movements between different music and care related groups that were connected to SB.

3.4 Analysing the Data

The grounded theory approach enables the exploration of concepts to emerge from the data gathered rather than trying to impose pre-existing concepts onto the data analysis process through the use of predefined hypotheses. Thus it is useful in studying social issues that are very personal (Strauss & Corbin 1997). For instance, it enabled Clare et al (2008) to study awareness, experience and function of people with dementia while allowing Cuesta (2005) and Wilson (1989) to approach the complexities of caregiving experience. This also worked well with my research interest which was closely to explore the experience of musicking by people with dementia and their caregivers. I therefore chose to analyse my data following the grounded theory approach. In this approach the analysis process was often closely intertwined with the data collection process, especially when the data was collected through an ethnographic study which allowed us to immerse ourselves deeply in the data. The analysis process could start early (Charmaz 1995). My analysis process was aided by my presentations of initial findings at conferences and in publications. For instance, as I had started being involved with the wider music and care world and started learning about the interrelationships between different music and care groups, themes such as “network “and “caring community” emerged in the early stage before completing interviews and my participant observation. The “continuing education” theme emerged in the earlier stage as well, as the aspect of learning songs and accomplishing the goal (e.g., to sing in harmony) in a group struck me as being unusual among people with dementia who were more often targeted for more clinical/therapeutic implications. In order to prepare for

my presentation at the European Congress of Music Therapy in 2010, I listened to all the interviews carefully, took memos and coded the rough transcription using the software Nvivo to develop preliminary findings. Three themes emerged; “SB as an ecological practice”, “SB and everyday dementia care” and “music and care pathways as resources”. The presentation became a base for my publication for *Voices* (Hara 2011a).

Later I started a more thorough analysis process. First, I listened to all the interview data again and transcribed them word for word. As the first step of analysing qualitative data was a careful reading of the interview and field notes from the observation and open coding as suggested by Ericsson et al. (2011), I also read the field notes while listening to the recordings of the weekly sessions, and added memos to the initial field notes. All these processes helped me to pay close attention to my informants' feelings and views as Charmaz (1995, p.36) has suggested. As my understanding of English was not perfect and I did not always share the cultural references with my informants, what my informants with dementia said was sometimes difficult to interpret. I was therefore careful to ensure that I had grasped the meaning with the help of a colleague who was local and experienced in qualitative data analysis to interpret the interview data by checking my transcription and adding comments relating to local idioms, music, etc. We often searched for the music that was referred to in the interview. One time *YouTube* file helped us to interpret what an informant with dementia was saying with regards to his associated memory about a song (“The Inch Worm”²⁰). It matched a specific scene from a film (further discussion in chapter 6). Although it took me a long time to transcribe the interviews in their entirety, I considered these challenges an advantage. As Charmaz

²⁰ A theme song for the film, “*Hans Christian Andersen*” (1952).

(1995, p.36) also claimed, it was important not to take for granted that I shared the same meanings as the informants. If I had shared the languages and cultural backgrounds with the informants and the interview data had been easy to interpret, I might have rushed to make the meanings of the data explicit without reflection.

Following this, I started detailed coding of all the updated transcriptions using Nvivo. I coded my updated field notes from the participant observation as revealing data that also resided in the researcher's own observations, as Charmaz (1995, p.36) has discussed. Nvivo allowed me to code sentences very carefully and closely. First I coded all the transcription and the field notes into free nodes. Then I categorized the free nodes into a three level hierarchical structure with grandparent, parent and child tree nodes.

Below are the 14 top level nodes (grandparent nodes).

1	Affordance, SB session
2	<i>Dementia Support Group</i> , bureaucracy
3	Belief, benefit of music, singing
4	Dementia, illness, person
5	Everyday life, care, music
6	Fieldwork, methods
7	Grounded aesthetics
8	Importance in dementia care
9	Music and care world, pathways, SB
10	Music and life, life style
11	Passing experience and unfinished caring
12	Publicity, showcase
13	Relationship between caregiver and care receiver
14	SB and other activities

Table 1: 14 top level free nodes

The process of coding forced me to think about the material in new ways and look at the statements and actions of my informants in ways that may not have occurred otherwise as Charmaz (2006, p.55) has suggested. For instance, I would not have noticed themes such as “structure as an important device” and “transformation, growth of the group”, which became important themes to be developed in the study, without the close coding process.

For writing-up purposes, I have further categorized and organized the above tree nodes again as listed below.

I. Mechanism		Structure as an important device
		Belief, benefit of music, singing
		Grounded aesthetics
II. What the mechanism affords		
	II-1. Musical Affordance	Affordance, SB session
	II-2. Affordance in everyday care	SB session and everyday life, everyday care
		Dementia, illness, person
		Everyday life, care, music
		Relationship between Caregiver and Care receiver
	II-3. How distinctive these affordances (music) are	SB and other activities
III. Music and care world, SB as a hub		
	III-1. Pathways (location, interlink of knowledge, people)	Music and care world, pathways, SB
	III-2. Pathways (Time)	Music and life, life style
		Passing experience, unfinished caring, reflect with own life in SB
		Transformation, growth of the group
	III-3. Possibility and limitation of SB as a grass-root activities	SB as a grass-root singing activity
IV. Grand narrative		Publicity, showcase
		<i>Dementia Support Group</i> , bureaucracy

Table 2: Organized highest level tree nodes

Out of the 14 highest level tree nodes, I omitted some, for instance, “importance in dementia care” as the issue on dementia care alone is not the topic of my research.

As the above list shows, three major themes emerged; 1) mechanism, 2) affordances and 3) music and care world. I decided to use these three themes as the core concepts to build my discussions around for the chapters on findings. For example, I felt that close examination of the structures of the music activities and unpacking their “*mechanism*” (how they work), including the grounded aesthetic generated in the music activities, would help highlighting discursive musical “*affordances*” within SB sessions and in participants’ everyday life. By highlighting the quality of various music and care pathways I was led to highlight how SB worked as a node of a wider “*music and care world*”, which would also help us to understand discursive musical affordances of weekly SB sessions that developed along with those pathways. In the process of writing up my finding chapters the theoretical themes emerged, one of which was “musicking and permeable borders across time and place”, which led me to do further data collection (Charmaz 2006). I did additional participant observation while I was still involved with the weekly session as a volunteer to explore the theme further by observing what it was to continue singing in the SB sessions for former caregivers after their partners (or friends) died. The finding of this will be discussed in chapter 8.

The feedback I received on my presentations at various conferences and meetings further sharpened the development of themes. For instance, I was advised to highlight the distinguishing characteristics and the quality of music and care pathways at the European Music Therapy Congress in 2009 and at a research seminar at Kobe University, Japan in 2011, which encouraged me to explore more on “pathways” as shown in chapter 9. The possibility of stereotyping participants due to the use of specific repertoires was pointed out in the research seminar at Cardiff University in 2011, which also sharpened the discussion on the “mechanism” of SB repertoires as shown in chapter 6.

3.5 Self-reflection

Before ending the chapter, I would like to reflect on my experience of preparing and carrying out the research as well as analysing the data.

First of all, how did my role as a volunteer member influence the whole research process? It prepared me to start participant observation smoothly as I had already become familiar with the contexts of the music making; my informants were familiar with this as well. However, as I continued my role as a volunteer while I was also collecting data as participant observers, I have often felt the dilemma of the dual roles. Lain (2000, p.2) discussed how “overlapping or multiple roles and relationships presented researchers with a range of complex and unavoidable ethical and practical dilemmas”. For instance, in the beginning I sometimes felt frustrated in the one hour before the session started and members arrived which was my communication time with informants. I tried to make appointments for interviews with them, but since I was the only student volunteer and had to continue doing the jobs as before, finding time within “my previous volunteer hours” was sometimes hard. Later on, I figured out that calling them to make appointments was more efficient as I already had their contact details when I received the feedback from them at the start of participant observation and this solved the problem.

The continued role as a volunteer also impacted my analysing process. Through my continued involvement, I kept observing the development and transformation of the SB sessions even after the set data collection period; thus new data kept coming in for my attention. This made it difficult to analyse the existing data on a theoretical level.

Relocation to another town in the UK after 2 years curtailed my weekly involvement with the field, which allowed me finally to analyse the collected data on the theoretical

level. The analysis process also coincided with a period when several informants with dementia deteriorated and passed away. This made the writing up process emotionally difficult as the long-term ethnographic involvement had made me close to the informants. However, other informants sometimes contacted me and we attended funerals together, as a result the emotional difficulties of writing up eased.

I have already mentioned earlier how my Asian ethnic background was not common in Watertown. Stock (2004) has discussed how a researcher's gender, age and ethnicity may encourage certain attitudes by fieldwork contacts. Thus my ethnic background, as well as my university volunteer status may have resulted in certain attitudes among my informants; however these were mainly positive. For instance, members were willing to explain to me the background of songs whenever I asked them. One time, when we were singing a song without any song book, a volunteer member insisted that I should have a song book saying, "Mariko is from a different culture, so she doesn't know all these songs!" Overall there was only one negative incident related to this issue: a person in a late stage of dementia suddenly reacted to my ethnicity in a disapproving manner by treating me discourteously on her first day of participating in the SB session. I was surprised and puzzled at the incident; however, the other members became protective of me soon after, which solidified the bonds between me and them. The person participated in the sessions only a few more times and did not show any negative reaction to me after the one-off incident even when I chatted with her caregiver. She left the group soon after. Thus I did not have the chance to interview her, or to observe her closely.

Some of the interview data touched on very private issues. In those cases, I decided not to use them although consent forms had been signed each time before the interviews took place. I sometimes found it difficult to draw the line whether they should be or

should not be used. In these cases, I always consulted with my supervisor. I also tried to keep my main informants informed about my research process by circulating any published articles or through casual chatting to make sure to avoid any possibility of causing harm to my informants through the ways the data were used as Laine (2000, p.14) also suggested. Overall I aimed to maintain an ethical stance in all my fieldwork, without sacrificing the general goal of making a contribution to knowledge.

3.6 Summary

In this chapter, I hope that I have shown the usefulness of my own multi methods approach in order to help uncover the meaning of music in dementia care. The multi-methods were not only useful, but highly necessary to explore the meaning of music-making in the *everyday lives* of people with dementia and their caregivers. This applied particularly to discursive musical affordances that were not restricted to a single setting (the weekly SB sessions), but that developed expansively in the longer term in ways to benefit the everyday life of people with dementia and their caregivers. For instance, it would have been difficult, if not impossible to find the key themes (“mechanism”, “musical affordance” and “music and care world”) without situating the SB sessions in a wider ethnographic study of the Watertown music and care world. By investigating the music and care world as an active agent and mapping the social context in which I was placed, as Latour (2005) also suggested, I could trace the connections between various groups to explore how these connections were “activated” to support people with dementia and their caregivers. The combined research focus on longer-term participation observation also helped me to build mutual trust with caregivers 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. The music-elicitation interview with people with dementia and their caregivers also developed as a very useful way to elicit data, combined with the other methods, especially in ways to involve people with dementia, who were often excluded in the research process.

Music, or rather musicking, did play a vital role as a "lifebuoy" in the data collection process by providing a means to access thought and experience related to music activities (See Hara 2011b for more discussion on this). I believe that the multi methods discussed in the chapter represented an innovative way to capture the essentials 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 meaning of music use in everyday dementia care. In the following chapters, I will discuss details of my findings that were developed through the methods.

Chapter 4: Preparation for the Events

4.1 Prologue of chapters on findings

Over the next five chapters I will present the findings that have emerged from my ethnographic study of a particular music and care world centred around *Song Birds* (SB) in Watertown which included my two-year-long participant observations of SB sessions and related interviews. As mentioned earlier, my research has focused on investigating the musical affordances that benefited the everyday lives of people with dementia and their caregivers, and I have suggested that such benefits have a discursive root rather than causal root often suggested in the current literature. Small's work (1998) was important in my study, as discussed earlier, because he has highlighted the process of people participating in musical performances in a multitude of ways through the use of his concept of "musicking". Therefore, I have closely investigated the process of **how** people participated in music and interacted with it, in this case mainly through the weekly SB sessions. Here I will be highlighting the range of participants' actions from the obvious to the subtle that all contribute to the overall music making processes. My detailed study also led me to the discovery of a wider music and care world in Watertown where the process of musical participations at SB sessions developed and extended to the wider community. As a result, various socio-musical processes were illuminated "underneath" the music and care world not dissimilar to how Becker (1992) highlighted the social process underlying the production of an art world. The findings of this will be presented in the following five chapters. First I will explore and explain how the crafting of SB sessions took place in three temporal phases around the regular weekly events: before the events (chapter four), during the events (chapter five), and

in-between and after the events (chapter eight). Here I utilised DeNora's (2003) methodological model, "The Musical Event" which was discussed in chapter two. In addition I will highlight certain mechanisms found in the SB repertoires in chapter six. In chapter nine I will conclude my findings by discussing the music and care pathways that connected people and groups within and outside of SB to aid our understanding of the solid and discursive musical affordance that could be utilised in dementia care.

Throughout these chapters, not only do I hope to shed some much needed light on the use of music in dementia care in the community that has largely been overlooked in the existing literature on the topic, I am also attempting to show the innovative and alternative ways of collaborating with others in order to care for local people with dementia care.

4.2 Introduction

In order to improve the experience of singing, the venue of the weekly SB sessions was carefully prepared to provide a safe and stimulating environment. This was an important issue as the World Health Organization & Alzheimer's Disease International (2012) has emphasised, particularly when providing an activity that aimed to support the physical and mental functioning and wellbeing of people with dementia and their caregivers. I have already described the general symptoms of dementia as well as the overall distress that caregivers experience; however it was useful to describe some specific conditions suffered by participants of SB as a context for my later discussions.

The participants with dementia and their caregivers generally joined SB because they faced changes and difficulties in their everyday lives caused by the memory problems or the physical changes caused by dementia. For example, Arnold, who had dementia, his wife Monica and Arnold's friend Bob, joined SB because Arnold had difficulties

continuing singing in the local choir where more complex pieces like Handel's *Messiah* were sung. Similarly, Michael and Laura had to give up singing in local choirs due to Laura's dementia.

Chris and Kelly meanwhile, were having difficulties getting out of the house because Chris was dependent upon Kelly's continuous care and he was unable to handle other local services provided for people with dementia. Kelly told me that at the point I met them SB was the only thing Chris could cope with. Such isolation was not uncommon. Hannah told me that her social life and that of her husband Simon faded away as Simon's condition progressed. Thus, for most of the caregiver/care receiver teams, SB was the only social activity in which they participated.

Two of these caregivers also expressed how they experienced the stigma of their partners having dementia. Monica described, with some irritation, that dementia was still a taboo and even though things had changed, people were often shut away and not brought along to social occasions. Similarly, Hannah described her frustration about how they were treated in another group that she and Simon came across before they joined SB:

*(...)it was appalling and I wouldn't ever go back. [Q: really?] Quite simply that... They [people with dementia] were considered not having any brain, that is **stupid** [very angry]. And what was being offered was shoddy and second rate. And there is a lot of that going on. Well-meaning people, people who are well-meaning, wanting to be helpful, to do something, but talking down, condescending, not nice. We went once, didn't we darling [confirms with Simon. Simon nods], came out, rushed across and looked at the sea, and said, that is the end of that, we are not going back there.*

She pointed out the “*enormous difference between most Alzheimer's groups and Jessica's group (SB)*”, and that:

The atmosphere is wonderful. And it is because of that atmosphere, she has people like you, like Nichola and Sophie doing the teas, Rosie at the door. All these people. She has people who are happy to be part of it at all. Because the atmosphere is so good.

Hannah's comment emphasized how crafting a safe, welcoming atmosphere was important when planning activities for people with dementia and their caregivers. The fact that SB was the only social involvement they chose to participate in as well as their negative experiences of other attempts at dementia care reinforced the importance of this. As far as Hannah was concerned, SB was obviously successful in generating a safe and welcoming atmosphere that met their needs. This in turn attracted volunteers who were happy to be part of SFTP and did not act in a condescending way, thus establishing a virtuous cycle. In fact, many of the volunteers were, like most of the participants, retired people and many of them were great music lovers. They often expressed (as I will discuss later) how meaningful it was for them to join SB so they could make use of their music skills to contribute to SB's purpose while at the same time allowing them to expand their interests in music uses in care in joyful ways. As implied by Hannah, the stability of the personnel (e.g. Nichola and Sophie were always helping with the tea, Rosie was always at the reception) also contributed to the creation of a secure and pleasant atmosphere. In addition to what Hannah pointed out, there were a number of considerations and collaborative actions that also helped to create this atmosphere that will be discussed in detail below.

A few participants described their hesitations when first joining SB. Peggy who came with Nichola (her mother-in-law who had memory issues but not full blown dementia) said that, "*When we first started, we were quite shy.*" Nichola also told me how worried she was when first coming as she thought she had to sing a solo in the group. However,

both of them explained that they started enjoying themselves from the first session despite the initial hesitations.

Nancy, one of the volunteers, expressed similar experiences although as a volunteer she needed to deal with it differently.

When I first came, I wasn't sure how I would feel. Because when you come through the door and you see somebody in a position, like say... my father who I cared for... I got quite umm... for a little while I felt very emotional. [...] But as the weeks went on, you learn to detach from that.

Some of the volunteers, such as Nancy, had experiences in caring for their partners or other family members who had dementia, and later started coming to SB hoping to pass on their experiences or to learn more about dementia. Their first encounter could be as difficult as those experienced by new participants with dementia and their caregivers. Even the service manager of *Dementia Support Group Southwest*, Irene, was feeling nervous for personal reasons prior to her first visit to SB, however her first encounter became a very pleasant experience despite her nervousness:

I went along and it was the best thing I ever done. Because I walked in there, and there is this milling around, that was a meaningful milling around. They were people calling to out each other.. 'hiya, how are you?' people with dementia, there was hardly any agitation, it was obvious signs of dementia were prevalent with some people, then everybody sits down, everybody is friendly, books are being handed around, little jokes all around, so the whole thing was one of openness that I was made welcome as a stranger.

Presumably part of the reason why people felt hesitant in their first encounters with SB was the fact that SB sessions targeted people with dementia, an illness that often provoked awkward social responses. This is why Irene felt relieved to witness “hardly any agitation” (one of the most distinctive symptoms of dementia as discussed in chapter one) in the participants in her first encounter with SB.

If Nichola, Peggy, Nancy and Irene felt hesitant in their first encounters with SB, participants with late stage dementia may have felt hesitant **every** time as they may have continued to experience every SB session as something new due to their memory issues. What were the key issues that SB needed to consider helping everyone overcome their worries, be it for the first time, or every time?

First of all, it was essential to tackle the symptoms of dementia; loss of memory, loss of orientation, the inability to plan ahead and the overall sense of isolation and anxiety caused by these symptoms as Ohi (2008) has discussed. The venue therefore needed a) to be prepared to help improve the orientation of those suffering from dementia, b) to help them regain a sense of continuity so that they could reestablish the connection with the surrounding world. This connection in turn helped reduce their anxiety and caregivers' stress. The friendly atmosphere that was established through a range of practices also helped to deflect any hesitation in joining in on the part of new or even regular participants. When the world became understandable in this way, a degree of "ontological security"²¹ was achieved, which in turn encouraged people to **want** to be creatively involved with other people as discussed by Parker (2001). Such involvement helped people to establish meaning in their lives as Giddens (1991) has discussed.

Therefore it was clear that SB had managed to create a safe, non-clinical place, just as the *Dementia Support Group* encouraged it. Below I discuss in detail the considerable crafting and framing of the venue that took place before the actual musical events happened in order to make it sustainable for SB purposes. This was explored in three

²¹ According to Giddens (1991), ontological security is as a sense of order and continuity in regard to an individual's experiences.

parts; 1) basic physical/material framing, 2) session specific material framing and 3) social framing that took place within the former.

4.3 Basic physical/ material framing

The sessions were hosted in a local community centre. The venue was chosen by the facilitator, Jessica, and a few other volunteers who considered general safety and accessibility requirements as well as the appropriateness of the place for singing. This was followed by an assessment directed by the *Dementia Support Group* to ensure that the venue followed the DDA²² accessibility and health and safety standards.

The venue was located on the ground floor of a community centre, a few minutes away from the city centre of Watertown. The entrance was easy to be found as it was facing the main street. The venue also had plenty of parking spaces, a requirement as most of the participants used their cars to get there. There was also a door directly from the parking space with a slope for wheel chair users. The room had good acoustics with the wall echoing back the sound of the singing, which was very important for the participants' aesthetic experience. Two of the walls had several windows which gave a lot of natural light as well as a pleasant breeze when the weather was nice enough to open the windows. It was also important that participants were able to experience the season from the scenery and weather outside through the window as some of the songs were chosen specifically to suit the seasons or the weather of the day, which also helped

²² The UK's Disability Discrimination Act (DDA) defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. (http://webarchive.nationalarchives.gov.uk/+/www.direct.gov.uk/en/disabledpeople/rightsandobligations/disabilityrights/dg_4001069)

improve their orientation related to place and time. The floor of the room was just a simple plain cream colour without any pattern which helped to avoid any confusion or negative reaction by participants with dementia, as Jessica explained. Most of the volunteers arrived at the venue one hour before the session to prepare the venue. For example, balloons with the *Dementia Support Group*'s logo were hung up on the door of the community centre for participants to find the venue easily (picture 2).



Picture 2: Volunteers blow up the balloons to hang up on the door. The two volunteers on the left are from a local secondary school. They participate as part of community works in the school. The man in the right is a local volunteer.

Figure 1 below shows the basic physical setting that was prepared by the volunteers for the regular weekly sessions. This was always done in the same way except for a few occasions when local school children were invited to join in the singing, something that will be discussed later in this chapter.

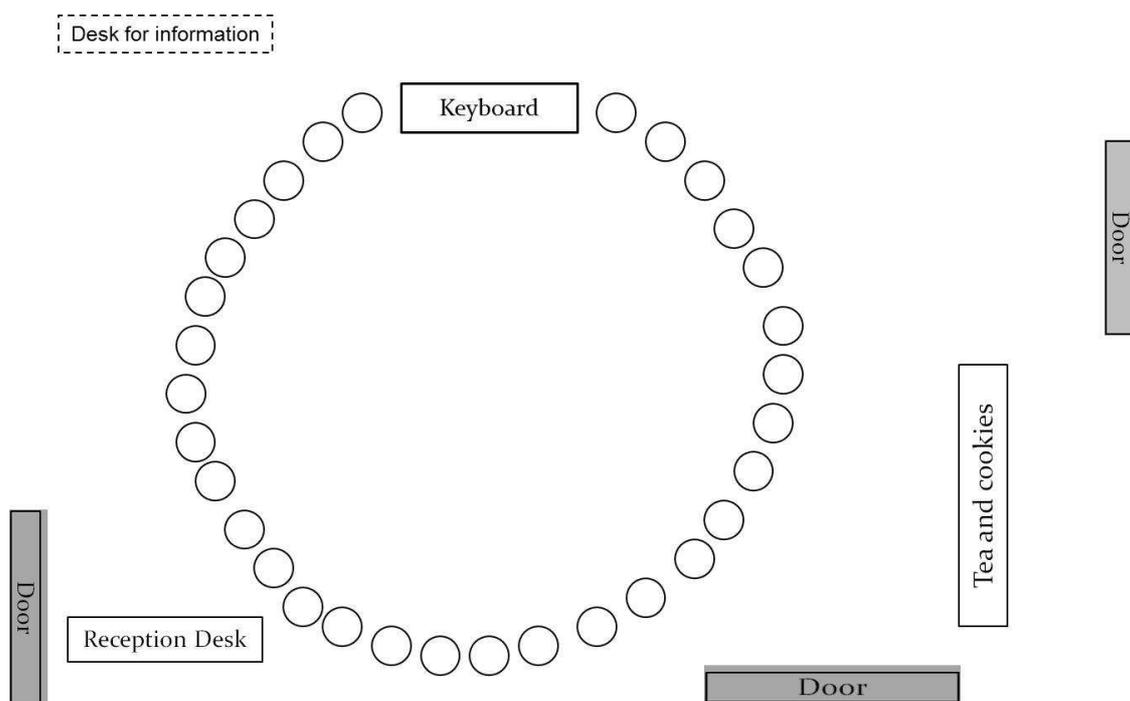


Figure 1: Physical layout of SB sessions

The door on the left is the main door, where most of the participants came in. Several wheel chair users used the door on the right which was directly connected to the parking space²³. The small round symbols were all chairs, which were set in a circle that allowed everybody to face each other at the same time. About 35 chairs were prepared each time. The numbers of participants varied from week to week, but usually approximately 30 participants (10 participants with dementia, 10 caregivers and 10 volunteers) attended. Some of the preparations for this layout were quite physically demanding (e.g., taking out the chairs from storage and putting them into a circle) especially when considering that the majority of the volunteers were retired females.

²³ This had been a matter of concern among Jessica and volunteers as the fact that wheelchair users had to use a different door was not respecting their dignity. The new venue that they moved to after 4 years resolved this issue as its main entrance had wheelchair access.

Thus the volunteer team made sure at least one of the three male volunteers was present for the preparation and tidying up of the venue.

SB sessions were planned carefully to be as inclusive as much as possible so as not to make the participants with dementia feel exposed. The physical layout was therefore a very important element of this as Jessica explained in the interview:

They are in a circle, with a lot of volunteers dotted in the circle who sing very well. In that way, they can hear the nice echo back, and feel comfortable, not exposed.

In SB, therefore, all the participants sat in a circle once the actual singing session started. There was no solo singing except when there was a request from the participants, and Jessica avoided any layout that distinguished singers from listeners (e.g. the common layouts used in concerts with performers in the front and audience facing them in rows at the back). This type of circle layout has also been recommended for use in (group-oriented) music therapy sessions for people with dementia by Bright (Bright 1988, p.31) because “people may gain stimulation from seeing other people joining in a music activity and be more inclined to participate when their turn comes”. The keyboard in the centre was for Jessica to lead the session with occasional accompaniment when required. Jessica brought her own keyboard every week, positioned it and prepared the sheet music for the songs she was going to use for the session.

Two tables were usually used; one as a reception desk and the other for tea and biscuits. Rosie, the longest serving volunteer, was in charge of the reception together with a few other volunteers. Name tags were prepared by volunteers beforehand with the first name of participants written on paper in large letters and inserted into plastic badges. Rosie displayed these name tags on the desk for participants to put them on when they arrived so they could identify each other by name. A sheet was put on the desk for all the

participants to sign in and fliers for music concerts or care-related events in Watertown were displayed for the participants to pick up. If any participants were hospitalized or had passed way, a card was prepared for the people to sign when they came in.



Picture 3: An example of the tea table with home-made scones and cakes

As shown in Picture 3, tea cups as well as biscuits and cakes were available on the table, which was covered with a tablecloth. Karen, another longstanding volunteer, was in charge of tea and biscuits, often helped by some of the other volunteers. She brought biscuits as well as flowers from her garden and decorated the table. Picture 3 is from the special intergenerational event where a choir from a local primary school was invited to sing with SB. This time caregivers also brought homemade scones and cakes.



Picture 4: Tea table specially decorated for seasonal theme, "Easter"

Picture 4 is an example of the tea table decorated with the seasonal theme of the day, in this case “Easter”. However, even for sessions without a special theme, the table was decorated in a similar manner.

The whole process described above was repeated for every single session. A sheet setting out the schedule was circulated among the volunteers at the beginning of the month to make sure that all the roles required to create this regular framing activity, so necessary for successful events, were filled.

As music was often associated with opportunities to engage in “special events” such as visits to local pubs, social clubs and live music, as discussed by Sixsmith & Gibson (2006, p.134), this kind of physical/material preparation also helped participants to distinguish the SB activity from their daily lives. This tied in with the experiences of the majority of the participants of SB who were in their 80s who told me that they had sang the songs used in SB weekly sessions earlier in their lives at family parties, music hall

visits and local pubs. Thus, the fairly simple physical and material framing that set the community centre apart from their home lives may have helped to reconnect their current experiences of the music activities with their memories from earlier occasions where the same music was sung or heard.

The consistency of these physical/material framings also helped to reduce the participants' worries and hesitation in their encounters with SB by building on the feeling of familiarity while providing a general ontological security, just as the stability of the volunteers contributed to the welcoming atmosphere. This may also have helped the participants to recognize the SB events as weekly events, which in turn helped them to build their everyday life around these joyful occasions, something that will be explored further in chapter eight.

4.4 Session specific material framing

Within the continuity of SB's physical framing there were also variations according to seasonal themes and special occasions. Next I will discuss the additional decorations and preparations made when there is 1) a special event, in this case an intergenerational event and 2) a seasonal theme, exemplified by the Easter event.

4.4.1 The "showcased" intergenerational event

The benefits of intergenerational activities have been discussed within geriatric and dementia care and it has been shown that this gives a higher level of positive engagement (Abbott et al. 1997; Jarrott & Bruno 2003; Lee et al. 2007). Jessica also organized semi-annual intergenerational events together with a colleague who worked as a music teacher at the local primary school. The members of a choir at this school came and sang together with the SB regulars. For these events, the physical layout was

slightly different from the usual sessions: chairs were put against the walls for SB participants to sit, leaving space for pupils to sit down in the middle as seen in Picture 5.



Picture 5 : The physical layout for the intergenerational event

One time, the intergenerational event grew to become a showcase event with the local mayor invited, and it was also featured on the local BBC evening news. A special cake to be cut by the mayor was prepared for the event by the *Dementia Support Group* as seen in Picture 6 below.



Picture 6: The special cake prepared by *Dementia Support Group* for the intergenerational event (the juices and chocolates were for pupils)

This event was perceived differently by the participants than the usual sessions due to a range of differences: the BBC crew, the presence of mayor, the presence of the primary school pupils and their contribution to the singing. I witnessed several participants with dementia being more engaged in the activities and more proactive in relating to people than what was usually the case, with some of them taking the initiative to communicate with the pupils. Although the special event was received very positively, these joyful moments were temporary for those of the participants who had problems of recalling it later on. However, material framings were then used to rekindle the memories of these joyful moments time and again. For example, a printed copy of the BBC web page about the event was displayed and the video recording from the local news was played at the reception desk two weeks after the event. An additional table was also prepared to display the hand-made thank you cards that were received from the pupils who came to sing at the event (Picture 7).



Picture 7: Thank you cards from pupils who joined in the intergenerational event

Laura who had dementia told people excitedly how she was on TV when they were watching the recording of the evening news two weeks later. There were a few participants who missed the evening news, but were able to relive it thanks to this; for example Robin, another participant with dementia, told people how she enjoyed children's singing while watching the recording. Marjorie and Jake, a caregiver and receiver, sent a card to Jessica and the other volunteers, thanking them for making the event happen, and the card was read out by Jessica in the beginning of the session a week later. Such additional material framings, together with spontaneous but caring actions by participants and Jessica during the session, helped all the participants to relive the moments and share the memories once again. Further discussion of the devices developed to extend the moments and why they were important will be explored in chapter eight.

4.4.2 Seasonal theme: Easter

The sessions occasionally had special seasonal themes such as Valentine’s Day, Christmas, Easter, Burns night²⁴, etc. The participants were encouraged to wear colours or patterns that matched the seasonal theme (e.g. red for Christmas, heart and red for Valentine’s Day, checked tartan for Burns night). Additional decorations were made by the volunteers. For instance, for a session with the Valentine’s theme, Rosie put red heart stickers in the corner of the name tags while another volunteer brought red heart-shaped balloons to hang up in the room. For the session with the theme of Easter, a bonnet competition was usually planned, and all the participants were encouraged to bring their home made bonnet and wear it during the session²⁵. Additional bonnets were prepared by the volunteer members for people who could not have their own. Picture 8 and Picture 9 below show some examples of bonnets brought by volunteers.

²⁴ Burns Night is an annual celebration in Scotland around January 25 to commemorate the life of the poet, Robert Burns, who is best known for “Auld Lang Syne”.

²⁵ Easter bonnets are funny, extravagant hats, often homemade, worn in the UK around the Easter period usually in a specific setting such as a school competition for the “funniest hat”.



Picture 8: Example of Easter bonnets brought by volunteer 1



Picture 9: Example of Easter bonnet brought by volunteer 2

During the Easter event, the volunteers wore their bonnets and started appraising each other's bonnets and welcomed other participants wearing their bonnets, which, together with other decorations (e.g., Picture 4) made the atmosphere of the room very festive. The additional material culture not only added another fun factor to the session, but it also reinforced, together with the seasonal songs such as "Easter Parade", the positive

orientation in time and space. These material and musical framings helped participants with and without dementia to remember their past social gatherings from childhood and later. Moreover, since these seasonal themes were repeated every year, associated memories built up and were shared among the participants as time went by. For example, the Easter Bonnet competition was an annual event, where the person with the best bonnet was given a prize. Many of the participants attempted to make as unique and creative a bonnet as possible. Here we also saw how these special events become devices to offer additional roles for the participants to perform instead of their regular roles such as “a person with dementia” and “a caregiver”. The winning and unique bonnets were talked about year after year among the participants. In this way, these events provided a framework for the participants’ experiences of SB, which also provided shared memories among the participants to be reflected upon later. For instance, Marjorie who was Jake’s caregiver won the prize for the best Easter bonnet one year, but Jake passed away soon after the event. Remembering and talking about Marjorie’s bonnet the year after was associated with remembering Jake among the participants. The annual event thus gave the participants the opportunity to remember fun moments with lost ones, and reflected on the passage of time together.



Picture 10: Participants with their hand-made bonnets

4.5 Social framing

So far in this chapter, I have described the physical and material framing for the sessions and additional material framing that is related to special sessions. I will now look closer at the social framing that occurs “on top of” the physical and material framing. Non-volunteers usually arrived at the venue fifteen to thirty minutes before the actual singing activity started. By the time they started arriving, the physical/material framing was usually ready. Therefore, the remaining time was used for the participants to settle down before the singing session started. In the session plan that Jessica circulated among key volunteers each time it was also specified how arriving participants should be cared for by volunteers:

*Arrival of clients and carers – met and greeted by volunteers. Registration and refreshments. Settling down period then all invited to find a seat in the circle of chairs, with **volunteers interspersed**, a perceived equality [sic] and an encouragement to participate both in singing and in conversation. (Bold in original)*

Volunteer members therefore took initiatives relating to the participants to help create a safe and welcoming atmosphere by serving tea and biscuits, initiating conversation with participants with dementia and their caregivers and making sure that they settled in. In addition to such deliberate caring actions, I also discovered other elements that contributed to the social framing of the venue into a secure and non-clinical, friendly place so that everyone felt ready to participate by the time the actual singing sessions started. Below, I will discuss the essential elements that contributed to the social framing of the SB events.

4.5.1 Equal numbers reduce boundaries

The SB Watertown group emphasises the importance of having a roughly equal number of participants from the caregiver, dementia sufferer and volunteer categories. Although the numbers varied slightly with each session 10 caregivers, 10 participants with dementia and 10 volunteers were seen as an ideal mix in order to help reduce the differences between those with and without dementia. The reason for this focus on the number of participants was explained to me by Jessica and other volunteers. Rosie, for instance, stressed the importance of keeping a sufficient number of volunteers:

We need quite a lot of volunteers, though, you know, really. Because, we don't want to ask the carer to help. Because they are coming as part of their therapy... part of their relaxation, to come and share a singing time with their, most of them with their husband or wife or... Not all of them of course, with their daughters or..., mothers and daughters. So we don't want them to help really. We just want them to sit and enjoy themselves and relax and chat.

Due to these considerations by the volunteers tea time became an essential occasion for the participants with dementia and their caregivers to “*get together and share, the carers particularly, come and share their concerns with one another*” as Rosie pointed out. Thus the large number of volunteers enabled caregivers to enjoy the time with the person they were caring for or socializing with other participants without having to perform a lot of care related work at that point themselves.

Several caregivers (e.g., Lisa, Monica, Michael and Kelly) also expressed how they cherished this opportunity to meet others in the same situation as themselves, others with whom they could share their problems. For practical reasons the venue was cleared out soon after the session ended. Thus the tea time before the session was the only time that participants could chat with each other if they did not meet outside SB. They would not have had opportunity to utilise this important coping mechanism if they also had

had to do the preparation for the session. Several informants discussed this participatory levelling as a positive factor in reducing the boundaries between people with and without dementia. One of the volunteers, Dennis explained that:

One interesting aspect of the group at the moment is that Jessica has managed to get a lot of volunteers along. [...] Generally at the group there are far more volunteers/carers than there are people attending who actually have Alzheimer's. If you think about it. Let's say we have 30 people there, probably only 10 of them are suffering from the condition. Which may seem odd, but at the same time that's comforting for them, they are just one of the crowd in other words. It's for them. But they are not feeling, they are not marked out. They are there as part of the group.

Initially SB was geared towards the participants with dementia and their caregivers, just like its parent charity “*Dementia Support Group*”. Jessica’s earlier description also made it clear who the service receivers were (“carer and client”) and who the service givers are (“volunteers”) and the actual preparation described above was mostly done by the volunteers. However, the boundary between service receivers and providers was not clearly visible because the even mixture of participants (i.e. 10 volunteers/participants with dementia/caregivers) allowed the participants with dementia to be part of the overall group and not marked out as Dennis put it. Considering the stigma and distress they were experiencing in their everyday life this was no doubt a great relief to them. This distinguished SB from other types of services or more clinical places where the boundary between “clients” and “non-clients” could be very obvious, whereas in SB they were all “participants”. Jessica stressed how SB was distinctive from these services, where services were provided to people with dementia, whereas SB was about joint participation; people with dementia and their caregivers get to join in together with other participants. Hence it requires a relatively large number of volunteers.

Hannah, the caregiver who attends with her husband Simon, described how this differentiates SB:

*Another unique thing is the levelling, **the levelling**, that is going on, in a group where you have half carers and half Alzheimer's people. And because of the activity they are doing, you can't, in many cases, tell one from the other, and I think that is wonderful. [...] You cannot tell which is the carer [sic] and which is the person with Alzheimer's. I mean in some cases, it is quite obvious, but in lot of cases, because the music awakens the spirit, and people are more animated than they would otherwise be..*

Thus we can see that the form of levelling that the equal number of participants seems to afford the group provides a good basis for inclusive musical activities. Although I was not able to collect data from the participants with dementia in terms of how they felt about this levelling process I know some of them were not aware the group is targeting people with dementia and their caregivers. Instead, they recognize the group as a singing group just like the choirs they used to join before illness. The memory problem may be causing this false recognition, but the social framing of the activity as well as the physical, material and musical framing clearly allows them to connect with their surroundings in a non-threatened manner and enjoy their own participation in the SB activities. This “levelling through numbers” may be a contributory factor to this as they become part of the crowd just as they have been on many other (musical) occasions in their past, such as singing in the pub, attending music hall, singing at family gatherings or in choirs.

4.5.2 Mutual care, a safe and sound ambience

As mentioned before, a number of different actions can be observed within the physical/material framing. During the half an hour before the actual singing session starts the volunteer helped the participants (with dementia), their caregivers, new

volunteers and visitors to settle in. For example, as soon as the participants arrived at the venue, they were welcomed by volunteers. Visitors or new participants were usually greeted by Jessica, and she chatted with them briefly about the activity²⁶. Once the participants found their seats, usually they did this by themselves unless they were new. Other volunteers brought them tea and biscuits, which usually triggered some conversations between caregivers, care-receivers and volunteers. As it was said in Jessica's session plan, volunteers were "interspersed" to help the participants with dementia and their caregivers to settle in. Figure 2 below shows an example of participants' engagements during this time.

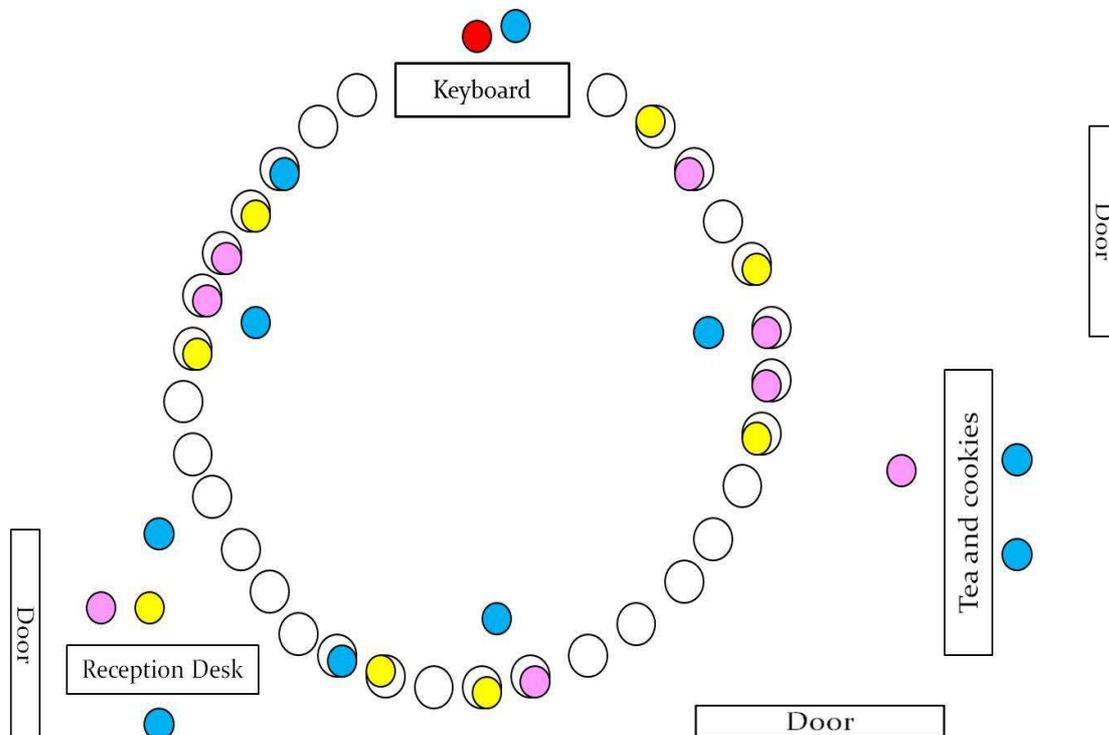


Figure 2: an example of people's engagement before the event (red=facilitator, blue=volunteers, pink = caregivers and yellow=care-receivers)

²⁶ Jessica usually had a phone conversation with caregivers to explain about the activity beforehand.

Here we can see the strategic placement of volunteers. Their involvement with the participants at this time ranged from casual chatting, listening to their worries, advising them on practical matters or sharing bits from their own experiences if they are previous caregivers, serving tea and biscuits, keeping their eye on participants with dementia when their caregivers talk to other caregivers or are leaving the room briefly to freshen up. As the session was weekly and participants tended to attend regularly for anything from a few months to a few years, they got to know each other well enough to develop a friendship or at the very least to feel comfortable in each other's company. All the involvements by volunteers mentioned here occurred in a very relaxed, friendly and natural manner together with other actions and interactions.

When I asked Susan, one of the volunteers, what she enjoyed most in the SB session, she explained that:

I think I like chatting to people, before and after. Yeah, talking to them. It is nice to see when they actually recognize you, because sometimes they forget that they have been, and it is like going to something new every week for them, yeah. But it is nice when they recognize you. I enjoy just chatting to them and...

As it is implied in the interview with Susan, the experience of interacting socially with people who have memory problems may differ from being with people without such problems. However, the nice feeling of being recognized is even greater when people with dementia recognize you. This again shows the importance of the continuity and coherence in the framing and atmosphere at the session in order to help participants with dementia to connect to the environments and achieve ontological security. The presence of (young) student volunteers also contributed to the social framing of the place as well; it helped to break down the boundaries between cared and caring for by making the group intergenerational. For example, students, whether from the local university or

secondary schools, were always asked by other participants how their studies are going. Some caregivers sometimes gave them a lift home which further reduced the feeling of being marked out as a service receiver.

Thus care was not always given unidirectionally from volunteers (or charity staff) to participants with dementia and their caregivers. Rather, this was a time of caring for each other regardless of background/reason of being in the group, asking each other how the previous week was or just sharing the experience of being there in the space. As for me, I always enjoyed my time there, savouring the taste and warmth of tea and biscuits while enjoying the ambience as much as I enjoyed chatting with people. Several caregivers and care-receivers were sitting down and relaxing with tea and biscuits without any further interactions. Whether one is chatting, interacting or just relaxing, this was the transitional time from everyday caring to the weekly music time for the participants with dementia and their caregivers. What was very important during this time of “preparation for the event” was that caregivers’ daily caring tensions were released and the participants with dementia also felt safe and comfortable within the safe and sound ambience, which allowed things to emerge in their own time without any pressure of how things should happen. This also assured them that they were accepted as they were regardless of whether the outside world seemed confusing and agitating.

4.5.3 The role of individuals when coming into the event

Among the participants there were distinctive individuals who contributed in particular to the safe and joyful social framing of the space, such as Dennis and Laura.

Dennis was one of the volunteers who always joked and made people burst into laughter. He was definitely the life of the party and he enlivened the atmosphere with his action and was in many ways an anchoring presence. One time, several participants were

watching the aforementioned recording from BBC local evening news before the session started. Dennis, Lisa and Caroline (daughter and mother who were interviewed in the news) were among them. Dennis made a joke about Lisa's interview. Despite Lisa's comments on how Caroline, who was sitting right next to Lisa, was more alert after participating in SB sessions, she looked very sleepy during the interview. Dennis always teased people (very gently) in the group. The participants with dementia were not given special treatment. Sometimes they become the target of teasing just like the case I have described. This was possible and positive in the friendly atmosphere that existed at SB. Dennis shared with me his thoughts on respecting one's dignity and its balance with humour.

*[If you just thought of any of these particular circumstances [having dementia], [...]] you need to respect other people's dignity. I think it's a question of, for instance, if you are talking about humour, you laugh **with** people, you don't laugh **at** people. Do you see the distinction? If you take that through dignity, etc, you always respect their dignity. You need to be welcoming... You need to have a format which is informal, and welcoming.*

Dennis was one of the core volunteers who knew what was needed to be done both on the practical and emotional level in order to create a welcoming structure and joyful dynamics. As he said, 'Whatever I can, I try to contribute. [I'm a] Jack of all trades as they say'. In this way, jokes are also effective as they are used as a caring strategy that joins people together by socially framing the inclusive atmosphere, which even made people feel safer about behaviours that are prompted by dementia.

Laura was another lively member of the group. She had dementia and attended with her husband. She often started singing as soon as she arrived at the community centre without being prompted or accompanied. I occasionally met them on the way to the community centre but I have never seen her singing outside of the SB venue. Therefore,

it must be something about the “space” that triggers her singing. The tune is most of the time “*Just Walking in the Rain*” a song from the 1950s which was often sung in the sessions as well. When she sang, people started chatting with her, and she cheerfully kissed the participants on their cheeks. She often told the group proudly how she used to be a singer and how she knew all the songs. Being able to sing well was definitely part of her identity, and she retained her identity through her spontaneous singing and the interactions with others throughout the session and even before the session started.

“*Encouragement to participate both in singing and in conversation*” is one of the volunteers’ roles that are described in Jessica’s session plan. But as we observed, people with dementia such as Laura also helped to encourage others to sing. She enhanced the conversation and most of all, lifted the atmosphere. Her spontaneous singing may have been one of the traits of dementia outside of the SB space. Or it may have been an automatic reaction once she saw the participants and the space. Either way, this again emphasised the importance of the physical, material and social framing, and the consistency of those framings to help people to know that it is a secure, jolly and friendly space. Because of these framings, Laura’s singing and behaviour is not seen as a negative trait. Rather it contributed to enlivening the space and preparing the others for joining in the singing.

4.6 Material and social framing creates a coherent transitional time and space

I hope to have shown how careful preparation for the singing event was essential. Physical and material framing was developed to enhance the ontological security of the participants. It also helped people with dementia to recognize the activity as a part of their weekly routine, yet at the same time, something special that was distinguished

from everyday life. The coherence of these framings helped caregivers and care-receivers to develop structures in their everyday life that enabled them to cultivate further habits that pivoted around the SB sessions. This, as a result, helped to sustain the positive experiences from the session (this point is further discussed in chapter eight). Additional material framing specific to the seasonal theme also gave coherence in the longer term (e.g. annual Easter Bonnet competitions), and provided a means for sharing memories among participants. These physical and material framings also became the basis for the social framing to be crafted by the participants as discussed above. They also laid the foundations for the musical framing which will be discussed in the next section.

In this way, the well-crafted social-spatial environment helped participants to regain a sense of coherence that led them to move toward the healthy state in the continuum of “health/dis-ease” suggested by Antonovsky (1987), and at the same time transcend the bodily experience of dementia as discussed by Freud (2001). The well-crafted environment also helped participants temporarily to transcend the negative expectation of dementia as we have seen in this chapter. These physical, material and social framings, as a result, generated the important transitional time and space that took the participants from the daily caring life (which involved stress, anguish and possible defamation) to the collective singing activities. This allowed participants to loosen up from any tensions they might have had, and most importantly, to feel ready for the singing activity and contribute to the actual experience of music activity later on. These well-crafted framings could also help people with dementia and their caregivers towards

a smooth transition to SB from the regular choirs they used to join.²⁷ In the following chapter I will discuss how musical activities are crafted “during the events” in relation to the physical/material framing discussed in this chapter and how positive musical affordances are generated during the SB events.

²⁷ The smooth transition from previous musical engagements to SB will be further discussed in the chapter 8.

Chapter 5. During the events

In chapter 4 I described the elaborate environmental and social framing that was developed by the volunteers together with other participants in preparation for the musical events: the weekly SB sessions. Such preparation was essential in creating a transitional time and space from everyday life to the collective singing activities. In this chapter, I will discuss the actual musical event itself and how musical activities were collaboratively crafted during the event.

In planning and facilitating SB sessions, a wide range of constraints and capabilities posed by the participants with dementia needed to be taken into consideration. The constraints could include a) disorientation and associated anxiety and lack of confidence, b) stiffness in bodily movements due to dementia and general aging and finally, c) short attention span and failing short term memory. SB musical events adapted to these constraints in order to facilitate participants' involvement in a number of ways. First of all, the sessions were carefully planned in advance in order to promote orientation in time and space for the participants with dementia, the details of which will be discussed below. A large part of this was achieved through physical, material and social framing discussed in the previous chapter. The music was then, as it were, "inserted" into this frame. One of the main considerations when planning and facilitating the sessions was adapting to the constraints participants have to make the session as inclusively as possible. This is done so that the participants with dementia do not need to feel anxious about being exposed, but instead feel safe and relaxed when joining in the various activities. But how is it possible to craft such inclusive sessions for a group of people that have widely differing cognitive capacities?

In order to explore the crafting of the sessions themselves I will first introduce the basic structure of the weekly session. Then I will describe each segment of the SB session in detail using data from my participant observation and interviews to show how the musical events are crafted collaboratively in order to bring positive benefits to participants with dementia and their caregivers. This will be followed by a summary of the overall session.

5.1 Basic structure of the musical events

What are the key aspects of the structure which enables the participants to feel so comfortable that they join in the singing and which leads them to the positive experience that they have come to value? How can the participants come to feel proud of their engagements and achievements within SB (musically and otherwise) despite their limited physical and cognitive abilities?

SB sessions follow a basic structure prepared in advance by Jessica. The format, which is common to all SB groups, starts with warm-ups and the “Hello” song. These are followed by various songs and activities and they end with a calm song. Jessica adopted this basic format and came up with the structure in Table 3, after having been coached by a more experienced facilitator from another town who initially acted as her mentor when she started SB in Watertown.

Notices and birthdays	2 minutes
Warm-up	10 minutes
Familiar waltz tunes	6 minutes
Song activities	26 minutes
Quiz	10 minutes
Familiar song or song activities	2 minutes
Participation dance	5 minutes
Shalom (calm song)	2 minutes

Table 3: The structure of SB sessions

The session usually runs for about an hour without any breaks. The session was facilitated by Jessica. It involved using her voice, bodily movements, eye contact and some keyboard accompaniments, occasionally helped by Susan and Karen with the keyboard accompaniments. Once the activity started, all participants sat in a circle with the volunteer participants dotted throughout following the format that was shown in the previous chapter (Figure 1 and Figure 2).

The songs used for the session were provided in a folder for all participants. Each folder contained 58 pages. Each page had lyrics for one or two songs printed in a large font (see Appendix 12 for an example of this). There was an alphabetical index of the repertoire provided so that the participants were able easily to find the relevant song. The songbooks were usually placed on the chairs by the volunteers before the participants arrived. Some activities (e.g. circle songs, singing in harmony) as well as the musical quiz were done without referring to the song book. Using the data I collected I will describe typical activities from each section and discuss them in terms of their musical affordances.

5.2 Reaffirming memberships and creating continuity: Notices and birthdays

The sessions always started with *notices and birthdays*. By the time the session started, most of the participants were sitting down in the circle and chatting with each other. They were enjoying tea and biscuits, and the venue was filled with the cheerful noise of chatting and laughing. This made the atmosphere relaxed enough to start the activities and collective singing as discussed in chapter four. Jessica stood up in front of the keyboard and called for everyone's attention. This was usually the sign that the session was starting. Important information was briefly mentioned at this point, such as any developments and news related to SB on the local and national level, any media exposure of SB, reports on fund-raising, Jessica's involvement and activities around SB (e.g., attending meetings, giving talks at conferences) as well as previous participants' passing away or other changes in their circumstances. If there were any new participants, they would be introduced and welcomed by the group during this time. The notices sometimes extended to Jessica's personal news such as her grandson's birth or her participation in bicycle training which often caused laughter from the participants.

Participants' birthdays were celebrated during this time as well. Birthday cards were given out to those who had a birthday in the previous week and "*Happy birthday*" would be sung. As a rule the group made sure that everyone's birthday, including those of caregivers and volunteers, was celebrated. As care-receivers often forgot their caregivers' birthdays, this helped create an atmosphere of bonding not only within the group but also between caregivers and care-receivers more specifically. Rosie, the volunteer, explained to me in the interview how hard it could be for the caregivers to have their birthdays forgotten by their partners with whom they may have been celebrating their birthdays for

60 years or more. For example Chris, a participant with dementia, had no idea why his wife Kelly was receiving flowers and cards on her birthday, something that left Kelly feeling rather sad. By celebrating all the participants' birthdays, not only those with dementia, the group helped to reduce the sense of loss experienced by the caregivers, and at the same time, celebrate and reaffirm their sense of belonging.

5.3 Exercising to gain momentum: The warm-up

A variety of warm up exercises were performed for about ten minutes without any breaks. These exercises changed weekly but usually five or six exercises were used to loosen up the bodies, deepen the breathing, prepare the voice for the singing activities and help the participants to focus. Jessica made sure she was not leading the exercise mechanically and repetitively. Instead she engaged in various forms of emotional work and used different techniques to draw people into the exercises. Below is a field note where I described the warm-up exercises of a typical session from the middle of March. Thus a spring theme was adopted for use in the exercises. On that day, Jessica used six warm-up exercises: 1) Shaking hands and rubbing faces, 2) Climbing up and down an imaginary ladder, 3) Taking deep breaths, 4) Buzzing in various rhythms, 5) Saying "AHA" following Jessica's hand movements and 6) Articulating various colours in tune.

At the start of the warm-up exercises, she changes the tone of her voice to be a bit more forceful, "So, let's start with a little warm-up". Thirty participants' murmuring voices are gradually fading, and attentions are gradually focused.

"Let's shake... (she shakes her body), rub your face, give your face a little massage."

She pulls her chin skin and deliberately makes funny face, and the group laughs. Then she leads people to give themselves a gentle massage around the chin, cheek, up in the forehead and around the back of the neck.

“Let’s shake your hands. Nice shaky, shaky hands. Let’s do something with your feet if you can. If you can shake them, shake them. If you can’t, just wiggle about.”

Her instruction induces the laughter again. The volunteers, especially Dennis and Rosie, put the instructions into action rather elaborately. Since the volunteers are dotted in the circle and initiate the actions, other participants (caregivers and care-receivers) seem to be drawn in to engage in the physical exercise without hesitation, and engage in these movements rather easily by imitating the actions of others. At least for me, the volunteer’s elaborate anchoring actions are very helpful in shifting my mind and body to join in with the collective physical exercise. All the participants are following the exercise and I hear Arnold clapping his hands with a random rhythm when other participants start shaking their hands, stomping their feet against the floor. Some people are just wiggling their hands and legs.

Jessica often suggested alternative ways to participate in the exercise just like above (“If you can’t, just wiggle about”). When Jessica showed consideration with regards to the capacity of the participants with dementia in this way, she said it in such a way that it induced laughter, which helped to create a common and inclusive culture. Below is my field note on the exercises that followed, which shows the crafting process involved in tuning people in through the warm-up exercises.

It is followed by an exercise which encouraged a vertical physical movement, one of the typical warm up exercises, climbing up and down an (imaginary)

ladder. Afterwards, Jessica leads us to take a deep breath, breathing in for four counts (counted by Jessica) and breathing out for four counts.

This is followed by another exercise which was sensuous and rhythmical, but at the same time seasonal. Some activities and songs are chosen according the season of the time.

*Now, I was thinking “what can we do that is a bit seasonal today”?.
It’s the lovely sunny day, so I thought about BEES...”*

*She makes BEE sounds by slowly articulating “Buuuuuz, Buuuuuuz, Buuuuuuz.”
The participants of the group follow her. After that, she leads the group to make bee sounds while feeling the buz all around our faces. People laugh and say “Buuuuuuuz.” It is a very sensuous exercise, it makes my lip tickle, and feeling bees buzzing around is awkward. Then Jessica leads people to buzz in rhythm.*

“This time I want you to listen carefully and I want you to buzz. These bees are very rhythmic bees and buzzing in rhythm.”

She starts with buzzing in 4/4 rhythm, “Buzz, buzz, buzz.”(see bar1 and 2 in music insert 1)- The participants follow her and before they finish buzzing, Jessica introduces a new rhythm (see bar 3 and 4 in music insert 1). The majority of the participants follow her and Jessica pauses for a moment, and start buzzing in a more complex rhythm (see bar 5 and 6). Some participants just continue buzzing the same pattern in 4/4 rhythm while others follow her (the participants 2 in music insert 1 indicate them).

She waits until the participants finish, and then introduces another rhythm (see bar 7and 8).

It seemed that this was a rhythm that everyone in the group knew. She emphasizes the last two buzzes to indicate that it was the end (see bar 9). The participants tried as best they could to follow the rhythm. When the last two buzz were articulated by Jessica, the participants burst into laughter again. Jessica often controlled participants' attentions in this way by using her improvisatory skills for effective facilitation. This buzzing exercise was also a seasonal item that attempted to help participants' orientation in time and season as the session was in the middle of March when the flowers started blooming in the Watertown region.

It was followed by another warm-up exercise using the voices.

Without any pause, Jessica, leads the group to voice 'AHA'. Start A with the lower note and sharp, pitch HA in octave higher. She uses her hands as a conducting stick, moving up and down, and tells the group to go higher when her hands are up and go down as the hands go down. The participants are looking at her hands' movement and trying to follow the movement with their voices. Next, she tells the group to say the sounds A, and asks the group to imagine that her hands are a pair of doors.

“As the door opens, you hear more of the sound, and it gets louder. Very quiet to start with.”

She opens and closes her hands using her whole body as if she is playing a big accordion. The participants follow her movement with the voices.

“aaaaaaAAAAAAaaaaaaaAAAAAAA.”

The collective voice becomes stronger and deeper. All of us look at Jessica's movements carefully and try to synchronise our voices to her movements which helps our attentions gradually tune in and focus, this is heard in the collective voice that is becoming deeper and louder.

These exercises were the first to use the voice in this session. One of the challenges people face when ageing is their decreased vocal capacities. Therefore, vocal expressions can be very challenging for some participants, especially for those who are in their 80s. It can also be challenging for the participants with dementia who are experiencing a loss of confidence, although some of them can become more uninhibited in their behaviour due to the symptoms of dementia. However, with these exercises, the participants did not need to worry about the quality of their voice or the accuracy of their

glory my Rs.²⁸ (she trills her tongue very obviously and the participants laugh) No laughing in this call! (she says strictly)."

One participant immediately says, "Sorry!" and the other participants laugh. She performs and modulates her voices and instructions for effect. Jessica pronounces "red" trilling her tongue as much as possible, and sings the simple tune with "red" with a very Scottish accent.

Here we can see how Jessica's crafting involved emotional work, for instance she signalled the changes emotionally and led them through different experiential stances, in this case with a focus on humour. The exercise also helped people to articulate the words of the songs in singing activities. This kind of articulation exercises was usually included in the warm-up exercises, but using the name of the colour with the simple tune was the first attempt. Jessica explained to me that:

It's based on colours, and it actually is a warm-up, too, you know, you have vowel and consonants. Well, if you use the colour, have short words, like 'red'. you've got R [pronounces a rolling R], you've got 'D' and you've got 'E'. So you've got 3 sounds there, you've got a rolling, which is good for the getting the RRRR sound, and you've got Da which is good for consonants. Some people have difficulty with consonants. Endings of words, they sometimes drop them. You say, 'Re', instead of 'reD'. So that's something. And also, we always practice different vowel sounds. Susan does this, she is very good at that. A, E, I, O, U, you know, so you know, RED, BLACK, GREEN, all e, a, I, there are all these consonant sounds. So it is doing loads of good things for people, practicing the sounds, in a kind of fun way.

As she said, "red", "black" and "green" were useful words to practice articulating vowels and consonants; at the same time they were simple words that were easy to remember,

²⁸ Generally speaking the Scottish dialect has strong rolling Rs which sound very distinct to people in England and are often used to amusing effect.

which allowed participants to practice the articulation exercises easily. Using her emotional skills and sense of humour she made it fun and enjoyable for the participants to do these exercises.

All these warm-up exercises were introduced with her own clear vocal and/or physical engagement. Throughout Jessica used her hands as a conducting stick and moved it vertically and horizontally to indicate how the voices should go lower or higher as well as louder or quieter. She also moved around to demonstrate the movement accurately to each participant as well. These physically- embodied instructions helped the participants to follow without hesitation – they were not merely verbal instructions in other words. The size of the group (almost 30 participants) and the group dynamics that emerged also seemed to help the participants to engage in the exercises without feeling exposed.

The ten minutes of non-stop warm-up exercises described above had profound effects; various body parts were used in combination with vocal, breathing and sensuous exercises. Many of the participants with dementia had difficulties interpreting the instruction cognitively. Therefore, the instruction combined with bodily movements which were then repeated by the anchoring volunteers dotted around in the circle, and common group dynamics helped the actions (of the participants with dementia) to be enacted and entrained, as Rosie put it; “*We are enthusiastically doing it right, and they tend to copy*”. In this way, by repeating each action several times, the action became embodied, and the effects of the exercises were attained. These warm-up exercises helped the group participants to become more focused and engaged. They shifted the participants’ attention from the relaxed social time to the actual activities. This was necessary so that the group gain momentum for the following activities.

5.4 Welcoming participants to support affirmative reality orientations:

Hello song

The warm-up exercises were followed by the “*Hello song*” where the names of those present were sung to make sure that all the participants were welcomed individually. In the Watertown group, there were two versions of the hello song, one with a very simple tune and rhythm, and the other using a long ribbon to hold up and down while singing the tune. The former one was more common and was often used to welcome everyone in the group. A field note from a typical session when it was sung describes what happens during the song.

She initiates the singing of the hello song, and goes around the circle, stops and sings in front of the participant when her/his name is sung, pointing her palm towards the person to welcome her/him. The participants sing the hello song together with the names of all the participants in turn, looking at the participant when her/his name is sung. The group is drawn to a nice flow of singing with a feeling of togetherness.

Singing the hello song was about establishing a personal connection and, at the same time, welcoming each other and performing community identity.

Jessica leads the end, pointing out herself.

“...Hello Jessica, hello everyone, you’re very welcome here.”

The hello song ends, and laughter and murmur start again.

Deborah who brought several of her friends who had dementia was very positive about how the “hello song” combined with the name badges worked:

I was telling Elderly Support Group, could we sing [the Hello song], because we go there, but you don't know people's names because they don't have badges. And we ought to sing that.

Singing the hello song as well as the name badges obviously helped people to recognize and remember each other's names. The hello song also made us aware of the attendance of the participants. Almost two hours had passed since volunteers arrived to prepare the venue by the time we started singing the hello song. This was the first time one could see the faces of all the participants and thus recognize the state of the participants (e.g., who were present or not, who were in a good mood and who were less so). At the same time, it made us aware of the space as we look around the room slowly, focusing on the face of each participant in turn while singing the hello song. This also made us realize how the venue was filled with the participants and a friendly, jolly atmosphere.

I have already discussed the importance of helping people with dementia to connect with the surrounding world in chapter four. Music can also be used to support the reality orientation of people with dementia as suggested by Bright (1988, p.34):

What IS important is that the dementing person retains an awareness of the place in which they live, of those who love them and care for them, those with whom they share a home. (...) To use music to support this affirmative reality orientation is a happy way of achieving this awareness.

The hello song is a good example of this support of the participant's reality orientation in practice. By singing the names of all the participants in turn, the participants with dementia could be made aware of where they are at that moment as well as who they are in relation to the surroundings for instance, the physical space, the participants of SB and their own partner or family participant sitting next to them.

5.5 What is singing familiar waltz tunes really about?

Following this warm-up the main musical segment of SB usually started with the singing of some familiar waltz tunes²⁹, usually three. The actual repertoire varied in each session but the songs were generally well known to the participants and sung repeatedly over time and often they were chosen to fit the season or theme of the session. Some examples of the familiar waltz tunes used in the activities include: “*She was one of the early birds*”, “*When Irish eyes are smiling*”, “*I’ll be your sweetheart*”, “*Edelweiss*”, “*I’m forever blowing bubbles*”, “*Daisy Bell*”, “*Beautiful Dreamer*” and “*My favorite things*”.

The waltz section was unique to the Watertown group as Jessica explained:

Jessica; [The waltzes are] Not everybody does that. No. I just think it’s good to have some movement at the beginning. Because if people have been sitting through the warm up, they need to just... you know... It’s just part of the warm up really. [Singing the waltz, you mean?] Yes, singing the waltz is, I just think that waltz is very, it’s very inside people. Waltz rhythm, wanpapa, wanpapa, wanpapa, it’s very inside of people and easy. I think. I mean you could do, one, two, three, four, one, two, three [claps, sings], it’s not so easy I don’t think. [...] I like it a little bit lilting. Yeah, it’s just me, it’s just my way of doing it. Not everybody does that.

The potential for opening up participants’ voice, body and mind for further activities through waltz tunes fit in with the idea of the effectiveness of singing familiar songs, which has been discussed by others with regards to dementia care. This has generally focused on familiar music as a way to access memories (Cuddy & Duffin 2005; Ridder 2003) or to manage agitated behaviour (Sung & Chang 2005). As discussed in chapter

²⁹ Familiar waltz tunes sung in SB sessions are familiar folk songs or familiar songs that are in 3/4 beat.

two the majority of such studies focus on proving the effectiveness of music as a stimulus for the brain without trying to investigate how they really work. Therefore I want closely to explore what singing familiar waltzes affords in its local context by highlighting certain phenomena that might have been overlooked in the literature of music and dementia care so far.

5.5.1 Collective voices provide a framework for various affordances and help to form a group culture

Below is the detailed description from a session where three of the Watertown group's favourite waltz tunes were sung; "*Tulips from Amsterdam*", "*She was a dear little dickey bird*" and "*Edelweiss*". These tunes had been sung on many occasions throughout the years. However, on this occasion, a session in March, they were also chosen to match the season (spring) as Jessica pointed out in her introduction:

"Anyways, let's start with some songs... a little bit seasonal today. But I am leaving complete spring things to next week, Susan's got an idea [for next week]. I thought we start today with number 7, that's 'Tulips from Amsterdam'. It's spring again!"

People laugh at Jessica's comment; the sessions are usually filled with these moments of laughter.

Jessica plays the complete melody of "Tulips from Amsterdam" with the keyboard accompaniment. This is the first time in this session that actual songs are introduced with a full accompaniment. The murmuring starts again, several participants are flipping over the pages of the songbook to look for a page for "Tulips of Amsterdam". Volunteers assist care-receivers in finding the pages if

they have difficulties. Several volunteers and I look around to see if everyone has access to songbooks.

“Are you ready? Tulips from Amsterdam.”

Jessica starts playing the melody again. I hear Laura starting to sing the tune with the accompaniment.

“When it’s spring again, I’ll bring again. Tulips from Amsterdam”

Participants start to join in gradually, and Jessica repeats the accompaniment of the first verse. As soon as the second round of the accompaniment starts, the whole group starts to sing the song from the beginning all together.

“When it’s spring again...”

I hear the collective singing sounding very solid and stable and it is carried out well. Everyone’s body and voice seem to be warmed up enough to get their voices out. After the song ends, Jessica says,

“Lovely! Good voice today! Well done!” (Appendix 11. Example recording no. 1)

“Tulips from Amsterdam” was first released in Germany and the English version became a hit song in England when recorded by Max Bygraves, a popular singer in the late 1950s. The majority of the participants of SB Watertown group were white British³⁰ who would have known this song as a mainstream pop song when they were in their 20s and 30s. This may be one of the reasons why this song became one of the popular songs

³⁰ White British is an ethnic classification used in the 2011 United Kingdom Census.

in the group. It was also a waltz which repeated a very simple tune, which also made it easy to be sung.

This was the first song that was sung in this session, approximately 13 minutes after the actual session started, and almost 40 minutes after the participants (not the volunteers) started arriving at the venue. Thus the music started gradually after the physical/material/social framing the short notices by Jessica, the celebration of birthdays, the warm ups and the hello song. All of these activities had helped to set the tone that has emerged and by the time the first waltz tune was introduced the participants with dementia looked comfortable with being in the venue with others and were clearly orienting themselves to the surrounding environment. The attention of the participants was also more focused after their bodies and voices had been warmed up. This was the specifically tailored temporal frame that fitted the participant with dementia, who required a different process of tuning in than people without dementia. "*Tulips from Amsterdam*" was followed by two other seasonal songs, "*She was a dear little dickey bird*" and "*Edelweiss*". Both songs were sung very firmly and beautifully from the beginning to the end. The collective voice became stronger with Arnold's (a long time participant with dementia) deep voice carrying well until the end of the second round of "*Edelweiss*".

Although the collective sound was very stable and solid, the level of participation varied depending on each individual. Arnold and Laura for example sang with deeper voices than the other participants and their voices carried very well, partly because they were experienced singers, having sung in choirs and been musically active throughout their lives. Other participants with dementia such as Jake, Simon, Celine, Chris and Caroline sang rather quietly but I could see their mouths moving. Although their participation was

not so obvious, one could spot changes among several participants with dementia before and after these exercises. It was therefore useful to describe some of the individual participations during the exercise and highlight any changes in their engagements before and after these exercises using my field notes from the actual session as well as later interview data.

For instance, I observed gradual changes in the behaviour of Simon before and after the warm-up exercises and the waltz singing:

Simon often looks anxious when he arrives at the venue. I see him sitting down being nervous and holding the songbook uptight or holding Hannah's (his wife/carer) hand tightly. One time, Hanna asked me to be with Simon while Hannah goes to freshen up before the session starts. He was so worried about the absence of Hannah and restlessly kept asking me where she went in spite of my attempt to help him sit down in the seats and chat. However, he gradually releases his tension and restlessness as he is joining in the warm-up exercise (although there are some exercises he is not able take part in). By the time the familiar waltz singing starts, Simon looks calm and relaxed and join in singing.

Similarly, changes in Arnold's behaviour before and after singing familiar waltz tunes were evident several times. He was often agitated when he arrived at the venue, sometimes clapping hands continuously looking like he had lost control of his own behaviour. However, as the singing of the familiar waltz tunes started, he usually sang away with his deep voice which was carried around the room, holding on to the high notes beautifully. He clapped his hands during the session as well, but he was more in control and the clapping was somehow more in time with the structure of the songs. Throughout the sessions, many different songs were sung but Arnold only responded strongly to the

ones he knew well. Changes were also observed in Jake's engagement; he was often taking a nap in a sitting position during the SB sessions, and would sometimes wake up and join in with the singing or chat with the participants around him. However, during the warm up and the familiar waltzes he was usually always awake and sang along to the tunes. The familiar waltzes also allowed Chris and his wife Kelly to simply "be" as a part of a social activity that would otherwise be difficult due to his condition. Chris's participation was very subtle; however, he joined in the singing and sat down calmly throughout the session. He opened his mouth and sang all the familiar waltz tunes as he knows well. According to his wife, Kelly, "*this is the only thing he can cope with*". The familiar waltzes could also increase personal connections in the group, something I experienced personally as a volunteer participant with two participants who suffered from dementia, Caroline and Celine:

Caroline's participation is not obvious either. But she joins in the singing, and during the session is often chatting with her daughter (presumably about the song) and giggling. She is generally in a very good mood during the session, and shows engagement. When singing "Edelweiss", I was sitting next to Caroline, and told her how I knew the tune from Japan while showing her the page where its lyrics are written. She said, "yes, nice" and smiled and laughed casually. I also told her, knowing that it is one of her favourite tunes from the interview, "It is from the movie, right? Sound of music." She said, "Oh, yes" and laughed again.

Celine is usually very quiet, shy and looks hesitant to communicate with others. When I sit next to her, I try to communicate with her casually but it is usually difficult to get eye contact with her. Her response is always very brief, either

just “yes” or “ok”. However, as the singing session starts she sings all the songs clearly articulating the lyrics and singing in tunes. Sitting next to her one time I realized that I heard her voice for the first time for such a long consecutive period of time. This made me feel closer to Celine.

Both of these cases are based on my rather subjective experience of being engaged in the singing as a volunteer; feeling connected through singing simple waltz tunes together or even talking about the song. However, it would have been difficult for me to feel that way if there had been no music involved or if the music had not been familiar to Celine and Caroline. With Caroline, I acted to prompt her memory and her engagement with the shared joy of remembering with other participant (in this case, me). This is part of the vast array of “lay” practices of care that go unnoticed without ethnographic studies. In SB sessions care is not only given from a person to a person with dementia, but through a range of this kind of lay practices, care is promoted through musicking and assembled to produce a joyful atmosphere similar to the concept of “patching care” (Nishikawa 2007) that was discussed in chapter two.

Because these waltz tunes were simple and familiar to all of the participants, the participants with dementia were able to join in in their own personal ways regardless of the various limitations and difficulties they faced in their everyday life. The fact that they were in a 3/4 waltz rhythm may have the effect, as Jessica was aiming for, somehow to entrain their movements and as a result, loosen the bodily tensions they may previously have had. This also implied that singing waltz tunes was a part of extended warm-up exercises. These waltz tunes were sung in unison, which helped to build up the confidence of the participants. Procter (2011, p.9) has discussed how a shared musical norm in his music therapy work affords:

a framework within which to interact, to perceive our interaction, and to add this to our accrued experiences of interactions characterized by trust, reciprocation and enjoyment – in turn preparing us to risk trusting another person another time.

The shared musical norm of the familiar waltz, as well as its musical elements (e.g. the 3/4 rhythm) also provided a strong, comfortable framework in which participants could develop their own embodied musical participations that contributed to the overall aesthetics. Within this framework participants were able to join in in whatever way they could or felt like and develop their engagements in their own way and at their own pace. This in turn, could help a) to change the level of arousal as seen with Jake, or b) to release tension or anxiety that some of the participants may have as experienced with Simon or c) to calm agitated behaviour by allowing them to focus on the singing as with the example of Arnold discussed above. Within the framework, musicking could also become a resource for people to have their voice heard for a prolonged period by others as I experienced it with Celine. Otherwise anxiety and hesitation could stop them from talking for more than a few seconds. Furthermore, it could provide a framework that enhanced the experience of joyful interaction between those present, as Caroline and I experienced it, an interaction characterized by the trust, reciprocation and enjoyment that Procter (2011) mentioned. Finally, this also provided a time and space within which the participants with dementia could focus (or cope) without wandering or becoming restless as the example of Chris showed. The collective voice that emerged through the use of familiar waltz tunes built the strong, comfortable framework and afforded a sense of belonging, which as a result forged the group culture. This was important in driving the whole group forward to more challenging activities later in the session, activities that developed a positive response to the challenges.

5.5.2 Collaborative crafting of aesthetics

The strong framework discussed above also afforded micro negotiations among the participants when contributing to the overall aesthetics. While most of the participants sang the melody line in unison, there were a few participants who contributed to the sound of collective singing in innovative ways. Below is the detailed description of a session when “*She was a dear little dicky bird*” was sung after “*Tulips from Amsterdam*” which was described above.

When Jessica starts playing the last phrases of the song, “ She was a dear little dickey bird” on the keyboard, Laura joins in the singing in the middle singing “I was one of the bird³¹” Jessica pauses and makes sure the group participants know which tune they are singing, “Are you all right? Number 13.” Jessica starts playing the last phrase of the song again, and everyone starts joining in singing from the beginning of the song collectively.

Laura started singing one of the lines soon after the accompaniment started. This shows how the brief introduction of the melody by keyboard was enough for Laura to recognize the tune, broadly remember the words of the song and then instantly sing it. Familiar songs in this way allowed participants to enjoy the joy of collective singing very easily. Thus the strong framework of the collective voice was formed quickly and easily.

She was one of the earrrrrrrrly birds, Iiiiiii was one of the bird.

³¹ The correct lyric is “I was one of the worms”.

Arnold's deep voice continues to carry and he holds the note for a long time as the musical excerpt shows. He has a very beautiful, deep voice. Jessica adjusts the keyboard accompaniment to his singing and waits until he finishes singing the phrase. Craig (a volunteer) starts to sing the base line, and makes the harmony. This is not so obvious but adds depth to the collective sound. He starts whistling and continues whistling after the singing ends, and lets it fade out, which makes people' laugh (Appendix 11. Example recording no. 2)

I mentioned earlier that majority of the volunteers were musically experienced and active singers in local choirs. One of their roles in SB was to support the group singing in order to make a comfortable framework for others to join in without feeling exposed. Here Craig added a little extra by making quick aesthetical adjustments to the singing. These adjustments, as well as engagements by Arnold and Laura, emerged in relation to the event rather than being planned deliberately beforehand. All these engagements contribute to the aesthetics of the collective voice in a *collaborative* manner. The familiar and relatively simple waltz song afforded creativity, collaboration and fun. In this way, collective singing of the song in unison became a framework within which the participants could add some unique voices to craft the aesthetic of the collective singing to make it more beautiful and pleasant. As a result of this collaborative aesthetic crafting a democratic group culture was formed.

One good example of this was how the group developed Craig's initial, improvised, whistling a few weeks later when "*She was a dear little dickey bird*" was sung again. As soon as Jessica started playing the beginning of the tune, several people started whistling as if making the birds' sound and during the bird singing part ("*Cheep Cheep Cheep! She went*"), a few participants whistled instead of singing the words. Again laughter emerged

at the end of the song. In this way the crafting of the aesthetic developed as it was repeated, which over time helped to form the continuous and sustainable group culture. Fine (1979) also discusses the formation of group culture with its emphasis on informal group interactions. For instance, the informal cultural products (e.g., jokes, slang or superstition) developed in the course of natural group interaction and people may later catch on, thus become the basis of further interaction. These informal cultural products are termed by Fine as “idioculture”, which is explained as:

[T]he process by which collective decisions are selected, and thus permits an understanding of how a group increases its sense of "groupness," cohesion, and commitment (Fine 1979, p.737).

The whistling that developed as a result of the process of collaborative crafting around the song is clearly an important group interaction, where idioculture was developed and brought additional interactions that increased the sense of groupness, hence (further) forging the group culture. This is a key characteristic of SB where local people from various backgrounds and in differing circumstances (university volunteers, volunteers who are retirees, people in various stages of dementia and their caregivers) come together to sing once a week and develop their group culture in a bottom-up manner.

5.5.3 Meeting him again: mutual musical care through his song

As these familiar waltzes were sung repeatedly in SB, the shared meanings of these songs developed as well. This is also discussed by Fine (1979) as the on-going negotiations of meaning that contribute to the generation of the group culture.

For instance, one of the popular waltz tunes, “*Irish eyes are smiling*” started to be known as Arnold’s (favourite) song. I observed the process of how it went from being “a song” to being “Arnold’s song”, and it is instructive to examine this process to learn more

about how mutual care emerged in the process of the negotiating the meanings of “a song” with in a group.

Once “*Irish eyes are smiling*” was introduced although it was not in the session program. Jessica had chosen it because Arnold was present at the session after a few weeks of absence due to his health condition. His rapid deterioration was shown in his behaviour as well. He was anxious and was less able to control his agitated behaviour than before³². However, he became much more focused once Jessica started playing “*Irish eyes are smiling*” and showed great concentration and sang away the tune with his usual deep voice.

Why did Jessica come to choose “*Irish eyes are smiling*” especially for Arnold on that day although he previously responded to many other songs as much as he responded to “*Irish eyes are smiling*”? In the interview with Jessica, she explained that she monitored people’s reactions to songs closely to learn what works for them³³:

I just watch what people respond to, and I see when they like songs and I remember. I mean, I know that, those songs we've talked about for Arnold, the songs that he really enjoys. When he came last week, I changed the program. Because I didn't know he was coming, well I knew he might come, but until he arrived, I didn't know he was going to be there. So I put an extra song, especially. Because I said to him, would you like to sing... it was 'Irish eyes' you know, 'When Irish eyes are smiling', he loves that one. So I said, would you like to sing that? And he said, 'yes'. So I said, 'right we'll do it'.

³² In fact, he was experiencing changes in his everyday life due to the progress of illness at that time. He had moved to the nursing home and this was the first session that his wife Monica had brought him to after the move.

³³ Jessica often asked Susan and Karen to play the keyboard to lead the session from time to time as it gave chances for Jessica to “monitor” more carefully to see the participants’ engagements with activities and to relate closely , to the participants.

She used her knowledge of people's previous responses to songs to give Arnold some additional care through the use of a favourite song at this session when he had been absent for a while. As a result, he did sing beautifully as he always did, and obviously he was focused and his agitated behaviour was subdued. In this way, Jessica often changed the program according to the situation, as she also explained in the interview: "*I prepare a program as you know, but it's not completely set in [...] concrete, I can change it and I do*".

The notion that this song had strong links with Arnold is not only something that Jessica and I noticed. Cecily, who is a volunteer, expressed her feeling regarding Arnold's singing "*Irish eyes are smiling*" without any prompting:

Cecily: You know Arnold. When we sing 'When Irish Eyes are smiling', you know, when he just sort of comes to life... I find it quite moving actually, I do.(...) He was a very good singer, he was a very good [speaker] apparently as well, in his day, and teacher. But he is getting more and more confused. But whenever we sing "When Irish eyes are smiling", he really sings out at the top of his voice.

Interviewer: Still now?

Cecily: Still now, yes. And the voice is still there, and he obviously enjoys it.

The knock-on effects for others when Arnold is singing "his" song is that at that moment his illness is displaced and they meet the person he used to be. Therefore, Arnold is not only cared for by Jessica, he also takes on the role as a performer, who responds to the expectations from the participant by singing out "his song" beautifully as the great singer he used to be known as. Becoming a person with dementia is not only distressing for Arnold and his wife, but also for his friends, especially as Arnold was known as a great teacher and was very involved in the local community and many participants from SB knew him for many years before the illness. Therefore, "meeting him again" through

musicking clearly is a powerful experience and meant a lot to the other participants. In this way, musical care was given and received by **all** participants in the group within the framework that had been tailored especially for the group, in this case, through a very familiar waltz; *“Irish eyes are smiling”*. This, as a result, helped participants to cope with the sadness of slowly losing someone they had known for a long time due to the onslaught of dementia.

About 20 minutes of the session have passed when the familiar waltz exercises were completed. By this time the session had usually entered a nice flow. Participants gained momentum as their voices and bodies were warmed up through the warm up exercises followed by the familiar waltz exercises that forged the group culture. This flow prepared participants for the challenging exercises to follow.

5.6 Exploring new skills through various challenging activities

In the main section of the session that followed, various activities (usually four to five) were introduced. Sometimes, the musical quiz and/or simple sing-along exercises (i.e singing familiar tunes) were sandwiched in between the activities. One of the unique elements of the SB sessions was its format which consisted of a variety of activities that gave the participants the joy of a challenge.

The idea of pushing the limits of the participants with dementia through different activities was a crucial and even unique element of SB when compared to the majority of music activities for people with dementia, as these are usually limited to very simple sing along activities using familiar songs. In the Watertown group, however, three or four activities from a list of seven potential ones were selected each week. The potential list included the following:

- 1) Call and response songs: the group was divided into two. A succession of two distinct phrases was sung by the two groups. The second phrase was sung as a response to the first phrase. The pattern was repeated several times.
- 2) Round songs (canon): the group was divided into more than two groups, and two or more voices sang exactly the same melody but began at different times. In this way, different parts of the melody coincided in the different voices, but fit harmoniously together.
- 3) Partner songs: the group was divided into two to sing different songs that had a similar harmonic structure and length, which could be sung together.
- 4) Clapping songs: a song was sung with a distinctive rhythmic clapping.
- 5) Harmonized songs: the group was divided into more than two groups to sing a song in harmony
- 6) Songs with percussion accompaniment: several participants were given roles to play the percussion for a song
- 7) Action songs: a song with physical movements, some included hand and/or arm movements, others included a dance³⁴.

These exercises were all challenging when considering the limitations that people with dementia had in terms of short term memory and general cognitive functions. Therefore, it required careful crafting to achieve the exercises as a cohesive group. Usually, these

³⁴ Although some action songs were introduced in this section, the participation dance was usually done at the end of the session before closing the session with *Shalom* , which will be discussed later in this chapter.

exercises were difficult to achieve in one go, unlike singing the familiar waltzes. A lot of time was therefore spent on each activity and instructions were broken down to simple discrete elements. For example, some activities started by singing in unison or repeating the first verse several times. After ensuring it was sung well, the group was divided into two or more groups and moved on to the next level. The instructions were given in various ways: verbal explanations using voices and using bodily movements. All these processes were supported by musically experienced volunteers throughout the circle.

Within one term, the same activities were repeated several times in order for the participants to enjoy the process of learning and improving. So, the session was planned not as an isolated one-off event but as part of a sequence. Below is the example of activities introduced during ten consecutive weeks.

Song Title	Activity type	Week									
		1	2	3	4	5	6	7	8	9	10
Mango Walk	Partner song	○	○	○		○	○				
A Song of the Weather	Call and response song	○	○	○		○		○			
The Orchestra Song	Round song		○ 3v	○ 4v		○ 5v	○ 5v				
Dumpling	Call and response song			○		○		○			
Day Oh	Call and response song							○	○		
I like the flower	Round song								○	○	○
Mocking Bird	Song in harmony								○		○
The Ten Green Bottles	Action song					○	○				
My Father's Clock	Song with percussion							○	○		

Figure 3: Example of activities during ten consecutive weeks. Red circles = in harmony, V = number of voices. The highlighted week is the week of the intergenerational event.

Within these specific ten sessions as shown in Figure 3, it was difficult to hear distinctive improvements from one session to the next. However, with each repetition the participants seem to feel more confident and comfortable with the activity. This helped the singing sound to become more stable and beautiful over time and as a result the participants felt a sense of achievement.

In addition to these repeated activities other activities were also introduced. Some of these were specific to the session with special themes: “*Auld Lang Syne*” (an action song where participants stand up in circle linking arms with each other) for *Burns Night* and “*There is a hole in my bucket*” (a call and response song) for the *Valentine* session. These one-off songs were usually not complicated and rather easy to be accomplished in one go. The repertoire sometimes overlapped with other activities, for example, in one session, “*Deep in the heart of Texas*” was sung in harmony once as an activity, and two months later it was used in the musical quiz section.

For a discussion of how the challenging activities achieved their dual objectives of inclusion and challenge, I will highlight two activities that were done over a period of a few consecutive weeks: the round song (“*I like the flowers*”) and the call and response song (“*Day Oh*”). It is necessary to discuss the considerable crafting involved in these activities so that we can understand how the two seemingly contradicting objectives of the comfort in the group and the challenge were reconciled.

5.6.1 Repetition works! Repetition works! Repetition works!

First, I will discuss the transformation of the crafting techniques deployed over three consecutive weeks when practicing a round song (“*I like the flowers*”) using my field notes from each session. I will start describing how it was introduced for the first time, which will be followed by changes in crafting techniques and participants’ engagements in the second and third times.

Jessica explains to the group how she is in a flowery mood and thinking about singing the song that we haven’t sung for a little while. First, she introduces the canto part.

“Bunti-bon dadadaBonti-bon dadada, bonti-bon dadadabonti bon....”

Several participants slowly start to follow her, and someone starts taking the rhythm by tapping their foot against the floor.

“Let's do it once more, let's have everybody join in, it's a very easy word, bondi bon, bundi bon. (laugh) if you get bun and bon in the wrong place, it doesn't matter. Are you ready? One, two, three, go! “

This time the participants sing with more confidence.

After singing the line for a while, she stops it, and directs the group to open the page of the songbook. Then she initiates the singing without accompaniment, and the participants follow.

“I like the flowers, I love the daffodils....”

She briefly explains to the group that we will be singing the canto part (Bunti-bon dadadabunti-bon) to see it fits the melody. She divides the group into two, and asks Susan (one of the volunteers) to be in charge a group as Jessica will be in charge of the other group.

First, everyone sings only the melody and next, one group sings the melody and the other take the canto part. It sounds OK.

Then, the group is divided into three groups; a group to sing the canto part, the other two sing the melody as a round song. Craig (one of the volunteers) keeps the rhythm of the canto part very steady. Susan's group starts the melody first and Jessica's group follows after the first line. It was repeated twice and sounds good. The singing slowly fades out as Susan's part ends first, Jessica's part ends a line after, with the canto part remaining. The canto part ends after several repetitions

and Jessica sings two lines of the rhythm section very quietly to indicated the end, and let the singing fade away smoothly. After it ends, laughter emerges.

“Well-done, we'll practice that more.”

This song was a challenging exercise for the group because the group was ultimately divided into three parts, with two groups singing the melody in rounds and the other group singing the canto part simultaneously. However, as the description shows, the exercise was introduced step by step. Initially Jessica did not explain what we were aiming for, and did not encourage people to use the songbook. Rather, she gave instructions using her own words, and made sure the participants were following each step. By doing it this way no-one was confused in spite of the final complexity of the exercise.

When the groups were set up, musical volunteers such as Craig and Susan (a former music teacher) led each group through their parts by articulating the words and keeping the rhythm and melody clearly for other participants in the groups to follow. In this way, the other group participants managed to follow them and the full group eventually accomplished the activity. Here we can see how musically experienced volunteers contribute to and underpin the group's singing when undertaking challenging activities.

The first time *“I like the flowers”* was introduced and rehearsed the focus was mainly on making participants follow the basic instructions rather than enjoying the singing as such. The activity was revised two more times in the following weeks. When the song was sung again in the following session, the whole session was run by Susan because Jessica was away for holiday. First, the whole group sang the canto part together. Afterwards the group was divided into two groups; one sang the canto part and the other sang the melody. Arnold's voice was very deep and carrying well on that day. It was repeated again after

Susan had made sure each group knew and sang their parts well. The collective voice was much stronger and stable than the previous week. After the melody part ended, the canto part still continued and eventually the song ended altogether after one verse. The end was indicated by Jessica the first time, but the second time, it ended without any indication by the facilitator (Susan).

The session in the following week was run by Jessica and again the song was sung. The group was divided into four parts at the end instead of three parts. My field notes from the session describe the development of the song at this point:

After telling the group the next song will be “I like the flowers” on page seven (in the songbook), Jessica starts reading out the lyrics without the tune.

“I like the flowers, I love the daffodils, I like the mountains...”

The participants start opening the page (in the song book), some people join in reading out the lyric, following Jessica. Laura is also reading the lyrics. After finishing reading all the lines, Laura says to me,

“I knew this when I was six!”

Jessica starts playing the melody with the full accompaniment; soon after the participants pick up the melody and start singing. Some people are singing the tune with “ta-ta-ta-..” Arnold starts clapping his hands and sings out with his deep voice. By the time it reaches the last line, the collective voice gets stronger and deeper. When it finishes, Jessica pauses and tells the group to sing only the melody part. The melody part is sung in unison, with the correct words this time. After they finish the last line, some people continue singing repeating the last line

(the canto part repeats the last line of melody part all the way through, so participants might have become familiar to the line by this time).

“Boom-ti-a-ra, Boom-ti-a-ra..”

Jessica tells the group that if they get stuck or get lost in the middle, they can just repeat the part (“Boom-ti-a-ra, Boom-ti-a-ra.”), which results in laughter from the group.

Here Jessica provided new opportunities for the participants to engage in the collective musicking in ways that were comfortable for them, for instance by simply repeating “*Boom-ti-a-ra, Boom-ti-a-ra*”. As Jessica read out the words they were quickly picked up by the participants in their own personal ways; Laura followed by reading out the lyrics, Arnold sang the tune with his deep voice and clapping his hands and several participants continued repeating the last line. These spontaneous actions took place in response to each other and contributed to the overall aesthetics. This beginning warmed up the group for further challenging tasks:

The group is divided into two groups. Both groups sing the melody part but in round, which is different from previous times when one group was in charge of canto part. Craig and Susan become in charge of each group again. It sounds very stable; Arnold is singing the tune in his deep voice. Afterwards, the group is divided into four groups and all groups sing the melody tune but in round. Jessica assigns two more volunteers to lead the groups. Surprisingly, the four parts round sounds very stable, and each group sings very accurately. The volume of the collective voice is much louder than the two part rounds we just sang. It may be because people feel more responsible with their parts when they are divided into

smaller sections. The male voices are carrying very well; especially Arnold's voice is much deeper this time.

However challenging it seemed to sing in four parts, it did not confuse the group participants, they sang it very well with the collective voice of each group becoming even stronger and deeper over time. This gave us a very important insight into the use of music in dementia care; it is possible to push people further through challenging tasks by using careful framing and appropriate crafting under a joyful, inclusive atmosphere as I have described above. This also showed that even though people with dementia have difficulties with short time memories, the experience of singing is somehow built up over time, in this case several weeks. Therefore, the more an activity is repeated, the more engaged they become and the faster they recognize the tune the next time, as Laura and Arnold did. This allows the collaborative aesthetic crafting to be accumulated over time and encourages all participants to achieve the best aesthetic experience they are capable of in consecutive times. The repetition also allowed all participants to be more spontaneous in contributing to the overall aesthetics rather than just following the instructions rigidly, and, the joy of singing seemed to increase through repetition.

5.6.2 Trial, error, negotiation

Repetition is also important as it helps to develop the appropriate crafting techniques through trial, error and negotiation. Sometimes, the first introduction of an exercise did not go well, but it was possible to lead the exercise to success by amending the techniques used through negotiating with the participants as to what works best for the group based on the failure of the first attempt. Below I examine an example of this; the call and response song ("Day oh") which was sung in two consecutive sessions.

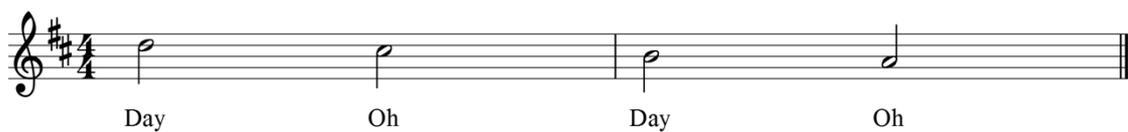
“Day Oh” was introduced as part of the theme of a session on “time of the day”. Jessica explained the background of the song. It was a workers’ song from Jamaica and sung at day break there as the lyrics of its chorus imply (“Day light come and me wan go home”)³⁵. Jessica played the melody on the keyboard and sang the first verse, and quite a few of the participants followed her. It seemed that most of them were familiar with the tune. However once the singing started, it became clear that there was some disagreement as to how it should be sung.

Jessica sang the first line in this way:



Musical Example 3: Day Oh exercise 1

Meanwhile, the majority of the participants remembered the melody of this line in this way:



Musical Example 4: Day Oh exercise 2

Jessica chose the one that most of the participants remembered as it was simpler than her version. This kind of negotiation was often made in order to conclude the exercise successfully without too many problems. Without referring to any lyrics, Jessica told the

³⁵ Day-O is a traditional Jamaican folk song, it is most well-known in a version that was sung by Harry Belafonte in the early 1950s.

group to sing the chorus part (“*Day light come and me wan go home*”) each time after she sang the melody line. Some of the participants sang the chorus part with the last note going down:



Musical Example 5: Day Oh exercise 3

while others sang with the last note going up:



Musical Example 6: Day Oh exercise 4

This created some uncertainty among the participants; the collective singing voice was filled with inconsistency. The crafting techniques used by Jessica clearly did not work so well this time.

However, when this exercise was reintroduced the following week, Jessica changed her way of facilitation and led the group to success:

This time she brought copies of the lyrics for the participants. People hold the paper with lyrics and start singing discretely any way they want to.

“Day oh, Day oh, Day light come and me wan go home.”

Caroline who has dementia is sitting next to me, she is singing as well. As there are not enough lyrics to be circulated, I ask Caroline if she wants to share with me. She says “no”. She looks like she knows the lyrics.

It seemed that the lyric sheet, which was not used the previous week, was helping people to tune in with the song. These lyrics might have meant more for the volunteers than the participants with dementia and their caregivers, as Caroline did remember the words as shown above. In fact, the majority of volunteers who were in their 60s did not seem as familiar with the song as people with dementia and their caregivers in their 80s, presumably because the song was a hit song in 1950s when they were in their 30s.

Jessica starts playing the melody on the keyboard. She explains how to sing this as a “call and response” song slightly different from the last week. She does this by carefully referring to the lyric sheet, explaining how each alternate line has a different style of writing (ordinary writing and Italic) and how it is repeated. She gives instruction (by singing) how she sings the “call” section (Day oh, Day oh), and other participants to sing the response part (Day light come and me wan go home).

She makes sure that the last note of the first line of the response part goes up, and that of the second line goes down, and repeats the call and response several times together with the participants.

This time, Jessica spends more time making sure that the participants understand how to do this exercise, using the information from the lyric sheet (words, different styles of font in “call” and “response” part) as well as use of her own voice, which is followed by the participants.

While Jessica is counting four before repeating again, Caroline sings the “call part” of the next verse, “Tallyman come tally me banana” which has not been introduced by Jessica yet. After singing the tune, she looks at me and her daughter

Lisa and grins. Lisa and I laugh and other participants who are sitting close to us laugh.

The fact that Caroline's humorous action caused laughter among the participants presumably happened only because the exercise was going well with everyone knowing what was happening. In other words, the collective voice had become a safe and comfortable frame for the laughter to occur and allowed Caroline's subtle but humorous action to be noticed among the participants.

Jessica kept leading the group by signalling with her hands, pointing at herself when it is her turn (call) and opening the hands towards the participants when they should respond. This was very effective in making sure the pattern of the exercise; singing in turn, was followed.

This time, the activity went very well and people seemed to understand and follow Jessica's instructions. As the collective voice became stronger and stable, this became a strong, comfortable frame that enabled additional aesthetic crafting to be made by Craig who added a walking bass to it, something that contributed to the overall aesthetic.

This example highlights the importance of flexible plans as well as the need for constant adjustments to make it work, an important crafting skill for a facilitator. Such negotiations were also essential in building democratic relationships where shared and where a grounded aesthetic could emerge, which in turn helped to build a shared group through idocultural actions. Here we saw how Jessica's crafting technique led a challenging exercise to success in two consecutive sessions through trial, error and negotiation. In sum, the crafting process that was necessary for the eventual success included: a) distribution of the lyric sheet where the response part was clearly distinguished from the call part, b) making sure everyone understood and remembered

the melodies of the chorus and c) utilising bodily movements when leading the participants. These techniques were important when a group consisting of people with different cognitive levels tried to do complex things together musically.

5.6.3 Challenges as devices for creating group culture

As I have demonstrated, SB sessions emphasised variety in its activities. Besides this the challenges, within the well-prepared format discussed at the beginning of the chapter, were also an important element of SB sessions that distinguished them from the more common informal sing along activities such as those used to aid everyday care in nursing homes for instance (Gotell et al. 2000; Gotell et al. 2002).

We have already seen, through the two examples (“*I like the flowers*” and “*Day Oh*”), that it was possible to embark upon and succeed in doing rather challenging exercises. Jessica, the facilitator, was not afraid of temporarily failing as we saw in the example above. She always pushed the group forward into new tasks and more challenging exercises. If one way did not work, she developed alternative ways through trial, error and negotiating with the participants to find what works best for the group.

A key question however is why these challenges were important in the context of SB? Why could they not simply continue to sing familiar songs, a task that is easily achieved without much difficulty? The answer is twofold: First of all, it is important not to underestimate the capabilities of the participants with dementia. Repeating the same activities that are simple and easy to be achieved in one go may be safer as they could be achieved with minimum hassle. However, it may make participants feel patronised, especially those who are experienced in singing challenging pieces in choirs (e.g. Arnold and Laura). The activities undertaken in SB sessions were not simply based on trying to find the lowest common denominator, although the song repertoires were carefully

chosen. Instead they were offering participants opportunities to learn something new as a part of a supportive group through carefully tailored collaborative exercises. This also gave them the chance to explore what capabilities they still have left in a joyful manner. This was empowering both for the participants with dementia and their caregivers who were both suffering from the progressive effects of dementia in their everyday life.

Secondly, these challenges as well as the variety of activities were important in sustaining the interests of other participants: caregivers and volunteers. As SB's aim was to benefit both care-receivers and caregivers, it was important that caregivers enjoy the weekly session as much as possible.

Below is a snippet from the interview with Michael, the husband and caregiver of Laura, where he touched on the challenges embedded in the weekly activities:

I like [the songs we sing in the SB]. The ones you know, you know, and we are always learning new ones. [...] Every week, you know, she brings out something new. It's good fun! I look forward to it.

When asked if he had ever been particularly moved by anything in SB, he again mentioned the challenging activities and how he enjoyed the improvement and achievement of such challenges:

I like it when she [Jessica] does the three parts. You know, one part sing one part, you've got to think, you know, when to come in at the right time. Yeah. [...] Yes. It seems to get better every week.

Michael and Laura were active musicians in local theatres and choirs before Laura's dementia made it difficult for them to continue. However, SB had enabled them to continue singing in a group. Therefore, it may be important for Michael that, like in regular choirs, tasks are set and worked towards, something that allowed him to enjoy the achievements that come with it. This also shows how the challenging activities in SB

sessions acted as devices to draw people with dementia and their caregivers closer together. The devices may work differently for care-receivers and caregivers. For instance with Laura and Michael's case, they afforded Laura the joy of exploring her remaining capabilities and regaining her confidence, while Michael was offered the chance to continue learning new things and enjoy the collaborative aesthetic creation through group singing. Volunteers also took the initiative sometimes and added new and "fun" factors to the overall aesthetics rather than simply repeating the basics required to keep the collective singing going. Craig for example added harmony to the collective singing as described above while Rosie, Karen and Dennis often added additional material framings and actions (for instance they once danced with umbrellas when they were doing "*Singin' in the Rain*")

In this way, these activities, through the use of flexible techniques, gave all the different types of participants some challenges, which as a result drew them together by promoting cheerful participation through the same activities at the same time but in different ways suited to their abilities. This sustained the interests and motivations among the participants to continue attending, which fed the virtuous cycle and which thus led to the continuing generation of further enjoyable group culture.

5.7 Achieving flow through music-based cognitive exercises: musical quiz

Following these challenging activities there was usually a musical quiz. This was initially an activity specific to the Watertown group, but in recent years other groups have started to do it as well. In the Watertown group this part was generally run by Susan or Karen. For about ten minutes, eight to ten songs were introduced on the keyboard without referring to written lyrics or mentioning the titles. The participants tried to guess

what the song was by singing the tune or saying the song title. The songs used for the musical quiz usually had a common theme, which often corresponded with the theme of the session. This gave people some clues as to what the songs were as well as providing further challenges to think what the links could be. What distinguished the musical quiz from the previous activities was that it was not focused on accuracy or achieving certain goals, rather it was about trying out participants' memories in an enjoyable manner. The crafting involved in this was worth investigating in detail.

One example of the crafting used occurred during a musical quiz with a bird theme. This was facilitated by Susan and started with four songs which, although they were all familiar to the participants, all varied in terms of their musical structure, connections to the theme and the introductory crafting techniques. The first one, "*Feed the birds*" had a simple waltz rhythm, a familiar musical style as discussed earlier. "*Feed the birds*" was from the popular 1960s movie, "Mary Poppins" (1964) as someone correctly remembered and responded. Susan skipped the first nine lines of the song, and started from the chorus part which was the most memorable with a lyric that went "*feed the bird, tuppence a bag*". All these elements as well as Susan's reminding them of the link with birds just before the song was introduced made it easy for the participants to recognize the song from its melody,

The next song was also known to many of the participants as it was a very popular tune from 1926 "*When the Red, Red Robin (Comes Bob, Bob, Bobbin' Along)*" which became a hit again for Doris Day in the 1950s. In contrast to "*Feed the birds*", this song was in a faster tempo, and Susan kept the tempo fast from the beginning to the end and even transposed it to a higher note in the beginning of the second verse to challenge the participants, while they followed Susan's keyboard by humming or singing. This song

excited the group as evidenced by murmuring and laughter that started in the middle of the song.

The excitement carried over into the next one, "*A Nightingale sang in Berkeley Square*", which was from 1940 and was sung by the very popular singer during and after the war, *Vera Lynn*. This song was in a slow tempo, again a contrast with the previous song. Only the first verse was played, but most of the participants recognized the tune as it approached the last line of the verse. The last line "*A Nightingale sang in Berkeley Square*" was sung collectively.

The following song was also in a slow tempo; "*Hey little hen*" was a very popular nursery tune. It was recognizable to the participants from the very beginning, which made the collective voice strong even before the first verse ended.

These four songs were followed by five more songs. "*Five little ducks*", which was also a popular nursery tune in a slower tempo, and became the hardest one in that no one was able to remember the words until the end of the verse. What followed was a very familiar song in a faster tempo, "*Bye Bye Blackbird*", a "standard" from 1926 which appeared in several films in the 1960s. The majority of the participants knew the tune and words, so it was sung collectively from the beginning. The next one ("*There was an old woman*", the nursery tune) was a tricky one in terms of guessing its link with birds. Susan sang the tune clearly and slowly to lead the people. The participants followed her with humming, and the word, bird came out finally in the 3rd verse: *There was an old woman who swallowed a bird, how absurd! to swallow a bird.* At that point someone shouted "*swallow a bird!*" rather excitedly. This was followed by a very familiar tune, "*Mockingbird*" (a popular song from the 1950s), whose words were picked very up quickly. The musical quiz ended with "*My favourite things*", a song from the film "*Sound of Music*" which was very

familiar to the participants and it was easily sung with the lyrics and some occasional “lalalas” when the words slipped. Although it was sung well, its link with “bird” was challenging for the participants, so Susan had to give away the clue as soon as the actual word (“geese”) was sung. Soon after someone else shouted “*Geese!*” Throughout the exercises laughter emerged at the end of each song.

As we can see, the musical quiz in SB was not just a collection of songs that were related to the theme, the combination of styles and the order were actually very carefully planned to make it interesting and challenging, but not overwhelmingly so, as an activity. Christina, one of the volunteers, echoed this:

I think the music quizzes are good [...]. They play bits and you have to know what it is, and then join in the singing... I think that's a very, very good one. I think [that's] brilliant. It makes them think of colours, names, you know. It's a very well-thought out activity. It's music-based, but you have to think along various lines you know, surnames, flowers, places. And it's stimulation [sic].

As Christina pointed out, by adding the theme, the musical quiz becomes a challenging cognitive exercise that consisted of remembering the melody and words of the song as well as thinking of its link with the theme.

As a music-based cognitive exercise the format was well-thought out in order to maximize its affordances. The order of the songs was planned carefully not to induce any frustration or confusion with these challenges. For example, the first four songs described above were all very familiar and were introduced without any pauses between them. This gave the participants momentum and allowed them to familiarise themselves with the format of the activity. After this soft opening, more challenging songs were introduced in between very familiar songs (“*Bye Bye Blackbird*”, “*Mockingbird*”). As these were very familiar songs and easy to guess, they effectively acted as anchoring practices to sustain

the overall flow of the activity. The songs with a faster tempo were also introduced in-between the songs with a slower tempo, so that it gave a variety to the activity which helped sustain participants' interests and attention.

As I have discussed earlier, the session initially achieved a good flow through the warm up exercises and the familiar waltz (exercises) which warmed up the voices and bodies of participants, helped participants with dementia to regain connections with the surrounding world and empowered their identities. The more ambitious activities that followed pushed the participants forward to work on challenges together, which helped create and affirm the pleasant group culture. With the musical quiz that came afterwards, all these musical affordances from the previous exercises came together and the sessions usually reached a peak in terms of participants' collective energy levels and excitement.

For instance, the catchy melody from familiar songs and other participants' singing enhanced their memory, which helped to (re)build their confidence as exemplified by Laura who often said in the middle of the musical quiz: "I knew all of them!" During the musical quiz, Laura sometimes even stepped into the centre of the circle (see Figure 1 for the session layout) and started dancing alone. Jonathan, another participant with dementia, often told me gleefully when I sat next to him how he had known these songs since he was a child. Celine and Caroline, although they were usually quiet, as soon as they recognized the song title, shouted the song titles with excitement (although in a subdued way). Jake, who often took a nap during the session, got excited and made funny jokes about the songs, which induced laughter in the group. Any agitation that had been observed at the beginning of the sessions, especially with Arnold and Simon, gave way to their joyful engagement and complete focus on the activities.

During the musical quiz it seemed that participants had reached their ultimate “flow state”, states of concentration and complete absorption in the activity as discussed by Csikszentmihalyi (1988). Csikszentmihalyi points out that a balance between the challenges of a task and the skills of the performer is important in terms of achieving this flow state. The musical quiz fulfilled these criteria as it was crafted with the right amount of cognitive challenges within the framework of a well-structured format that provided a range of anchoring practices. Participants’ skill as well as their confidence when it came to performing the activities had already been attained through the previous activities. In this way, careful crafting and framing negotiated among the participants allowed the group to achieve their flow states within the musical quiz period. This, in turn, empowered the participants with dementia by giving them a chance to enjoy the skills inherent in retrieving these songs from memory in pleasurable and safe, yet challenging ways.

The activities described here validated my suggestion in chapter two, namely that it is not music acting as an isolated stimulus that brings positive effects to the brain as is often suggested within the neuroscientific approach to music and dementia (e.g., Baird & Samson 2009; Crystal et al. 1989; Cuddy & Duffin 2005; Norberg et al. 1986).

Instead, each individual connects the music to other things, in this case, the social environments which include the presence of their partners and other participants, the physical and material environment prepared for the sessions, the musical crafting that enhanced the act of remembering in gratifying ways, and the associated memories of the songs. Careful and collaborative crafting of the environment is therefore required to allow participants with dementia to latch on to music and make use of various structuring resources for self-stability and self-care as DeNora (2007) has discussed in more general terms. The use of music in dementia care as described here also resonated

with the idea of resource oriented music therapy as discussed by Rolvsjord (2007). She emphasised the importance of democratic participation where both therapist and client used their strength and resources to engage in the musicking as a key to empowering the clients in music therapy. Similarly, in the SB sessions the mutual lay care and democratic participation were also key factors in the successful use of music as I have demonstrated earlier in this chapter.

5.8 Participation dance: forging the feeling of being together

Following the musical quiz one or two songs were usually performed, sometimes a revision of an activity from the previous week or one of the familiar tunes (in unison). After that, there was a participation dance. This was the last activity before “*Shalom*” closed the session.

Most of the time, “*Lambeth Walk*” or “*Hokey Cokey*” were danced with Jessica’s accompaniment on the keyboard and these two songs were very popular among the group participants. Common descriptions of these participation dances were 1) “active and light” (as Jessica said), 2) “known to the participants very well” as most of the older participants had danced them many times in their lives, 3) “standing up” if feasible and 4) “involving physical contact” with other participants or partners.

In “*Lambeth Walk*”, which was a famous song/dance from World War II in the UK, participants stood up in pairs, crossed arms with each other and marched rhythmically in a circle while singing. Each chorus ended with a shouted “Oi!”. This was done together in a very lively manner every time. The lyrics were as follows:

*Any time you're Lambeth way
Any evening, any day*

*You'll find us all
Doin' the Lambeth Walk. Oi!*

*Every little Lambeth gal
With her little Lambeth pal
You'll find 'em all
Doin' the Lambeth Walk. Oi!*

When doing the “*Hokey Cokey*”, everyone stood up in the circle and danced to the tune by moving their arms and legs in and out following the lyrics of the song:

*You put your left arm in
your left arm out
In, out, in, out, You shake it all about
You do the Hokey Cokey and you turn around
That's what it's all about...*

*[Chorus]Woah, the hokey cokey,
Woah, the hokey cokey,
Woah, the hokey cokey,
Knees bent, arms stretched, rarara!*

During the chorus all the participants held hands with each other and on each "whoa" raised their joined hands in the air and walked toward the centre of the circle, then walked backwards away from the centre still holding each other's hands. This was repeated three times. With the last line, participants bent their knees, stretched their arms and clapped hands three times while singing “ra, ra, ra”. “*Hokey Cokey*” was a well-known music hall song from the 1940s, but it is still known and sung by people of all generations in the UK, particularly at Christmas time. Participants in SB would therefore presumably have sung and danced “*Hokey Cokey*” on many occasions throughout their lives.

When dancing “*Lambeth Walk*” and “*Hokey Cokey*” during the SB sessions, there were a few people who preferred to sit down due to their physical condition. Jessica handed out percussion instruments to them so that they can also feel a part of the situation and contribute to the overall aesthetic experience.

In fact, this kind of dance activity for therapeutic benefits has seen a recent boom in the UK (along with singing) as Davidson and Emberly (2012, p.141) explain:

Social tea dances³⁶ have had a massive revival with older participants of society, not having been practiced since the Second World War. Participants clearly engage for reminiscence, as well as companionship and physical benefits, with regional support for such events increasing rapidly with groups like Independent Age (Dublin) and Age Concern (across UK) supporting regular Tea Dances.

Many participants at SB also told me in the interviews that they felt that the participation songs worked best; for instance Monica (Arnold’s wife) said, “*I think he likes songs he can dance to*” while Lisa (Caroline’s daughter) also told me how these songs were good and enjoyable for Caroline because she enjoyed dancing. Likewise, it was observed that Jonathan (a care-receiver) often requested “*Lambeth Walk*”. Some of them explained the reasons why they thought the participation songs worked well.

Christina, a volunteer and a former occupational therapist said that:

³⁶ A tea dance is a traditional English afternoon or early-evening dance from the Victorian Era. People danced with light classical music, waltzes and tangos. Refreshments (tea, biscuits, sandwiches, cakes) are served. This is a YouTube example of its revival which shows how it is run by the charity Age Concern, UK:
<http://www.youtube.com/watch?v=MKvjJWxjres>

Your motor skills are improved and while you are doing it and enjoying it you don't realize how much benefit, in other ways, is coming in. Yes, action songs are important. And movement songs are important. And... I suppose that is the physical side of it. And there is an emotional side of it and there's the sheer pleasure of it, so yes...

Dennis (volunteer) voiced a similar view:

I think anything physical helps. In other words, getting up and dancing, etc., like that... I think that's useful. I think the whole thing, joining in, is a beneficial activity just in itself [...] everybody just singing. But I think also getting up, moving about, again just exercising, memory in relation to rhythm, etc. [...] Lambeth Walk or the Hokey Cokey, etc. Again, these are all things which most of them will remember from past times as having enjoyed. So there you've got the memory side, you've got the physical side, of joining in and doing something collectively.

It seemed clear that dancing, using cultural forms that were familiar to the participants, recalled embodied memories, which made it a pleasant activity where they could make use of their remaining physical and cognitive functions. Violets (2000) has discussed how such dance movements with people who suffer from dementia would let them regain the connections between the brain and the body that often atrophy as a result of long term dementia.

Susan who often led certain exercises also emphasized the collective aspect of the exercises when she was interviewed. Palo-Bengtsson and Ekman (2000) have suggested that dance events work as an effective caregiver intervention for persons with dementia as they encompassed the ontological state of “being together”. Palo-Bengtsson and Ekman (2000, pp.163–164) further discussed the benefit of dance activity as a result of caregivers being able to observe different parts of the body as well as the eyes and faces of their (dance) partners which enhanced the overall emotional communication. In short, the bodily capacities that were usually dormant took over in the dance activity and

might lead to alternative strategies in caring for a person with dementia. With the “*Lambeth Walk*” and “*Hokey Cokey*” in the SB sessions, people stood in a circle closely, holding hands with each other as described earlier. Therefore, as indicated by Bob and discussed by Palo-Bengtsson and Ekman (2000), these participation dances helped the participants to forge a sense of being together by letting mutual emotional communications flow more intensely than what occurred with other, less physical activities. They also made the whole group aware of the bodily capacities of the participants with dementia in addition to their hidden memories that had already been demonstrated through the earlier activities. This point will be further explored below.

The promotion of physical contact was a distinctive element of the participatory dances that set them off from the other activities in the SB sessions. What was the specific meaning of the physical contacts for people with dementia, their caregivers and other participants in the SB session? Henry³⁷ emphasized the importance of emotional communication and gestures such as smiling and eye contacts when relating to people with dementia, and discussed how touching people’s hands or the side of the face could also give “*extra expression of warmth and affection that people with dementia seems to respond to a little more* “. Furthermore he suggested that:

[...]to stress how important such a gesture is, to create warmth for somebody with dementia. You can talk all you like, but sometimes if you hold their hands as well as talk, you often get the person suffering from dementia responding by putting their hand on top of your hand.

³⁷ Henry was a former caregiver for his own mother who had dementia, and a chairperson of the local branch of *Dementia Support Group*. He helps out at SB from time to time.

Physical contact could therefore enhance the feeling of connection both for the person who was trying to communicate with people with dementia and possibly for people with dementia themselves, while at the same time helping participants with dementia to improve their ontological security.

More specifically, Jessica felt that the physical contact worked in the SB session:

I like things where we all join together. This is why I do the ribbon song,³⁸ as I think there is something very nice about feeling part of a whole, of a whole group. You know, being close, and actually being in contact. [...] That's why I like singing, doing things in a circle, like the bell, because we are all in contact and there's something nice about that.

Overall the activities involving physical contact, participation dances as well as the ribbon songs, seemed to help participants secure the mutual ontological security of being together and enjoy the feeling of togetherness and closeness as Jessica discussed. Thus it could also remind participants of the group culture that was established in the session, which in turn reinforced it, again taking a turn in the virtuous cycle. All this occurred while they engaged in happy reminiscing through the embodied exercises that made use of their remaining cognitive and physical abilities. Promotion of the emotional connections thus seemed to be a key element of the participatory dances, which will be explored further below.

5.9 Participation dances as emotional moments

In January Arnold enjoyed the *Hokey Cokey* dance and was very involved as my field notes from the time showed:

³⁸ The ribbon song was sometimes sung as an alternative to the hello song in the beginning.

Arnold was very excited today, and his shout “OH” at the end of the chorus was as loud as they are this time (Arnold ends the chorus with “OH!” which is something he has improvised himself. We always end the chorus of “Lambeth Walk” with “Oi!” so this pattern may have been on his mind. At one point he stepped into the centre of the circle and Deborah (caregiver and friend of Celine), who was in the opposite side of the circle, stepped in, held his hand and danced with him in the centre of the circle. Arnold danced forcefully while singing the tune out loudly. Monica, Arnold’s wife who was sitting down at that moment, watched them contentedly. It was definitely the highlight of the session, at least for me.

Two months later, in March, “Hokey Cokey” was danced again, and Arnold was again very vigorous, however this time things turned out differently:

“Ohhhhhhh! The Hockey Cokey!!”

Arnold's voices stretches, he starts clapping his hands. The collective voice gets stronger and deeper as we move in and out of the circle together. The energy level of the group goes up. I hear laughter and giggling in the middle.

“ (...) That is what it’s all about.” “OH!”

Following Arnold’s lead, others shout “OH” after the second chorus. The collective voice gets stronger and stronger. After the next chorus Arnold again shouts “OH!”. Jessica speeds up the keyboard accompaniment, which makes the participants more excited with more giggling and laughter and a louder collective singing voice.

Then Arnold takes his hands off from his wife and the participant on his other side and steps into the circle, possibly trying to dance by himself in the centre. I expected him to dance successfully as he did in March. However, this time he loses his balance and almost falls down. His wife runs to him, takes him back to the seat and helps him to sit down. Arnold looks clearly displeased about having to sit down. His friend Bob, who is also present, takes his arms and dances in front of him, as do two other volunteers, all trying to help him still feel involved. Deborah quietly says, “he is getting worse.”

These two incidents were both very emotional moments but obviously in very different ways. The exact same activity that afforded Arnold moments of breaking away from his dementia created constraints, which helped to displace his illness, but later forced him to be aware of the progress of his illness. In both cases, the participation dance brought out a range of emotional experiences for the other participants, particularly the caregiver and close friends of the person with dementia. This is what I would call “the double edged affordance”: an activity that could provide positive experiences, but also has the potential to suddenly “turn around” and become a negative event. This is something that is rarely discussed in the literature; I will therefore discuss these double edged affordances of participation dances in some detail.

5.9.1 Breaking down inhibition: the moment of displacing illness

The physical movements associated with “*Hokey Cokey*” were deeply embedded in participants’ (physical) memories as it is such a well-known song in British culture. All the participants were familiar with the tune and also how it was danced. Therefore, as soon as it started, the participants were quickly “stirred up” emotionally and physically as Rosie put it and the collective voice got stronger and deeper with a lot of laughter and

excitement. In these sessions Arnold took the initiative to shout “Oh” at the end of the chorus and other participants followed. The collective excitement accelerated Jessica’s accompaniment, which in turn accelerated the collective excitement and joy even further. This was quite common at SB sessions: participants usually got most excited during the participation dance just before the session closed with the calming “Shalom” song.

Legrand and Ravn (2009, p.389) suggests that the reason why participatory dances are experienced so intensely is that, in the dance performance, “subjectivity is bodily expressed, thereby allowing the experience of the body’s subjectivity directly during perceptual experiences of the body”. The participatory dances in the SB sessions were also experienced in such ways that the physical perceptions and the subjective experiences became tightly linked, which then accelerated the participants’ excitement. These participation dances were also the only activity in SB that required all the participants to stand up and dance side by side in a circle, holding hands with each other. In other words, they were the most physically intimate activity which afforded a chance to celebrate solidarity, thus further establishing group culture, in a fun way.

Rosie discussed her emotions in relation to “*Hokey Cokey*”:

(...) when you see us doing the Hokey Cokey? Now this is back when we had Trevor, and you don't know Trevor. But he and Arnold were together, standing with the two lots of couples and doing the Hokey Cokey, that was when Arnold was really, really lively. And they just ripped the roof off I mean they were both absolutely so joyful. It was fantastic. They almost lifted the roof with the noise they made and the excitement they had.

Rosie knew Arnold before he got Alzheimer’s disease as they were from the same church, and she had seen the progress of his illness every week both in church and at SB sessions. According to Rosie, Karen (another volunteer) and his friend Bob, Arnold was known for his very social, upbeat interpersonal skills and his great ability to lecture

publicly in the local community. However, Arnold, like everyone else with dementia, found it difficult to have a happy time with others as he was used to, due to the regressive effect dementia had on his cognitive abilities. Seeing Arnold and Trevor dancing joyfully no doubt made Rosie even more emotional and moved because of her past acquaintance with him and her knowledge of how dementia worked. At that moment the illnesses Arnold and Trevor suffered from were overtaken by their joyous excitement in Rosie's eyes.

Christina, another volunteer, also described her mixed emotions during SB sessions; sadness at seeing someone she knew deteriorating and happiness filled with a feeling of elation when seeing them uninhibited:

But by knowing [Arnold] personally, it's very, very sad. But you know, he is enjoying this group and you know he is able to express himself. Where he's lost his ability to lecture you know... so it's thinking about what was and what is. And yeah, that's very upsetting and moving. And sometimes when you have what song, you know a spontaneous "what shall we sing"? And you hear a certain song comes out, and you think "that was part of their busy life, that was part of them a few years ago". [...] When they were active and when their brain was working with them. [...] It's sad. But you've got to go forward at this level now. You mustn't keep... you know. But it is sad. Because you recognize what was and now what is. So I find that quite emotional. But again, it's to do with the music I think, the type of music. What comes up and... But yes. But it also it makes you very happy, when you see them get up and walk around, dancing, or somebody gets up spontaneously and dances, you still get that feeling of elation. You think "wonderful", you know, they are uninhibited, they can go out there and do it and then other people join in, and I think what a wonderful freedom! So that's a very happy moment. (laughs)

The sad feeling and sense of loss of a friend are hard to be displaced; however, in SB sessions people were able to see him enjoying the group and expressing himself, which lessened the sadness. Therefore in the moments Arnold was fully engaging himself with

the music, his illness was displaced in his friends' eyes, which helped them to think positively about Arnold's current situation. Thus, any joyful, bodily engagement from the participants with dementia seem to be very important for caregivers and volunteers as it successfully overtook their sense of loss and the illness was forgotten, even though only temporarily.

Christina's words suggested that the lack of inhibition experienced by participants in SB sessions was inseparable from their sense of losing their loved ones (partners, mothers and friends). Within the music space of the SB sessions, just like Christina, Rosie and other volunteers and caregivers had to deal with **their** own sense of loss of loved ones in various ways. Therefore, SB sessions provided a way to cope with the sadness and stress associated with the process of "the long good-bye" as Harrison (2010) terms the extended period of caregiving in dementia care.

Jessica, the facilitator, also shared with me a particularly moving episode which was also related to a participation dance, in this case "Lambeth Walk", which involved Clair who used to come to SB with Leslie, her husband who had dementia.

She was always a very good carer, she was a wonderful carer. And he came along, and he always had a nice smile on his face, especially when he was singing and he joined in, and he could hardly say a word, but he sang. And I always remember the very last time he came in to the group, we were doing the "Lambeth Walk", and I never know what to do when there's a person with wheelchair, because I always think, they can't really get up and dance, but they need to be a part of the group. And I don't know why I did this, but for once I said, "look, we live in the middle [sic] put him in the middle, we'll dance around you", which sounds a bit strange. And you know, I don't know how she did it, she got him up and she stood with her arms around him in the middle of the group, and you could have cried, you could have cried really. And we all went around and there we were, doing the Lambeth Walk, and she was doing the Lambeth Walk with him, in the middle of the room. And afterward, she said to me something like: "You gave me the chance to put my arms around him,

and just pretended I was dancing with him.” I thought that was amazing. It was just a one-off really, I didn't know whether I was doing the right thing. I said to her afterwards, were you happy to do that? She said “[Yes], I was”. But that was really quite moving. But she said “it gave me the chance to be up there and imagine I was dancing with him, and we used to do that”. It was lovely to give her the opportunity to do that in a group of people where everybody understood. And everybody was so moved, that she took that, you know, she took that chance. And she just picked him [up] and he was heavy, he was a big man, she had him, she just stood with him, as if she was dancing with him and it was so lovely.

Jessica repeatedly expressed her hesitation with regards to her actions in this particular instance. Her suggestion of putting Leslie in the middle and dancing around him was clearly beyond her usual carefully considered actions. In fact, Jessica has always been cautious about the levelling structure and very careful not to make any distinction between participants with and without dementia. Suggesting that they had a participant with dementia in the centre of the circle and others dancing around him was something that Jessica would usually avoid. Therefore, it was clearly beyond her usual practices and roles, and she took the risk. It might have resulted from an emotional reaction stimulated by the collective energy within the group. Despite Jessica's hesitation, it gave Clair a chance to transform her everyday role as “a good and wonderful carer” powerfully to the role of Leslie's loving wife by putting her arms around him and pretending she was dancing with him, as they used to do in their younger days. At that moment, just as Christina and Rosie related to Arnold in the participation dances, Jessica and Clair were also uninhibited. In other words, their actions deviated from their usual roles, Jessica as a careful facilitator and Clair as a good caregiver. As a result their roles, as well as the relationship between Clair and her husband, were temporarily transformed, which also had strong emotional effects on the rest of the group as Jessica explained.

All this suggests that the participation dances offer a powerful means of temporarily displacing the illness in other people's eyes as their joyful bodily engagement overrides any signs of illness and overtakes the sense of loss experienced by their friends. As a result, participation dances can transform normative roles and relationships.

5.9.2 Fighting against the illness?! The moment of recognizing the progress of illness

Turning now to the flip side of what can be offered by musicking in general, and participation dances in particular, it is important to understand why and how music and dance can sometimes end up emphasizing the illness to the participants. When Arnold was almost falling down the participants around him reacted to the incident in various ways. His wife, Monica, ran to him and tried to take him back to his seat. There was some tension between Monica and Arnold at that moment as Arnold resisted Monica's help. After reluctantly sitting down, Arnold bent down with his head in his hands. His friend/carer, Bob, and other caregivers went close to him and danced in front of him to help him still feel involved. It was quite an emotional moment because his actions seemed to indicate that he was fighting against his illness. It was also emotional because he was obviously pushing himself to his limit, and as a result, his (by now reduced) limit became very clear to the other participants in the group as Deborah quietly expressed at the time ("he is getting worse"). Here musicking actually created a contrast structure that showed us how he was "failing".

In order to use singing as a means to facilitate the social engagement and regulate the arousal level in dementia care as discussed by Ridder (2004), it is important to offer the appropriate level of intervention that takes into consideration the capacities of participants with dementia to avoid any incidents. Similar issues have been discussed by

DeNora (2000), with regards to how too much hardcore dance music in aerobic exercises can lead to injury as participants are pushed beyond their limits without realising it, due to the entrainment of the music. This is an important, but difficult, issue when providing music activities that involve people with dementia at a collective level. It also brings up the issue of where to draw the line between “safe for all” and “enjoyable challenge”. For instance, Kerem (2009) discusses the importance of gradual introduction of music (e.g., start by using simple percussion instruments, listening to recorded songs that have only a melodic line, having vocalized conversations, and playing vocally-based rhythm games) when promoting music as a communicative medium for young children with cochlear implants. The SB sessions obviously prepares participants for a long time before the participatory dances that require bodily engagements as has been clearly demonstrated above. However, an even more careful and gradual approach in a one-to-one setting as discussed by Kerem may also be necessary in the use of music for dementia care for people, particularly for those with advance stage dementia.

The incident described above also affected the caring situation around Arnold. Nancy, one of the volunteers, reflected upon this issue from the caregiver’s (Monica) perspective:

I think this must be very difficult for a carer to be dealing with. Like, for instance, Arnold wanted to dance didn't he, but Monica knew that he was going to fall over, so... But you know, looking at it from distance you can see that she's got his consideration at heart so... But I think somebody who is not used to dealing with somebody with Alzheimer's looks at this from different viewpoint?

Nancy used to care for her own father who had Alzheimer’s and the interview snippet above tells us how she was empathising with Monica and her difficult position at the

time of the incident. Monica was obviously torn between wanting to support Arnold's wish to dance independently and taking care of his safety as a caregiver. Nancy's thoughts around this also remind us that dementia care is a sensitive issue that requires careful consideration and understanding. For instance, although Arnold attended several sessions after the incident, from then on he remained in his seat during the participation dances and instead sang along with the songs. Monica, sitting next to him, pointed at the lyrics as he sang so that he would not lose his place. The second to last session he attended, I told him how great his voice was. He tried to say something, looked uncomfortable with his own struggle in voicing out the words. I said to him again, "*I liked your voice so much.*" He looked into my eyes and told me, "*thank you for saying that*" calmly but with a regretful expression. He looked as if he was aware of his situation and feeling frustrated about the progress of the illness. It was obvious that both Monica and Arnold were experiencing considerable changes at that moment. As a result, they experienced strong emotional difficulties in adjusting to these changes. Two weeks later he had to stop coming to the sessions altogether.

Arnold's friend and caregiver, Bob, who used to bring him, touched on the difficulty in caring for Arnold during and after the "*Hokey Cokey*" incident. He explained how his role as Arnold's caregiver at SB had been transformed from someone who was just bringing Arnold there and giving a hand to get up and sit down in the beginning to later on having to pay close attention to Arnold's safety. Bob was also very regretful both when he told me that Arnold would not be able to come back to SB anymore and when he discussed how he had to sit Arnold down at the "*Hokey Cokey*" incident. Bob's strong personal reaction implied that he might have felt torn between his role as a caregiver (or at least someone who was in worried about Arnold's safety) and his older role as an old good friend of Arnold's.

In sum, the moment Arnold almost fell over crystallised a range of issues for those present: it highlighted the progress of Arnold's illness to the SB group at large, it made the distress of caring more visible and recognized by his caregivers as well as the overall group and it probably triggered Arnold eventual withdrawal from the sessions.

5.10 Closing the session with “Shalom”: a reflective moment to crystallize the sense of sharing and work through emotions

The session always closed with the song called “*Shalom*”. “*Shalom*” is a Hebrew word which means peace, completeness and welfare. It is also used as a greeting word which means both “hello” and “goodbye”. There are several versions of the “*Shalom*” song, some are hymns. The one sung in SB was translated into English from Hebrew:

Shalom, my friends, shalom, my friends, shalom, shalom.

Until we'll meet again my friends, shalom, shalom

It was a simple folk tune which was easy to sing and remember, but had a blessing like, almost “spiritual” quality to it because of its calm, smooth melody in a minor key as well as what the word “*Shalom*” implied as explained above. In the SB session, this song was sung first in any way that people liked. The second time it was sung with a quiet voice and the third and last time, it was just hummed. At some point in the past, Jessica started encouraging people to hold hands with each other while singing the tune. “*Shalom*” always came after the most exciting part of the session, the participation dances. The collective energy level was usually very high after finishing the participation dances as discussed above and “*Shalom*” worked very well in terms of calming this energy level down and giving people the space required to have a few reflective moments. Below is a field note from a session, which describes such a

transition of energy level from a very lively rendition of Lambeth Walk with high spirits and a lot of laughter going on (Appendix 11. Example recording no. 3):

“All right, we will just finish with ...” Jessica continues, but her voice vanishes into the general murmuring and laughter. She plays the first two notes gently on the keyboard, d and a, d and a to indicate the starting of the song. She pauses and asks the group, “Are we all OK? Now, quiet song to finish with. We are singing “Shalom”. Some of you might know this one” and she initiates singing (without any piano accompaniment), “Shalom my friends” and others follow her. Jessica now also sits down in a chair in the circle; no one is outside of the circle. The murmur and laughter were totally subdued at this point, and the singing voices harmonise beautifully. Everyone here knows this song very well, no one needs to look at the lyrics or feel marginalized for not being able to participate, nor is anyone worried about marginalizing anyone. Because, with this song, everyone is on the same level.

After the first verse ends, Jessica says gently “and quietly”. This time, it is sung quietly and very beautifully.

“And humming...”, it is hummed quietly; I see people’s peaceful faces. Some people are closing their eyes while humming. I catch Lisa having tears in her eyes. Karen notices it too, and looks as if she is moved by it. This is a subtle “chain reaction” of emotion that singing “shalom” affords. It is a song that everyone knows without having to think or worry about “singing” so attention can get drawn elsewhere to notice small thoughts, while still singing the song.

The humming ends, followed by one second of complete silence. Jessica says “Thank you very much indeed” and everyone applauds; the murmuring starts

again while volunteers slowly start to tidy away. A few minutes later I see Arnold standing near the entrance presumably waiting for his wife to finish chatting with someone. He is singing “Shalom” to himself.

5.10.1 Reflecting upon one’s own emotions

Because *Shalom* was such a simple song and everyone was familiar with it, it provided a space for people to reflect upon their emotional experiences in the SB sessions. This resonated with a forgiving role of music discussed by Bergh (2011); how music provided a socially acceptable space which also allowed people to be emotionally affected. Many informants told me that “Shalom” was their favourite song in SB sessions, and some of them felt that the most moving moments during the sessions were when they are singing “Shalom”. Peggy, who came with her mother-in-law, Nichola, explained that:

For me, the most moving time is when we sing “Shalom” at the end. I just love that. Just love it. [...] It is just very emotional I think. I just think it is a beautiful way of ending the whole session. Because it does, it is a very calming piece of music, very lovely.

Singing “*Shalom*” afforded Peggy a moment of reflection, which allowed her emotion to come out. Therefore, “*Shalom*” in SB sessions was not simply about adjusting participants’ energy levels; in this case it was also about allowing people to be contemplative. Sloboda (2005) has suggested that one of music’s roles in emotions was to strengthen existing emotions rather than creating new emotions from scratch. This we could see through the reflective processes that were invoked by “*Shalom*” where emotions were catalysed and intensified, as shown, for example, by Lisa’s tearfulness. At that time, Lisa had a very busy life taking care of her own mother and father who lived half an hour’s driving distance from her home, and she also had three children to

look after. So, coming to SB worked as a joyful interruption of her daily hectic routine and it gave her the opportunity to spend time with her mother. Lisa also said that “*when mum makes me laugh [in SB sessions], this is the moment I meet my old mum*”. The “respite” that SB provided for Lisa highlighted the idea (Bergh 2011) that music allowed and enabled interruptions of mundane routines. Musical interruption provided a liminal space, a temporary and transient space, where new ideas, thoughts, and emotion were allowed to enter. SB sessions also provided Lisa a liminal space where she could put on hold her many mundane roles in everyday life. They allowed her to enjoy the moments when she “met” her old mother rather than a person with dementia. This also meant that Lisa was freed from her caregiver role in the SB space and could cherish the time and just be a daughter as she used to be before the onset of Caroline’s dementia. In this way, identities emerged and shifted in ways that were interdependent with the environment, and music helped to configure this environment together with other socio-cultural elements as Ansdell and DeNora (2012) have discussed. In this context it was important that SB sessions were run weekly, so that the process of interruption and emotional work was repeated which reinforced music’s effects, as Bergh has discussed (2011).

5.10.2 Awareness of emotional reactions of others, bring the feeling of togetherness

“*Shalom*” provided further affordances to the group in its role as an ending song; it emphasised a feeling of togetherness and quietly reminded the participants of the group culture that had been created during the SB session. For instance, Hannah said she found it “*a little touching*” to “*look on people’s faces of peacefulness*” when singing “*Shalom*”. Because of its qualities singing “*Shalom*” enabled us to pay attention to others around in the room and to be aware of any emotional reactions that surfaced in

others, which might cause a “chain reaction of emotions”, as I described above, as well as the nice feeling of experiencing the peaceful moment together (Hannah).

One of the volunteers, Craig, expressed his own fondness for “*Shalom*” and emphasized that it brought out a feeling of “togetherness”:

[...] I like the Shalom at the end, it's rather nice you know, calming down silently. It's rather nice, we altogether sing and calm down. Sense of everyone together and you know... It is a nice feeling that we are all together, sharing something special at the end of a session. I think possibly that is quite moving. Shalom... I think so. Yeah, sort of, something special there. (laughs)

Interviewer: Some people are closing their eyes... right?

Craig: Yeah, yeah. It's a nice atmosphere after we had all that singing, [a] feeling of coming to the end and we all enjoyed it [...] just quietening down, a more reflective sort of moment. It is nice, it is good

Craig repeated the word “*together*” several times. Obviously, singing “*Shalom*” afforded feelings of *togetherness* as well as a sense of sharing. In this reflective moment, the happy and pleasant feelings that the participants experienced during the previous hour were emphasised and the feeling of togetherness and sense of sharing were crystallized. It was important to end sessions like this so that the participants were able to leave the session with a positive feeling as Peggy suggested. These musical affordances available through the singing of “*Shalom*” developed further outside the SB sessions in ways that helped participants’ in their everyday life, something that resonated with the “grounded aesthetic” discussed in chapter two (Willis 1990). The creation of this aesthetic was not restricted to a single setting, instead travelled across various boundaries, as I will discuss further in chapter seven.

5.11 Summary

In the opening of this chapter, I questioned whether it was possible to craft inclusive music sessions for such a diverse group of people with widely differing cognitive capacities while adapting to the constraints and capacities of those participants who suffered from dementia. I hope to have shown how the detailed process of collaboratively crafting the SB sessions enabled a democratic participation, which brought important discursive and positive musical affordances, rather than simple causal effects, not only to participants with dementia, but also to caregivers and volunteers. The specific characteristics of SB sessions that enabled such participation were discussed by several of my informants. Rosie for instance said that:

[the participants] just join in and they can just take part, and there is no difference between Laura and you and me... they're all the same, you know. We are all singers, we all go there to sing and have fun.

This did not mean that a full and identical participation by all the participants was guaranteed, but rather that the format of the SB session allowed participants to engage in the activities in whatever way they could or wanted to. Then, how did volunteers view the different levels of engagement among the participants and how were these differences reconciled? Bob touched on this issue when he said that:

Well, I've got, possibly a bit mixed feeling about some of them. When there is an activity going on with a song, I'm thinking back now when we used to do the one about the hats and so on, or the chestnut tree, you know the hat with corners and stuff [...] Well, it's not something I personally find desperately interesting, but you do it because if it is good for them, it's good. But, for those who can manage it, to try and do the actions, you think it looks really good for them. Quite a few of the [participants with Alzheimer's] obviously can't cope with doing the physical part and just watch. But for those who can, it's a good activity, because obviously you are doing two things at same time: you're singing and you got to remember where the hands are going, here or there or

everywhere. So that's the general point, there are activities, I think, on the whole, that are good to try and stimulate those people who can benefit from it, [while] some of those who can't [...] are quite happy to just watch it.

Bob was discussing songs with hand movements that were often sung in the term when I interviewed him, such as “*My hat, it has three corners*”³⁹ and “*Ten green bottles*”⁴⁰. The latter one was sung several times, in particular at the intergenerational event with the local primary school children. As Bob pointed out, several participants with dementia could not follow the hand movements (e.g. Caroline, Simon and Chris). Instead they were just sitting down and singing the tune. Capacity levels could vary not only according to the stage of dementia but also from week to week depending on people’s condition on that day. Since SB sessions were not individual but group-oriented, it was challenging to tackle the conditions of all the participants. It might have been possible to ensure the full participation of all the participants if the sessions had consisted of only simple activities such as singing along the familiar tunes; but as we have seen, SB emphasised variety and challenges that gave participants a sense of joy and achievement. This was why the careful preparation was important combined with a willingness to change and hone the approaches used so that all participants felt part of a group that achieved something new every week, albeit at different levels of participation. Hannah, who came with Simon, implicitly confirmed this when she told me how great SB was for them as Simon was

³⁹ “My hat, it had three corners” is an action song, which is usually repeated five times, with specific gestures accompanying each repetition. Each gesture is associated with a word in the song. <http://www.mamalisa.com/?t=es&p=518&c=23>

⁴⁰ “Ten green bottles” is a nursery counting rhyme. A single verse is repeated eleven times, counting down from ten bottles, with associated hand gestures.

“quite able to” participate in the activities, obviously relative to the constraints Simon experienced in his everyday life.

In addition to the careful crafting of individual activities the overall format also seems to have been of key importance to these positive, discursive musical affordances.

Several people talked positively about the format and Irene, the area manager of *Dementia Support Group* was one of them.

SB, the way that it's put together with the activities as well, the way its taught, the way it's put across, it's just so perfect, because it is so accessible to people whose mental capacity is not as good as it used to be. And when you remember and you've sung a song, you're really proud. [...] it's a brilliant thing.

Therefore, the crafting of each activity **within** the overall format of SB sessions allowed the exploration of the abilities that they still had left, rather than making them aware of their own constraints, although there were rare incidents that forced participants to be aware of their constraints such as was the case with Arnold as discussed earlier.

Peggy, who came with her mother-in-law Nichola was similarly positive about the organisation of activities within the one hour session:

I think every part is so well organized. Well, we never realized we've been singing and working for an hour, it just goes. Time just whizzes by, doesn't it? It always goes too fast. (Nichola: Yeah, [laughs]) [...]

I think as much as anything, it is the fact that it is so well-planned and prepared, that it feels like it runs itself. So there is no waiting around: oh, which song shall we sing? And people [would] then drift off and go to sleep. Everybody is being focused all the time. And Jessica makes it more interesting, because she has some funny jokes in between, doesn't she? She brings up some ideas, and then other people will bring in ideas as well, because they are all listening.

The crucial value of the SB session then, was to be found within the well-planned structure. This was emphasized by Peggy later in the interview: “[i]f it hadn't been planned, people would start talking with friends, then it wouldn't be as good.” Within the well-structured and prepared format, Jessica and other volunteers kept bringing in new ideas and exercises which stimulated the participants with new experiences rather than the repetition of the same activities. This also contributed to the democratic atmosphere where everyone's enthusiasm contributed to the successful execution of the events.

The high quality and success of the format as it was developed over time in SB had results beyond Watertown. After I finished my fieldwork, *Dementia Support Group* (the parent charity of SB) made a leader's guide⁴¹ with the help of current SB facilitators as an aid for prospective SB facilitators to refer to. SB started as a grass-roots activity to meet the local needs by a local former music teacher in 2003. However, because of the increased interests in use of music in dementia care in recent years in the UK, SB grew from a group to more than 40 groups across UK within 7 years. In the beginning, facilitators shared their ideas and supervised each other informally, but as the number of groups grew, *Dementia Support Group* decided to pull these ideas together formally in order to standardize the number of emergent SB sessions and guide prospective facilitators, and thus made the leader's guide. Therefore, the content of the leader's guide showed the accumulated knowledge among the SB facilitators through trials and errors in their sessions and the sharing of these experiences with each other over 7 years. The basic instructions necessary to run SB sessions were given in the leader's guide:

⁴¹ Due to the need to anonymize my informants, I am unable to site the publication.

general format, the role of volunteers, suggestions for useful resources (song books and instruments), ideas on activities and repertoire. The balance between building of confidence and offering of challenges, the balance between a sense of purpose and a feeling of informality, and a variety of activities were emphasized in the leader's guide as they were also articulated fully in the discussion in this chapter. Therefore, we could assume that these positive aspects I discovered in Watertown were also to be appreciated within the wider *Dementia Support Group* and among current and prospective SB groups.

In the following chapter, I will highlight the SB repertoire more in detail, as it is an important driving force behind the various musical affordances that were discussed in this chapter.

Chapter 6. SB Repertoires

As I have discussed earlier, songs used for SB sessions consisted of familiar music. This music was biographically relevant to the majority of participants with dementia and their caregivers, although it did not necessarily match their personal tastes. The use of familiar music for people with dementia has been discussed as having had positive effects in allowing them to access their memory (Cuddy & Duffin 2005; Ridder 2003), and working as a means for emotional/behavioural management (Sung & Chang 2005) as discussed in chapter two. I have also pointed out, however, that there is a need for further investigation of “how” and “why” these familiar, biographically relevant songs worked as useful means in dementia care in relation to individual musical background.

When presenting my work at conferences and seminars I have also often been asked whether using these songs becomes patronising and stereotypes elderly people and people with dementia. Therefore, I have investigated the musical affordances of these biographically relevant songs through ethnographic interviews and participant observation. I have also explored how the collection of songs used for the SB Watertown group (SB repertoires) were carefully chosen by Jessica and negotiated among the participants rather than maintaining a fixed repertoire that was repeated every week. Through such focused examination, I have found that the SB repertoire itself was crafted so as to afford opportunities for empowerment, pleasure and making connections. Therefore, it was not chosen to match a stereotypical view of people or to act as a simple “stimulus”, but rather to evolve through interactions from week to week. In the following sections I discuss the results of my investigation, starting with an analysis of the type and quality of SB repertoire, highlighting why and how it worked with the SB participants.

6.1 Type and quality of SB repertoire

6.1.1 Introduction: SB repertoire as Familiar aesthetic

A key distinction needs to be drawn between the songs' capacitating effects in SB sessions versus participants' personal tastes of past and present. Through interviews with participants, I have found that SB repertoire did not necessarily match with individual musical tastes and preferences. For instance, several expressed a musical taste that was very different from the SB repertoire, such as Arnold, who had dementia.

Sometime before my fieldwork he expressed his own musical taste in an interview in a magazine⁴² that he loved classical music such as Beethoven and Mozart. In the choir that Arnold participated in before joining SB, he was singing western classical pieces (e.g., Mozart, Vivaldi, Handel and Bach) similar to what he expressed as his favourites. However obviously, these songs were not sung in SB sessions.

Similarly, Hannah, who was the wife/caregiver of Simon, discussed their musical preferences as:

[The] musical bit comes in when you get Schubert songs, and bits from Mendelssohn's opera and Mozart's opera. That's real music, isn't it? That is what we enjoy listening to.

She also told me how they liked Mozart, Beethoven, Strauss and Chopin. The use of the phrase "real music" implied that she was clearly differentiating their long-term personal aesthetic preferences from the SB repertoire. Chris, a participant with dementia, also expressed this clear divide between his long standing personal favourites and the SB

⁴² No citation is given here to avoid identification of the informant.

repertoire. He always preferred brass band music because of his background in the Salvation Army band. Chris also told me there are no overlaps between his favourite brass band tunes and the songs used in SB. When I suggested that he could request that his favourite tunes were sung in SB, he regretfully said that brass band tunes “*wouldn't be everybody's cup of tea.*”

However, there were also some interviewees that had some overlap between their own musical tastes and the SB repertoire. For example, Caroline's favourite music has always been “*show music*” such as tunes from “*Cats*” and “*Sound of Music*”, as her husband explained in the interview with which Caroline agreed. Her daughter, Lisa, who always brought Caroline to SB told me that “*Edelweiss*”, a famous tune from “*Sound of Music*”, was one of her favourite songs of those sung in the SB sessions. Similarly, another participant had some overlap with her own taste and the songs sung in SB sessions. When I asked Martha if she had experienced being moved by music, she listed “*Chopin music, some Beethoven*” and “*Shalom*” from SB sessions. Therefore, “*Shalom*” was one of her aesthetic preferences along with her long-standing musical tastes.

Thus, the SB repertoire did not necessarily match with the participants' musical tastes/preferences. However the SB repertoire was familiar to them from their past, thus biographically relevant to the participants. Yet the question remained as to why biographical relevance was important, more than just matching with individual aesthetic preferences.

Although there was a gap between the songs used for SB sessions and participants' individual musical tastes, the benefit of the SB repertoire was that it was *recognised* by

the participants of SB. In the following six sections, I discuss how and why these repertoires worked with the participants of SB in more detail using the empirical data.

6.1.2 Being able to remember songs is empowering

A key benefit to remembering songs was that they were converted into energy and power in interaction with others, such as in SB sessions. Below is my observation of the interaction between Jonathan who had dementia, Laura, Michael (Laura's carer) and myself before the SB session started, where they expressed their excitement about the ability they shared with their partners in being able to remember songs.

I sit between Jonathan and Laura. I take the songbook that is on the chair and start flipping through it with Jonathan. I ask him, "Which song is your favourite song?"

He answered little hesitantly, "I don't know, my memory is not good, but when I hear the tunes, I just pick it up."

We sing several songs we find in the songbook; "Irish eyes are smiling", "My father's clock", "It's a long way to Tipperary". Jonathan explains to me the last one is a war song from Second World War. It is followed by "Edelweiss". The following page of the songbook shows the lyric of "I whistle a happy tune". As I can't remember the melody, I ask Jonathan. While Jonathan is thinking, Michael prompts Laura if she knows "I whistle a happy tune". Laura starts singing and Jonathan, Michael and I follow her. I am the only one looking at the lyrics and other three are just singing from memory. After having sung the tune until the end of fourth verse, Laura says excitedly, "I am born to sing!" I

ask her where she learned all these songs, and she answers very excitedly, “I just pick them up!”

On a different occasion Jonathan also told me with his fists in the air, how he always felt young when participating in the SB sessions, because he was able to share the joy of singing with others. So, although Jonathan was not sure why he was able to remember all these songs, he was obviously aware of the positive effects singing had on his well-being. Jonathan was in the early stages of dementia at that moment; he was aware of his dementia. He explained to me one time how he had problems with his brain but there was no worry for me as it would not harm others. Therefore, Jonathan joined in SB, with the support from his wife, knowing the positive effects of participating in the music making activities using these biographically relevant songs.

Laura’s dementia, on the other hand, was more advanced than Jonathan’s at that point. Although she was not aware of her condition, she was fully aware of her ability to remember these songs and obviously very excited about how she could pick them up so easily. Laura and Michael discussed how well she remembered songs:

Michael: It is funny, she can remember the words of these songs you know.

Laura: Every word I can remember, in the songs.

Such memory recall allowed her to regain her confidence as she often proudly expressed to others how beautifully she could sing. Rosie also commented on this:

She always wants to talk about [herself], how beautifully she has done it and everything. But that's her world, really. It's great for her [to come to the SB session], you see. She can do all that, whereas, ask her to cook lunch or go out to the shop, she can't do any of those things.

Rosie pointed out how Laura's ability to sing blossomed in SB sessions and how it empowered her and gave her pride as singing beautifully was now one of the few abilities Laura had left. Otherwise, her everyday life was filled with confusion and a lack of confidence due to her progressive cognitive impairment. In this way, the SB repertoire was an important element for musical affordances that gave members with dementia a joy and excitement of being able to achieve a sense of mastery by remembering and singing those songs. I often observed how other participants with dementia also become more alive when the words come out naturally as soon as Jessica introduced the melodies of familiar songs from the past on the keyboards. Similarly Cecily, a volunteer, also told me that what she enjoyed in SB sessions was:

[...] watching the people with dementia kind of come to life in front of you. The confusion seems to lift for a minute while they are singing.

Here we see how familiar songs helped SB to shift the role of a participant from someone who was "just" a dementia sufferer to someone who could remember songs and sing them beautifully. This had a positive impact on caregivers, as it elevated their estimations of their partners' present and future cognitive capacities, a point discussed by Gregory (2011, p.170). In the case of Michael and Laura we saw how Michael was excited, yet mystified by Laura's ability to remember all the songs as described above.

6.1.3 "These songs stick with you": recalling associated memories from formative years

The songs used for SB sessions were familiar to the participants with dementia from their formative years rather than from recent (immediately pre-dementia) years. How did the songs from the past work well, beyond just giving participants the ability to feel good by being able to master a pleasant task? The songs from SB were familiar to

participants with dementia and their caregivers who were in their 70s to 80s because these songs were sung or heard when they were young. For instance, “*Just Walking in the Rain*”, which was one of the songs most often sung in SB sessions, was written and became a hit song early in the 1950s when a majority of the participants with dementia, and their caregivers, were in their 20s or 30s. Another favourite song among the participants, “*My Favorite Things*” was from the soundtrack of the popular movie, “*Sound of Music*” (1965) when the participants were in their 30s to 40s. Several of them described how these songs were strongly connected with memories from leisure times associated in the past with their families or social groups. Their connections with these songs seemed particularly intense for Nichola, Peggy (Nichola’s daughter-in-law), Chris and Kelly (Chris’s wife) as they shared their thoughts with me. Interviews with them also became an exploration of how these songs interacted with their memories and how they were embedded in the everyday life of their formative years.

Peggy (daughter-in-law of Nichola), for instance, told me about these songs in everyday life:

This is what I think so good about singing. Because it’s something that most people have done right from very young and certainly for mom’s⁴³ generation, coming through the war, there were loads of songs during the war that everybody sang, and it brought people together. It is just up here all the time. So as soon as the music comes on for a particular song, you immediately remember the words. If somebody said “tell me the word to... ‘I love the flowers’” mom would think, “no, I can’t do this”. But if the music came on, then the words will come out. I think that for mom’s generation particularly, it is absolutely wonderful. Because it is getting to the back of that memory, bringing it forward, you know, and you can join in with everybody.

⁴³ Peggy was referring to Nichola, her mother-in-law, as mom.

Peggy also felt that it worked particularly well for Nichola's generation in recalling associated memories, a theme that was developed further to discuss a specific song, "*After the ball was over*".

Peggy: Well you see, when I said about the war, I mean the war is just one "collection" of songs, but if we go back before then, there is a group of songs for the [19]30s, a group of songs for the [19]20s, and like you say, they would be the times when people like mom were at school, growing up, so very formative years. And this is the time when they remember those songs. Songs that come out now, won't have as much meaning [to Nichola].

Interviewer: So, those are the songs that mean something to you?

Peggy: The old songs, yes.

Nichola: Yes, that's right ...

Peggy: They are more meaningful, aren't they?

Nichola: Yes, yes...

Peggy: Certainly things like the old music hall songs... What was it we were singing the other day about... oh, "After the ball was over"

Nichola: Oh, "After the ball was over".

Peggy: Do you remember that? We couldn't remember all the words, so we went on the Internet, didn't we?

Interviewer: After the ball was over?

Nichola: (singing) "After the ball was over. After the..."

Peggy: "day's gone". I can't remember how it goes now... (laughs)

Nichola: I can't either. My memory is absolutely wup! [sic] (laughs)

Peggy often paraphrased my questions to help along the conversation between us.

Peggy brought up one of the popular songs sung in SB, "*After the ball*", which was a song from the 1890s, first sung in the musical, "*A Trip to Chinatown*". The film version

of the musical came out in 1930s, so it was probably heard in many places in the 1930s. Nichola started singing the very first part of the song and then faltered. Like Peggy said, if the melody had been provided at the interview, Nichola might have been able to sing the whole song.

Peggy explained how “*After the Ball*” was a very funny music hall song:

[...] it goes on about, “see her take out her glass eye, stand her false leg in the corner, hang up her hair on the wall, then all that's left goes to bye-byes, after the ball...”

As Peggy described parts of the lyrics, both Peggy and Nichola burst into laughter. Afterwards, I (with the help from Peggy) tried to find out how Nichola learned these songs. First Nichola was just agreeing and nodding to what was said (e.g., Peggy asks, “*did you learn it with your friends?*” and Nichola says, “*yes, yes*”). She might have been trying to remember how she learned the song. The songs might have been more ubiquitous in many different contexts in those days, which might have made it difficult for her to specify how she learned the song. However, Nichola showed more positive answers when Peggy mentioned Nichola’s parents, as if her memory was suddenly retrieved.

Peggy: so I would imagine that when you were younger, you used to go to the theatre with your mom and dad?

Nichola: Oh, yes.

Peggy: And the music hall, I am sure you went to the music halls when you were little.

Nichola: That's right. That's right. Because mom used to sing quite a lot.

Nichola: I couldn't follow on, (laughs) [Interviewer: I see. So your mother was very musical?] Yes, she was very clever, yes.

As the above interview shows, Nichola had strong associative memories with “After the Ball” (and by extension, possibly other songs sung in SB):

Interviewer: So when we were singing at SB, do you remember those memories?

Nichola: That's right, yes, comes back.

Therefore, songs that were sung in SB were meaningful for her because they were sung and learned in her formative years. Therefore singing these songs, or even talking about these songs, brought back memories of her past social occasions. The same effects might not have been achieved with songs she was unfamiliar with or more recent songs that she learned in years when there were many other demands on her time. Thus the associations formed more recently may not have been as strong and were subsequently more difficult to recall. This point was further explored in the interview with Kelly, Chris’s caregiver:

Kelly: You know, everyone puts themselves out. It took a week or two to get used to it, you know. But now, it is ideal, it really is.

Interviewer: Would you tell me more about how ideal it is? The way it is carried out?

Kelly: Oh yes, yes. And all the different, you know, music and they're all songs that you know, of the bygone days, so that it's the ones that we remember from when we were young you see...Yes.

Interviewer: Do you know all the songs?

Kelly: Most of them, yes, yes. Which, you know... I mean, I say, you know, I like the pop music.⁴⁴ Then I mean, I wouldn't know the words not to those [i.e.

⁴⁴ Earlier in the interview, Kelly told me her favourite music was ABBA, and how she loved to listen to it at home.

today's pop], it would only be the music that I would listen to. I wouldn't know the words, not these days.

Interviewer: I see I see.

*Kelly: But, you know, going to [SB], you know, we know **all** the words, well, the biggest part of the words, you know, from years ago.*

Interviewer: right... and you can sing.

Kelly: You can sing it, that's right, yes. And tunes stick with you as well, you see, yes. You see, you were brought up with that sort of things, and you don't lose it.

The two interviews shown above answer the questions I have raised earlier; why SB repertoire has to be biographically relevant but not necessarily the participants' favourite music. The songs from the formative years of the participants, the so-called biographically relevant songs, work well as participants can remember the words so they can sing these songs. At the same time, these songs allow them to retrieve the associated memory from the past. Ridder (2003, p.41) also discussed how the familiar songs learned in earlier life worked well as they acted as cues to help retrieve long-term memories, which people with dementia could often access despite their problems with short-term memories, as Schillmeier (2008, p.148) explains. Clair (1996, p.74) pointed out that such retrieving processes were immediate and did not require cognitive processing. This was also because they were embodied responses which were laid down when they were young, very similar to Bourdieu's "habitus" (1990, p.73): something learned by the body was not something one owned like knowledge, which could be brandished, but is rather what **one was**. Therefore, these songs took them forcefully back to their past, eliding cognitive reflection and producing, as it were, immediate musical responses.

In order to investigate such embodied memories of these songs further, I asked Kelly the cultural context of these songs. For example, how were these songs sung in “bygone days”?

Kelly: [...]Yes, because there wasn't TV or anything of that in those days [sic] [...] it is 80 years ago. So, you know, it has been quite a lot of changes. Yeah... because I am 82, Chris is 86 this year, you see. So, obviously we have seen a lot of changes. And when we were growing up, you know, we had to make our own amusements. And, you know, it used to be like musical evenings. Mostly on a Sunday evening you know, the family would sort of sit down and then, you know, have a sing song and that sort of thing. (Interviewer: Really?) Oh, yes, it was quite a common thing in those days. (Interviewer: The family would sit down and sing?) That's right, and sing all the old songs that we are singing at SB, you see.

Interviewer: So when you sing those songs...

Kelly: It brings back memories, that's right. Yes, definitely.

Nott (2002, p.99) discusses how there was a dramatic transformation in the late 1910s to late 1930s within the sphere of live music in England; the period saw “a huge shift away from private performance in the home and a rapid increase in the public performance of live music”. However, until late 1910 and even during the transformation period, home remained one of the main spheres of live music where the general public was an active performer according to Nott, something that would understandably depend on demographical issues. Kelly and Chris spent their childhood in the 1930s to early 1940s, thus, there must have been many self-made forms of entertainment at home in this period in England as Kelly expressed. If singing along in family gatherings was quite common when she was young, as Kelly described, singing the same songs in SB sessions was a reproduction of similar settings, which allowed participants to relive or at least evoke their past social contexts.

Later in the interview I brought out the songbook that was used in the SB session and tried to explore even further their memories of the songs with an interview strategy discussed in chapter three. When the interview took place, Chris had mid-to-late stage Alzheimer's while Kelly had no distinct memory problems. I asked both Chris and Kelly if they liked any particular songs from the SB sessions. I showed them the index page in the songbook and prompted the conversation by singing "Auld Lang Syne" gently, which was the third song listed⁴⁵ and sung in the most recent SB session.

Kelly held the songbook with her hands and read out the titles of the songs, "Auld Lang Syne", "Bless them All", "Deep in the Heart of Texas", "Down at Old Bull and Bush", "Easter Parade", "Edelweiss", and said that all of them brought back memories. Chris made minor comments throughout the interview as he always did at the singing sessions.

Interestingly, his memory on the songs was clearer than Kelly's. For instance, Kelly could not recognize "Orchestra Song", expressing that "it must be another new one". However, Chris immediately said, "Of course I know. It was sung in the band⁴⁶." As soon as Kelly made comments on a song called "Inchworm", Chris started describing the song:

*Kelly: "Inchworm" is **not** so popular.*

Chris: What's that? [title repeated for him] Oh, "Inchworm"? No. It's for the children see. They kept it to the youngsters.

⁴⁵ The repertoires were listed alphabetically in the index in alphabetical order.

⁴⁶ This comment indicates that there was an overlap between the songs he played in the Salvation Army band, which he expressed as his favourite, and the SB repertoire. This contrasts with his earlier comment (how there were no repertoire overlaps).

Interviewer: It is only for the youngsters? It was like a nursery song?

Chris: [inaudible] go out on the green you see. Watch the worms they'd say, the teachers [inaudible]. It's the same with all the little instruments and things that you see in your life. They know more about it when they leave school you see, than they do when they go [to school], which is the idea of school you see.

His narrative was very difficult to understand as he often mumbled. However, as I transcribed his narrative I found out that he was describing a scene from a film, "*Hans Christian Andersen*". "*Inchworm*" was from the film soundtrack, which was sung by Danny Kaye, a famous actor and singer from the 1930s to 1960s, and became a popular children's song later on as Chris also described in the interview. In one of the scenes from the film, the arithmetical part of "*Inchworm*" was sung by school children who were in the arithmetic class with a strict-looking teacher. The lyrics are as follows:

*Two and two are four, four and four are eight, eight and eight are sixteen,
Sixteen and sixteen are thirty-two.*

In the movie, Andersen (acted by Danny Kaye) was listening just outside the classroom, looking at an inchworm crawling on the marigold. The boy from the hat shop where he used to work was with him, and said "the first inchworm of the year". Then, Andersen starts singing the main part of the song as below:

Inchworm, inchworm, measuring the marigold, you and your arithmetic, you'll probably go far.

If I try to put together what Chris meant in the interview ("*If you watch the words...*"), Chris seemed to be describing the scene from the film when "*Inchworm*" was sung by

Danny Kaye⁴⁷. The film was released when Chris was 29 years old so it was possibly something he saw with family or friends.

This speculation shows that music was remembered not in isolation but as part of multi-sensory, audio-visual experiences. Therefore, even with cognitive difficulties he had due to his Alzheimer's at that moment, the "*Inchworm*" song allowed him to instantly recall these images and stories associated with the song and he could describe them to us during the interview. Music's role as a visual enhancement has been discussed elsewhere (Hara & DeNora In Press; Bonny 2002), so this issue also highlighted a topic for further research in the use of music in dementia care. I have mentioned earlier how the SB session was the only social activity Chris could cope with, which means that it was also the only common social activity for Kelly and Chris to be involved in together. It was also the only musical engagement that Chris had except for watching the choral church music on TV. Therefore, Chris's musical and social lives were both secured through the SB sessions at that moment.

The cases of both Nichola and Chris showed how the associative memories evoked by the SB repertoire were deeply embodied in past (and often repeated) socio-cultural occasions and multi-sensory, audio-visual experiences. Therefore, singing or referring to songs from this repertoire brought back those memories immediately. SB session could therefore be seen as a reproduction of these experiences at the present time, which allowed people with dementia to have a joyful time despite their short-term memory loss.

⁴⁷ The scene from the film "Hans Christian Andersen" can be found here: <http://www.youtube.com/watch?v=fXi3bjKowJU>

6.1.4 Biographically relevant songs and memories: Connections bring orientations

Earlier I discussed how Peggy mentioned that biographically relevant songs not only allowed people to connect with associated memories but simultaneously helped people's present lives move forward. This point deserved further investigation. Jessica and several volunteers had further insights on this issue:

[...] part of it is also, if you forget, if you are a person who has, in the past, had good memory. And then your memory starts to let you down, and that isn't the only thing that tells you that you've got dementia, there are other things, behavioural things as well. But the memory lets you down, then you lose confidence, and if you can come to the group like SB, where suddenly your memory of those songs is quite strong and you can remember the words like Laura says, 'I remember that song!' Yet, if you ask Laura what she had for lunch, she might not even remember, you see. It's a long-term memory [sic], and those things that... and music, I think, helps fix things in the brain. You know how you have a song going through your head?

The memories of these songs were so strong that they brought powerful transformations in the cognition, mood and confidence of people with dementia. Jessica continued talking about the music and memory based on her extensive lay knowledge as a result of her experience as a facilitator of SB and her experience of caring for her own parents with dementia:

[...] people who can't remember all the words will hum along with the tune. Or they'll sing lalalalala (sings). And I think that the fact that people can link in to that, and relate to that, is quite empowering. Because it means they haven't totally lost all their memory. They've got something they can remember, and for the person with dementia, I think that's wonderful. Because it means that they are still able to do that, you know, and just actually having fun. Smiling, laughing, I hope! Having a bit of fun and I try and put a, I mean, I say some silly thing I know, but it makes people laugh.

The emphasis on how people with dementia could **relate to** music suggested that the connection was not unidirectional; it was not that music “fixed the brain” or gave stimulus to the brain, rather it was an interconnection between their memories and the music they were familiar with from the past (i.e., biographically relevant songs) and the here and now, represented by SB volunteers, other participants and their caregivers, all together in a total “package” that empowered them. The fact that they could “link to” and “relate to” the music in their own ways, based on their own memory, empowered them.

Cecily, a volunteer, had been witnessing the effects of music in SB sessions for more than three years.

I think it's that the people that are affected with dementia, they are in a world of their own, somehow, aren't they? They don't kind of connect. They don't really know the people they are with. But as soon as the singing starts, it seems as though the brain gets into focus and they can remember the words and they can join in. And I am sure that's what's so beneficial. [...]The singing itself and remembering the words. Because that focuses the brain I think, the memory side of the brain, seems to come into use again, whereas in their condition it is a bit dormant.

Singing familiar songs opened up the unconnected world and allowed them to connect with the surrounding world in the present time, which was important in regaining their self-confidence as Ohi (2008) also discussed. Christina, another volunteer, also discussed this:

It's vitally important, especially you know, in other environments. Because... well, as we said, it's a background for reminiscence, for remembering. Lots of them, if they have short term memories [sic], they can't remember, you know, like yesterday. But they can still evoke memories, or emotions of their past. And you have songs about the weather or about places... So you are encouraging them to think of their environment and where they are [...] it's making them

look out of the window, and be aware, so it's bringing awareness into their lives. It's vital. You can use music in so many, and words you know, singing, in so many places I was gonna say, in so many environments, yes, incredibly beneficial.

Therefore, the biographically relevant songs also worked as a background for more general reminiscence, evoking powerful memories or emotions of the past. Furthermore, the songs that were often sung in SB sessions with seasonal themes and songs about weather and places also helped participants' orientations in time and place in the present. Material framings prepared specifically to seasonally themed songs (e.g. decorations for "Easter" as described in chapter four) also contributed to these positive, affirming orientations together with the music.

6.1.5 Entrainment affords shared and joyful memory exercises

Nichola, who had memory problems, once told me excitedly how she could sing "*some lovely ones*" without looking at the lyrics. Therefore, because these familiar songs were easily recalled, they also musically entrained participants with dementia by regulating temporal parameters of moods and feelings as DeNora (2000, p.79) has discussed. The recalling of the songs became stronger despite any initial hesitation. Such memory retrieval was empowering and helped orientate the participant to the present. As I have discussed earlier, SB uses one-hour sessions that were structured around a variety of activities using mainly biographically relevant songs. The one-hour session effectively became a continuous memory exercise for participants with dementia and this exercise was carried out in a friendly and enjoyable way. Dennis, a volunteer, reflected on this issue:

I think it is useful for them. There is the question of memory. Because, as I think we have talked about, these are songs which most of them will have known, and it's just giving exercise to [...] what memory they've got. Some of them relate

very well to those songs, don't they? It just sort of comes back to them when they sing. So I think anything which helps on the memory side is really useful. So I think it's memory. I think it obviously helps things like sense of rhythm, etc. like that, and participation, joining in with others. So if you got the exercise side, in the aspect of using their memories, making sure that doesn't all go away.

The memory exercises, through singing familiar songs, were supported by the rhythm of the songs (simple rhythms using either 3/4 or 4/4/). These rhythms entrained their bodies, enabling an almost automatic participation with the others. Dennis pointed out that participation is also an important aspect of what “biographical relevance” can enable the participants with dementia: it allowed them to share the excitement (or joy) of remembering with other participants. In fact, the memories or associations prompted by singing these songs were often shared among the group members during the session.

For example, one time I was sitting next to Jake and Marjorie (Jake's caregiver and wife), who were in their early 80s. After we danced “*Lambeth Walk*”, Jake told me how his father used to sing it when he was doing his military service. Marjorie supplemented him by saying that it was from a musical. Another time when we sang “*Easter Parade*”, Jonathan, who was sitting next to me, told me it was a war song. On the same day after we sang “*Down at the Old Bull and Bush*”, Jonathan also told me how he used to sing this song when he came out of the pub. I asked, “*So, is it a drinking song?*” Animatedly he answered, “*yes!*” Other than what I could record specifically, a murmur would always occur among the members after singing a song, often discussing or reminiscing about the songs just sung. There was no official reflective time or any prompted reminiscing; rather singing songs prompted the memory exercises either at the individual level introspectively, or by giving the participants a chance to retell their memories to other participants. In this way, biographically relevant songs afforded a

joyful memory exercise where the fun and excitement of remembering these songs and associated memories were shared among the participants, which was otherwise difficult given their short-term memory problems, with reference to the discussion of their musical engagements in chapter five.

6.1.6 Evoking associative memories helps reconnecting with each other as a couple

In the chapter five, I discussed how familiar waltzes worked as effective devices in order to start off the singing because 1) the strong collective voice became a framework that allowed participants to engage with the music making in their own ways and because 2) they helped to generate an inclusive group culture, which prepared the participants for further challenging exercises in the sessions.

In order to strengthen the group culture, it was important that the caregiver and care-receiver units felt more relaxed and happier about each other's presence than they might feel when the everyday caring tensions affected them. The biographically relevant songs worked by nurturing the relationship between them as shared memories of songs were recalled when they sang them together. This point came clearly into focus during my interview with Hannah and Simon.

This interview ended up with a lot of singing songs from SB as well as talking about music in everyday life. Every time we sang a song or referred to a song in the interview, Hannah reflected upon the feelings and memories it elicited. The excerpt below showed one instance of this:

Hannah: [To Simon] You want to sing one more? From the book? Since we got the book here. [She looks through the songbook.] How about "I'll be your sweetheart" Simon? Shall we have that one to finish with? Because we all

know that tune don't we. Do you remember it darling? We had it on Valentine's day. "I'll 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 & Interviewer laughs]

Hannah: Long time.

Interviewer: Did he use this song when he proposed?

Hannah: I think that is a Valentine's day song, you know. I think that's it. (laugh) I can't remember the actual proposal. I can't remember when we suddenly decided that actually we would get married.

The conversation above further developed; they continued telling me about their life starting from the time they first met during the war, their married life, their children and so on. Although neither Hannah nor Simon mentioned a specific association or memory related to “*I'll be your sweetheart*”, one of the volunteers, Rosie, mentioned a touching moment involving this song during an earlier SB singing session:

When Hannah and Simon first started to come, we sang that 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 now. I mean, obviously they have loved one another a long time, and she adores him still, but she doesn't get back the same as she now gives. Because he can't do that... And he is different person than he used to be, you know, now. He follows her around the house and she doesn't have any time on her own at all now. But really, that was very moving...

I have often observed how Simon's tension and agitation were calmed when he joined in the singing during the familiar waltz exercises, as also discussed in chapter five. Additionally, I have seen how Simon and Hannah looked content and peaceful when singing this particular familiar waltz song in SB sessions. “*I'll be your sweet heart*” is a

theme song of the 1945 musical, at which time Simon and Hannah were in their late teens, therefore they must have heard or sung it with family or friends at that time. Singing this familiar song in SB sessions may have created an enjoyable moment that reminded them of their previous life and reconnected their relationship as a couple once again. I have discussed in chapter five how Caroline's humorous actions caused laughter among the participants during the SB sessions. The moments Caroline made people laugh reminded Lisa of her pre-dementia mom, as she expressed, "*when mom makes me laugh [in SB sessions], this is the moment I meet my old mom*". The activities using the biographically relevant songs helped orientate Caroline to time and place, and the strong collective voice became a framework from where she could participate in her own ways by singing the song and making some humorous actions. As a result, this rekindled the relationship between Lisa and herself. Such rekindling of relationship between caregiver and care-receiver unit was important to sustain the quality of caring in everyday life. It also strengthened the group culture among the participants in SB sessions.

6.1.7 Boosting the joy of singing

The SB repertoire also gave participants the joy of collective singing. Collective singing is a powerful way of connecting with others, although it did not necessarily match with individual music tastes.

Chris told me in the interview that the songs he liked were not everyone's "*cup of tea*". From the interview, I knew that Chris and Kelly were very familiar with the songs used for SB sessions from their past, therefore I further investigated what they thought of these songs if they were not necessarily to Chris's personal taste.

Kelly: Everybody likes those, yes, yes... because there is a bit of, you know, well they are quite lively, aren't they, most of them?

Interviewer: Yes, jolly.

Kelly: Yes. Very jolly, that is right.

Interviewer: Do you enjoy singing those songs in SB?

Chris: Yes yes. As long as there're plenty of people there [...] the good ones.

Kelly: Well it boosts it, doesn't it?

Chris: Yes.

Kelly: If everyone is singing.

Chris: Yeah.

Kelly: It gives you more encouragement to sing, doesn't it?

Chris: Yeah...

Thus, the SB repertoire, even though not necessarily matching with individual aesthetic preferences, acted as a strong medium to bring people together. It allowed people to have a joyful time together, which is a powerful experience considering the everyday life situation the participants were in (e.g., gradually moving away from social engagements and feeling isolated from the community as dementia progressed). Thus the SB repertoire also became a device for forming group culture.

Several people also commented on this aspect. For instance, Lisa also expressed how Caroline could sing the songs (without looking at the lyrics) she learned when she was young; “*I’ll be your sweet heart*”, “*Edelweiss*” and “*It’s a Long way to Tipperary*”, which are also parts of SB repertoire. “*I’ll be your sweetheart*” was a theme song from the 1945 musical as mentioned earlier, “*Edelweiss*” was also a tune from the musical, “*The Sound of Music*” in 1959. “*It’s a Long way to Tipperary*” became popular among soldiers during First World War, and was featured as one of the soundtracks of the 1951 film “*On Moonlight Bay*” as well as in the 1960s musical “*Oh, What a Lovely War*”.

Caroline, however, lost concentration with songs that she was not familiar with.

Therefore, she must have heard or learned the familiar songs when she was in her late teens to early 20s. They were biographically relevant to her. Lisa told me how SB sessions allowed Caroline a chance to be involved with community activities. Thus, these biographically relevant songs strengthened her involvement in SB sessions, as pointed out in the discussion of her musical engagement in chapter 5.

Deborah, who brought several of her friends to SB sessions, also commented on the unique benefit of SB as:

[...]people are singing together and enjoy it, isn't that most unique? Joining in and being part of... like a family, you know, being a part of an organization.

This reinforces the important point of argument in this chapter: SB repertoire did not necessarily match individual aesthetic preferences; rather, the joyful, familiar aesthetic experience of collective singing was given priority over individual aesthetic preferences. Individually preferred songs might not have been able to enhance collective participation as much as these familiar songs did. Because they were familiar to the participants from their past, the songs used for SB sessions boosted the joy of collective singing, increased the level of their involvement, and thus as a result, allowed people with dementia to be part of the group. These familiar songs probably provided a more neutral musical territory, coupled with the “deep” multi-sensory, audio-visual memory described above, and thus afforded a musical place that could be shared more easily among the participants.

6.1.8 Summary

I have now investigated the key elements related to the type and quality of the songs in the SB repertoire. The essentials of these elements can be summarized as follows:

The SB repertoire did not necessarily match with participants' individual preferences. Rather, they were broadly biographically relevant. The importance of this was described in the following six points.

1. Firstly, the majority of the SB repertoire had to be familiar to the participants with dementia so that the words and melodies could be recalled easily. Being able to remember and sing these songs empowered people with dementia and gave positive knock on effects to their caregivers.
2. Biographically relevant songs were strongly connected to individual, multi-sensory, audio-visual experiences from the past. Singing these songs helped people with dementia quickly to retrieve such memories. This worked well because people with dementia could often access long-term memories while having problems with more recent memories. Therefore, for participants with dementia, SB sessions were a joyful reproduction of these multi-sensory, audio-visual memories in the present.
3. Biographically relevant songs, as well as songs with seasonal themes and associations to places, brought awareness of the surroundings into their current lives, and thus help their orientation in time and place.
4. Biographically relevant songs afforded participants memory exercises where the joy of remembering these songs and their associated memories were shared in real time among the participants.
5. Singing biographically relevant songs in SB could bring back memories that couples shared from their past life and rekindled their relationship. The increased sense of sharing among couples/pairs became important foundations for strengthening the overall group culture in SB.

6. Biographically relevant songs acted as a strong medium to bring larger groups of people together, giving the opportunity to have a joyful time together, which contributed to the generation of the group culture as Fine (1979) discusses.

Here we could see the profound effects of biographically relevant songs, which explained the importance of careful repertoire selection when running musical activities aimed at people with dementia and their caregivers. Therefore, these songs were not patronizing to people with dementia or stereotypical representations of the older generations. Instead, the biographically relevant songs afforded forms of movement (e.g., “*Hokey Cokey*”) or immediate retrieval of associated memories of the past which fostered empowerment and joy that would have not otherwise been achieved through, for instance, Mozart or more recent songs, even if they were aesthetically preferred by individuals. At the collective level, the familiar songs fostered connections between couples, pairs and participants, and acted as a strong device to enable collective musicking, which in turn helped to generate a strong and sustainable group culture.

Similarly, DeNora (2010) discussed the value of music in community music therapy by investigating how “goodness” in music was relationally established. She emphasized that “goodness” in music was not self-evident; rather it was produced and nurtured among the participants, and its value-identity was “realized in relation to contextual factors that are themselves realized and selectively mobilized as contextualizing factors” (DeNora 2010, p.6). The sociological concept of “grounded aesthetic” as developed by Willis also highlighted the locally generated aesthetic values while emphasizing the process of collaborative aesthetic creations. Willis defined grounded aesthetic as “a view of an aesthetic not necessarily enclosed in a single artefact, but one articulated as the creative quality in a process wherever meanings are carried” (1989, p.141).

Therefore, it was a matter of lay crafting and its repetition time after time and place to place that forged the link between music and the various things that made it “good”, rather than the structural character or property of music.

6.2 SB repertoire as an outcome of continuous negotiations among the participants

The SB repertoire was not simply a matter of the facilitator selecting biographically relevant songs for participants with dementia; it was the outcome of negotiations among the participants that always had room for further development and changes. The result was a repertoire that was unique to the SB Watertown group. It also represented the characteristics of the SB Watertown group participants. What follows was the discussion of such process using interview data with Jessica.

The SB repertoire was primarily chosen by Jessica based on her tacit knowledge of what participants would know and enjoy singing; they were bound in a songbook. However, the lists of the songs were continuously updated based on the requests and ideas developed among the group members. For example, Hannah and Simon brought their favourite songs from a songbook to Jessica and some of them have now also been included in the SB songbook, which will be discussed in chapter 8. There were cases of songs that were avoided upon request. There were also songs chosen specifically for the intergenerational events (e.g. “*My hat has three corners*”) as discussed in chapter five. When I interviewed Jessica at her home, she showed me a room filled with songbooks. She called it the “Song Birds resource centre”. Before starting the SB group in Watertown, Jessica had been working as a music teacher, running choirs in several primary and secondary schools. She had been an active singer in choirs herself. Jessica had also used music when she was caring for her own parents who suffered from

dementia. This was what eventually triggered her involvement in music activities for people with dementia:

[...] I would take my keyboard, and play, and they enjoyed it in the nursing home. So I got used to knowing what kind of songs people liked, and learned about the songs from doing that, just because my parents were there.

Jessica also gained new ideas from the choirs she belonged to and arranged the exercises she learned at the choirs for SB sessions (e.g., the articulation exercise discussed in chapter five). In this way, Jessica had many resources available when planning the sessions:

I just pick things up and use them and develop them and play around with them, throw them out again. I am just very lucky that I mix with a lot of musical people and I just pick up things. Well, I go to choir and I am with other musical people there.

Jessica also kept herself informed about new songs by collecting requests from participants, which was done informally as well as officially by circulating a form for members to write down their requests at the end of the term. Although the ways and means of running SB groups had started to become standardized as it developed nationwide, the song repertoire seems to have remained unique to each group while facilitators from different groups continue sharing ideas through an online forum system that the *Dementia Support Group* provided.

The selection of songs also touched on sensitive, personal and emotional issues among the participants. For instance, Jessica shared with me an episode when she was asked not to introduce a particular song in a SB session:

We do sometimes have songs which [sic] people say “oh please don't sing that song, because it makes me cry”.

She herself had certain similar issues as she was going through the recent loss of her husband at that moment:

*Jessica: [...]I am keeping off them myself at the moment, because they might make **me** cry. But on the whole, I'm quite good; I can detach what I do for SB from **my** life. I try to do it, yeah, because otherwise I wouldn't be able to do it.*

Interviewer: If you have the personal association with...?

*Jessica: Well, **at the moment**, at the moment, because certain songs upset me because of my husband you see. So I have to make myself, detach myself from that, to be able to do the songs, and not get upset.*

Although Jessica was usually good at detaching her work with SB from her own life, she might have felt she was in a double bind here, between being a person who has been bereaved and being a facilitator of a group with the responsibility of leading the session successfully. This obviously led her to use this strategy of avoiding certain songs temporarily in order not to fail by being too emotional during the session. Similar avoidance of certain musical materials by people going through a bereavement period has been reported by DeNora (2000) and Hara (2007). In these cases the avoidance centred on songs in minor keys as people felt they affected their moods despite not being directly associated with their relatives who had passed away. Jessica later shared with me an episode when a song made her suddenly emotional unexpectedly:

Well, I don't do so many of the rather more sad songs I think, for the moment. I avoid those a bit. Because I think they might be a little bit... difficult for me... I was at a choir the other day, I was at the choir practice. There was a song called, oh gosh I can't remember the name of it right now. dedede (she sings) "It's all about the way you... drink your tea, the way you wear your hat" you know that song? And that...! It's not predictable, not predictable. So I keep off things I think might be a little bit like that. Touch wood, I've been fine. I am OK, I am OK, but that's just me at the moment; don't worry about that. Normally it's fine. But I am aware of that with other people too.

Jessica was not a therapist or professional who was dispatched by an external organization to work with this group only for a set time every week; rather she started the group as a grass roots activity with her own local friends. Therefore, many participants including Jessica had regular contacts with each other outside SB. When her husband passed away, the news was shared among the participants, and her close friends among the volunteers were supportive enough to run the group without Jessica for a while. So, this was a relatively close-knit local group that Jessica was also a part of, as a participant who could also be vulnerable.

A professional therapist might have been able to detach his/her emotions better than Jessica; however, this was one of the special characteristics of SB. It was a democratic local music group where the facilitator's own subjectivity was also considered. This also meant that the roles of others were not set in stone, for instance other volunteers were able to take over the running of the group when Jessica was away.

Jessica, while considering her own emotions in SB session, was also cautious about the possibility of music having an (unpredictable) emotional impact on others:

There was this song and somebody said "please, please don't do that song again". [...] It's a song called "You never walk alone". And it's actually a football song, it's used by one of the football teams as their "theme song". [Reading lyrics] "when you walk through a storm, hold your head up high and don't be afraid of the dark. You'll never walk alone. You'll never walk alone." And it's quite emotional. I haven't sung it since then. [Reading lyrics] "At the end of the storm, There's a golden sky, And the sweet silver song of the lark, Walk on, through the wind, Walk on, through the rain, Though your dreams be tossed and blown"

Now, that produced tears with one of our ladies and she said, please, please don't do that song again. So I've never done it since. But, you don't know until you try and I am quite sensitive to how people feel. That's quite a sad song, you see. It's from a musical. In the context of the musical it's not particularly sad,

but for her, it was, you know. So, yeah. So at the moment maybe my choice of songs tends to be a bit more cheerful.

I do not know who asked her not to sing “*You’ll never walk alone*”, however I never heard the song being sung, at least during my two years of involvement with the group. It is an essential consideration, as Jessica pointed out, to be sensitive to what people felt with regards to the repertoire. Some songs could affect someone personally to the extent that they had difficulty handling it emotionally even if they were favourite songs among the majority of the participants. This consideration was especially important for this type of group as the participants with dementia were obviously close to the end of their life and some caregivers were already experiencing the “bereavement” of being with their partners with dementia, whose character had drastically changed or who are no longer able to recognise them (Sweeting & Gilhooly 1997; Matthew 1999).

Such important considerations, however, conflict with “a school of thought” prominent among the facilitators of SB as also expressed by Jessica:

But there is a school of thought, there is a group, an idea, going through the leaders of SB that we should be reaching all emotions, not just the happiness, because it gives people a chance to bring those emotions out a bit, you know. But I am feeling that at the moment, I don't want to do that. But there are people who do. And do it successfully, I think you have to know how to manage it. Because there are lots of people, I mean, emotions are a difficult thing really aren't they? It's difficult to... And we don't go around singing, “oh what a lovely morning” [sings] all the time. We do have some times when we want to be a bit more thoughtful. But at the moment, I am avoiding those songs, but that's just personal.

Another important issue was raised here, that highlighted the difficulties of group-oriented activities. Reaching and bringing out a variety of emotions among individuals were more difficult under such circumstances as the emotions a song recalls were not uniform for all participants. Although not all SB facilitators do the same,

Jessica prioritized her considerations and she was cautious with the possibility of the intense, sometimes unpredictable emotional impact of music on the participants, including herself. In this way, the SB repertoire was not only a list of biographically relevant songs that could be remembered by the participants with dementia, but also the outcome of such continuous implicit or explicit negotiations. The SB repertoire was not a fixed list but evolved according to the transformation of participants and the changes that occurred in participants' personal relationships to songs. What these repertoires afforded in SB sessions was also not static but rather developed through the collaborative aesthetic crafting during and after the SB musical events, the latter of which will be discussed in chapter 8.

Chapter 7: Interlude: Humour and Joyfulness

In chapter four I discussed how the joyful atmosphere of SB was collaboratively crafted and how this helped participants with dementia to regain a sense of coherence, while at the same time helping them to transcend negative expectations of dementia among the participants. This collaborative crafting of the elated and excited mood continued throughout the session, and helped to nudge the participants forward through the challenging activities without inducing any feelings of pressure or stress. Hence, humour and merriness were not merely a pleasant side effect but were in fact a means to an end and thus important factors in generating the overall group culture in SB. In this interlude I will therefore use a few examples from my data to highlight how fun and exhilaration is embedded within the musical framings, and how this helps to activate the group culture.

For instance, Susan, a volunteer who often led the quiz section, emphasized the importance of laughing. In the interview with Susan, I brought up an episode when her facilitation caused laughter from the participants:

Interviewer: I really like the quiz you did on food; “Mary had a little lamb”.

Susan: Oh, yes. [laughs] I couldn't think anything else, so LAMB, that's right, yeah... I do like to make everybody laugh, I think that's really important, all the laughing you know. It's nice. We are like a family, aren't we really, SB? Nobody minds if you make a mistake, which is wonderful, I think. We don't take ourselves too seriously, that's good. [laughs]

Before she played “Mary had a little lamb” at the quiz about food, she introduced this as “a song of desperation”. People picked up the melody and the lyric very quickly, and it caused a lot of laughter. Presumably, the laughter came from the amusing contradiction of introducing the song, which is about a girl (Mary) and her lamb, as a song to do with

food, which reminded them of the lamb meat for eating instead of the adorable image of Mary's little lamb. And as Susan emphasized, laughing together strengthened the group culture and therefore, no one minded making mistakes and the members did not take themselves too seriously, something that would induce stress.

As dementia is a progressive illness, SB as a group frequently faced the loss of some of its members. I previously discussed how everyday life could be very stressful both for the caregivers and care-receivers due to the symptoms of dementia, but despite the possibility of impending loss and the underlying stress, there was neither seriousness nor tension in the atmosphere at SB. Rather it was filled with laughter and joyfulness. Laughter was especially important for this group as it could help ease any tensions that caregivers and care-receivers might feel. At the same time, the happy atmosphere helped to break down the boundaries between people with and without dementia, as it took people's attention away from illness and anguish, albeit temporarily.

Nichola and her daughter-in-law, Peggy, also focused on the enjoyable atmosphere:

*Peggy: [To Nichola] Which bit do you like best when we go down to singing?
[sic]*

Nichola: What do I like?

Peggy: What songs do you like?

Nichola: I like the funny ones.

Later in the interview, I took out the songbook and showed it Nichola and Peggy to find out if Nichola liked certain songs (or activities) more than others. She insisted that "*I like them all (laugh)*" and added "*we get to know people, and it is very, very, good fun*".

For her, the songs sung in the session seemed not so important (or they might slip easily from her memory). However, she knew that she enjoyed the funny one as well as the overall session. From this we could surmise that Nichola enjoyed the joyful atmosphere music created rather than individual songs per se, in other words, songs during the session were not standing out by themselves, but were experienced as a part of the larger gestalt of the pleasant atmosphere. In the interview Peggy also made a positive comment about the flow of session, describing how it felt like sessions ran themselves as it was well-planned enough to keep people focused throughout the hour as discussed in chapter five. Peggy was also positive about the humorous banter between songs as an important factor to generate this flow; "*Jessica makes it more interesting, because she has some funny jokes in between, doesn't she?*" Jessica is adept at keeping the atmosphere filled with laughter and she explained to me that she felt the emotional framing of the session was important along with the musical framing.

In fact, Jessica frequently said intentionally silly things to keep the atmosphere light-hearted as an underlying frame for all the activities and the exercises. Some of the participants with dementia might not catch the meaning of jokes. However, the overall humorous atmosphere affected them emotionally, and this emotional communication was important in generating a comfortable atmosphere for people with dementia when verbal dominant communication was difficult as Ohi (2008, p.60) emphasized.

Therefore, together with the well-crafted socio-spatial environment and the positive musical affordances contributed by the biographically relevant songs, humour and joyfulness also contributed to make the overall atmosphere very comfortable for participants, and thus bring a good flow to help the overall structure function well.

Chapter 8: In-between and after the events

So far, I have discussed the crafting of the musical events in chapter four and five and detailed the functions of the SB repertoire that underpins this crafting in chapter six. In this chapter I will discuss how these positive musical affordances in SB events are integrated into participants' everyday lives and permeate them. This is important as the integration of positive music-based experiences have received little focus in the field of music in dementia care due to the emphasis on the (more obvious) temporal effects of music and it has been assumed that any positive effects were difficult to retain because of the short term memory issues common to people with dementia (Sweeting & Gilhooly 1997). Through my ethnographic study however, I was able to observe how the positive affordances brought by SB sessions were not restricted to the SB sessions. Instead they were sustained and further developed across a number of temporal and spatial boundaries and made real and positive changes to participants' everyday life. This applied both to active participants' everyday lives **in-between** the weekly SB events as well as to former participants' everyday lives **after** their involvement with the actual SB events ended. These findings will be discussed in two sections. First, I will highlight how the pleasant moments that the participants experience in SB events are sustained in-between the events through a number of extra musical benefits such as "expectations". Following this I will highlight how music acts as a resource across various boundaries in different ways that make an impact on people's everyday lives as their conditions change or even when participants pass away. As an illustration of this I will highlight "*Shalom*", a song that is sung at the end of SB sessions, as a distinctive example of a song that permeates across these boundaries and even develops as a symbolic song that becomes a resource to support the participants through to the end of life (caring).

8.1 Sustaining the pleasant moments in-between the events

Because the SB sessions were intermittent events, it was desirable to “sustain” the moments that the participants experienced positively in SB musical events so that they could be integrated into the everyday lives of the participants. In this way, the benefits of participating in SB events that were discussed in chapter five were not only effective during the events, but they also had positive impacts on participants’ everyday life when it came to maintaining their quality of life. I discovered several arrangements that were informally devised and developed in order to sustain these moments. The material arrangements devised for SB sessions were one example of this. For example, the sessions with a seasonal theme often set the “dress code” (e.g., Easter Bonnets for an Easter session and tartan checked clothes for the Burns Night session). This provided a process of preparation for the participants, which was also a way of sustaining joyful moments in-between the actual musical events. Individually developed arrangements that had not been directly prompted by SB arrangements could also help to sustain the pleasant moments.

For many members with dementia and their caregivers, SB was the only social occasion they attended as “*social life disappears at this stage*” as Hannah said and then continued, “*we don't have a regular arrangement with anybody now the way we did. It filled the gap very, very well. It is good*”. Participating in SB, therefore, provided a framework for the life of participants with dementia and their caregivers outside of SB by providing opportunities for them to develop habits that hinged on the SB sessions. This in turn helped to sustain positive musical affordances from the SB sessions beyond the immediate aftermath of a session.

For example, Kelly (wife/carer of Chris) told me how they used all morning to get ready; she took her time in finding nice clothes to wear for both of them before coming to SB sessions every Tuesday. This was an example of how the weekly SB sessions could provide someone with a framework which helped them by encouraging them to keep in good condition for social occasions they enjoyed with others. These events were distinctive from their daily life, yet integrated into it. Similarly, Hannah and Simon developed their own pleasurable routines associated with participating in the SB sessions:

Hannah: And we used to come up early, so that we could go and feed the ducks [...] and that was fun. We saved all our bread for them didn't we Simon?

Simon: Yes...

I often saw Hannah and Simon walking along the river after the SB sessions as well. Their activities centred on the river seemed to be an important ritual in their life that obviously had developed around the weekly SB session.

There were numbers of similar examples of such individually developed routines that helped participants to sustain the moments they experienced in the SB sessions. For instance, Lisa and her mother, Caroline, always sang the songs they had sung in the session in the car on their way home, whereas Nichola slept very well in the car every time after one hour of continuous singing exercise at SB. Peggy and Nichola also often searched on the internet for the background to the songs they have sung in the SB session and talked about the lyrics and their memories of these songs (this was also discussed in chapter six, see for example “*After the ball is over*”). All these habits became meaningful rituals or events themselves as the sessions were repeated. These developments, together with the weekly SB session, were important as they provided

regular and pleasant interruptions to their life with dementia which could otherwise have been stressful and isolated.

Several caregivers and care-receivers told me that SB was something they could look forward to and that this in itself was a great improvement to their lives. A number of caregivers also explained that the care-receivers for whom they were responsible felt better after coming to the SB session for a day or even several days. Michael (Laura's carer/husband) for example told me that Laura always felt better after singing in the session and that "[i]f Laura feels all right, I feel all right." Michael also looked forward to coming to the SB session because he knew he and Laura would have fun no matter how stressed they may have felt during the rest of the week. Jonathan, who had dementia, once told me at the SB session after the half term two weeks break how he was looking forward to coming to SB. He arrived earlier than usual that day and waited for other participants to arrive. Bob, Arnold's caregiver and friend, touched on this issue as well:

*[...] the people who come, enjoy the session, and I would guess insofar as they are able to look forward to it, well, I suppose, it depends on how far down the line they are, it seems fairly obvious to me that it is a high spot of their week. And then that obviously affects their carers as well, because it is something **they** can look forward to.*

In short, the positive changes that the musicking afforded within the SB sessions were developed further in participants' everyday lives not only through the use of music but also through post and pre musically triggered emotions such as looking forward to or reliving the weekly musicking which, as Aasgaard puts it, had the "ability of providing good memories and creating pleasurable expectations as an important spin-off from the actual song activities" (2002, p.203).

The arrangements devised for the SB sessions and the individually developed habits discussed above together reinforced the dual post and pre-musical emotions of having expectations before the SB events and feeling good after them. Finnegan (2007, p.335) describe music as rituals that were set apart from everyday life and provided an essential framework for participants' validations and true celebrations. SB sessions could also be considered to be rituals which provided the participants with dementia and their caregivers with an essential framework for their daily lives. However, I would disagree with Finnegan's notion that music, in this case SB sessions, were separated from everyday life; rather they were embedded in every individual's daily lives in a number of ways that affected positive changes in the daily caring lives of people with dementia and their caregivers. In other words, the moments of happiness they shared during the sessions, or any elated feelings that emerged afterwards might not last more than a few hours or a day or two. However, by expecting it and possibly reinforcing the expectation with personally developed habits and arrangements devised by SB sessions, the moments might spill over into other parts of their lives and thus "last" longer. As a result, they were better able to manage tension.

8.2 Music as a resource across temporal and spatial boundaries

The SB repertoire that had been developed was specific to the Watertown group as I discussed in chapter six. Because these songs were sung repeatedly in SB sessions, a song sometimes developed special localized meanings that were shared among the participants, for instance "*Irish eyes are smiling*" became Arnold's song as mentioned in chapter five. There were more examples of what it meant repeatedly to sing the same songs in SB session that I would like to examine here. This will further aid our understanding of how the musical affordances of songs continued to develop along with

the transformations of the members; either within the group, or when some left the group because of the progress of illness or passing away. Therefore, locally created aesthetic experiences were transformed and appropriated over time. Thus songs clearly acted as a health resource, moving through different temporal and spatial boundaries and have further positive impacts on people's everyday life, which is exactly what the idea of grounded aesthetic indicated. The first example showed how the repeated singing of the same songs in the SB sessions provided opportunities for people to still feel connected with the group even after they had to leave SB for good. The second example was complementary to the first in that it dealt with how this also helped to remind people of former participants after they have left. This would be followed by a discussion of how the grounded aesthetic through joint and repeated singing could help some caregivers to deal with the bereavement issues after their loved ones had passed away.

Hannah and Simon were interviewed just after they stopped participating in SB sessions due to the progress of Simon's dementia and in our conversation they discussed their continued connection to the group:

Hannah: And then Jessica had a lot of lovely songs that we knew well. And you took her your book of songs to see, didn't you Simon?

Simon: Yes.

Hannah: Yes. Songs from our Morris Traveller,⁴⁸ and she took some of them out for you, because they were your favourite songs and put them in her book.

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

⁴⁸ A car from the 1950s/1960s, presumably the car in which they used to travel with their children.

Simon: I gave her a book.

Hannah: Yes.

Simon: Lots of pages

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

Interviewer: Which ones?

Hannah: Lots of them. There were lots of them there weren't there Simon? We have "When Irish eyes are smiling", (He started singing the beginning). Would you like to sing it now with me darling? Help me?

The interview continued, sometimes by singing songs from the SB songbook. The interview snippet above clearly indicates how they were happy to imagine people were still singing their favourite songs that they brought to the group even after they had to leave the group themselves. SB had been the only social involvement Hannah and Simon had for the past three years, as they were not using any other dementia related services. Hannah did not want to use nursing homes even after Simon's condition deteriorated; thus he was cared for at home until the end. For Hannah and Simon therefore, departing from SB meant that they lost the only social involvement that had filled the gap they experienced in their lives, as Hannah put it, when they came to the final part of life with dementia. This was no doubt a very solitary period and Hannah's comments regarding SB still singing their songs might have been a somewhat one directional emotion as not many people were aware that Hannah and Simon had brought these songs to the group. Nevertheless, it must have been a comfort to Hannah to know that they could leave their favourite songs as their mementoes with SB and that these songs continued to be sung every Tuesday by the participants of SB, thus allowing them

to still feel connected to the group when they sang them alone at home or just thought about how they were still sung in SB.

This type of connection also worked in the other direction by keeping a former participant in the group's mind through the singing of a particular song. We have seen how "*Irish eyes are smiling*" became Arnold's song; how, in one session, it was chosen specially to provide musical care for him and at the same time, it gave a knock-on effect to other participants. Through interviews with a number of participants, I found further stories and reasons behind how "*Irish eyes are smiling*" became Arnold's song, which goes beyond it simply being Arnold's favourite song. Bob explained that at first "*Irish eyes are smiling*" was

Not really for him, there was an Irishman... I'm not sure whether he overlapped with you, but we did have an Irishman, Trevor, who died in November. So I am not sure quite at what stage he stopped coming. [...] That's the "Irish Eyes", that was done for him. Arnold obviously liked it but he hasn't got the Irish connection. But it was... It started with the Irish man and it's continued a bit with Arnold, because he... It's the sort of thing he likes singing, yeah.

In section 5.9.1 Rosie, a volunteer, mentioned how Arnold had sung the "*Hokey Cokey*" with Trevor and how "*they just ripped the roof off*" as she put it, with their enthusiastic singing and excitement. Jessica also explained that Trevor and Arnold had been close friends, also outside SB. Therefore, Arnold's "inheritance" of "*Irish eyes are smiling*" seemed like the outcome of this friendship. I am not suggesting that inheriting the song was consciously thought out by Arnold or anyone else at SB but rather that it probably was the outcome of Arnold's obvious enjoyment of singing the song, initially brought about by his friendship with Trevor, which over time made it "his" song.

Therefore, singing “*Irish eyes are smiling*” not only afforded various effects for the current participants in SB; in addition it provided musical care to Arnold and also reminded people of Trevor and the friendship that Arnold and Trevor had. This allowed Trevor, who already left the group and passed away, to continue living in the memory of the group members. Later on, after Arnold died, it became a song that carried strong connotations with Arnold for the group as we shall see.

After my initial two years’ extended participatory observation period I returned to SB and Watertown several times. One time was six months after Laura had passed away, and it was the first time I experienced Michael (Laura’s husband and former carer) working as a volunteer. He told me, while putting the songbooks on the seats before the session started, that he remained in the group as a volunteer, as he and Laura had been coming to SB since its inception 5 years earlier. He told me that, “*Shalom is the hard one because I remember how Laura was singing it*”. On the same day, I sat next to Bob who used to bring his best friend Arnold to the SB group. It was 10 months after Arnold passed away, and Bob also remained in the group as a volunteer. As soon as Jessica introduced “*Irish eyes are smiling*”, Bob told me how it was Arnold’s favourite song and I nodded. Jessica was also aware it was Arnold’s favourite song and therefore told me later, how she could not look at Bob as she knew Bob was thinking the same. Bob also said to me excitedly, how “*Sailing*”, when it was sung in the session, was a favourite song among the residents in the nursing home where Arnold stayed in his final years. I saw some tears in Bob’s eyes when we were singing “*Shalom*” to close the session. Just like “*Shalom*” reminded Michael of Laura, it probably also brought on Bob’s emotions by making him remember Arnold.

In this way, outcomes beyond the sessions based on what the songs from the SB repertoire initially afforded (such as displacing illness) were developed as the songs were repeated in later SB sessions. These musical affordances dynamically developed and changed as the participants' lives changed and even reached participants who left the group by helping them feel still connected with the group and by reminding people of those who had left and of their friendships with current participants. As the continued singing of the same songs reminded people of these former participants, musical affordances also developed in ways that helped to support the bereavement process of caregivers and friends.

DeNora (2000, p.67) discussed this issue of music's ability to let people relive past experiences by explaining how music provides parameters for experience to be reconstituted in real time. She further suggested that:

Music may thus be seen to serve as a container for the temporal structure of past circumstances. Moreover, to the extent that, first time through, a past event was constructed and came to be meaningful with reference to music, musical structures may provide a grid or grammar for the temporal structures of emotional and embodied patterns as they were originally experienced (DeNora 2000, pp.67–68).

For Michael and Bob, the SB repertoire also served as a grid for the temporal structures of emotional and embodied patterns that they originally experienced with their partner and friend in SB sessions, which must have been one of the last happy moments that they shared. In this way, continuing to sing the same songs in SB sessions provided a way for them to process their bereavement, as it allowed them to remember their partner

(or friend) from a time when they were happy⁴⁹ despite its having been a time when they suffered from dementia. This was not to say that it could not sometimes be very hard and emotionally intense. Reliving past experiences they shared with their partner and friend through musicking also allowed them to produce one's self as a coherent being, as discussed by DeNora (2000). Therefore, music acted as a resource when maintaining and processing the relationships, a resource that was appropriated in different contexts beyond temporal and spatial boundaries, thus bringing the participants' sense of coherency to cope with challenges in life, in this case various challenges forced by dementia, which in turn enabled people to maintain their health as suggested by Antonovsky (1987). Continuing singing the same songs in the same group could thus be considered a form of self-care that aided their bereavement process. However my data here was somewhat sketchy and further research on this issue is therefore both necessary and desirable. As I pointed out in chapter 2 the sustainable actions were necessary to support people affected by dementia from the initial diagnosis to the bereavement process in an active, evolving network of people. Therefore, the potential of music use in bereavement should also be included and explored more in the study/practice of music use in dementia care.

8.2.1 “Shalom” and permeable borders: Singing through the end of life (caring)

As discussed in chapter five, because of its musical qualities and the structure of the session, the ending song “*Shalom*” tended to stay in participants' minds and ears after the session ended. The melody and lyrics combined to allow a peaceful feeling to be

⁴⁹ In chapter five I have discussed how Laura and Arnold were involving themselves with the singing with great confidence and joy and how, in these moments, their illness was displaced in other members' experience in chapter five.

sustained for some time. This musical entrainment was a key quality particularly for participants with dementia, who otherwise had difficulties sustaining their happy feelings due to their limited cognitive abilities. The sustained effect of “*Shalom*” also helped the participants to exit slowly from the musical event, sustaining the happy feelings while cooling down the excitement. This assisted them in their return to their everyday life, which was often filled with distress and bewilderment, in a calm and pleasant manner. This was observed in Arnold’s behaviour; he was often agitated when first arriving at the SB session, but it was somehow calmed after the session and he sometimes continued singing “*Shalom*” while the room was being cleared out. Similar effects were discussed by participants with dementia and their caregivers. These effects could not necessarily be traced to a single song (“*Shalom*”). Rather they were the result of certain behaviours that were afforded by the totality of the session. However, the quality of “*Shalom*” seems to have provided a particular strong affordance towards the calm feeling that was carried into participants’ everyday life and became an important medium that connected two distinct entities: the SB session and the participants’ everyday life.

This mediation seems to work primarily through the emergence of “*Shalom*” with its collective, symbolic meaning in interaction with participants’ everyday life, especially their end of life and related caring. Many people said that “*Shalom*” was their favourite song or that the most moving moment for them occurred when it was sung. This and probably the fact that “*Shalom*” was simple and easy to sing, have led to its being sung at several funerals of SB participants, including Jake’s and Laura’s. On both these occasions, Jessica led the singing. Through an ethnographic investigation of Jake’s passing away, I tried to capture the emergence of the symbolic meaning of “*Shalom*”

that developed as a resource to support people towards the end of their life and the attendant caring experience.

Jake and Marjorie were regular members of SB for almost two years. Jake had early stage dementia, and it was not necessarily obvious. Two days before I had arranged to interview Jake and Marjorie at their home, Jake fell down and suffered a brain haemorrhage. Needless to say, the interview was cancelled. In the following SB session, Jessica announced that Jake was in intensive care at the hospital. This was a shock to all the participants as he had not shown any sign of dramatic deterioration in the regular SB sessions. We wrote a card to them as we usually do when members are in care. We knew that Jake's condition was serious; thus there were tensions and worries about Jake among the participants in the group. It was therefore natural that when I interviewed Deborah (a caregiver) soon after, we talked about Jake and Marjorie, in particular a recent episode that had occurred:

[Marjorie] comes to Elderly Support Group on a Monday. So I knew Jake wasn't.... Then I happened to meet them [Marjorie and her son] in Lidl's in the shop. [...] She had just come from hospital, but he was drifting in and out of unconsciousness. But she said she thinks he was trying to sing "Shalom", it was awful. He was trying to sing Shalom, she thought. He is in intensive care, and she had his hand. So I said that hearing is the last thing that goes. He would know you were there and he was trying to sing "Shalom". He was trying to sing, yes, she said "I was sure he was trying to sing Shalom, to say goodbye". Ohhh... I told Susan and both of us were nearly in tears when we sang Shalom on Tuesday.

Marjorie clearly believed that Jake was trying to say good bye by singing "Shalom", although I was not able to ascertain the validity of her story. The narrative however, was shared among a few other participants at the next SB session, and this further impacted the aesthetic experience among the participants when they were singing "Shalom" that

week. Jake passed away soon after and several members of SB went to Jake's funeral where "Shalom" was sung as I mentioned, although Monica, who at that time knew that Arnold would soon pass away had to leave before it was sung as it was too emotional for her.

As it was pointed out in chapter two, the passing away of people with dementia can be taken as blessing (Sweeting & Gilhooly 1997). In fact, several caregivers expressed how they felt relieved, rather than sad, at their partners' funerals to see them finally finding peace after they had suffered from dementia for a long time. In fact, Deborah touched on this issue when talking about Jake's death:

Personally, I feel the only good thing is that that at least you know the end of them. Whereas, if she [the caregiver] died first, she would never know what happened to Jake, would she?

If we considered the death of a person with dementia a "positive" thing, singing "Shalom" at the funerals of participants with dementia was one of the ways to commemorate their passing or rather, "peaceful ending", among the SB community who had watched over their lives with dementia and shared joyful times with them through their collaborative musicking at the weekly SB sessions for a few years. What we clearly saw here was that what "Shalom" afforded was not bound exclusively to the musical events alone. Rather, the aesthetic experiences of "Shalom" permeated through different boundaries. This resonated strongly with the concept of grounded aesthetic discussed in chapter 6, how the meanings of aesthetic experiences were parts of the process of their being transported across time and space. In this case the meanings around "Shalom" were first developed through musicking in SB; later Deborah met Marjorie at the super market and talked about Jake's condition and his use of the song. Marjorie's narrative was later shared among the members, and after Marjorie had been

to a SB session to inform Jake's fellow participants about his death, several members of SB went to Jake's funeral, and at the funeral Monica was unable to sing it due to her own interpretation of the song. In sum, the new and old meanings of "*Shalom*" were carried through different domains and developed further as the aesthetic experiences of the song permeated different boundaries. As a result the meanings of "*Shalom*" grew beyond affording just a peaceful, reflective ending in the SB sessions. The "goodness" of the song which was nurtured in SB sessions was then actualized in different spaces (**outside** of SB) as DeNora (2010) suggested to be possible, which in turn affected later aesthetic experiences of "*Shalom*" **inside** SB sessions.

8.3 Summary

In this chapter, I hope to have shown that the various musical affordances provided by the SB repertoire were not tied to the particular physical and temporal boundaries of the musical events. Instead they were sustained and developed in-between the weekly SB events and after participants left the group as it interacted with participants' everyday life. The joyful moments of musicking at SB sessions were sustained through personally-developed habits and material arrangements devised around SB sessions. By repeating the events, the expectation before and good feeling afterwards were also reinforced. These findings reminded us of the importance of the regularity of the events as they helped to structure people's everyday lives, which could be filled with distress and a feeling of isolation.

As DeNora (2000, p.66) noted, "music moves through time, it is a temporal medium". My discussion in this chapter also showed how music offered new meanings at different times and in different places in relation to what it offered in one context. For instance, although the same repertoire continued to be sung in SB sessions, the actual musical

affordances of these songs developed to reach people who had left the group by helping them to feel still connected with the group and reminding them of people who already left the group and the friendship they had with current members.

These findings helped us to understand how musickings that were in seemingly different arenas formed part of a coherent ecology as pointed out in chapter two. As a result, they gave us very important insights, something that is currently overlooked in the literature of the use of music in dementia care. Music's role is not just to create a temporal effect. Instead it is a health resource used to support the lives of people with dementia and their caregivers in sustainable ways as the positive musical affordances are maintained and further developed across boundaries. This is particularly important because dementia is a progressive illness which continues for up to 10 years and consequently caring is a long term issue. Therefore, the sustainability and development of the musical affordances discussed above were crucial in supporting the quality of life of people with dementia and their caregivers in the longer term.

Willis (1990, p.22-23) has also discussed how grounded aesthetics provides “a motivation towards realizing different futures, and for being in touch with the self as a dynamic and creative force for bringing them about”. We could observe this in “*Shalom*”. It acted as a resource across different boundaries by affording individuals opportunities to process their bereavement while at the same time allowing participants in SB to develop and forge a social network. This network and SB's particular role in it is the topic of the next chapter.

Chapter 9. Pathways: in and out of SB

So far I have been fairly descriptive in my treatment of the crafting of the musical events and the musical affordances that emerged out of this. In this last chapter on findings I will try to pull back and discuss the workings of music in dementia care on a broader, somewhat more theoretical level. This will be rooted in an emphasis on the importance of links and community networks in some of the literature on dementia care (e.g., Brodaty et al. 2005; Fortinsky 1998; Lindsay 1994) which spurred me to do further investigation on the wider music and care world in Watertown. As a result, I discovered a variety of music and care groups in Watertown and traced the links between these groups. In effect, these connections constituted routes for older people with dementia and their caregivers to access music and care opportunities, and they acted as specific “pathways” that led them to SB and further music and care opportunities beyond SB. This notion of pathways resonates with how Finnegan (2007) described musical practices as providing “musical pathways”, that is, significant routes through musicking to the wider society. However, to avoid any confusion, pathway is used here to describe the actual connections and routes between different groups rather than the music practices themselves. These (music based) groups could be understood as being nodes in a network, and SB was one node along the music and care pathways in Watertown that in turn connected to further nodes. In short, the music and (dementia) care world in Watertown constituted a network which was made up of a fluctuating set of pathways and nodes, some more dominant in time and size than others.

It is therefore useful first to position SB in the context of the wider community and show how SB was connected with other groups and activities through different pathways. This will be followed by a discussion on how SB worked as a particularly

safe node, due to the crafting of its safe and inclusive environment that was discussed in chapter four and five. As a safe node it provided an important junction of various pathways leading to the wider music and care world. When focusing on the music related aspect of the network, it was clear that moving from one node to another required participants to do some aesthetic renegotiation as each node had different properties in terms of their repertoire and the levels of skills required. The second part of the chapter therefore will discuss how SB allowed participants with dementia and their caregivers to renegotiate their aesthetic priorities in order to adapt to the new aesthetic practice, something I will suggest to be essential for them if they wish to share aesthetic experiences together as the cognitive functionality was slowly regressing for the person with dementia. The last section will highlight the specificities of SB when viewed as a node in a network: I will highlight how it brought people at different life stages together through different pathways; which in turn encouraged informal learning about dementia and dementia caring; this will be followed by a concluding discussion of how the quality of a node allowed SB to endure over time as a sustainable action.

9.1 Music and care pathways and groups in Watertown

The ethnographic study I have conducted enabled me to explore the various relationships as a “music and care world”. This gave me a holistic understanding of how local music and care nodes were linked to and through each other. This also allowed me to contextualise the role of SB and its connected resources within the music and care network in Watertown. Through this work I also gained an understanding of what the everyday lives of SB members were like: where they accessed information about dementia care and relevant events, other social involvements, relationships with other informants and even their daily shopping. I often encountered informants outside of SB

when I lived in Watertown, which added to my understanding of them in other situations and helped to fill in the details of the complete and complex care network picture that they were a part of. To help us understand how all these groups and activities were connected into a cohesive whole, it was useful to visualize them. Figure 4 below depicts the complete network of the pathways and nodes that constituted the music and care world in Watertown. It is useful briefly to discuss this, before starting the detailed discussion of pathways and how people went in and out of SB.

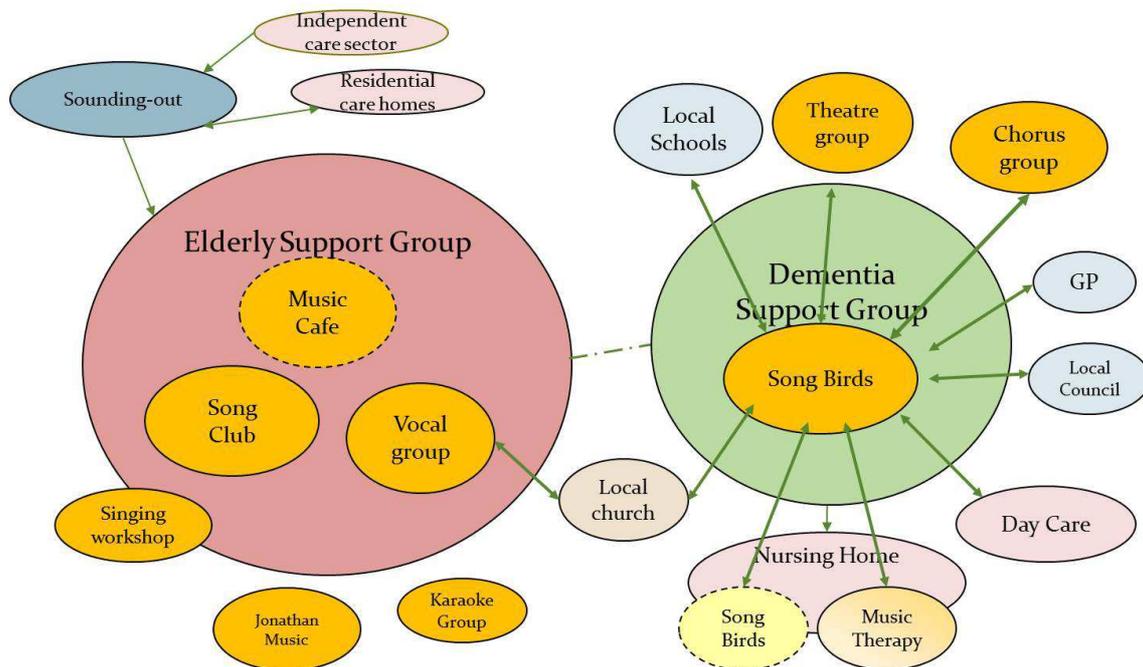


Figure 4: SB and the network of music and care in Watertown (Orange circles denote musicking opportunities. Other colours are for clarity only.)⁵⁰

- The biggest organisation here was *Elderly Support Group*, which supported older people. In Watertown it ran three different music activities.

⁵⁰ Names of the groups are anonymized.

- *Elderly Support Group* introduced *Sounding-out* to run musical activities for older people with learning disabilities.
- *Sounding-out* also ran training programmes for general care-workers on how to use music in various care settings.
- The *Dementia Support Group* was responsible for running SB, whose volunteers (and attending caregivers), came from various local backgrounds such as choirs, churches, theatre groups, local schools, *Dementia Support Group* as well as *Elderly Support Group*.
- A local school choir was invited to sing with SB several times a year; this was organized through Jessica's personal connection.
- *Elderly Support Group* and *Dementia Support Group* were linked through a number of care support workers who were involved in both charities.
- Some of the participants were referred to SB through their local doctors.
- The Watertown mayor and representatives from the local council were involved with certain key events at SB (e.g. the anniversary of SB, collaborative events with the local school choir).
- *Jonathan Music* was a local organisation that ran various music workshops for people of all ages.
- Several participants of SB used a local day care centre (e.g. for respite care).
- Several participants of SB moved into nursing homes in their late stage and participated in music therapy session there.

- Finally, there were various choirs and a karaoke group that older people could join.

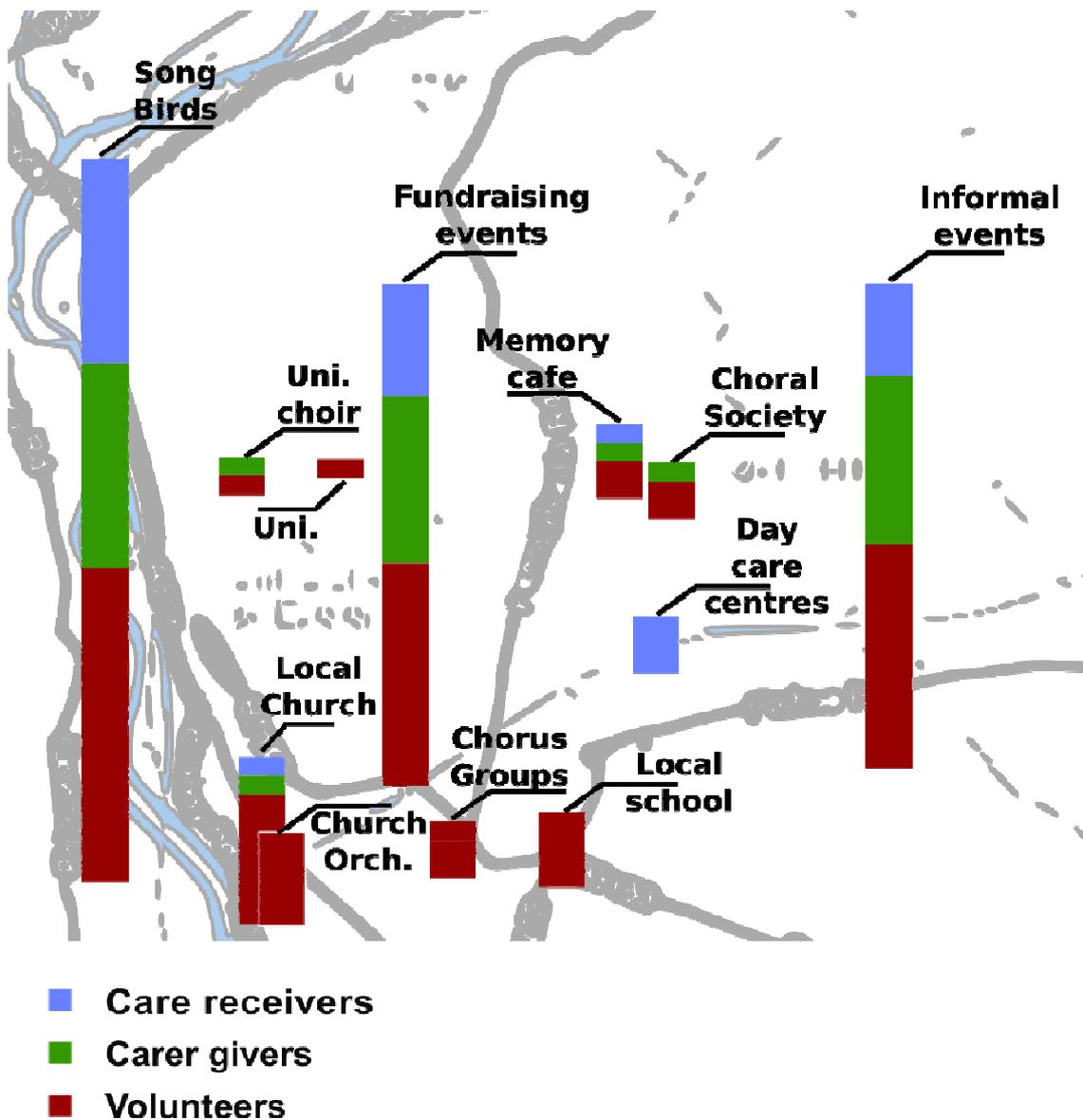


Figure 5: A zoomed map showing only the centre of Watertown and the activities that took place there.

Figure 5 shows the number of SB participants that were involved in other activities in Watertown (most of these activities were shown in Figure 4). I have located the locations of each activity on the anonymized map of Watertown, which showed that the majority of these activities took place within 1.5 to 2.0 miles distance of each other.

From Figure 5, we could see the network of groups and music-making activities for older people that overlapped via their supporters and participants. Hence, participants of SB shared not only SB but a variety of other nodes in Watertown. The range of activities and the number of participants in these groups were fluid and extended from a handful of people meeting occasionally to regular activities such as SB which attracted 30 or more participants to their weekly sessions. Together they constituted the music and care world in Watertown. These opportunities were developed primarily through local volunteers' initiatives and efforts that first and foremost catered for local needs. The proximity of these activities as shown in Figure 5 told us that multiple music and care related groups were available locally. This meant that local supporters or groups were easily reachable for local people affected by dementia when needed according to their continuously changing situations. All of these groups and activities were nodes that constituted the whole network, terms commonly used when discussing actors, organizations and events within a social network (Scott 2000).

These nodes were connected through pathways, that is, routes for older people and their caregivers to access music and care opportunities. The local network in Watertown thus helped to "channel" potential participants to the SB sessions. For example, the SB participants who were active during my field work period had learnt about the group from a variety of sources including local doctors, the Internet, *Dementia Support Group* and *Elderly Support Group*, local churches, choirs and a carers' day organised by the local council. Here we could see the emergence of multiple, interlinked virtuous cycles within the network that helped sustain these local, and largely voluntary activities, a point I will return to later.

9.2 How music and care pathways emerge from music-led network

The pathways to and from SB that connected the various nodes in the wider music and care network were developed and maintained through the efforts of the volunteer members together with local people with dementia and their caregivers through their activities inside the nodes themselves. Before discussing the functions of these pathways, I will describe the characteristics of the volunteer team of SB as they were important resources when it came to creating and preserving these pathways.

Most members of the volunteer team, including Jessica, were retirees. As the majority of the volunteers were of a similar age and locally based, they were also connected to and through other parts of the local network, be they churches, local music groups or previous jobs. Among these nodes, the music-led ones⁵¹ were the most common ones as the majority of volunteers had a strong background in music either through choirs, orchestra groups or music teaching. Many of them were still actively involved with other local music groups. Some of them worked with SB because they had specific experiences with and/or interests in the therapeutic use of music for people with disabilities or dementia. In this way, many volunteers already shared a membership in other local music nodes (and by extension also shared some interests) and thus strengthened the network even further when they came together as a volunteer team at the SB node.

Rosie, a volunteer, described the specific character of the SB volunteer team, especially those that also sang in choirs:

⁵¹ For example, theatre groups, festival choruses and church choirs that were also shown in Figure 4.

Because they like doing music, they like to share it with other people, and are quite happy to give their time. If you sing in a choir, you tend to get on with everybody, and you share things with everybody and you are part of a group. And somehow, if anybody says "would you like to come and help with this sort of singing?" you'd rather do that than go and, well serve coffee somewhere, or, you know, lunches or something, you go and help with the singing.

The organization of the volunteer team obviously required considerable collaboration. The volunteers' contributions in crafting the events materially, socially and musically that were discussed earlier in the thesis may have had a similar quality to those that Rosie suggested to have been gained from singing in choirs. This went some way towards explaining why collaborations in SB's volunteer team ran so smoothly as the majority of them sang in choirs. Singing in a choir obviously required careful listening and constant adjustment of one's own voice in relation to those of the others in order to craft the aesthetic of the collective voice as the adaptive characteristics in the group singing were also perceived by Bailey and Davidson (2005). Similarly, volunteering for SB also required constant adjustments and adaptations to different roles in order to help craft the environment of SB. For instance, Bob described his volunteer works at SB as "*mixing in*" whereas Dennis suggested that he was a "*jack of all trades*" and Rosie described her work as being able to "*just generally fill in*".

Obviously, the shared interest in music and singing was at the centre of what held the volunteer team together. Rosie also emphasized "interest in music" as an essential quality of the volunteer:

*I think it wouldn't work without the volunteers. And it wouldn't work with volunteers who aren't interested in music. It only works because volunteers are interested in the music, not necessarily talented, but they **like**, they **enjoy** the music.*

The bonding we saw within the volunteer groups was a form of social capital as discussed in chapter 2. In this case it brought together volunteers who already loved music and knew how to craft musical events collaboratively and to enhance the solidarity of the volunteer team. This music-led network, which was developed and forged within the volunteer team, thus worked as a springboard for people to develop and explore music and care pathways further, which will be discussed in the following sections.

9.3 The roles of music and care pathways

9.3.1 Leading people to SB

Above we saw how various pathways (which always originated in a node or activity) led people with dementia and their caregivers to SB. For example, Caroline and Lisa learned about SB through a local charity, Laura and Michael discovered SB through a local one day care event and Jonathan and his wife Kathlyn came through a local day centre where Jessica used to run small music sessions. Arnold and Monica knew Jessica through their church whereas Kelly and Chris were recommended to attend SB by a local doctor. Peggy and Nichola joined SB as Peggy and Jessica sang in the same local choir. Some of the people who joined SB had no previous experience of singing in choirs, but as they enjoyed it, they continued with it (e.g. Nichola, Caroline, Jonathan, Simon and Chris). On the other hand we had people who had been singing in choirs before and looked specifically for music opportunities that allowed them to continue singing (e.g., Laura and Arnold).

I will highlight three examples, Simon and Hannah, Michael and Laura and Arnold and Monica, to explore in detail how different music and care pathways effectively and smoothly led them to SB albeit from very different starting points.

Hannah told me how they had become involved with SB through information obtained on the Internet:

About two and half years' ago, Sophia, one of our daughters, knew we enjoyed singing, and knew that it was difficult, now, with the wretched Alzheimer's, and she checked it on the internet and found it. I went once to see what is like and we thought it was lovely.

Simon and Hannah joined SB soon after their first visit and continued as regular participants until it became too difficult for them due to the deterioration of Simon's condition. Although Simon always loved to sing, he had never been involved with group singing. This was therefore a new pleasure for them that they discovered only after joining SB.

Laura and her husband/caregiver Michael had been active singers in local choirs for a long time. However, this had become too demanding for Laura's condition, and Michael had to quit singing in order to look after Laura, as he said, "*I have had to give up a lot... being a carer, you know. I used to like playing boules*". It was after this that he discovered SB:

Michael: Well, it was last year, or a year before, I don't know. I went to a carer's service in the cathedral and Jessica was there with SB, and Laura was singing away, you know.

Interviewer: I see.

Michael: So afterwards, I saw Jessica, and asked her about, oh no, at the same day, we were invited to the other Guild Hall by the Lord Mayor, and they were singing there as well. They were doing everything you know, with the ribbon⁵², you know. I saw Jessica afterwards and that's how I got involved.

⁵² In the SB sessions the hello song was sometimes sung using a long ribbon, which was passed between the members in a circle.

The intention of the carers' event was to show appreciation for local caregivers and provide them some comfort. The majority of SB participants joined the event and sang a few songs from the usual SB repertoire led by Jessica. For SB this event was also meant to recruit new participants for the Watertown SB group. This provided a clear and positive pathway for Michael and Laura as she responded so well to the singing. Although Michael and Laura lived some distance outside town, they started joining in the weekly sessions regularly, even though it meant using several buses to get to the venue. Based on my participant observation at the SB session, it seemed clear that Laura was not aware that this group was aimed at people with dementia and their caregivers. Her dementia might have advanced already at the time they joined SB, which made Laura unaware of her own condition. This was implied in the exchange that took place when I asked them what they thought the benefit of *Song Birds* was:

Michael: Well, it does help, it helps Laura, it stimulates, you know.

Laura: What do you mean, it helps Laura? [slight anger in tone]

Michael: It keeps her singing, you know.

Laura: I love singing.

Laura was slightly irritated with Michael's comments ("it helps Laura"). In the interview, Michael had earlier whispered the word "dementia" so Laura could not hear it. It might be that dementia was something Laura did not want to accept. Either way, Laura seemed to consider SB to be a regular choir just like the ones they used to participate in. The levelling that took place between the members and the material, social and musical crafting of the environment must have worked very well for Laura not to feel awkward or feel that she was targeted because of her dementia. In this way, the multiplicity of pathways leading to SB in Watertown which makes it easier to "stumble" across one, later combined with the careful crafting of the actual SB sessions

that helped Michael and Laura to make a smooth transition from local choirs to SB. This, most importantly, allowed them to continue singing together in a group as they had for large parts of their lives.

Like Laura, Arnold had also been an active singer in local choirs. As Monica and Arnold went to the same church that Jessica and a few other volunteers attended, they found out about SB when it was initially started, which was also when Arnold was gradually experiencing difficulties singing “big pieces” like Bach’s and Handel’s in his choir. Bob, Arnold’s friend who used to sing in a same local choir with Arnold, joined in SB so he could bring Arnold there. Monica told me that:

Song Birds enabled him to carry on singing. It wasn't the classical type of music he sung in the choir, but it lifted his spirit. When he had to give up singing in the choral society, it was hard for him to accept it, but he felt a lot better [by joining SB] and it was good for him therapeutically and emotionally.

In the SB sessions, as discussed in chapter five, Arnold showed great concentration and sang along with a fine voice and with the confidence that he had always been known for. Unlike Laura, Arnold was aware of his illness in the beginning of his involvement with SB. This led to Arnold and Monica being featured in a magazine. In this interview they also talked very positively about the benefits of SB for them; how it allowed Arnold to keep on singing and helped him feel positive and better, which as a result supported Monica in caring for him. Monica also mentioned that SB did not replace Arnold’s life-long engagement with local choirs as it was a different type of music, a view she repeated in my interview with them, something I will come back to later in this chapter. However, it was clear that SB provided a joyous time for Arnold to keep on using his voice and allowed him to share the joy of singing with others including Bob, with whom he had been singing in local choirs.

As Simon, Laura and Arnold's cases showed, they had all followed different pathways into SB; Simon's daughter found the group through Internet searches, Laura and Michael learned about it through the local carers' events and Arnold discovered SB through his church. What these pathways had in common was that all of them lead people smoothly into SB. The SB node not only allowed people with dementia and their caregivers to continue their musical participations (or give them a chance to learn a new activity in an appropriate and achievable manner), it also helped participants maintain their social life. Hannah mentioned:

We don't have a regular arrangement with anybody now in the way we did. And it has filled the gap very, very well. [So this is the only activity you feel comfortable with?] Yes, absolutely. Yes, because all the many activities we have done before, we just gradually moved away from. And so, it has been a great joy to us. So many kind, nice people, like you, like the other helpers. Dear people and it's been lovely going.

Other caregivers also told me that joining SB had helped them and their care receiving partners to remain a part of the community. For Chris, his wife Kelly told me, SB was the only thing that he could cope with, not even other activities and services for people with dementia were suitable for him.

In this way, a number of interlinked local music and care pathways initially lead people to SB; here they received help to carry on singing or enjoy the new pleasure of singing together with others. Equally importantly, this node helped them to sustain their social life by providing a pleasant time that couples could share with others. Therefore, SB was one of the key nodes along the music and care pathways in Watertown that people could join at a certain time of their life with dementia and also gain access to additional nodes in Watertown as I will now discuss.

9.3.2 Providing further access to music and care opportunities

The music-led network that emerged around SB provided a wide range of pathways to further music and care nodes that SB participants could utilize. Moving along these pathways brought further opportunities for the participants to engage in community-based nodes in various ways that (in part) filled in the gaps between the weekly events. I will discuss in detail how such pathways provided 1) access to various local music and care resources, as well as opportunities to be involved with publicity for SB, and 2) opportunities to participate in events specially planned for the SB members during the vacations.

Further access to music and care opportunities was accessible through SB's links to other local music and care resources. For instance, people accessed information about further services run by the *Dementia Support Group* such as the annual walk⁵³ and the monthly Memory Café⁵⁴. Several of the volunteers and caregivers circulated information about concerts they were involved in. The proceeds from these concerts were often donated to SB. However, these pathways were not only flowing out of SB, pathways that led new people to SB were also temporally created as people were encouraged to be involved with fundraising events and promotion of SB in their local communities. The above mentioned "Memory Walk" was one of these and the local carers' event (where Michael and Laura found out about SB). Some of the SB

⁵³ The walk event was one of the fundraising events organized by *Dementia Support Group*.

⁵⁴ Memory café was a monthly event run by *Dementia Support Group*, where people with dementia and their caregivers chatted over tea and biscuits. The group was also open for those who were worried about memory issues but had not yet been diagnosed with a specific illness.

participants with dementia and their caregivers discussed their experiences at the collaborative session with local primary school pupils, which was also featured in the local BBC news. This resulted in a lot of inquiries afterwards. When Arnold and Monica were featured in the magazine discussing the benefit of singing in SB for Arnold a lot of prospective participants also contacted SB.

In addition to these rather formal events and arrangements, Jessica sometimes arranged informal tea parties at her home where people brought things to sell, and the proceedings were donated to SB. These tea parties sometimes involved singing and the participants in SB were invited to join in. They were also involved in a fundraising event for another local music group that some of the volunteer members belonged to. This was called the "*Song Birds Half Hour*", and participants of SB were invited to join in with the singing and thus helped the fundraising effort for another node in Watertown. These opportunities were often intermittent. Thus they represented temporary rather than permanent nodes, but nevertheless they were nodes that provided safe spaces and had membership overlaps with SB. This multiplicity of nodes were not simply alternative social occasions for SB participants to meet, they also helped to sustain their interest in SB which in turn helped the main node (SB) to survive as a sustainable community action.

Here we saw how pathways to further music and care resources were opened up for SB participants and kept alive through their use by local people who were involved in these various activities. Many people with dementia and their caregivers tended to withdraw from social involvements or hesitated to get as involved as they used to. Therefore, it was important to keep them informed of the pathways that were still open to them and could lead them to safe nodes, particularly as the prominent negative stereotypes of

dementia could easily cause people with dementia and their caregivers to withdraw from various social situations. Some of the SB participants had relocated from other areas just for caring purposes (Watertown being the main town for quite a large surrounding area). In such circumstances it was particularly important that participants had access to as many care opportunities as possible that felt comfortable and safe given their situation.

I attended several local concerts and events that I discovered through SB as part of my fieldwork. At these events I often met other SB participants: (1) people who were volunteering for these events, (2) volunteers and caregivers who were involved as singers or (3) participants with dementia and their caregivers who were part of the audience. The overlaps between the participants of SB and these local music events (as seen in Figure 5) positively enhanced the accessibility to these events for SB members with dementia as the overlaps provided a familiar feeling to the events. For instance, the welcoming and inclusive atmosphere of SB was often echoed in other nodes and activities along the pathways. Furthermore, the overlaps allowed information to flow freely between the nodes, thus activating other pathways and nodes.

This network activity provided social capital which emphasized the social connections and the norms of reciprocity and trustworthiness that arose from these connections as an important building block of society. The music and care nodes that were interlinked through pathways provided a caring network that enhanced the awareness and understanding of dementia in the local community, while providing local people who suffered from dementia and their caregivers further opportunities to renegotiate their roles in the community rather than isolating themselves. The overlap of members between the nodes also allowed participants of SB to strengthen their internal mutual

support, resulting in an accumulation of their bonding social capital (Putnam 2000). In addition to the external events described above, as SB Watertown group follows the UK school calendar⁵⁵, several SB specific outings were planned during the breaks so that the members were still in touch. During my fieldwork these outings ranged from dinners in local restaurants and a visit to a cafe where one of the volunteers worked, to a visit to Hannah and Simon's house in a nearby coastal town which was made into a small event called, "*Singing at the Seaside*". All the participants were invited to these events. The visit to Hannah and Simon's house was suggested by Hannah, so caregivers were also involved in planning these additional meetings.

I attended two of these events; one was a visit to the cafe outside of town and the other one was a dinner at the local pub. The meeting at the cafe was in the day time, and many participants attended. Photos from recent sessions were circulated and the members chatted and caught up on recent events that had taken place during the break. The cafe was attached to a gardening shop, so it felt like a place with plenty of space, surrounded by flowers and gardening equipment, which was distinctly different from meeting up at the usual community centre. The other occasion was a Christmas dinner at a local pub on the same day that SB closed for the winter break. A room had been booked and we enjoyed a nice Christmas dinner. Although all the participants were invited, only volunteers and one paid carer showed up as it was too late for members with dementia and their caregivers to join in. As a result it became more of a "job well-done" party for the volunteers.

⁵⁵ The first term started in September and ended just before Christmas in December; the second started in early January and ended in March and the third started in April and ended in late July.

Both meetings became a chance to talk with each other, which was different from the usual chatting over tea before the sessions started as there were no scheduled activities afterwards that imposed a time limit. This created a different dynamic among the members, with volunteers free from any obligation to prepare and tidy up, but with plenty of time to just sit and chat with each other. Hence, meetings in these different contexts, for example temporal spin off nodes of SB, helped affirming the memberships in a different way, and further increased the bonding capital among the members. These additional events were particularly important during the long breaks as they reminded us all that we belong to a SB group.

9.3.3 Supporting people as the dementia progressed

At some point, participants with dementia stopped attending SB due to the progress of their dementia. There were a few examples of participants who suddenly passed away while they were well enough to participate in SB (e.g., Jake), but these were rare cases. After leaving SB, some continue to stay at home while being cared for by family, whereas others moved into nursing care. Even after people left SB, further music and care nodes provided resources to be utilized by them and their caregivers. For instance, there were music (therapy) activities provided in some of the nursing homes for the residents to join if they could. A key issue at this point was still the role of the pathways between the nodes. One good example to highlight this role was a spontaneously developed pathway that emerged from SB in order to reach people who had already left the group. To illustrate this, I will highlight the development of Rosie's volunteer role.

This pathway involved the development of Rosie's volunteer role in SB. Apart from her general work as a volunteer (e.g. setting up, supporting group singing and tidying up), Rosie also had a specific role with regard to the admissions:

I do the administration and the welcome. So I keep notes who comes and contact them if I don't see them, tell them, keep in contact, to make sure they are all right. And obviously I help wash up and do the refreshment and talk to people, so.... I just generally fill in.

At the time of the interview Rosie had been involved regularly with SB for more than two years, and her role had developed beyond these basic administrative tasks. When I asked Rosie if she knew any of the participants with dementia or their caregivers before she started volunteering for SB, she explained:

No. I knew Monica and Arnold, because they go to [the church I go to]. And I knew two people who came before, but she is in a nursing home now, so they don't come. Because they went to another church that I know. I didn't know any of the other people. [...] And now I call them my friends, you know. I ring up some of them for a chat every now and again, and... Yeah, and send them the odd card or whatever... Especially Simon and Hannah, Monica and Arnold of course, but also Jonathan and Kathlyn now that I got to know them.

Through her initial administrative and later more personal work, Rosie obviously felt closer to the participants over time and also became more aware of the transformations of the participants in terms of their health conditions and situations around them as she further explained:

It does change you see, as people get too old to come. Or too ill to come or they die of course. We have had... Three people have died actually since I started. That is in two years and a bit, three people died.

Rosie also kept in touch with a few caregivers even after they stopped coming to SB and sometimes visited them. Jessica referred to this aspect of Rosie's roles as her "pastoral care" role, a role that helped to build a pathway between current participants and those who had left the group. During the SB sessions, Rosie would tell the current participants how people who had already left the group were doing, and presumably, would keep the former participants informed about any news from SB. In this way

former participants are able to stay connected with the group; and their memberships were sustained through Rosie's work, which constituted another pathway connecting SB to a smaller node, in this case a dyadic node consisting of a former participant and their caregiver. This was important as SB had often been the main (or only) social involvement for many participants for several years, and losing the connection to SB could negatively impact their everyday life in addition to their already increased distress caused by the progress of the illness.

As a part of Rosie's pastoral care Rosie once asked me if I could make a CD of some of the songs that I had recorded in the sessions. She wanted to bring the CD to Simon and Hannah when she was next visiting them and see whether it could help them when they were trying to sing some of the songs from SB. I made a compilation album using various recordings from the sessions and personalized it for Simon and Hannah by adding a song called "*Black bird*" that Simon and Hannah had spontaneously sung during my interview with them (Hara 2011). However, Simon unfortunately passed away before they could receive the CD. Rosie kept it aside as she was worried that listening to it might bring back too intense memories for Hannah at that point. It was handed over to Hannah a few months later before I left the field. I later received a thank you card from Hannah saying how she enjoyed the CD and their time in SB.

This impromptu CD project, combined with Rosie's pastoral care, suggested some very important insights that not only people but also music, in this case a CD, could function as an actor (Latour 2005). Music could travel along pathways to reach nodes and/or help create them. For instance, spin off nodes from SB could be generated among people who had already left SB or even among the active participants to fill in their time between their weekly participations in SB by using CDs to prompt memories of their

pleasant times in SB (which also prolonged the pleasant moments as discussed in the previous chapter). A CD might be able to trigger further musical interaction among a person with dementia and his/her caregiver, a form of participatory CD design that Batt-Rawden has suggested was helpful in maintaining health in everyday life for people with a chronic disease (2006; 2007). This encouraged me to create and pass on CDs to other SB participants with dementia and their caregivers as gifts to thank them for their participation in my fieldwork. These CDs consisted of favourite songs from various SB sessions (see Appendix 8). Unfortunately, I could not gather detailed feedback on these recordings, however, one caregiver, Kelly, told me they listened to the album when their granddaughter came to visit them, which prompted them to talk about their involvement with SB with her, and this could be considered as another temporal node connected to SB. I received thank you cards from several people who had already left the group. They said they had enjoyed the CD and remembered their time in SB. Overall, one could say that this ad-hoc CD project, combined with the pastoral care, could have been improved; for example the songs of the CDs could have been selected according to individual needs (Batt-Rawden 2006; Batt-Rawden 2007), but given the circumstances this did at the very least suggest itself as a useful “node generator” which warranted further investigation. In this way, the mutual care that was musically fostered during the SB events was sustained and further developed through volunteers’ and caregivers’ initiatives even after they left the group. Thus, the music and care network was not only available at a particular stage of dementia, but it also offered continued support along with the progress of dementia.

9.4 SB as a safe and interconnecting node for continued musical participations

As discussed in chapter one, the cognitive abilities of people with dementia regressed as time went by. This forced changes upon people with dementia and limited their aesthetic practices. It was discussed earlier with reference to Arnold and Laura who had to leave their choirs. Joining in aesthetic practices that were feasible for people with dementia helped them and their caregivers to remain part of the community. However, in many cases it required (considerable) aesthetic renegotiations to start new aesthetic practices that were different from what they have been enjoying in their pre-dementia lives. For example, people who had specialised in singing in Bach choirs for a large part of their life might feel hesitant about singing the “*Hokey Cokey*” in public. One was “high art”; the other was a simple Christmas related tune. This is where the aesthetic renegotiations came into the picture. There was no defined end goal of these renegotiations as the cognitive conditions continuously regressed. Therefore, constant aesthetic renegotiations and adaptations were required from care-receivers and caregivers to adjust to the changes that occurred in their everyday life. A large part of these renegotiations depended on caregivers’ initiatives and their support, especially when someone was approaching the later stages of dementia. Obviously, this renegotiation could become very frustrating and additional local support was required in some cases. We have seen how local music and care pathways were reasonably efficient in letting people move smoothly from past aesthetic activities in the physical sense. More difficult, but just as important, was the need to make the same journey emotionally and aesthetically.

Although SB was a safe node, adopting and enjoying SB activities might also require renegotiations to adjust participants' aesthetic priorities, especially among caregivers who obviously did not have any cognitive difficulties but who joined in the activities to support their partners. I will therefore describe how SB supported people with dementia and their caregivers in such renegotiations (among other related actions that might be initiated privately), which were important to remain together as a couple in music related activities. In this case SB acted as an interconnecting node with a number of pathways leading to it from other nodes where the "old" aesthetic preferences had to be left behind as the illness progressed. I will discuss the case of three participants with dementia, Laura, Arnold and Simon and their caregivers as examples that illuminated how this process could take place.

Although Michael and Laura had to stop singing in local choirs (the "old nodes"), their renegotiation of their shared aesthetic practices seemed to have been relatively smooth and low key. Both Michael and Laura had been actively involved with local choirs and music groups and they also used to sing at family gatherings. In general they seem to have engaged in a variety of different aesthetic practices together. Michael privately took the initiative to reproduce those aesthetic practices after the onset of Laura's dementia by helping her to sing songs that she knew very well with his organ accompaniment. At home, they sang the "*same sort of songs*" as in SB Michael told me. After joining SB they continued to share the same aesthetic practices in a different physical setting. Interestingly, Laura seemed to have become less shy about singing in front of people than before:

Interviewer: You have always been singing all your life?

Laura: Yes I have, everybody said, didn't they?

Michael: No, you haven't sung so much as you have lately.

Laura: But I should have done!

Michael: You should have done, but you were... you were too shy.

Laura: I wasn't too shy? [Michael: To shy to get up and sing.]

Seeing Laura in SB for over one year, it was difficult for me to imagine that Laura used to be too shy to sing, as she was always very proud and confident when singing or dancing. Being “*the best singer*” as she put it was a strong aspect of her identity as she repeatedly said in my interview with them as well as in the weekly sessions. Michael’s support and initiative to keep them musicking together, including their involvement with SB, must have helped her identity to be reconfigured as a confident singer. This identity was, obviously, highlighted and intensified given her situation where her regressive cognitive ability continuously made her disoriented in time and place. However, music seemed to work as a last resort as it allowed her to connect to her surroundings throughout the SB sessions as discussed in chapter five. At the same time, these continued practices allowed Michael and Laura to remain close until just before Laura passed away. SB was the only node where Laura and Michael could join in the singing with others who experienced a similar situation, thus the pathway from the local choir to SB provided a safe passage that allowed Michael and Laura to keep on sharing the joy of singing with others.

Arnold’s caregivers (Bob, Arnold’s best friend and Monica, Arnold’s wife) also started exploring the possibilities of continuing to share aesthetic practices with Arnold while adapting to the changes that occurred in their everyday lives after Arnold had to stop attending the local choir. Bob explained the importance of such efforts:

Arnold and Monica, they never let it stop them doing things you know. Monica has always taken the initiative and taken him out and met people and so on.

But I guess in some families that's not so easy ... you do hear about or read about situations where people say that no, we don't see anybody. The carer and the person they are caring for, not feeling a part of any community. And that's very sad, because the carers need a lot of support as well.

As we can see here, Bob also understood the importance of pathways that could bring people to suitable nodes where they could still keep active in a safe environment. Bob also knew, based on being a long-term friend of Arnold before and after the onset of dementia, that singing was a key tool for Arnold to remain involved with the community even after other social occasions (e.g. church) had become inappropriate. This drove Bob to explore available pathways and even create their own personal pathways to support Arnold so he could be involved in different musical nodes that suited Arnold's changing conditions from joining in SB, singing hymns in the car together, participating in music therapy sessions in the nursing home with Arnold to initiating casual singing with Arnold in his room at the nursing home. These continuing shared aesthetic practices between Bob and Arnold that moved between multiple musical nodes not only benefited Arnold, but also allowed Bob to continue to relate to Arnold.

Before his dementia advanced, Arnold himself expressed his love of music and how music and singing in the SB worked for his dementia in the interview with a magazine.

In the interview, Arnold expressed how music helped his dementia and how participating in SB became a special thing. He was especially aware of the positive impact of singing by explaining how the whole person gives themselves with singing. He had been consciously engaging himself in any opportunities to sing within his capacities and with support from others even after the onset of dementia, as he also said in the interview: *"it's important to keep doing things you enjoy"*. There was some discrepancy between Arnold's personal, lifelong aesthetic preferences and the SB

repertoire as pointed out in chapter six; however this did not seem to matter to him compared to what the actual singing afforded him and the benefits of singing overrode this discrepancy. Therefore, Arnold seemed to adapt to the new aesthetic practices in SB successfully and smoothly. However, Monica did mention both to me and the magazine that SB did not replace Arnold's life-long engagement with local choirs as it was a different type of music. Despite this, Monica was very aware of the positive effects Arnold experienced during and after the sessions and how it affected her as she explained that: "*Arnold is more upbeat, jolly and relaxed after he's been to SB, which makes my life better too*". She also told me that participating in the SB sessions was good for Arnold as he could be a part of communal activity with people who understood his situation as dementia was still a taboo subject and it was difficult to "*be themselves*" outside home. Monica also said that she herself also enjoyed the company of caregivers who were in the same situation. No doubt these considerations allowed her to adapt to these new aesthetic practices and enjoy her participation in SB session.

Bob also mentioned a similar discrepancy that he experienced between **his** own aesthetic values and the SB repertoire. For example, "*My hat, it has three corners*", was not his aesthetic preference; "*it is not something I personally find it desperately interesting*". However, he did engage wholeheartedly as it was good for the participants with dementia. Bob also said that, "*if you look around and see people enjoying it, that is what you enjoy yourself*". Bob might have felt hesitant in adapting to these new aesthetic practices. Despite this, he escorted Arnold to various singing activities and adopted these aesthetic practices to support Arnold and their continuing ability to enjoy various activities together as they had choir prior to the onset of Arnold's dementia when they were cycling, walking, traveling and singing together.

Knowing how well the musical participation worked for Arnold in SB, Bob encouraged Arnold to join in the music therapy sessions at the nursing home after he left SB. He occasionally joined in the music therapy session together with Arnold and other residents, although the format of music therapy sessions did not necessarily encourage caregivers' participation. After Arnold's dementia deteriorated to a degree where he was no longer able to participate in the group music therapy sessions, Bob arranged with staff and a music therapist in the nursing home to provide Arnold with an individual session in his own room. Bob also initiated singing a few songs they used to sing at SB when he visited Arnold in the nursing home. In this way, Bob tried his best to find and make pathways by himself for Arnold to be involved with musical nodes so that Arnold could continue to have opportunities to sing albeit in a very different form than before.

Bob's four years of close support for Arnold to continue singing could be seen as Bob's attempt to continue sharing aesthetic practices with Arnold after they were unable to share other activities. Monica could also, by also adapting to new aesthetic practices, enjoy participating in SB with Arnold, during their last a few years together. This continued sharing required aesthetic adaptations that SB actively encouraged through enjoyable activities that were collaboratively and sensitively crafted as I discussed in chapter five. Because of this aspect of the group, SB itself, the pathways that led into and out of SB and the further musical nodes in Watertown all together emerged as a safe passage for Arnold, Monica and Bob to continue sharing musicking no matter what the state of Arnold's dementia was.

Hannah and Simon also expressed personal musical preferences that were very distinct from the SB repertoire, and their everyday aesthetic practices were built around these preferences (e.g. listening to Mozart, Beethoven and Chopin). However, Hannah

explained that they also found considerable enjoyment in the new aesthetic practices that came out of their involvement in SB:

Interviewer: During the session, can you think of a particular song or activity Simon liked?

Hannah : I think The Lambeth Walk, don't you Simon? A chance to get up and shake about, because you get a bit stiff sitting in those chairs all the time. And to get up and move about a bit, even if it is something silly like The Lambeth Walk, that's quite fun. I would think that was your favourite Simon, would you?

Simon: Occasionally.

Hannah : Or did you prefer Boopsy Daisy or one of those things? I know they are all incongruous and silly but fun!

Simon: Depends on the rest of the people there, you get some very...

Hannah : Yes, but always when we had The Lambeth Walk, you always enjoyed that because it's moving around and moving back.

Simon: [inaudible] hardest time keep it away from all your [parents?]

Hannah: Well, that's silly isn't it? Just need to enjoy yourself, that's what it is all about. That's what we were supposed to be doing, just getting out and enjoy ourselves....

Here we see some aesthetic tensions between what they felt was “real music” such as Chopin and Beethoven, and the SB repertoire, which meant that songs that they actually enjoyed were labelled as silly. I witnessed many times how Simon and Hannah danced in a very lively way together in these participatory dances. Hannah was often taking the initiative by holding Simon’s hands, encouraging him to stand up and dance with her. I observed how Hannah was always very positive about having a good time with Simon in SB, enjoying their time as much as possible without showing any hesitation. In this way, Hannah and Simon adopted new aesthetic practices that may have felt “silly” to them and that were obviously not within the scope of their pre-dementia aesthetic

preferences, however, in the process of participating in these dances they seemed to find a way to enjoy those songs and activities just as Michael and Laura and Arnold, Monica and Bob did. As we have already seen in chapter five, the affordances of the participatory dances were very distinctive from the other activities; they stirred people up emotionally and physically, broke down inhibitions and as a result, the elated bodily engagement pushed aside many of the signs of illness by their elated bodily engagement. They powerfully transformed normative roles and relationships between those with dementia and those without. Perhaps because of these affordances, participatory dances allowed Hannah to reorient her aesthetic priorities and adapt to new aesthetic practices without hesitation as they permit Hannah and Simon to share a joy of singing and dancing just as they must have done many times in their 59 years of married life.

In sum, SB could be perceived as a node where local people with dementia and their caregivers could reorient their aesthetic priorities which helped them to find new aesthetic values together with other participants who were in the same situation. Thus they continued to have an active musical connection for most of their caring period. This aspect of SB allowed it to act as an interconnecting node that provided a safe and joyful passage alongside other music and care pathways to further musical nodes where local people with dementia and their caregivers could continue to participate in musicking practices and ultimately remain together for a longer period than was often the case. This again reminded us of the importance of careful crafting the musical space by material, social and musical crafting discussed earlier, which emphasized inclusivity without condescending or patronizing attitudes but with a focus on having a democratic and pleasurable atmosphere that helped participants' process of renegotiation and adaptation.

9.5 SB as a node for informal learning

I have discussed earlier the overlaps of the node memberships with the SB that allowed for ad-hoc information distribution. A specific case that highlighted how information was developed and distributed to other nodes along the various pathways that were connected to SB can serve as a useful illustration of the importance of this casual information sharing.

Because SB was a node that interconnected multiple music and care pathways in Watertown as shown in Figure 4, it also functioned as a meeting place for people in various life stages: people with dementia, their caregivers, former caregivers, volunteers who were retired, university and local secondary school students. Thus SB not only offered opportunities for local participants with dementia and their caregivers to bond with others who were in similar situations. It also brought together people who had gone through very different circumstances from a range of backgrounds. As a result, everybody increased their social capital for bridging (Putnam 2000), which was a connection to bring people in different situations and background together. What was the benefit of the latter aspect of SB, as it was at heart a musicking activity? I will suggest that this bridging was the key to improving information sharing and learning about dementia in everyday life. The uniqueness of this function was also discussed by Bob:

It (SB) brought people together, in a way that they wouldn't have... I know they have a meeting, social meeting, once a month, the Dementia Support Group. I have not been to that so I don't know what happens there, but this must be different. Because it brings them together and everybody is doing the same thing together. At a social meeting you probably just talk to this person or that person, but.... It does bring people together and encourage a sense of togetherness for the group, a sense of identity, which helps sufferers and carers feel part of a larger group with others in the same situation. And it brought

other people in who are not primarily carers but helpers, to get involved in a situation they would otherwise not really touch, apart from if they had an individual they were concerned with.

As Bob points out and I discussed in chapters five and six, the SB sessions, because of how they were crafted, improved the participatory capabilities of people with dementia, which allowed them and their caregivers (once again) to feel part of the community. The importance of understanding dementia as a social process (that people with dementia were participating in) in order to challenge the normative victimization inherent in the common biomedical reductionism used to understand dementia was discussed in chapter 2 (cf. Beard et al. 2007). This was challenged very efficiently by the sort of collaborative musicmaking that SB sessions provided, and this is also a context where people who did not have any friends or relatives with dementia could get involved with and learn about dementia caring in an informal way. For example, some of the volunteer pupils from the local secondary school remained as volunteers afterwards. Other pupils gave talks at their school about their experiences that may have led to an increased awareness about dementia among their peers. The area manager of *Dementia Support Group*, Irene was very positive about how their involvement could affect attitudes:

(...)the attitude of the volunteers... there were so many young people there, and that makes a difference. Because young people, if they are involved in their late teens or early 20s, they carry these experiences throughout their lives. So older people with behavioural problems aren't going to be scary, they are going to be, "Ah, could be a [sic] dementia there, just need to be a bit careful how I communicate". Because you communicate in a slightly different manner.

In this way participation in SB gave young volunteers a chance to learn about dementia and how to communicate with dementia sufferers by becoming familiar with people with dementia through collaborative music making activities. This also resonated with the person-centred care approach advocated by Kitwood (1997), who emphasized

communication and relationships as essential means in dementia care. When the knowledge was shared by the pupils in schools and other places, another node was added to the network. Albeit not a music and dementia specific one, this node was then connected to SB through the “curriculum pathway”.

SB provided further contexts for other participants to learn about dementia caring. Among the adult participants, a few saw dementia as something that might affect themselves in the future. Rosie for instance, a volunteer who was around 70 years old, told me that she felt that she was looking at her own future when she was spending time with people with dementia and their caregivers at SB. Rosie was a retired music teacher and had been an active singer and soloist in local choirs. However, she left these choirs as she was no longer able to sing at their level due to her own aging. Her husband was also an active musician in a local church, but like Rosie, he was having difficulties continuing because of his own health. Therefore, working for SB as a volunteer meant that she could also learn what it would be like to care for a partner (possibly with dementia) or being cared for within a music and care framework.

Susan, another former music teacher and volunteer in her early 50s, also reflected on her future and the possible care issues she might encounter:

[T]here are a few couples there, what moves me is the way they are with each other. Simon and Hannah, the way they are, they love each other so much and they care for each other or she cares for him so much. That moves me, seeing them together, you know. How she just cares for him, well in fact, a lot of them you know, the way they are with each other, the way they love their partners so much, they are caring for. That really moves me you know. And it makes you wonder, if it was you, or me, say my husband got Alzheimer's, you know, would I be like that? How would I be? You know, it makes you think, doesn't it?

Rosie and Susan's examples also show how working for SB as volunteers after retirement, while it could fill certain gaps in their retired life. It was also a place where they could recycle and cultivate experiences and knowledge from their past careers. At the same time they could also learn about what it meant to care for people with dementia or to be cared for.

Then, what is the specific character of SB's context that encouraged these learning processes when compared to other local dementia care activities? Bob distinguished SB from other social meetings arranged by *Dementia Support Group* by explaining that SB encouraged a sense of togetherness by doing the same thing together. How did this aspect make a better context in terms of dementia caring and learning about dementia/caring?

9.5.1 Dual experiences as a foundation for informal dementia care learning

In chapter five, I discussed how the moments of happiness, such as those that displaced illness and inhibition among participants in SB, were inseparable from the sense of (slowly) losing loved ones. Thus, positive and negative experiences coexisted and neither of them erased the other completely. I also suggested that the dual experiences that emerged in SB provided caregivers and friends the opportunity to deal with their sense of loss. In this section, I will expand on this duality issue. This will hopefully increase our in-depth understanding of what specific aspects of SB contributed to maintaining SB as a node of sustainable action.

When I asked Bob if he had any moving moments in SB, he said:

Apart from Arnold, well sort of fairly recently, when you are looking at, you know Simon? To see how he is declining and you can sometimes see someone slumping rather more, he was a case in point. That I suppose if you see

evidence of somebody deteriorating, which is what we've seen with him the last few weeks and that's sad to see. On the other side of coin I would put down where you sometimes, when you look around, and everybody is smiling. All the suffers, whatever's going on you know, there is something that they are singing and enjoy and then, that's quite moving as well. And you think, well this is what it is all about: that they have found a bit of happiness, a bit of joy in their lives, today, at the moment.

Regardless of how visible Simon's deterioration was, Bob also recognized that people were enjoying the activities together during the SB session, which is "the other side of coin" as Bob said. The duality is particularly intense because things can flip over so easily to the other side. Any joyful moment might also become the last joyful moment. However, this did not stop them from sharing the joy and happiness even if it was momentary.

Similarly, Hannah also touched on the duality of people's experiences in SB. After explaining to me how she found it touching to look on people's faces of peacefulness when singing "Shalom", she said:

(...) and, just, not getting to know people, [but] getting to recognize them. You know, not being with them enough to know them, but to be able to see changes in them, as changes occur, and I find that quite touching.

The dual experiences are also important in allowing participants to learn about dementia and dementia caring. Nancy, a volunteer, chose to work for SB rather than other dementia support groups, as she explained:

I was interested in learning about people that got Alzheimer's and I mentioned that to somebody I worked with, and was introduced to Jessica. Because of the involvement to do with singing and activities and things... so I, you know, I mean I wanted to join something to do with Alzheimer's but it's very difficult not to get emotionally involved. So I wanted something a bit more lighthearted and then I heard about the group as well through contacts . (...)originally, I went on the Internet and found out about Alzheimer's, and they have like a

drop-in coffee afternoon, once a month on a Saturday afternoon down at Elderly Support Group. But I didn't quite know if that's what I wanted it, you know what I mean? I wanted something a little bit more than just sitting down and chatting (...) the singing as well was a draw!

Nancy had earlier cared for her own father with Alzheimer's Disease, thus coming to SB made her somewhat emotional until she had learned to become detached from it. However, the singing made the context more light-hearted and stopped her from focusing solely on the caring issues. Nancy further explained that:

[Participating in SB] made me feel a bit more positive about things, got a more positive outlook on things [Interviewer: On people with Alzheimer's?] Yes. It makes you think, how other people, like the carers, how their situations are and how they're dealing with it. And it just makes me feel more positive about other things that I deal with at home. It does wake you up a little bit, makes you aware of situations.

Therefore, the key to learning about dementia in the SB context was exactly this dual experience. They could learn about the social process of dementia/caring while sharing a pleasant time through music activities, thus the learning was naturally mixed with more light-hearted moments.

What distinguished SB from other activities of catering for people with dementia and their caregivers were the following features; 1) participants were doing the same activity together in an inclusive manner and 2) while doing these activities they experienced the two sides of the coin at the one and same time. Shared positive happy experiences were mixed with the manifestations of the illness and the knowledge of the impending loss. This is not the case with other caring groups. One such group for instance, where people came for a cup of tea and a chat was generally focused on dealing with worries and difficulties in coping with dementia, which was only one side of the experience.

Although this no doubt gave people comfort and a sense of belonging, it was difficult to “flip” to the positive side of the coin.

The dual experiences in SB were therefore an important foundation for people in different stages of life, who were brought together through different pathways to learn about dementia as a multifaceted experience. It was not only about distress or sorrow, but also had real possibilities for people affected by dementia to have positive experiences, such as continuing singing in a group as a couple, being confident about themselves, stimulating laughter among people with their funny actions, singing beautifully, being recognized as a “great singer” once again, dancing excitedly, sharing joyful moments and making others feel “ uninhibited”, in short, living their life vitally even with a progressive, incurable illness.

9.6 Conclusion: Music, the care world and SB as sustainable action

Throughout this chapter I hope to have shown how music and care pathways were utilized and kept alive by volunteers and participants of SB. All these interlinked pathways helped local people with dementia to increase awareness of available local music and care opportunities and led them smoothly to nodes that were appropriate for them and that enabled their active participation. Thus it also supported and enhanced their quality of life in a way appropriate for people’s needs and situations as they went through rapid transformations. As I discussed in chapter two, local musical participations were not about “solving” problems such as possible isolations or behavioural/emotional difficulties that people with dementia have. Rather they were valuable activities in themselves that allowed people to (re)gain a sense of being a part of society.

I have also investigated the quality of SB as a node in relation to the pathways connected to it and the nodes to which those pathways led. For instance, SB functioned as a safe node where bonding social capital among the SB participants was nurtured. This bonding social capital was further strengthened in different nodes that were connected with SB as there were overlaps of members. The overlap of memberships in multiple nodes also allowed information to be distributed along the pathways that connected them. SB also supported the aesthetic renegotiation process that was necessary for participants with dementia and their caregivers to continue enjoying the aesthetic practices that benefited their quality of life. This continuity was also supported by the fact that SB acted as an interconnecting node to link a variety of pathways and further musical nodes. In this way it provided a safe passage for local people to move smoothly from one node to another, both emotionally and aesthetically. I have also suggested that SB was a node that managed to bring people in different life stages together, and as a result, provided them with opportunities to learn informally about dementia and dementia caring. I am proposing that a key to this learning process is a dual experience that was often experienced in the SB sessions. Positive and uninhibited music related experiences co-occurred with the continuous anguish and sense of impending loss of loved ones. This informal learning about dementia caring in SB also spread along the pathways that were linked to SB. Therefore, the music and care world that I have outlined in this chapter, in many ways represents what Kurita (2012) discussed as an “ideal community” that people with dementia and their caregivers could remain a part of, a community that was created and that evolved through the knowledge and work of local people.

Despite the obvious turnover in participants due to deteriorating health or students' moving away, the SB Watertown group kept attracting new participants: local people

with dementia and their caregivers, new student volunteers, newly retired people, former caregivers who wanted to work as volunteers. Therefore the music and care pathways were kept alive by everyone who was involved at any given time. In part this was no doubt due to the increased interest in the use of music in dementia care as well as the increasing number of people suffering from dementia in the UK. However, I would argue that the dual experiences discussed above, where people were reminded of the multifaceted experiences of dementia while they learned about the process of dementia and dementia caring and also increased their social capital in a light hearted way, made the SB a particularly visible node in Watertown. In this context, “visible” meant that people kept discussing it positively in other nodes and contexts. This in turn kept attracting people through pathways that were maintained and strengthened by the sheer number of people that used these pathways, which then made SB easier to be found by local people with dementia and their caregivers. This, as a result, enhanced SB as a strong and safe node through the number and quality of volunteers and participants and through the virtuous and sustainable cycle that was emerging.

Chapter 10: Conclusion

Due to the rapid aging of societies in many countries dementia is now one of the key health issues worldwide. The questions raised and the findings discussed in this thesis are therefore not just of purely academic interest. The interest in dementia care is rapidly increasing to support the needs of people with dementia and their caregivers so they can live “well” with dementia. A more equal distribution of support than what we currently find is necessary. Community support is therefore emerging as a central plank in maintaining the quality of life for people affected by dementia. This would apply from the time of their diagnosis, through to the end stage of dementia. Responding to the urgent need to develop non-pharmacological methods that such community dementia care represents, the aim of my study was to explore how music could be used locally to support people with dementia and their caregivers in sustainable ways, given the fact that life with dementia is a long-term social process. In contrast to traditional biomedical reductionist views on dementia, recent literature on dementia care emphasizes the usefulness of relationships and communication in dementia care (Kitwood 2012). There is also increasingly a focus on the need to involve people with dementia and their caregivers in research on this topic (Beard et al. 2007; Iguchi 2007; Reid et al. 2001) as well as in the actual formulation of policies and care services planning (World Health Organization & Alzheimer’s Disease International 2012). This in turn challenges the static view of dementia that is present in the biomedical reductionism of dementia. A focus on “efficiency” can easily hurt the dignity of people with dementia. The need carefully to craft a social environment where people with dementia can regain their connections with the surrounding world is therefore of great importance (Ohi 2008).

In view of these attempts to humanize dementia and to respect the personhood of those in dementia care, the literature on the use of music in this area has currently been lagging behind. The recent increased interest in singing as a cost-effective means for health promotions among older people has resulted in studies that evaluated the health benefits of such activities. However, most of these studies focus on the immediate outward reaction to these activities and avoided any detailed investigations of *how* music actually helped to craft a caring environment. For example, there are studies that highlight the benefits of music in dementia care as a means to access long-term memories (Cuddy & Duffin 2005; Ridder 2003), manage agitated behaviours (Raglio et al. 2008; Ridder 2003; Vink 2000; Vink et al. 2009) and help build relationships between therapists/caregivers and clients (Clair 2000; Clair 2002; Simpson 2000). There are also studies that discuss music as a means to enhance the reality orientation of people with dementia, for instance, by raising the “awareness of the place they are in as well as of those who love them and care for them” (Bright 1988, p.34). However, the majority of these studies focus on the temporary effects of music in managing the “problems” related to dementia. This still leaves a lot of room to explore what music can do to help to maintain the quality of life of people with dementia and their caregivers in a sustainable way by providing a space where care can emerge as a part of dynamic everyday relationships. As this thesis suggests, sociological investigations applying ethnographic methods were essential when exploring this issue and my research eventually focused on three key points:

- 1) The investigation of the crafting of a socio-musical environment that allowed people who were affected by dementia to participate while, at the same time, helping to transform the conditions of people with dementia.

2) The observation of the actors and musical phenomena to explore whether the positive affordances brought by organized weekly musical events were sustained, how they were sustained and how they were further developed across a number of temporal and spatial boundaries.

3) The exploration of the musically fostered ecology of connections between various local music and care groups to discover what pragmatic significance a regular music activity had within the wider music and care world.

In this concluding chapter of the thesis I will therefore summarize and highlight my findings related to these three points.

10.1 Crafting inclusive musical events that involve people with dementia

As Small (1998) has suggested, there are numerous ways of contributing to a musical event that are as significant as the actual music making when it comes to crafting the musical performance and participating in it. Through the discussions of my findings using the empirical data gained from my long-term ethnographic study with the SB Watertown group, I hope to have shown an example of how such innovative crafting was developed through local initiatives within a local setting where careful consideration was given to individuals' abilities and needs. For instance, before the music session started, the space used for the weekly music activity was crafted materially, physically and socially as a safe and pleasant environment. That opened up the node (in this case SB) for people who arrived by following existing pathways that led to SB. The SB Watertown group attempted to have as many volunteers as there were participants with dementia to help craft this environment for every session. The predictability of this personnel as well as the physical and material settings provided a sense of coherency (Antonovsky 1996) to any participants with dementia who may have

experienced every weekly event as their first weekly event. The occasional seasonal themes (e.g., Valentine, Easter and Christmas) further supported the material crafting which increased the affirmative reality orientation of place and time for the dementia sufferers by connecting to regular social gatherings that they might recognize from their childhood and onward. The aim was also to enhance the sharing of distinct memories from past events in the group itself, thus nurturing the group culture among the participants. In short, SB weekly events were prepared in such a way that participants felt relaxed, safe and comfortable, which allowed actions to emerge in their own time and prepared participants for the actual music related activities. Such preparatory crafting was as important as the actual music making in creating a transitional time and space that took the participants from everyday life into the collective musicking.

The actual musical events were also carefully crafted as on-going, inclusive activities. These activities considered the limitations and capacities of people with dementia and encouraged the democratic participation of all participants. This was essential to transform the boundaries between people with and without dementia. As a result, the “conditions” of those with dementia was transformed. The weekly sessions of the SB Watertown group were mainly led by one facilitator (Jessica) and lasted for one hour. Sessions were planned following a regular format with considerable flexibility so the facilitator could respond to the here and now. It always started with warm-up exercises. These provided cues for the participants’ concentration while utilizing various body functions (with voice, eyes and ears) to follow Jessica’s lead. The physical layout of the room (sitting in a circle) allowed people with dementia to be entrained by the engagement of musical volunteers who were distributed around the circle. After the voices and bodies were adequately warmed up, three familiar waltz songs were sung followed by the “Hello song” to welcome all the participants. When the familiar waltz

songs were sung, the collective singing voice generated a strong framework within which participants could join in whatever way was possible for them: by singing out loudly or quietly, by moving one's mouth or simply by being there. Within this framework micro negotiations were possible, allowing some participants to contribute to the overall aesthetic, for instance, by starting to sing before the others, holding a high note or adding a bass line to make up the harmony.

The main activities that followed provided slightly more challenges gently to push the participants forward. Although these activities might initially be challenging, the facilitator and the volunteers worked with the participants to help them perform the songs after practicing them in small chunks over several weeks. Despite short term memory problems among some of the participants, the common experiences were somehow accumulated and the group together learned the activity in the space of a few consecutive weeks.

Building on increasing speed and group entrainment, the group usually achieved flow in the musical quiz that followed. Here the participants' memories were tried out in joyful ways that were not necessarily about achieving goals. Therefore it became a music-based cognitive exercise whose format was well-thought out in order to maximize its affordances. For instance, there was always a theme that gave a clue to the songs. At the same time, the order of the song prompts were planned carefully not to induce any frustration or confusion with these challenges. Clues to easy and difficult songs to guess were mixed.

The participatory dances that followed were group dances to well-known British songs such as "*Hokey Cokey*" and "*Lambeth Walk*". This provides an embodied exercise with happy reminiscing that allowed people to enhance their mutual ontological security that

came from “being together”, which further nurtured the group culture that emerged throughout the session. As the exciting collective bodily engagements helped push aside symptoms of dementia, the sense of loss experienced by caregivers and friends was overtaken and the normative roles and relationships around dementia were transformed. If it fails, however, this activity also had the potential accidentally to highlight the underlying deterioration and anguish that was ever-present in dementia situations.

The session closed with a simple and quiet song, “*Shalom*”, which calmed the excitement from the participatory dances, allowed people to reflect on their emotions and induced a peaceful feeling of being together, which helped the participants to transit smoothly from the SB events to everyday life.

In this way, the one hour session flowed naturally but not by itself. Jessica used her own voice, eye contact and emotional and physical cues while continuously walking around the circle of 30 participants to facilitate the music activities with the help of volunteer members while considering the changing capacities and limitations of the participants. This well-crafted structure became a framework that accepted any form of contribution to the overall aesthetic. Thus democratic participation was ensured and encouraged.

There were several devices used to stimulate this. Achievable challenging activities were one of these devices. The challenges motivated all the participants to achieve some degree of success in the activities, for instance, by singing in the harmony or in rounds as well as they could after a few weeks of practicing. In this way, challenges allowed weekly sessions to be experienced as part of a continuum, rather than as segmented experiences. They encouraged regular participation. This also meant that a strong group culture was cultivated as it was repeated. Such challenges were also important to sustain the interests of caregivers and to encourage their long term participation. This was a key

requirement as SB was a locally based activity and, in most cases, family caregivers were responsible for keeping up the attendance. If SB had been only about singing along to familiar songs (common in activities run in nursing homes) it might have bored caregivers. Although simpler to achieve and more immediately obvious to focus on therapeutic benefits for care receivers, this would have excluded a wider communal participation. Secondly, the frequent use of humour and the merry atmosphere were important factors that helped the sessions flow well. This also generated a joyful group culture by enhancing emotional communication among the participants and avoided the emphasis on verbal communications which would have required a higher level of cognitive functionality. As a result, participants' attention was also redirected, so they did not only focus on illness and the distress caused by the illness. Thirdly, the SB repertoire was an essential resource that undergirded democratic participation. The songs used for SB sessions were carefully chosen to be biographically relevant for the participants with dementia. They were familiar (but not necessarily personal favourites) from their past. As a result, the melodies and lyrics were recalled more easily. Thus, by utilizing familiar aesthetic materials, participants with dementia experienced the joy of remembering the songs, which was empowering when their memories were ravaged by dementia. This also allowed caregivers and care receivers to share any associated memories with each other and in this way rekindle their relationship by remembering pre-dementia life. The SB repertoire was not fixed; instead it had been allowed to evolve according to participants' requests and their (emotional) reactions to the songs. Thus equal opportunity to influence the repertoire was also an important element of democratic participation as Rolvsjord (2007, p.221) has discussed.

This well-crafted socio-musical environment also prompted the emergence of lay care practices. This happened by prompting participant's memories of songs, by sharing the

knowledge of songs with each other or by giving additional care through the use of a favourite song for participants when they returned after an absence. These subtle interplays of lay care were assembled and together generated something that was very similar to what Nishikawa (2007) proposed as “patching care”.

Based on my observations before and after the events, it was clear that the condition of the participants with dementia was transformed through the one hour sessions that I have described here. Their tensions and agitations were usually calmed and their confidence was built up as they experienced the joy of remembering and singing songs with others. My careful examination of SB has hopefully demonstrated that music did not work as an isolated stimulus to “fix the problems” that people with dementia experienced and that individuals were not simple objects to which unidirectional musical interventions could be applied to reach a predetermined outcome as the existing literature so often suggests. Instead it was a carefully crafted socio-musical environment that allowed individuals to latch on to music that worked as a mediator and a useful resource for self-care and self-stabilization (DeNora 2007) to restore their personhood. The affordances of music, therefore, were discursive and not prescriptive. They were appropriated by individuals who took into consideration other resources at their disposal: their condition, their relationships with other participants, their caregivers and other environmental physical factors (e.g., objects or even the weather). The double edged affordances that were available in the participatory dances, for instance, reminded us that musical affordances could not be predicted, but were discursive in relation to a range of factors at that moment.

It was therefore possible to craft an inclusive musical event for a diverse group of people with widely differing cognitive capacities which continuously considers the

constraints and capacities of those who suffered from dementia. Collaboratively crafted musical events enabled a very democratic participation. This did not necessarily mean precisely equal participation; rather it implied that equal opportunities were given to contribute to the overall aesthetic regardless of the capacities of the participants at that moment.

10.2 Permeation of Musical affordances into everyday life

The discursive affordances of the music that were generated in the SB sessions were not bound to a single time frame (the weekly event). Instead, the positive affordance generated in SB sessions developed over time and across different physical boundaries. The sustained developments of musical affordances outside SB brought additional (positive) changes to people's everyday life. This is important to bear in mind, given the fact the current literature tends only to focus on the temporary effects of music rather than the sustained affordances, as it indicated the further possibilities with regard to the use of music as a means for sustainable community support.

As the SB events were repeated weekly, informal devices were developed by participants to sustain the pleasant moments of the SB sessions. For instance, one couple arrived early at the venue to feed the swans and walk along the river afterwards. Other participants sang the songs that were sung in the session in the car on their way home or explored the songs on the Internet afterwards. These habits were developed around the weekly events, and as they are repeated they grow into important rituals in themselves. Occasionally, seasonal themes encouraged additional dressing up such as Easter Bonnets for Easter. These material devices not only added a fun factor to the overall experience of the sessions, but also were integrated into participants' everyday life as they spent additional time to prepare for the session, which in turn increased the

expectations before the session. Therefore, the personal habits and devices that developed around the SB sessions not only filled the time, but also prolonged musically triggered emotions by allowing people to look forward to the regular musical events or to relive past events. Such activities were important spin-offs from the actual music sessions as Aasgaard (2002, p.203) has discussed. The regular participation in SB weekly sessions therefore gave participants the opportunities to extend the framework into their everyday lives both emotionally and pragmatically, which could further improve their life. There is one caveat however. The annual calendar of SB in Watertown had several long breaks between each term. During these periods the framework that had been established around SB events might fade away. This was especially true for older couples who had difficulties leaving town for vacations during the holidays. Avoiding such breaks might be something to consider for groups working in this area although it would obviously require more effort.

The positive affordances that were brought about by attending the SB sessions developed over time, across different temporal and physical boundaries, through the songs that were sung repeatedly in the weekly sessions. This provided opportunities for people still to feel connected with the group even after they left SB permanently due to the deterioration of their health. Sometimes a song developed strong connotations with a particular participant or with some moment in the SB sessions that was carried along with the song. Singing the song afterwards then reminded people of the person after they moved on and/or allowed people to relive past moments of happiness with their loved ones. This “reliving of the moment” also supported the bereavement process of former caregivers who decided to stay on in the group after their friends or partners passed away. One distinct example of this permeation of aesthetic experiences from SB to the wider world was “*Shalom*”, traditionally the closing song of the sessions. As it

was sung in different contexts outside SB, the collective, symbolic meaning of “*Shalom*” developed in interaction with participants’ everyday lives, particularly the end of their life and the related caring. Therefore, the positive meanings of “*Shalom*” that were initially generated and nurtured in SB were not bound to a single physical frame, but were actualized in different spaces and in turn affected later aesthetic experiences of “*Shalom*” within SB sessions. Therefore, musicking that took place in seemingly different areas formed part of a coherent ecology, in which music acted as a resource to live “well” with dementia as musicking was integrated and adapted in people’s everyday life.

As dementia care is a long term issue, this sustainability and the in-between/after sessions development of the musical affordances are essential to the ongoing support of the quality of life for people with dementia and their caregivers, a consideration that is generally missing in the relevant literature.

10.3 Musically fostered patchwork of care and sustainable community support

As my ethnographic study allowed me to contextualise SB as a part of a larger music and care world, I discovered the relationships and network that were fostered through musicking. These were not bound in a single temporal frame (the SB sessions), but developed further as SB was interlinked with various local groups (nodes) through pathways. Pathways were instrumental in connecting SB with various other music and care related nodes: local choirs, schools, churches, care groups and events. For instance, various pathways were used by people to reach SB when they started facing difficulties in continuing the life they had in their pre-dementia lives, for instance, not being able to sing in the local choir, losing social connections or just wanting to do something

beneficial to their health. Because SB was connected to other nodes through these pathways, participants of SB gained access to further music and care opportunities. The overlapping membership among multiple nodes in this network also increased the ad-hoc distribution of dementia and care related information. They also increased the accessibility of those nodes for people with dementia and their caregivers because the “shared” memberships provided a familiar feeling to the events. Therefore, the patchwork of care nurtured through musicking in SB sessions penetrated into other nodes through these pathways and developed further, just as the musical affordances developed and penetrated through different temporal and physical boundaries as discussed earlier.

There were further pathways that were developed through the efforts of a single volunteer or caregiver in order to make sure that care receivers (and caregivers) had access to music and care opportunities after they left SB. An example of such a pathway was developed by Bob, Arnold’s friend and caregiver, to help Arnold to continue musicking in different ways after he had to leave SB, within the limitations imposed by his dementia. Another pathway was developed by a volunteer to help former participants still to feel connected with SB through the distribution of news and CDs. Such pathways functioned well but tended to be rather short term as their functioning depended on a single person’s efforts and the users of these nodes only included two or three people. Pathways had to be maintained through the use of a larger number of individuals, be they long term attendants or newly recruited people; otherwise the connection to the node was not sustainable.

There were some pragmatic functions that SB provided as a node within the wider music and care world. One of these related to the aesthetic changes that participants

experienced due the changes brought on by dementia. When people moved from one node to another, they often had to renegotiate their aesthetic preferences and priorities as each node offered different kinds of repertoires, activities or support. Caregivers often experienced some aesthetic tensions as they needed to adapt to SB activities that did not necessarily match their long standing aesthetic preferences. However, even though the repertoire might initially conflict with these preferences, the joy and the experiences of transformative moments in the collective musicking helped them to renegotiate their aesthetic preferences. This is important in so far as it helped them to remain in touch with their partners with dementia and maintain their involvement in the local community. For these objectives musicking was often a last resort. This obviously helped delaying the “social death” as musicking could rekindle caregiver/receiver relationships and remind them of their pre-dementia life.

The careful material, social and musical crafting of the environment was essential to provide a node that felt safe for existing participants as well as for people who may have felt hesitant when encountering SB for the first time. This “safe-ness” helped to initiate the aesthetic renegotiations as it is aimed at people in the early to middle stages of dementia, who often moved on from musical nodes for people without any cognitive impairment. The musical nodes that people moved to after attending SB tended to be either music therapy sessions in nursing homes or informal musicking among caregivers and friends, where they continued to sing a similar repertoire to the one from SB. Therefore, SB and the outgoing nodes that were connected through various pathways together provided a safe passage for people with dementia and their caregivers to travel relatively smoothly to appropriate nodes as their condition transformed their lives emotionally and aesthetically.

It is also important to bear in mind that the crafting of such “safe-ness” becomes increasingly important as the node becomes more widely recognized by people who are not necessarily directly involved in the musicking and thus do not know or understand it in detail. This means that it will become more exposed to external judgements and expectations. Daykin (2005) has discussed that problems may arise from such dissonance between external actors’ expectations and the expectations of the musicking insiders when they are engaging with musicking. She has suggested that this can affect the performers through “feelings of insecurity, disappointment and unease in relation to risk, competition and expected roles” (Daykin 2005, p.74). For instance, journalists may want to create certain narratives on how music works for people with dementia using SB in ways that maybe do not correlate with what actually takes place⁵⁶. Facilitators of musical activities therefore need to extend their crafting skills to take these external expectations into account to maintain the “safe-ness” of the activities, while at the same time open them up to others as accessible nodes. Another pragmatic function of SB was that it brought people in different situations together, including volunteers that did not necessarily have relatives or friends with dementia, but who had arrived through various pathways from other nodes such as local churches, local choirs, secondary schools and universities. Local dementia care activities such as SB in this way provided a context for those who were not currently affected by dementia personally to learn about

⁵⁶ One time, a local journalist suggested to Jessica that she should change the format of the session so that the participants would all face towards the camera as a regular choir would do, and not sit in a circle. She refused and kept the usual format and explained that SB is not about performing for audiences, rather it is about enjoying the process of music making among the participants.

dementia caring while also helping to sustain the quality of life for those affected by dementia. The knowledge gained in SB was then often shared in other nodes such as a local school or a choir. Related forms of knowledge could be utilized individually by older people to think about their own possible futures as a carer or care receiver. In this way, SB together with the various pathways that were connected with SB helped to raise awareness of dementia as a multifaceted experience in the wider music and care world.

One specific quality of SB that distinguished it from other types of activities and services was what I termed “dual experiences” (which is distinct from the double edged affordance discussed above). The sorrow and distress of life with dementia did not disappear; however, musicking in SB sessions allowed the emphasis to be shifted to the shared and positive experiences where the illness was displaced temporarily, but powerfully. These dual experiences made SB a very visible node, which kept attracting new people in various life stages to be involved. In this way, the pathways to SB were developed and strengthened through the continuous use by numerous people. As a result, SB was maintained as a sustainable action to provide on-going support for people who were affected by dementia in the community.

These pathways, and the ease with which people could move along them, encouraged people to travel smoothly between nodes and also enhanced the permeation of the aesthetic experiences across temporal and spatial boundaries. Thus music could act as a resource to help people with dementia and their caregivers in maintaining their quality of life as the changes occurred in their lives at a variety of times and locations. This comprehensive perspective was largely missing from the current literature, but it was essential when we considered music as a means for sustainable community care.

As we can see a double layered virtuous cycle of a musically fostered network was at work here. One was the carefully crafted socio-musical environment in SB sessions. The other was the wider music and care world that consisted of various music and care related nodes and pathways. The two layers in this network were obviously interlinked and kept each other alive and active through the constant and consistent use of the pathways that brought new people into SB, which ensured the quality of the node and which brings more people in. In this way, as musicking was continued; a patchwork of care was fostered in the wider music and care world, which also helped in the virtuous cycle that maintained SB as an ongoing and sustainable action.

However, there are further opportunities that should be explored in this music and care world. I have pointed out that some pathways were developed through individual efforts. These pathways were dependent on a single person's efforts, thus not sustainable. Therefore more people or possibly more devices (e.g., CDs) could be involved to help strengthen these individually developed pathways and nodes. Potential interventions to help the aesthetic negotiation process among couples in the private sphere are also something to investigate (Dennis 2011). Here collaborations between different professionals, community and lay practitioners and researchers will be indispensable to help the music and care world to expand and support local people with dementia and their caregivers in a sustainable manner.

In closing it is important to emphasize that the musical phenomena described here are not viewed in a romantic light by the members of SB (or myself for that matter) as a magic bullet that fixes all problems related to dementia or brings people unfettered happiness. On the contrary, SB participants are very realistic about what it can offer as they are always aware of the underlying possibility of anguish and loss. However this is

also the reason why they continue their participation in SB. Michael for instance, told me that he brings Laura every week because he knows they will have fun at SB, despite the underlying stress and frustration they felt during the week due to Laura's dementia.

As a part of its national dementia strategy, the Japanese government launched a nationwide campaign to train dementia supporters in local communities in 2004 in order to raise awareness of dementia and disperse the knowledge on how to care for people with dementia in local communities. As of September 2012, 3.6 million people have been trained. This has also created synergy effects between different local governments to report their own attempts at making use of local resources to facilitate the building of dementia care networks⁵⁷. Adapting this Japanese innovative strategy, the UK government launched "a dementia friend scheme" in November 2012 (BBC News 2012a) to provide opportunities for people to understand the condition of dementia, and eventually to help build a network of dementia friends across the country. As we have seen in this thesis, the knowledge about dementia and dementia care is obviously an important element in building active and evolving networks to support people affected by dementia in their local communities. The use of music should be considered as a device to facilitate such befriending, network building and awareness raising. This is because, as this thesis has demonstrated, musicking first brought people in local communities together and then dementia knowledge was acquired as a part of many different affordances that emerged from musicking. Its possibilities should be examined in various forms, not only the group-oriented musicking researched in this thesis, but

⁵⁷ The website of dementia supporter campaign is <http://www.caravanmate.com/>. A non-profit organization, *Community-Care Policy Network* publishes the booklet of many of these innovative cases.

also activities such as one-to-one musical interactions, music listening alone or together, song writings, composing, etc.

The quality of such lay care networks should not be measured or judged from the outside using a simple causation model based on a given hypothesis and simple quantitative measures. The networks should instead be considered ethnographically as they evolve so as to capture the quality of contacts and the actual meaning of social capital for participants. Such research should also facilitate narrative creations with people who are actually involved, including those with dementia where possible (and as I have done in this thesis).

My ethnographic study focused on one particular group that targeted people with dementia who were cared for by family members at home. It then situated this group in the wider music and care world. Therefore most of my informants were in the early to mid-stage of dementia, which meant that the research largely missed out on the experiences of those who were newly diagnosed or in the late stage of dementia. Perhaps this study will encourage others to examine the coherent, sustainable ways of using music for people all the way from the early to the late stages of dementia and their caregivers. For this, ethnographic research involving multiple music groups that target people in different stages of dementia may prove a better alternative, rather than working only with one group.

Music is often the most pragmatic activity to use in supporting people who are affected by dementia so they can live “well”, because musicking provides an affordable and sustainable activity that can be integrated and adapted into everyday life so couples, friends and communities can do it together. As Arnold put it, “*it’s important to keep doing things you enjoy*”. Musicking together is a way to imagine life together as Clair

did when she held her wheelchair-bound husband in her arms and danced with him for a last time surrounded and supported by her fellow SB participants.

Appendices

Appendix 1 Pilot study questions

A. About musical activity

- How are you enjoying (today's) session?
- How did you get involved in this musical activity?
How long have you been singing with this group?
- How do you like the songs you sing in the music activity?
- What do you like about them?
- Which song or type of activity do you like most?
- Does the song have special associations with you?
- How do you find the singing activity with action?
- Do you ever listen to or sing these songs elsewhere?
- In what kind of place/situation?
- Are there any songs you think wouldn't be appropriate to sing in the group?
- Do you sing them elsewhere?
- How do you find singing in the group?
Have you sung in a group before?
- What do you like about it? Is it fun? Is it different from singing by yourself?
- Have you made friends here?
What was it like at the beginning? (For example, were you shy at first?)
How do you feel being with others?
- Do you meet with the member of the group outside of this activity?
- Do you belong to any other musical group or do any other music activities?
- What do you think about the group?
What does this group mean to local community?

B. Background

Can you give me a few details about yourself?

- When were you born?
- Where were you born, and where did you grow up?
- What kind of work have you done?
- Where did you go to school?
What kind of school did you go to?

- Do you live nearby?
- Are you married?
- Who would say the most important people in your life?
- What else do you do other than singing with this group?

C. Musical Background

I am going to ask you about your musical background

- Do you play any instruments? Have you had any training?
- Were you involved with any musical activity?

D. Music in Daily Life

- Do/Did you go to live musical performance? How often?
What was the last one you attended?
Could you tell me about the live performance that meant the most to you in your life?
- When you are at home, do you listen to music? Where (in which room), when (time of day), what sort of things are you doing when you listen?
- Do you listen to music with other members of your household?
If so, can you recall the last time you did so?
What did you hear? Who chose it?
How do you decide to have music playing?
(Do you discuss it or does anyone put it on?)
- Do you sing/hum/whistle songs when you are at home or outside?
- Where? When? What sort of things are you doing when you sing/hum?

E. Personal Music Histories

Can I ask you about music you like?

- Are there any particular songs or pieces of music that have special significance or association for you?
- Can you give me an example?
- E.g., The songs remind you of specific event, or person?
- if you happen to have the piece, would you mind playing them?
- Or humming them?
- Can you recall any times when you were powerfully 'moved' by music? Could you tell me the situation as detailed as possible?
- What was it about this piece of music that made it special for you?
- e.g., the lyrics, the tempo or rhythm, the structure, the melody/harmony, the particular sound of instruments, groove, a particular moment within in, the conditions under which it was first heard

- Is there any music/soundscape that reminds you of particular scenery? Could you explain to me about the music/soundscape how it became to be linked with the scenery?

F. Musical Uses / Strategies

What do you do with music?

- What time of a day do you tend to have music?
- Do you ever put music for your partner, family, children for specific purpose?
- e.g., my mother used to listen to record called 'music for 0 year old baby' when she was pregnant with me. My father used to put on fight songs of local baseball team during the breakfast so that I am encouraged by it to climb the hill to go to elementary school. (My elementary school used to locate on the top of hill, and needed gut to climb especially in the cold weather)
- What about music as education, or music and childrearing?
- Have you ever put a particular music on or off to create or change a mood or situation? Has music ever had any romantic association for you?

G. Musical Taste and Conflict

Can you tell me about your musical taste?

- How would you describe your musical preferences?
- Have your musical preferences changed? If so, would you tell me when, and what/who influenced you?
- Are there any musics that you listens to but are embarrassed to admit you like?
- Do you ever argue with anyone about what music to listen to? Or argue about music you are or have listened to?
- Is there any music you dislike? Why? What is it about music you don't care for?

•

Appendix 2: Lists of the questions for members with dementia and their caregivers

A. Personal Background

Can you give me a few details about you?

- When were you born?
- Where were you born, and where did you grow up?
- What kind of work have you done?
- Where did you go to school?
What kind of school did you go?
- Do you live nearby?
- Are you married?

B. About musical activity, their music in everyday life, connection with other activities, etc.

- How are you enjoying (today's) session?
- How did you get involved in this musical activity?
- How long have you been singing with this group?
- How do you find this activity? What do you like about it?
- How do you find singing in the group?
- Have you sung in a group before?
- What do you like about it? Is it fun? Is it different from singing by yourself?
- How do you find coming with your partner/family/friends?
- How do you feel after Tuesday session? Do you feel like singing the tune we sing?
- Having involved in this group has any change in your life?
- How do you like the songs you sing in the music activity?
- Are there any particular songs you like most in SB?
What do you like about them?
- Would you tell me your musical background?
- What kind of music do you like? How and when do you listen to them?
- Do you sing at home as well? What kind songs do you sing?
- Can you recall any moment you were powerfully moved by music?
- Besides singing in this group, do you belong to any other community activities?
- What is your hobby besides music?

Appendix 3: Letter to SB January 2009

Exeter and District Branch

Mariko Hara
PhD Student,
Department of Sociology and Philosophy,
University of Exeter

January 13, 2009

Dear Song Birds members, Exeter Branch

As you may know, I've been involved with the *Song Birds* group in Exeter since May 2008 as a volunteer and I have really enjoyed my time here and I am very impressed with the project. In Japan I was involved in a similar project in my home town of Kobe when my own grand parents lived in a care home, and I decided that I would like to learn more about how music making can be beneficial for the well-being and quality of life of older people. As a result of this I am now doing a PhD at the University of Exeter, comparing music projects in Japan and the UK, and I would like to use *Singing in the Brain* as my UK site of research.

As a part of this research I would like to learn about the group, possibly by recording the music we are making in each session. It would also be very helpful if you could participate in interviews about your experiences so I can understand your different experiences within the group. I would like to speak to all the members, including leaders, carers and volunteers. (There is no pressure! If you don't want to answer any of the questions during the interview, feel free to say so, or, you can always withdraw the interview after it is done if you change your mind.)

All interviews will be anonymous! I will not mention 'Exeter', just describe it as one of the sessions in the Southwest of England. Names will be changed when it appears in the dissertation. My research has also been approved by the ethics committee at the University of Exeter and by my supervisor, Professor DeNora at the Department of Sociology and Philosophy.

If you have any questions, feel free to ask me/ call me anytime, and if you would like to talk about the session and your music/singing, please contact me at the following number.

Mariko Hara, Street, City, POSTCODE

Telephone: 00000 000 000

Email: hidden@hotmail.com

Please complete and return this form to Mariko Hara. Tick the boxes as appropriate.

I/we would be happy to participate in a brief interview

I/we would be happy for our music-making sessions on Tuesday to be recorded.

I/we would be happy for photos to be taken of me/us during the Tuesday sessions.

Your name

Address

Contact Telephone number

Email address (if any)

Appendix 4: Interview questions for volunteers

Points to ask:

- A. Background
- B. About the role as volunteer
- C. About music activity (influence of SB, their vision)

A.

- How long have you been involved with this activity?
- How did you become involved with this activity?
- Do you belong to any other musical activities /or community activities other than BFTB?
- Tell me about your own musical background.
(instruments you play, any training you had before)
- What kind of music do you listen in your daily life?
- Do you enjoy going to concert?

B.

- Would you tell me what you do as volunteer?
(Is there any difficulty being volunteer of SB?)

C.

- What do you think about the benefit of SB for members?
- During the session, can you think of particular song or activity that really works?
Why do you think so?
- In your point of view, what is the most unique thing about SB?
- From your volunteering experience, have you had any moment you were moved during the session? If you don't mind, would you share the episode with me? This could be very powerful
- What do you enjoy most about or during SB?
- Being involved with SB has any influence on your social life?
- There seems to be a recent trend to start singing and music activity for older people. If you are giving some advice to those who are starting activity like SB, what do you say about the most important thing to respect/ consider?

Appendix 5: Lists of the Interview questions for Jessica

Points to ask

- Her Musical background
- Motivation/history of SB and Jessica
- (About her specialties; networking, her idea on “teaching new songs”)
- SB repertoires
- Her idea of benefits of SB for people with dementia, their caregivers, volunteer members, herself and whole community.
- Impact/feedback of SB

History

- Would you tell me your musical background?
- What kind music do you like? What kind of music do you listen to/play in your everyday life?
- Would you tell me how you became to work with *Dementia Support Group*?
- Would you tell me again how you started SB?
- How is SB run? What funding are you receiving to run SB?
- What was your motivation?
- Would you tell me your role as a leader?
- How did you recruit volunteers? What are their roles?
- How did you recruit clients and caregivers?
- (How are they introduced to SB?)
- You told me that your specialty (you told me before) is networking, and community building through SB. Would you tell me more about it?
- Would you tell me how you choose the music every time?
- Additional questions:
- How did “*I will be your sweetheart*” become Arnold’s song?
- “*Hockey Cocky*” seems to work really well, would you explain to me how it became SB standard?
- Why did you mention Simon and Hannah when we sang “Morning had broken”?
- “*Auld Lang Syne*” the other day worked really well-. Did you assume that would work well?
- How did you come up with the format? (Warm up, hello, familiar songs, activities, quiz, participatory dances, and end with “*Shalom*”)
- How do you think SB is beneficial?

- What do you enjoy most during SB? Did you miss /think about SB while you were taking break?
- Is there any moment you were powerfully moved by the music? Or during the music use for people with dementia? If you don't mind, would you share the story with me?
- Being involved with SB has any impact on your social/musical life?
- What do you think about the uniqueness of SB?
- Would you tell me about feedback you are receiving? Locally, academically, and mass media?

Appendix 6: Lists of the questions for the charity representative

A. Background

- Could you tell me how you came to work with *Dementia Support Group*?

B. About *Dementia Support Group*

- Where does AS get funding from?
- How does AS work with NHS and Social services?
- How is the current economic crisis affecting AS?
- How does recent governmental focus and increased funding for dementia affect the *Dementia Support Group*?
- Before SB started what kind of services were provided for Alzheimer's patients and carers?
- Could you tell me how *Dementia Support Group* works with SB?
- In what ways have you been involved with SB?
- Could you explain to me how members are introduced to SB? And other activities?
 - (Do you/staff have interview with carers before placing them to the specific services?)
- Do you think there are any benefits of using music for Alzheimer's people or older people? Any particular benefits of SB?
- Could you tell me what sort of feedback SB is getting? Locally, academically, mass-media...?
- When you came to SB, what were your impressions, thoughts?
- Were there anything particular that you really remember well?
- What do you think is unique about SB compare to other singing/music activities for older people? (SB is a unique music activity, creating special format especially for people with Alzheimer's and their carer...) Anything special about Exeter branch?
- What are the plans of AS for SB in the future in Devon and in Britain in general?
- Are there other any particular service *Dementia Support Group* is putting emphasis on? Or planning to? Why?

Appendix 7: Informants or people discussed

<i>Informant</i>	<i>Gender</i>	<i>Background</i>
Arnold	Male	Participant with dementia
Bob	Male	Caregiver/friend of Arnold, later volunteer
Caroline	Female	Participant with dementia
Cecily	Female	Volunteer
Celine	Female	Participant with dementia
Christina	Female	Volunteer
Clair	Female	Caregiver/wife of Leslie
Craig	Male	Volunteer
Deborah	Female	Caregiver/friend of Sasha
Dennis	Male	Volunteer
Emely	Female	Volunteer
Hannah	Female	Caregiver/wife of Simon
Henry	Male	A chairperson of Local branch of <i>Dementia Support Group</i>
Irene	Female	Regional service manager of <i>Dementia Support Group</i>
Jake	Male	Participant with dementia
Jessica	Female	Facilitator of SB
Jonathan	Male	Participant with dementia
Kathlyne	Female	Caregiver/wife of Jonathan
Karen	Female	Volunteer
Kelly	Female	Caregiver/wife of Chris
Laura	Female	Participant with dementia
Leslie	Male	Participant with dementia
Lisa	Female	Caregiver/daughter of Caroline
Michael	Male	Caregiver/husband of Laura
Monica	Female	Caregiver/wife of Arnold
Nancy	Female	Volunteer
Nichola	Female	Participant with slight memory problem
Peggy	Female	Caregiver/daughter-in-law of Nichola
Marjorie	Female	Caregiver/wife of Jake
Martha	Female	Participant with slight emotional/memory problem

Robin	Female	Participant with dementia
Rosie	Female	Volunteer
Simon	Male	Participant with dementia
Sophie	Female	Volunteer
Susan	Female	Volunteer
Trever	Male	Participant with dementia

Appendix 8: The song lists of the compilation CD sent to participants

1. Hello Song
2. Down at the Old Bull and Bush
3. My Favorite Things
4. Irish Eyes are smiling
5. Tulips from Amsterdam
6. I like the flower
7. Spread Little Happiness
8. Grandfather's Clock
9. Lambeth Walk
10. Easter Parade

Appendix 9: Consent form

Information/Consent Form for Interviews

Title of Research Project

Music and Care for older people

Details of Project

This project tries to find out how music can be used in various care-setting. You are being invited to take part in this project run by Mariko Hara, a PhD research student enrolled in the Sociology Department of Exeter University.

Contact Details

For further information about the research or your interview data, please contact:
Mariko Hara, Department of Sociology, Exeter University, Devon UK.
nn@exeter.ac.uk

If you have concerns/questions about the research you would like to discuss with someone else at the University, please contact:

Professor Tia DeNora
School of Sociology, University of Exeter, Amory Building, Rennes Drive, Exeter, EX4 4RJ,
United Kingdom
Telephone: +44 (0)1392 263280
nn@exeter.ac.uk

Confidentiality

Interview tapes and transcripts will be held in confidence. They will not be used other than for the purposes described above and third parties will not be allowed access to them (except in the case of legal subpoena). I have no commercial interests to declare. However, if you request it, you will be supplied with a copy of *your* interview transcript so that you can comment on and edit it as you see fit (please give your email below).

Anonymity

Interview data will be held and used on an anonymous basis, with no mention of your name, but we will refer to the group/nursing home of which you are a member.

Consent

I voluntarily agree to participate and to the use of my data for the purposes specified above. I can withdraw consent at any time by contacting the interviewers.

TICK HERE: **DATE**.....

Note: Your contact details are kept separately from your interview data

Name of interviewee:.....

Signature:

Email/phone:.....

Member of which group:.....

Signature of researcher.....

2 copies to be signed by both interviewee and researcher, one kept by each

Appendix 10: Lyrics for “I’ll be your Sweetheart”

I’ll be your sweetheart

If you will be mine

All my life I’ll be your valentine

Bluebells I’ll gather,

Take them and be true.

When I’m a man my plan

Will be to marry you

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Appendix 11: Example recording (on enclosed CD)

1. Tulips from Amsterdam
2. She was a dear little dicky bird
3. Shalom

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