

Meaningful Music in Dementia Care: Anchoring Within Transient Situations

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Abstract

It is currently estimated that there are 54 million people living with dementia in the world, and that there will be 130 million people living with the condition by 2050 (Alzheimer's Society, 2020). In the United Kingdom alone there are around 850,000 people living with a formal diagnosis of dementia, and it is estimated that around a quarter of patients in UK hospitals have some form of dementia. (Alzheimer's Society, 2009). There is a clear need to support the emotional care of patients living with dementia alongside their medical care in order to reduce the negative impact that hospital ward environments can have on their wellbeing. The use of meaningful music in dementia care is one such way of supporting socio-emotional needs alongside medical care. This thesis demonstrates *how*.

The primary research question was to understand how patients in hospital who are also living with dementia engage with music and with what consequences, with regards to how music can support the relational aspects of care. Adopting elements of ethnography and grounded theory methodologies, the research focused specifically on the ways that live music was seen to support the wellbeing of patients living with dementia, through focusing on two specific objectives:

1. To examine how the environment and particularly the soundscape of a hospital ward affects the ward culture and hospital experience for patients living with dementia, and for care staff.
2. To explore how patients living with dementia respond to live music performances, and the 'spin off' effects of this for care staff.

The research was conducted at one major acute-care hospital in England within two Elderly Care Units over a period of four months from November 2016 to March 2017. The data was formed from 104 hours of observations over 37 days, of 201 people, consisting of patients (with and without dementia), staff and visitors, including 54 music sessions performed by six musicians. In addition to this, one focus group was conducted with five members of staff, as well as one-off interviews with four musicians.

The findings of the thesis reveal that familiar music can create positive associations for individuals living with dementia and their surrounding environment, creating increased feelings of emotional wellbeing. Additionally, shared experiences through music and its associations with reminiscence, were found to support social connections between the individual living with dementia and their care practitioners, which resulted in enhanced mutual understanding, that can be seen to continue after the music has ended. Through these shared experiences and increased connections, music is therefore able to create an environment which is more conducive to positive emotion. The thesis concludes that familiar, meaningful music delivered by musicians who can adapt their performance and connect with their 'audience' on an emotional level can support the wellbeing of people living with dementia within hospital wards, and possibly support staff to provide person-centred and relationship-centred care.

The study presents a wide lens picture of music's role within two dementia friendly hospital wards. I consider this to be 'wide lens' in that it looks beyond just the musical performance itself, to demonstrate music's role in creating positive environments conducive to wellbeing, to create and sustain social connections, and to reduce feelings of frustration, isolation and agitation; outcomes that last

long after the music has ended. The results are useful in the fields of music sociology, medical sociology, music therapy, community music, as well as practical applications in nursing and healthcare. Whilst the research was conducted in acute healthcare it is also anticipated that it presents wider implications for residential and domiciliary care of people living with dementia.

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1 Introduction

Jane sits staring out of the big window next to her bed. It is a cold November morning and the people outside walking past are wrapped in an array of coats, scarves, hats and gloves, walking hurriedly to get out of the wind. Jane calls out “hello,” but no one comes. She tries again, “hello”, she fumbles for her call bell which has dropped onto the floor. She curls her fingers around the cord and tugs the call bell up on top of the white crumpled bed sheet that lays over her lap. She presses the big orange button. Three seconds later she presses it again, calling “hello” for the third time, this time louder. No one comes. Jane rolls over so that she is no longer facing the window, she is now facing into the entrance of the bay, leading onto the corridor.

Jane starts to scream, a high sustained piercing sound. She stops, takes a breath, and screams again. Peggy who is in the bed opposite Jane presses her own call bell and shouts “oh for goodness sake, would you just shut up”, while Jane continues screaming. Nurse Kerry comes in shortly afterwards, and after resetting both Jane and Peggy’s call bells asks Jane if she would like a cup of tea. Jane shouts “no” repeatedly getting louder, her words straining each time she calls out. Nurse Kerry raises her eyebrows in my direction and says, “she’s often like this.”

While Nurse Kerry is seeing to Jane, the Musician in Residence, Claire, arrives with her ukulele. “Oh, look Jane” Nurse Kerry says pointing to Claire, “this young lady has come to play for you”. Jane looks at Claire as she takes out her ukulele and beckons her over with a slight movement of her index finger. Claire holds out her instrument and Jane reaches out and

puts her hand gently onto it, looking up at Claire with wide eyes and a small smile. Claire announces to the bay of six patients that she will start by playing some gentle pieces; she plays All I Have To Do Is Dream by the The Everly Brothers. Jane watches Claire the whole time, her mouth opening into a smile. Nurse Kerry stands next to her, one hand on Jane's shoulder, Jane lifts up her hand to rest it on top of Nurse Kerry's. "You liked that didn't you Jane?" Nurse Kerry asks Jane when Claire has finished. "Oh", replied Jane "you've reminded me of things I'd long forgotten."

1.1 Musical beginnings: my interest in music and dementia care

My interest in music and dementia began whilst I was in the final year of my Music Undergraduate Degree. In order to earn some extra money, I taught the clarinet to a 70 year old man, Phillip who upon retiring took up learning the clarinet, an instrument he had always wanted to learn, but had never had the time to dedicate to it. Every Monday afternoon in the university holidays we would sit in the dark living room of my parent's cottage, and we would work through the Boosey and Hawkes Learn as You Play Clarinet book together.

The thing that fascinated me the most was that Phillip was not learning because he wanted to master the clarinet, he did not want to do any grades, and in fact at times it felt that the lessons were not about learning music at all; the thing he really wanted to do was play together. This togetherness became his focus, each week he wanted to work on pieces we could play together as a duet, and before long we were working on building his skill so that he could play in the local wind band, something Phillip had aspired to do since starting to learn the clarinet. The wind band was an amateur ensemble of mixed abilities (mainly beginners) who

rehearsed in the village hall once a week, working towards their annual concert performed for family and friends.

I became fascinated by this idea that it was not really about the music at all, it was about what the music meant for Phillip - connection and community. When I went back to university after teaching Phillip for the summer I started thinking more about music in the lives of older adults. I began volunteering at a local hospital (which was the study site for my PhD research), playing the clarinet for patients on one Elderly Care Ward, Oak ward. It was there that I met the Consultant Geriatrician Dr Myatt, and the forward-thinking Ward Manager Robert (not their real names), both of whom are recurring participants within my research (note: this was seven years prior to the start of my PhD field work).

I had no experience of dementia myself, and perhaps naively I had not considered that I would be working with patients with dementia; I was focused on older adults generally. However, around a quarter of the patients I encountered in the ward had dementia, and I quickly realised that music seemed to have a particular benefit for patients living with dementia. I was amazed to see patients who had appeared withdrawn 'light up' when they heard a piece they recognised. Patients who were unable to communicate would suddenly sing along with a piece word for word. Staff seemed amazed by this 'transformation' and the live music performances became a regular occurrence.

It is not my intention to set music up on a pedestal. I am conscious that music is often objectified as almost 'magical' within dementia care, something which I am keen to unpack. I was however curious to learn why music had this effect on patients living with dementia. I ended up working at the hospital as a contracted Musician in Residence after graduating, performing weekly on Oak and other

Elderly Care Wards as well as overseeing visiting professional and student musicians. I took a personal interest in the wellbeing of patients, and the emotional aspects of care, where I could see music's usefulness might lie.

Alongside performing in hospitals, around the same time that I was volunteering at the study site, I also set up a social enterprise providing music workshops for people living with dementia in care settings, predominantly care homes. The social enterprise still exists today, 12 years later, and both my academic and creative worlds have remained very much intertwined. Professionally, I am what is known as a Community Musician.

Academically, I wanted to delve deeper into the specifics around the ways that music supported the wellbeing of patients living with dementia, with a specific focus on behavioural aspects, including agitation. In 2013 I began a master's degree in Music Psychology, and for the final year dissertation I conducted a pilot study, exploring the effects of live music for hospital patients with dementia, specifically focusing on agitation and anxiety.

The pilot study, which took place at the same site as my PhD research, used a mixed-methods cross-over design, where the participants (total 16), listened to a 20-minute live music performance three times per week for five weeks. The Cohen-Mansfield Agitation Inventory (CMAI) was used to measure levels of agitation in the participants, based on staff observations. Likert scales were used to assess the effect of the live music on the mood, anxiety, and wellbeing of the participants. Qualitative data was collected through observations of and interviews with the participants.

The results from the pilot study showed that live music 'significantly' reduced agitation and anxiety, and improved mood and overall wellbeing. However, whilst

the statistics appeared positive, they also made me question - what did they actually mean? The quantitative data did not tell us *how* people living with dementia engage with music, how they experience it, or what that process consists of. I found this detailed information came from the qualitative data, the observations, and interviews, providing a deeper insight into how patients living with dementia engage with music.

I wanted to take this research question further, adopting a qualitative, grounded approach to exploring the hospital ward environment for people living with dementia and music's role within this. Taking forward the earlier work of the pilot study, my PhD research aims to generate new empirical evidence on *how* music affects patients with dementia, by investigating music as part of daily life on two dementia friendly wards. To do this, I draw on DeNora's work (2000, 2003, 2013) around affordance and appropriation in the people's use of music, providing an 'in the music' (Proctor, 2013), observable understanding of the ecology of music, exploring its different uses and effects for people living with dementia.

Considering the affordances of live music in two hospital wards, an ethnographic methodology as I shall describe, provided an exploration into the question of music's role in dementia care. Its focus on process offers potentially better purchase on the question of music's affordances for empathic caregiving and how it gets into action. It allows for a detailed consideration of the ways in which live music intertwines with the relational aspects of dementia care, providing a detailed description of music within the social world of an elderly care ward.

1.2 Dementia in acute care

Dementia is an umbrella term for a collection of neurodegenerative diseases; symptoms include confusion, memory loss, change in mood, and difficulty in

carrying out everyday tasks. It is currently estimated that there are 54 million people with dementia in the world, and that there will be 130 million people living with the condition by 2050 (Alzheimer's Society, 2020). In the UK alone there are around 850,000 people living with a formal diagnosis of dementia, and it is expected that the actual number of people living with dementia is much higher than this. The Alzheimer's Society states that one in fourteen people over 65 years of age and one in six people over 80 years of age has some form of dementia (Alzheimer's Society, 2014).

In 2009 the Alzheimer's Society estimated that around a quarter of patients in general hospitals in the UK have some form of dementia. Recent research suggests that currently 42% of people over 70 years of age in acute hospital wards have dementia (Royal College of Psychiatrists, 2019). Individuals living with dementia are not admitted to hospital because of their dementia, rather the most common reasons for admission are falls, fractured hips, hip replacements, Urinary Tract Infection (UTI), chest infection or stroke (Alzheimer's Society, 2009). What we see then, is people living with dementia, a chronic condition, being cared for in acute settings - noisy, bright environments, without familiar routines and faces, which can be disorientating for patients living with dementia, resulting in an exacerbation of dementia symptoms (Featherstone and Northcott, 2020; Fukuda et al., 2015). Research shows that patients with dementia experience a variety of negative outcomes whilst in hospital, including multiple co-morbidities, increased confusion, increased agitation, risk of delirium, increased length of stay, possible complications such as falls, and delayed discharge. (Royal College of Psychiatrists, 2019, p.7).

On the other side of the coin, from the social perspective, certain manners and interactions within medical and personal care have been demonstrated to count towards better patient experience. For instance, Edvardsson, Sandman, and Rasmussen (2011), showed how certain staff actions such as making small talk, involving patients in tasks in meaningful ways, and 'going beyond routines to make the content of the day mean a little extra for patients' (Edvarsson, Sandman & Rasmussen, 2011, p.1139) improved the patient experience, and positively influenced wellbeing. We can consider these social interactions encompassed in the relational aspects of care.

The relational aspects of care, or compassionate care, centre around the relationships that staff form with patients during their hospital admission and can include communication, providing space for patients to highlight fears and concerns, and treating patients with respect and dignity (Graham et al., 2018). The Francis report (2013) identified substantial failings in relational aspects of care, recommending that hospitals should focus on improving relational aspects of care, in particular for older patients.

The essence of social interactions within a transitory environment is a key theme within my thesis. I question whether a sense of comfort and at times relating, can be found in an otherwise chaotic setting, such as that of a short-stay medical ward. There is clearly a need for both medical and social care to intertwine in order to reduce the emotional impact of acute hospital wards on the individual living with dementia. However, in short-term care facilities, with staff shortages and tightened budgets, we might question how realistic is it to support the emotional/social needs of individuals living with dementia?

In the UK the Department of Health has highlighted the importance of 'living well' with dementia (Department of Health, 2009), this means a focus on the social and relational aspects of dementia care (O'Brien et al., 2020). The most important development in response to, and indeed provoking, the call for 'living well' has been the focus on person centred care, a notion that takes forward Kitwood's concept (1997). In this regard, person-centred care appears illuminated as a 'gold-standard', intended to underpin dementia care wherever that care is delivered (O'Brien et al., 2020; NICE, 2018).

The concept of person-centred care was born out of the notion of 'personhood' which has been a key theme within dementia care over the past 20 years. Tom Kitwood, (the first person to use the term in relation to dementia care), offered this definition of personhood – 'a standing status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements. It implies recognition, respect and trust (Kitwood, 1997, p.7).

Kitwood's model of person-centred care has greatly influenced the ways in which individuals living with dementia are cared for, it shifts the focus from the condition to the individual experiencing dementia, as described by Kasayka (2002). Within this model to support personhood, Kitwood considered a cluster of needs of people living with dementia, at the core of the framework an 'all-encompassing need' for love.

Person-centred care was developed in relation to long stay settings (Clissett, 2013); in residential dementia care this deep understanding of the individual and their personal needs and desires is possible due to the long-term nature of this type of care, with relationships therefore built over a long period of time. However,

there are many challenges in delivering person-centred care in acute hospital environments highlighted by authors including O'Brien et al., 2020; Goldberg et al., 2014; Houghton et al., 2016; Dewing and Dijk, 2016. These challenges include the often short-stay nature of acute hospital admission, ward moves and with it a new set of staff, lack of time to develop relationships and understanding of the social needs of the individual patients (with or without dementia), and lack of time or resources to support occupation.

Certain behaviours have been cited as 'challenging' to care for, such as agitation, aggression, disinhibition, and persistence to exit the ward (see O'Brien et al., 2020; Goldberg et al., 2014). Communication is considered one of the biggest challenges of caring for people living with dementia in hospital; however, little training is available for staff to learn how to effectively communicate with patients living with dementia (O'Brien et al., 2020; Stanyon et al., 2016). We might consider that communication challenges in particular stem from the disorientating, noisy, unfamiliar environments of acute hospital wards, therefore increasing feelings of confusion, isolation and disconnect, perhaps for all patients to a certain extent, but certainly exacerbated in patients living with dementia. Whilst there are restrictions on staff time and resources to fully support social care alongside medical care, there is a need to explore other avenues, to create acute environments more conducive to the wellbeing of people living with dementia (DeNora, 2013), whilst also supporting their social needs.

One such avenue is the use of music. Research shows that music listening, particularly meaningful music, can support a reduction in acute confusion, and significantly improve feelings of pleasure in individuals living with dementia. For instance, Cheong et al. (2016) demonstrated how Creative Music Therapy (CMT),

including music improvisation, spontaneous music making and playing familiar songs of a patient's choice, delivered over three consecutive days (30 minutes of activity on each) in one acute medical ward over a 3-month period, resulted in increased feelings of positive emotions and general alertness, compared to observations taken before and after the CMT sessions (also see McDermot et al., 2014; Götell et al., 2012; Politis et al., 2004).

There is a substantial amount of literature on the benefits of music for people living with dementia in residential care (Dowson et al., 2019; McDermott, 2014; Camic et al., 2013; Simmons-stern et al., 2010; Svansdottir and Snaedal, 2006; Holmes et al., 2006; Suzuki et al., 2004). The current understanding is that recognition of music remains relatively intact even in later stages of dementia, and therefore many studies focus on the use of familiar, preferred music when exploring the effects of music for people living with dementia (Baird et al., 2017; Sung et al., 2012; Cooke et al., 2010; Götell et al., 2000; Gernder and Swanson, 1993). The majority of research to date (for example Sherratt et al., 2014; Svansdottir and Snaedal, 2006; Cuddy and Duffin, 2005) has focused on the use of recorded music played to patients within longer-term care facilities, where relationships are able to be built over time, and therefore caregivers are able to gain an understanding of what music is meaningful to the individual.

Very few studies have examined the use of music in acute dementia care. Within short-stay hospital wards it is understood that an increase in agitation and distress is experienced by patients living with dementia, who may find the experience of being in hospital frightening and disorientating. There is an increase in confusion and agitation for patients living with dementia due to the noisy and bright environment, high turnover of staff and patients, lack of

understanding of the hospital routines, unfamiliar faces, and unfamiliarity with each other's interactions (Daykin et al., 2017; White et al., 2017).

One small scale study involving nine hospital patients living with dementia observed positive effects on mood on the days that music therapy took place (Gold, 2014). Likewise, a larger scale study of 85 patients living with dementia, showed that on days when a visiting orchestral musician facilitated a group participatory music activity, prescription of antipsychotic medication was reduced, and out of the 20 patients observed using the ArtsObs scale (Fancourt, 2016), the observed effects of the music activity on relaxation, distraction, engagement and agitation were shown to be consistently positive. As highlighted by Daykin et al. (2017), there is a need for further research to explore the personal, interpersonal, and social factors that facilitate wellbeing outcomes from the engagement with music activities for hospital patients living with dementia.

My own research aimed to contribute to this understanding of the ways in which live music can support the relational aspects of dementia care in hospital wards. The study took place in two short-stay medical wards in one NHS trust in England; these wards were dementia friendly, designed to specifically address some of the common issues experienced by people living with dementia when admitted to hospital, as previously mentioned. For instance, the wards had clear signage, different coloured bays to help with orientation, framed photographs of local landscapes, and lighting set to imitate natural sunlight. Nonetheless, being short stay, they still retained some of the inherent problems such as patient confusion, distress and social disconnect.

In this regard, I explored live music rather than recorded music, as previous research has shown that live music affords more opportunities for social

interaction (Sherratt et al., 2004). Whilst most research considering live music in dementia care is situated within longer-term residential care, I wanted to explore how live music can become part of an ecology of social interactions in short-stay hospital wards, which as previously discussed, present many social challenges for individuals living with dementia. It is my intention to move away from seeing music as an isolated activity and instead consider music in dementia care as a situated activity, observing *how* music interrelates with the environment, social relationships, and its affordances for wellbeing.

1.3 Summary of the research framework

Situated within this growing research field of music health and wellbeing, my research aims to understand how patients in hospital who are also living with dementia engage with music and with what consequences, with regards to how music can support the relational aspects of care.

My previous pilot study focused on the interaction between live music, instances and severability of agitation, measuring outcomes through objective rating scales. The present study is more focused on the process of the ecology of music in two acute hospital wards, considering the affordances of music with regards social relationships, connections and relatedness, taking a wider lens approach to exploring music's interactions in acute dementia care.

Taking forward the earlier work of the pilot study, my PhD research addresses the question of *how* music functions in hospital wards for people living with dementia and those around them, through an ethnographic approach. I chose ethnography as the primary method of data collection as it allows for a focus on social and embodied processes of living and real-time events. This immersion into the field site offered an understanding of the ways in which people living with

dementia experience short-stay hospital wards, and social relationships within. Unlike previous research primarily focused on 'measurable' outcomes, through an ethnographic focus I was able to observe the relationships between social interactions, the sound ecology of acute hospital wards, and the affordances of music within this, considering music as an embodied experience, not exclusive but intertwined with medical and social care.

The specific research objectives were to:

1. Examine how the environment and particularly the soundscape of a hospital ward affects the ward culture and hospital experience for patients with dementia and care staff.
2. Explore how patients living with dementia respond to live music performances, and the 'spin off' effects of this for care staff.

The research was conducted at a major acute-care hospital in England within two Elderly Care Units over a period of four months, between November 2016-March 2017. Although these wards did not exclusively care for patients living with dementia, they had a higher-than-average number of patients living with dementia due to the age range of the patients on the wards (over 65 years of age). Both wards, Oak ward and Beech ward, had undergone refurbishments to make them 'dementia friendly', mainly around aesthetic changes, including moving the busy nurses' desk, clearer signage, colourful bay entrances to help with orientation, artwork, lighting to imitate natural sunlight, and pictures of familiar local scenes. As a result, the wards were much quieter and less busy than we would imagine hospital wards to be. However, as I shall discuss, these quieter environments may also mean

that social interactions and occupation are potentially reduced. To this end, we can see how music can literally and figuratively fill and shape the silence.

My aim was to take notice of small changes on the ward and in its inhabitants and to focus on fluctuating social interactions and the spin-off effects of music with regards to the relational aspects of dementia care, looking specifically at communication and social interactions. Over the four months of my research period, I undertook 104 hours of observations over 37 days. I observed 201 people: patients (living with and without dementia), staff and visitors. I was present for 54 music sessions performed by six musicians. In addition, I conducted one focus group with five members of ward staff, and one-off interviews with four musicians who were selected because they were either a contracted member of the hospital arts team, performing regularly on the wards, or else performed a series of consecutive weekly performances over a period of four weeks on the two wards observed hired through an outside music agency.

In the following chapters I detail the main themes which emerged from the data, unpacking the role of live music within acute dementia care. My overall finding is that music, supported by careful practices of delivery, can support the wellbeing of patients living with dementia in acute settings, through creating and sustaining social connections, mutual understanding, and agency, and by the aesthetic and affective shifts that occur in participants. In what follows, I seek to describe specifically *how* this occurs.

1.4 Thesis outline

Chapter two, the literature review, considers the relevant literature in two parts. Firstly, I review the literature that addresses the intertwining of physical and social

care, addressing the relationship between sounds and music within the healing environment, drawing on theoretical accounts and studies from the fields of music, health and sociology. I consider some of the key challenges with these theories, as well as exploring the emerging model of relationship-centred care, and its potential for application within acute medical care.

The second section of chapter two centres on the music in dementia care discourse, drawing on research concerning reminiscence, active participation, singing, live and recorded music. I identify the gaps within the literature, in particular the lack of research focusing on short-term hospital care facilities where structured participation in music is not always possible.

In chapter three, the methods chapter, I describe methodological issues around conducting an ethnography of ward culture. I describe the ways that an ethnographic approach can help us to understand to the best of our ability, the lived experience of music in dementia care, and the ways that music can support relational aspects of dementia care. I highlight key ethical considerations in my own research, and the processes as well as the specifics of data analysis, inspired by a grounded theory approach.

The data findings are presented in chapters four, five and six. Chapter four considers the hospital soundscape, describing the soundscape of the two wards, and the ways that live music interacted with the soundscapes of the two hospital wards observed. I draw on a main theme, disconnection and diminished sense of self as a common experience for patients living with dementia in hospital wards, and the ways that the disconnect may reflect a lack of habituation to the sonic (and social) environment. The data demonstrate how familiar music can create positive associations with the ward soundscape, resulting in a connection with

the environment and other agents, through affordances of positive emotions, a theme which leads into chapter five.

Chapter five builds on this theme of disconnection, looking at the concept of community in relation to the two wards observed and how music affords moments of social connection in this transient, and otherwise disconnected world. I suggest that by having a deeper connection through music it may be easier to care for patients living with dementia, focusing on how music can support the relational aspects of care.

Chapter six brings together the strands of musical connections intertwining with relational aspects of care, and the affordances of this in relation to emotional wellbeing. I consider how both agitation and apathy (common 'challenges' in dementia care) may for some be triggered by difficulties with regulating or communicating emotions. The chapter moves on to demonstrate how familiar music can 'unlock' emotions, highlighting how the emotional benefits of music lies in its delivery as well as the engagement of staff to support the emotional wellbeing of individuals living with dementia.

In the final chapter I conclude that music's role within acute dementia care lies in the affordances that music offers for supporting social connections within the transient environment of a short-stay hospital ward. I consider some of the limitations of my study and offer recommendations for future research and practice.

2 Literature review of music in dementia care.

2.1 Introduction

According to The Alzheimer's Society's report, 'Counting the Cost: Caring for people with dementia on hospital wards' (2009), up to one in four beds in general hospitals in England, Wales and Northern Ireland are occupied by people living with dementia. More recent findings suggest that this number is now higher (Featherstone and Northcott, 2020). Symptoms of dementia are thought to worsen during a hospital stay, and someone living with dementia is also more likely to stay in hospital for longer, and more likely to be re-admitted than someone living without dementia (Featherstone and Northcott, 2020; King et al., 2006). It has become a focus for many NHS trusts to become 'dementia friendly'. This agenda follows on from The King's Fund programme 'enhancing the healing environment' which supported 10 NHS trusts (including the site of the present study) to improve the environment of their elderly care wards, making them less alienating for people living with dementia. However, the transformation of the spaces appears to focus more on aesthetics, with less attention to the relational aspects of care.

Within acute short-stay hospital wards the emotional/social side of care is often neglected (Clissett, 2013) due to the turnover of patients, restricted staff time, and focus on rapid discharge. However, the literature points to the importance of social relationships within dementia care, and the need for individuals to be 'active citizens' (Bartlett and O'Connor, 2010) in their care through others supporting their sense of self within these relationships. Therefore, there is a

need to consider activities which can support the relational aspects of care within short stay hospital wards; one such activity is music, as I shall explore in this literature review.

The benefits of music within dementia care have become widely understood over the past 20 years, and the literature on the subject is vast. However, the focus has tended to be around longer-term care where it is easier to build up social relationships and connections over time. Likewise, the majority of studies focus on recorded music rather than live music, and those that do explore live music (Daykin et al., 2017; Sherratt et al., 2004) tend to concentrate on individual engagement during the music performance, rather than shared interactions which may last long after the music has ended. To explore this concept further, I consider the affordances (DeNora, 2000) of live music within short-stay dementia care, as DeNora (2002, p.21) describes, highlighting:

‘music’s potential as an organising medium, as something that helps to structure such things as styles of consciousness, ideas, or modes of embodiment. To speak of music as affording things is to suggest that it is a material against which things are shaped.’

It is precisely this shaping of things that this literature review aims to explore, developing an understanding of *how* music plays a role within dementia care, a current gap in the literature as demonstrated in this chapter. Considering affordance then, we are able to understand music’s role within dementia care at both micro and macro levels, and the interactions between people and things which contribute to the atmosphere, producing different conditions and states which emerge out of the mutual interactions within the ecological settings.

To this end I review a wide range of literature within the field of dementia care, focusing on the interconnectedness of social and physical care, including the importance of the sonic environment. The affordances of music in dementia care are explored through key studies which examine different elements of music, including meaningful music, caregiver singing, and live music. Taking forward the concepts of affordance, personhood, and relationship-centred care, I propose that we can gain an ecologically based understanding of music's role within short-stay hospital wards for patients living with dementia.

2.2 Healing environments

2.2.1 Physical and social care intertwined

Although physical changes to hospital environments can be introduced to make the space 'dementia friendly', it is the social environment for patients with dementia that is the centre of my research. It is through considering the social environment that we can truly explore the role of music in dementia care in terms of its interpersonal qualities, affording moments of connection in the disconnected environment found in an acute medical ward. Edvardsson, Sandman, and Rasmussen (2011) highlight the effects of the social environment on patients with dementia, discovering that patients living with dementia were emotionally affected by the presence or absence of staff in the ward bays - the presence of the staff gave the patients a sense of belonging and connection with their surroundings, a feeling of 'at-homeness'. In contrast, the absence of staff had the opposite effect, with patients feeling lonely, isolated and 'homeless.' Whilst we would not normally consider hospital wards in terms of home-like surroundings, within dementia care it is becoming more understood that there is a need for social connections with their surrounding environment (Featherstone and

Northcott, 2020; Clissett, 2013; Edvardsson Sandman and Rasmussen, 2011).and these feelings of security and comfort cannot be achieved by aesthetic changes alone.

The importance of intertwining physical and social care is highlighted by DeNora and Ansdell (2017) who suggest that care is something which can be considered to be 'mutual'. What they mean here is that these physical and social elements of care are not exclusive, but interrelated, one affecting the other. Although changes to the physical environment can and should be made, social factors and their interaction with wellbeing and quality of life for those within this space need to be taken into consideration in order to support the overall wellbeing of patients living with dementia. However, in the UK with a financially struggling NHS, caused in part by the social care needs of an ageing population (Nicol, 2017), we need to consider how realistic it is to support the social needs of patients living with dementia within acute, general hospital wards.

A particular challenge is that general hospital ward environments are unique, transient, in a constant state of flux, with various social actors entering and exiting, unlike any other community we may experience, making it difficult to form and sustain connections. We might compare this to longer-stay wards or patients who stay longer on general wards due to discharge delays. Whereby social relations might be similar to residential care, with an increased understanding of one another, and increased social interactions amongst patients, as described by Duval et al. (2018).

On the other hand, we might expect short-stay wards such as Acute Medical Units (AMU), where patients are expected to stay for less than 72 hours, to present less opportunities for building social relationships, due to the short nature of

admission. However, minimal literature differentiates between short-stay and general hospital wards. The challenge presented is not dementia specific, but applicable for the broader 'patient' demographic. However, patients living with dementia who may not understand the environment in which they find themselves when admitted to an acute hospital ward experience confusion and agitation as a result. My own research is situated within two general elderly care wards, where the average length of stay is 11 days, with patients admitted for a variety of reasons including delirium, falls, multiple medical conditions such as infections, heart failure or frailty.

Returning to the idea that physical and social elements of acute care are intertwined then, we need to consider how patients with dementia interact with both the physical and social environments of acute hospital wards. DeNora's (2013) concepts of 'refurnishing' and 'removal' are appropriate here, terms which she introduces through the concept of musical asylums, in relation to the interaction between health/illness states and the environment. Refurnishing *transforms* our surroundings and is more concerned with 'remaking the environment' (p.50), whereas removal moves the social actor out of the space, either figuratively or physically to somewhere more conducive to their wellbeing (p.49). Through these concepts we can consider music's role within healing environments, and the ways that music might support inclusion into the environment, or a removal from the environment, for patients living with dementia. The question is, *how?*

2.2.2 Sound ecologies of health spaces

Before moving specifically on to music within healing environments, I shall first consider the sounds and noises already within the environment to enable a better

understanding of music's role within the texture of sounds of the modern-day hospital ward as experienced by patients living with dementia. Devos et al. (2019) in the context of dementia care environments, make a clear distinction between soundscape, and sonic environments; the former being 'an acoustic environment as perceived or experienced and/or understood by a person or people, in context' (p.2), and the latter being the sounds that contribute to the environment. Building on Devos et al's definition of soundscape, we can consider the concept as a subjective experience, understanding the impact of soundscape on wellbeing of patients living with dementia by exploring their perceptions and experiences of the various sounds that contribute to the sonic environment of healing spaces.

Schafer (1993, pp.9-10) defines three key themes within the study of soundscapes:

- Keynote sounds – which are the key sounds within an environment and may be listened to sub-consciously
- Signals – sounds that are listened to consciously, sounds that must be listened to because they represent warnings such as bells, alarms, sirens etc.
- Soundmark – sounds which are unique to a particular environment – 'soundmarks make the acoustic life of the community unique' (p.10).

Considering each of these in relation to the environment of an acute hospital ward, I turn to the work of Tom Rice (2013), who demonstrates that several sounds and modes of listening coexist within hospital wards. We can imagine the keynote sounds, the very essence of the soundscape of the hospital ward; whilst each ward's key will be unique to that space, we might expect certain

sounds such as monitoring equipment, movement, chatter, beds being wheeled, curtains drawn, the sound of trolleys moving, bodily functions etc. Likewise, we might consider the signals, namely repeated sound of call bells, falls risk alarms, vocal sounds, sounds that might represent a warning, as represented by much of the literature on this topic. In addition, music might be understood through the soundmark, contributing to the unique sonic environment of the community at that particular moment in time, as I shall describe in the later section - musicking in dementia care.

Tom Rice presents the different types of sounds contributing to the soundscape within general hospital wards in his book 'Hearing and the Hospital: Sounds, Listening, Knowledge and Experience.' (2013). Rice's ethnographic study focused on the different forms of listening within two hospitals conducted between 1999-2004. The first part of the study took place at The Royal Infirmary, Edinburgh, conducted whilst Rice was working as a volunteer as part of the hospital radio team, talking to patients to gather feedback on the radio station and to gather musical requests. The second part was conducted over a year-long placement at St Thomas' hospital London, and formed Rice's PhD, focusing on the medical practices of listening to heart sounds; here he was authorised to observe consultations, ward rounds, training, and surgery (Rice, 2001, p.4).

In terms of music within the wards, Rice discovered that patients used music as a distraction, 'an opportunity to escape from the sounds of the ward' (p.3). In this regard we can understand this 'escaping' from sounds through DeNora's concept of removal - removing oneself from an environment whether figuratively or literally, to somewhere more conducive to their wellbeing. The challenges of escaping from the sonic environment are also highlighted by Busch-Vishniac and

Rhytherd (2019), and Brown et al. (2014), who reflect on the patients having no control over the soundscape, nor ability to escape unwanted sounds within the healing environment. Returning to DeNora's concept of refurnishing and removal, my own research seeks to address whether the use of meaningful music, might support refurnishing, inclusion *into* an environment rather than escaping from it, which is in line with the Brown et al. (2014, p.1521) reflection that 'a familiar soundscape helps create a sense of belonging, giving "feel" to a place'.

With this in mind, we can consider the role of familiar music adding to this soundscape, defining space and place. Rice suggests that 'for those who are immersed in it, then, the ward soundscape can play an important role in creating and confirming a particular experience of patient-hood, bringing patients to recognise their "patient-selves" (Rice, 2013, p.22). Focusing on patients living with dementia, it could be argued that music, especially familiar meaningful music, can play a role within the concept of refurnishing, and therefore I propose that what emerges from this is not necessarily for the patient an understanding of themselves in terms of *patient-hood*, but *person-hood*, a common theme within dementia literature as previously described, acknowledging the *person* behind the illness, a concept I introduce in the next section of this chapter. In this regard, through connections with previous memories and emotional associations, music can support feelings of self-identity, connection, and empowerment.

2.2.3 Health musicking and paramusical

To understand how people living with dementia and other social actors engage with music within their environment we can turn to the concept of musicking, which was first coined by Christopher Small (1998). Taken from the verb 'to music' it refers to:

'...taking 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. We might at times even extend its meaning to what the person is doing who takes the tickets at the door or the hefty men who shift the piano and the drums or the roadies who set up the instruments and carry out the sound checks or the cleaners who clean up after everyone else has gone. They, too, are all contributing to the nature of the event that is a musical performance'. (p.9).

In terms of an acute hospital ward, the concept of musicking is highly relatable. It is not only the musicians themselves who are involved in the process of the musical performance, but so too are the patients, staff and visitors. There is an interrelatedness between music and environment, intertwined with care. Inspired by DeNora's (2000) discussion of affordance and appropriation, Stige (2012) adapts the concept of musicking to health settings, describing musical affordances in relation to health and wellbeing, through the term 'health musicking'.

Stige discusses music as a situated activity, inviting us to consider the arena outside of the music, and the affordances of musical activities in terms of contributing to a 'continuous (re)construction of the arena' (Stige, 2012, p.186). Thinking in terms of music within general hospital wards then, we can consider the interplay within the sounds of the ward arena and the social interactions in relation to refurbishing/removal activities for patients living with dementia. It is from this understanding that we can see how music might support relational aspects of care.

2.3 Person/relationship-centred care.

2.3.1 Personhood

The concept of personhood has been a key theme within dementia care over the past 20 years. Kitwood offered this definition of personhood – ‘a standing status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements. It implies recognition, respect and trust.’ (1997, p.7). Whilst it might not have been Kitwood’s intention, this definition of personhood appears to place the control on one side, the caregiver, ‘bestowing’ a status of personhood upon the cared for person, therefore appearing to take away a certain amount of agency and has received criticism as a result.

For instance, Bartlett and O’Connor (2010) argue that personhood should consider the autonomy of the individual living with dementia. Autonomy has a range of different meanings and is often identified with ‘the qualities of intentional actions and being free from controlling influences.’ (Smebye et al., 2016). However, dementia care presents ethical dilemmas of how to balance autonomy with the individual’s health, safety, and wellbeing (ibid). Agich (2003) presents the concept of ‘actual autonomy’ when caring for patients living with dementia. Rather than focusing on independence and rational decision making, actual autonomy considers identity in the decision-making process. It highlights the need for caregivers to be aware of the individual’s identity and that patients living with dementia to a large extent are dependent on their caregivers to carry out their decisions. As Smebye et al. (2016, p.2) remark, ‘actual autonomy is less a state than a process of being in the world with others.’

Personhood, identity, and selfhood are often used interchangeably in dementia literature, but the general agreement is that as human beings we need to know that we are, and who we are, and that we are respected by others (Norberg, 2019). Kontos (2008) argues that selfhood is an embodied aspect of what makes us human and continues even in late stages of dementia. Sabat (2003) acknowledges the importance of others in our construction of 'self', presenting three aspects of the self, which he calls self 1, self 2, and self 3. Self 1 ('the self of personal identity'), which links directly to Buber's (1937) I-Thou, expressed through personal pronouns such as 'me, myself, my, mine, our'; takes responsibility for our actions and consider feelings and experiences as our own. Self 2 is concerned with physical and mental attributes and our beliefs about these attributes, and Self 3 considers our different personae in accordance with the social situations in which we find ourselves.

Sabat argues that 'each of these different social personae requires for its existence the cooperation of at least one other person in our social world' going on to explain that the loss of self 3 in Alzheimer's Disease is more due to the view from within the individual's social world and their interactions with other, when others see them as 'burdensome' 'defective' etc. rather than the neuropathology of the condition. When others reflect this stigmatic view, the only person who the individual living with dementia is able to construct is that of the 'dysfunctional Alzheimer's patient' (Sabat, 2002).

Going back to healing environments, we can see how other social actors within the space may support or detract from this sense of autonomy of self in the patient living with dementia. It is through (or through a lack of) these social interactions that the individual constructs their identity and feelings of self whilst in the hospital

environment. Drawing upon the concept of personhood, and the importance of maintaining the social citizenship of the individual living with dementia, we can see the need to put the individual at the centre of their care. It is precisely this individual focus upon which person-centred care is based, considering the social, emotional, physical and medical needs of the individual living with dementia.

2.3.2 Person-centred care

Person-centred care is held as a gold standard within dementia care, with care settings (including acute care) striving to provide person-centred care for people living with dementia. NICE (The National Institute for Clinical Excellence) describe person-centred care as 'good practice in dementia care' (2018). However, in reality it is a concept which is hard to implement particularly in acute care, according to Featherstone and Northcott (2020), and Clissett (2013), who highlight that identity, occupation and comfort are often not supported in acute care due to the busy nature of general hospital wards. Likewise, policy is often directed at an organisational level rather the individual or team, and staff are left without adequate training to deliver person-centred care, in addition to the wide range of interpretations of what person-centred care means and looks like in practice.

Based on the work of Rodgers (1951), Kitwood first used the term person-centred care in 1988 to describe a certain type of dementia care approach, moving away from a medicalised model towards a more humanistic one (Fazio et al., 2018). There is currently no universal definition of what it means to provide person-centred dementia care; for some it means individualised care, whilst for others it means values-based care (Brooker, 2006). This contention of definitions as

previously mentioned, is one of the main restricting factors in implementing person-centred care.

2.3.3 Relationship-centred care

Clissett (2013, p.149) highlights that person-centred care for patients living with dementia in acute settings can be problematic because 'the priorities are rapid diagnosis and therapeutic intervention with short lengths of stay.' A person-centred approach requires the time to understand the person behind the condition and understand the environment from their perspective; of course, this is easier to adopt in longer-term care settings compared with short-stay hospital wards. Within acute care the need to focus on rapid discharge becomes a limiting factor in delivering person-centred dementia care, and therefore the emotional/social side of care is often neglected, something which the present study seeks to address; exploring how the role of music within acute dementia care can support wellbeing and the relational aspects of care for individuals living with dementia.

Kitwood used the term 'malignant social psychology' (MSP) to describe the various ways in which personhood can be undermined in care settings, including episodes where individuals living with dementia are 'intimidated, outpaced, not responded to, infantilised, labelled, disparaged, blamed, manipulated, invalidated, disempowered, overpowered, disrupted, objectified, stigmatised, ignored, banished and mocked' (Brooker, 2007, p.17). Whilst no one would wish to subject people living with dementia to malignant social psychology, as Kitwood says the intent is not malicious, the current research indicates that it does still happen frequently within care settings (Brooker, 2006, p.17). Sabat comments that 'malignant social psychology can be avoided if the person diagnosed is positioned as (i) having intact selfhood, (ii) possessing the ability for creative

expression and (iii) where actions are driven by the meaning of situations, thus demonstrating semiotic behaviour.’ (Sabat, 2019, p.62).

We can consider that in order for this avoidance of malignant social psychology through the factors described by Sabat, individuals living with dementia need to play an active role in their care, and for selfhood to be supported by caregivers through empowering the individuals they care for. However, in hospital care it is difficult for patients (living with and without dementia) to play an active role in their care, by nature they play passive roles, under the medical authorities, highlighting the inherent power structures of the medical profession and institutions such as hospitals, as demonstrated by Scales et al. (2017), and Clissett (2010).

Therefore, offering a new way of thinking of personhood, rather than something which is ‘received’ by the individual living with dementia, ‘gifted’ by another, we can move towards seeing personhood as something which the individual living with dementia is able to manifest themselves, given the right support. In this regard, we move away from the concept of person-centred care, towards *relationship-centred care*.

A relationship-centred care approach sees the relationships within dementia care, between the individual living with dementia, their family, caregivers etc. as multi-dimensional and dynamic (Bartlett and O’Connor, 2010; Dewing 2009; Ryan et al., 2008; Nolan et al., 2003). Rather than focusing on the individual living with dementia as being dependent on others, with personhood being bestowed upon them by others, relationship-centred care focuses on inter-dependency, the reciprocity of giving and receiving care, as the key to the best care for individuals living with dementia (Garabedian, 2014). A relationship-centred care approach

looks at including activities which support the individual living with dementia *and* their wider support network (Garabedian, 2014; Ryan et al., 2008).

In order to support individuals living with dementia to be 'active citizens' (Bartlett and O'Connor, 2010) in their care therefore, we need to consider the individual's relationships and their sense of self within these social relationships. It is my understanding that both concepts have a role within dementia care, rather than one replacing the other, person-centred care and relationship-centred care exist side by side, under the mission of providing dementia care that supports the quality of life of the individual living with the condition and those around them. Taking these relational aspects of care, we can develop an understanding of music's role within relationship-centred and person-centred approaches to dementia care, with music supporting social bonding, individual emotional, social, and at times physical needs.

2.3.4 Social bonding

The potential of music in particular to promote social bonding has been discussed by previous researchers (Tarr et al., 2014; Davidson, 2008; Bailey and Davidson, 2005), who highlight music's capacity to create and strengthen social bonds, through self-other merging (Tarr et al., 2014). We can view music's potential for social bonding; moving away from a prescriptive theory which predicts outcomes, and instead moving towards understanding the social world by observing people as 'social actors' (Goffman, 1956) and the way they interact with one another and their environment.

The social significance of this collective musicking, can be seen through social capital (Putnam, 2000) in that it can afford social connections and builds relationships in the social context (in this case, an acute short-stay medical ward).

We can explore this further by turning to the literature in Music Therapy. Ansdell (2002) highlights that music making can generate social capital, and its impact on wellbeing through his definition of Community Music Therapy:

‘an approach to working musically with people in context: acknowledging the social and cultural factors of their health, illness, relationships and musics. It reflects the essentially communal reality of musicking and is a response both to overly individualized treatment models and to the isolation people often experience within society.’

One might naturally assume that music would generate social capital as it is essentially a social act. However, as Procter (2011, p.252) highlights, ‘if this is the case then why music and if it is simply a social activity in the sense that people are doing something together, then they may as well be doing anything.’ What then is unique to the social capital generated by musicking or the process in which this social capital is created? Procter (2011) answers this by suggesting that the opportunities for social engagement which musicking affords can generate social capital through the collaborative nature of musicking itself. This proto-social musical capital he argues, is sustained after the musicking has ended.

In terms of the role of music within the care of patients with dementia, we have much to gain from considering the ways that music capital is manifested, and the longer-term impact of this within acute hospital wards. Out of this literature we can see the importance of relationships and connections to support personhood; thus highlighting the need to pay attention to the relational aspects of care when considering music’s affordances for patients living with dementia.

2.4 Agitation

2.4.1 Definitions

Agitation is considered to be one of the main challenges of caring for individuals living with dementia (Featherstone and Northcott, 2020; Featherstone et al., 2019), and it has been noted to have a direct correlation with caregiver burden and decrease in quality of life according to Park (2009). It is for this reason that my research initially solely focused on agitation, as I knew it to be a main challenge within acute dementia care. Cohen-Mansfield, the first person to define agitation in people living with dementia, described agitation as ‘inappropriate verbal, vocal or motor activity that is not judged by an outside observer to result directly from the need or confusion of the individual.’ (Cohen-Mansfield and Billig, 1986). There are challenges with this definition in that it relies on an outside view, encompassing a broad range of behaviours which may be classed as agitation, and it raises the question, who determines that this is a ‘problem’ or ‘challenging’ behaviour, and what is classified as agitated behaviours and for whom?

Agitation has been shown to have wide physiological and psychological consequences for patients living with dementia including restlessness, disturbed sleep, higher risk of falls, increase in dehydration, reduction in social interaction and a decrease in quality of life. The consequences are not just for the individual experiencing instances of agitation, but there is a knock-on effect for caregivers too – increase in caregiver burden, reduction in job satisfaction, distress, irritability, and again a decrease in quality of life (Kong, 2005, p.532). In Cohen-Mansfield’s Agitation Index (the CMAI), a prominent measurement within the literature on agitation in dementia care, she considers agitation to be classified as a set of behaviours under four categories:

Verbally non-aggressive

Complaining, negativism, repetitive sentences or questions, constant, unwarranted requests for attention or help

Verbally aggressive

Cursing and verbal aggression, making strange noises, verbal sexual advances, screaming

Physically non-aggressive

Performing repetitious mannerisms, inappropriate robing and disrobing, eating inappropriate substances, handling things inappropriately, trying to get to a different place, pacing, aimless wandering, intentional falling, general restlessness, hoarding things, hiding things.

Physically Aggressive

Physical sexual advances, hurting self or others, throwing things, tearing things, scratching, grabbing, pushing, spitting, kicking, biting, hitting.

Cohen-Mansfield suggests that the behaviours listed above under the umbrella of agitation are 'always socially inappropriate' (1989, p.77). However, if we consider the social construct of dementia, understanding agitation as emerging out of social interactions (or lack of) within ecological settings, we are left with the question, for whom is this behaviour considered socially inappropriate? Dewing (2010, p.18) promotes a person-centred understanding of agitation for individuals living with dementia, one which inspires my own research, calling for nurses to 'look beyond the obvious and try to understand what the behaviour shows about the person and their needs' in order to understand agitation from the patient's

perspective. A person-centred care approach such as this, offers us a more grounded understanding of agitation, seeking to understand agitation as a lived experience, from the perspective of the person living with dementia and their carers.

Since Cohen-Mansfield's definition of agitation, other definitions have been presented, considering the environment in relation to agitation (Rosen et al., 1992), focusing on the patient's perspective, and the links between agitation and emotions (Zubenko, 1999). Zubenko (1999) proposes that 'agitation is not simply a behavioural disturbance but embodies a mood component as well'; this type of definition moves away from understanding agitation as a fixed set of behaviours as described by Cohen-Mansfield, and towards a more sociological understanding of agitation as fluid, relational, and individual. It is this more fluid understanding of agitation that I take forward, exploring agitation as a subjective experience, which fluctuates depending on situational and relational factors.

2.4.2 Theory of constructed emotions

In addition to these external factors influencing experiences of agitation, considering agitation as embodied, we may also understand agitation to encompass various emotions. With this in mind, I turn to the theory of constructed emotion here (coined by Barrett, 2018) to understand how emotions are experienced, which I then take further to understand the relational aspects of agitation for people living with dementia.

The theory of constructed emotion argues that emotions are not universally expressed, there are no 'fingerprints of emotion', that is to say that the way that two individuals experience an emotion for instance joy, will not be exactly the same experience. Instead, the theory considers emotions as concepts which are

constructed by the brain and are experienced subjectively. The brain makes predictions or 'simulations' as Barrett refers to them, based on our previous experiences, predicting what might happen next and then preparing the body to respond to this. Barrett offers the example of going to meet a friend you have not seen for a long time, your brain starts to predict feelings of joy and happiness, creating these feelings before you have seen your friend.

A sociological approach to agitation can be considered through the theory of constructed emotion, through what Barrett calls interoception, which answers the question what does the brain do when its predictions are wrong? Barrett argues that the brain is more likely to stick with its original prediction and filter the incoming data to match its prediction. According to Barrett if our predictions are constantly wrong, we can feel depressed due to a feedback loop of negative thoughts and feelings. In this regard, we might consider that threats to ontological security can also contribute to these negative feelings, through a disruption in continuity of life (Giddens, 1991; Anotvosky, 1987).

If our brain cannot process our surroundings, we experience what Barrett (2018, p.26) calls 'experiential blindness;' the inability to perceive what you have not experienced before. When people cannot find meaning in their environments, agitation often arises. Hospital environments can be disorientating and confusing for individuals living with dementia and it may be difficult for such individuals to process their perceived surroundings. It is not my intention to list the emotions that we may consider to be under the umbrella of agitation. However, understanding agitation to be fluid, incorporating relational aspects, and considering how the theory of constructed emotion might be applied to our understanding of agitation to encompass emotions, we can understand agitation

at a micro level, a subjective experience. It is at this micro level where we can see the role of music in dementia care. Considered at an individual level, focusing on music that is meaningful to the individual as I shall highlight in the following section.

2.5 Musicking in dementia care

2.5.1 Music and agitation

The literature surrounding music and agitation in people living with dementia is substantial but to date has tended to focus on long-term care settings. Studies of non-pharmacological intervention approaches in dementia care are lacking (Tang et al., 2018) and very few studies consider music and relational aspects of agitation for patients living with dementia in acute medical environments, a gap this study aims to fill.

In general, the findings demonstrate that one way music may reduce instances of agitation is by increasing feelings of positive emotions. Ziv et al. (2007) explored the effects of background stimulative music on behaviours of people with Alzheimer's Disease. The researchers compiled a list of behaviours displayed by people with Alzheimer's Disease and organised these into three categories - positive behaviours (including talking, laughing, smiling etc); negative behaviours (including agitation, wandering, throwing objects etc); and neutral behaviours (any behaviour that did not clearly fit into the positive or negative behaviour categories such as dozing or staring into space). The results displayed a decrease in negative behaviours and an increase in positive behaviours during the music intervention.

The authors suggest that based on their results ‘incorporating music in living facilities could be beneficial in improving patients’ quality of life.’ (Ziv et al., 2007, p.341). However, they do not explain *why* quality of life is improved, or indeed what aspects are even considered when exploring quality of life. In order to answer this question, we need to have an understanding of the lived experience within the research setting, to gain a grounded, ecological understanding of *how* music affects quality of life (positively or negatively), something which my own research seeks to address.

Park et al. (2009) agree with Ziv’s findings that music can reduce agitation in people living with dementia in their own homes. The authors state that ‘agitation was significantly reduced while participants listened to the [recorded preferred] music, but no significant difference was found in the effect of the music intervention or agitation between the music intervention weeks and no music intervention weeks in this study.’ (Park, 2009, p.53). The result may have been found because the participants were still able to listen to their own music during the ‘no music’ intervention weeks, which would have an impact on the results. However, this raises the question would it have been ethical to withhold a stimulus such as music for the purposes of research?

Park et al’s (2009) study highlights that ‘control’ is not ‘control’ in full, nor can it be in ‘complex interventions’ such as music. The question highlights how experimental designs such as this have their own limitations, as well as ethical issues surrounding dementia research. Thinking of music as an ‘intervention’, which is the case in much of the literature, which can be switched on or off at the decision of the researcher, or something which is ‘done to’ the participant, instead of thinking of music as a cultural event as discussed previously, turns music into

a rigid tool which is merely being used for the purposes of the research, without considering the participants' social and cultural needs.

Jennings and Vance (2002) discovered that agitated behaviours such as pacing, cursing, complaining, negativism, general restlessness were reduced after participation in group Music Therapy sessions (Jennings and Vance, 2002, p.30). These results differ from Sung et al. (2011) who found that music did not significantly reduce agitation levels. 60 residents from a care facility in Taiwan took part; they were randomly assigned to an experimental group (30 minute group music intervention using percussion instruments with familiar music twice per week for 6 weeks); and a control group (usual care no music. Similar to Jennings and Vance (2002), Sung et al. (2011) also used the CMAI to measure outcomes; however, unlike Jennings and Vance their participants' agitation levels were low at baseline and therefore the music was not shown to have an effect. I would suggest that had the study taken a more qualitative approach to agitation the researchers may have been able to use a more ecologically grounded method, providing a narrative of the smaller changes in agitation over time.

2.5.2 Meaningful music

Whilst the literature on music and agitation in dementia is relatively small, there is a substantial amount of literature focusing on the effects of music more broadly for people living with dementia (Dowson et al., 2019; McDermott, 2014; Osman et al., 2014; Camic et al., 2011; Simmons-stern et al. 2011; Svansdottir and Snaedal, 2006; Holmes et al., 2006; Suzuki et al., 2004). The current understanding is that musical recall is preserved in dementia even when the individual can no longer remember names, places or facts. Taking this into consideration, many studies focus on the use of familiar preferred music in

relation to reminiscence when exploring the effects of music for people living with dementia (Baird et al., 2017; Sung et al., 2012; Cooke et al., 2010; Götell et al., 2000; Gernder and Swanson, 1993).

In support of this literature, a case study presented by Cuddy and Duffin (2005) described an 84 year old woman with severe cognitive impairment from Alzheimer's Disease, who was seen to sing along with familiar pieces of music, and would continue singing even when the stimulus had finished; suggesting that despite being in the late stages of the disease, musical memory and appreciation for music seemed to be preserved. The current understanding is that musical memory such as this is preserved due to the strong associations between music and emotions; as Scherer and Zentner (2001, p.369) comment, 'music, like odours, seems to be a very powerful cue in bringing emotional experiences from memory back into awareness.' Whilst this was written in the context of music and emotions within broader sociological terms, it is exactly this notion which makes music powerful in dementia care, and as a result highlights the importance of *meaningful* music in dementia care, using familiar music to elicit feelings of wellbeing and recreate positive emotions.

The concept of meaningful music comes under the broader term of meaningful activities, which Jones et al. (2020, p.2) define as 'a wide range of activities and interventions, which are relevant and enjoyable to the person living with dementia, leading to improvements in either their physical function, emotional wellbeing, cognitive status or behavioural problems.' However, when considering music in this more general way there can be a risk of oversimplifying the role of music within dementia care. It is not necessarily the power of this all-encompassing 'music', rather music needs to be explored as a subjective activity,

with many variables such as personality, individual taste, and severity of dementia (Nair et al., 2011; Ragneskog et al., 2001). Likewise, music needs to be contextualised at both a micro and macro level, considering the setting, the particular piece, style, the persons(s) delivering the music and how it is delivered, in other words considering music as a nuanced activity situated within dementia care.

2.5.3 Active participation

Much of the literature on active participation in musical activities focuses on group music, generally Music Therapy, using percussion instruments and singing with or listening to familiar music (Gulliver et al., 2019; Chu et al., 2014; Sung et al., 2012; Cooke et al., 2010; Svansdottir and Snaedal, 2006). A dominant theme which has emerged out of the music in dementia care literature is how active participation in musical activities, and singing in particular, can support wellbeing or 'wellness' which Clair (2000, p.87) defines as something which is individual and includes 'components of physical, emotional and social functionality sufficient to maintain a good quality of life.' In terms of singing, many studies have reflected on the positive impact of group singing on wellbeing, for example Clift et al. (2012) discovered that there are multiple benefits to singing in a choir in later life, mainly the social aspects of interacting with others with shared interests and forming new friendships and connections.

Likewise, a meta-analysis conducted by Skingley and Vella Burows (2010) demonstrated how music may be used therapeutically by nursing staff in caring for older people. Reviewing 16 relevant studies, the authors reported that in relation to dementia care specifically, the literature shows that preferred music can support a reduction in agitation and increase in social interactions and co-

operation (Skingley and Vella Burrows, 2010, p.37). However, the authors also state that the conclusions should be treated with caution due to the nature of data collection – self-reporting (from the individuals living with dementia themselves as well as nursing staff), rather than in depth observations, which may therefore not be a true representation of music in practice. The authors suggest that nursing staff can play an active role in using music within dementia care, including assessing the musical preferences of people living with dementia, and using music and/or singing as a way of maintaining wellbeing of people living with dementia.

The theme of musical connections, and the social interactions which music affords, is observed in other literature around music in dementia care; in particular caregiver singing and caregiver-led musical activities. These activities are considered under the term Music Therapeutic Caregiving (MTC), a phrase coined by Götell et al. (2002, p.125) to describe ‘an active form of music-making by caregivers to and/or with patients during the course of actual caregiving activities.’ MTC is not limited to caregiver singing, but the research around the role of MTC in dementia care typically considers the benefits of caregiver singing and the effects on emotion, cognition and wellbeing.

Götell et al’s ethnographic study (2010) highlights the need for the effects of music in dementia care to be seen as ‘cultural events’, looking more at the social interaction between patients and caregivers during musical events, rather than being seen as an intervention, which as discussed earlier has been the tendency of previous research.

Götell’s study took place within a geriatric care unit in Sweden, over a nine-month period, observing the response and social interactions between patients and staff

to caregiver assisted music events (two members of staff led the sessions by singing and playing guitar) before, during and after the event. The findings were in line with previous research, the individuals living with dementia appeared to have an increase in attention and happiness, stemming from the memories that the music brought back for them. The patient/staff 'boundary' was reduced due to the musical events, and the staff developed a connection with the patients through experiencing this event together.

However, the study focuses primarily on the way that the music was delivered by staff, the techniques and repertoire used. It lacks a narrative voice, the individual stories of how these musical interactions enhanced caring connections, we do not have a sense of these relationships before, during and after the sessions at a micro level. Likewise, Götell et al. (2010) do not appear to situate the musical event within the context of the setting, we do not know what was happening in the arena of the space, outside the musical event itself (DeNora, 2013). Focusing on environmental and cultural changes before, during and after the music event (DeNora, 2013), enables an ecologically grounded understanding of music as a situated activity within dementia care, as discussed previously.

Research shows that there is currently a gap in training and support for caregivers to deliver meaningful music within care, despite the literature supporting this interaction and shared experiences of music. Vella Burrows (2009) presents a need for this type of caregiver training. In collaboration with the Sidney de Haan Centre, the author created a learning programme – Music as a Therapeutic Medium for Engagement – to support care staff to develop musical skills to use with individuals living with dementia, with a view to supporting wellbeing (of both the individual living with dementia and the caregivers themselves). Delivered over

a four-week period consisting of weekly three hour training sessions, the programme reached 84 participants, learning practical music making skills, theoretical understanding of music in dementia care, creative conversations and depictions of experiences of dementia. The research demonstrated that this type of training offered to care staff can help to increase caregiver confidence in delivering music within their care setting as well as the potential to support the wellbeing of people living with dementia through increased engagement in music.

2.5.4 Live music

In addition to the research on MTC, other studies have also explored the effects of patients and caregivers participating in musical activities together (Snyder et al., 2016; Davidson et al., 2014; Hammer, 2011; Hanser et al., 2011; Clair et al., 2002; Götell et al., 2000). Unlike MTC the research has often been centred around participation in structured musical activities (usually designed purely for the research), rather than spontaneous moments of interaction within the musical event.

Research which explores spontaneous music making, or musical engagement tailored to the present needs of the individuals or group has shown to provide more opportunities for wellbeing compared with structured, objective delivery of music. For instance, Cohen-Mansfield et al. (2011) discovered that the lowest levels of pleasure and interest were seen during the music intervention. The focus of the research was not primarily on the role of music in dementia care, rather they were exploring the impact of various stimuli (25 in total) on affect in people living with dementia, with around 4 different types of stimuli used each day for 3 weeks. The authors briefly describe the music intervention as: 'only listening to music', they do not explain what type of music, whether the individual listened to

the music alone, how they listened to it, how the music was chosen, what time of day in relation to the other stimuli the music was played, how the music was situated within the space etc. Without this holistic understanding of how the music was used and experienced, it is difficult to assess the efficacy of music within this study.

However, Cohen- Mansfield et al. (2011) did confirm that stimuli relating to self-identity i.e., meaningful stimuli, has a strong link with positive emotional responses. Whilst this personalised stimulus was not musical (the authors comment that it was the use of robotic animals and respite videos, but provide no further information), it is of relevance to my own study in that the researchers highlight a reduction in agitated behaviours and an increase in pleasure and involvement following activities that were aligned with the participants' self-identity.

Cohen-Mansfield and Götell's studies are typical studies in the literature on music in dementia care in that they focus on recorded music or caregiver singing. There are very few studies which consider live music within dementia care only, with the focus tending to be on individual engagement (such as Daykin et al., 2017) rather than exploring patients and caregiver participation. For example, Sherratt et al's (2004) study examining the emotional and behavioural responses of people with dementia to four music conditions – no music, recorded commercial music, recorded music played by a musician, and live music performed by the same musician.

Twenty-four people took part and were recruited from an NHS day hospital, the majority of whom were admitted to a continuing care ward, which is a longer-term care facility compared with acute hospital wards, where my own research is

situated. Using Dementia Care Mapping (DCM) the authors found that extreme well-being was evident more often during the live music conditions than any other condition, suggesting that this might be due to more opportunities for social interaction during live music performances, which is in line with other research on the topic (Dowson et al., 2019; Cox et al., 2014; Van der Vleuten et al., 2012; Holmes et al., 2006).

The authors suggest that the live music afforded more opportunities for social interaction. However, the observations took place with the individual listening to the music performance on their own. No details are given of the social interactions between the patients and musicians; in fact, we have no understanding of the musicians, instruments played etc. The missing link within this type of research commonly found within the field of study is specifically *how* music affords moments of interaction during live music performance, and by whom.

Sherratt et al's study is representative of much of the literature on music in dementia care, in that music is often seen as an intervention, something which is 'done to' the participants, focused on measurable outcomes, rather than looking at *how* the participants engage with music, and the spin-off effects that come out of the musical event itself. Thus, the gap in the literature seems to be that there is little understanding of the ways in which live music supports relational aspects of dementia care, and the ways that patients living with dementia and members of staff interact during the live music performances.

Likewise, the majority of studies exploring live music within dementia care are situated within longer-term care facilities where it is possible to observe engagement in musical activities and impact on behaviour and emotions over a longer period of time. For example, Van der Vleuten (2012) discovered that live

group music performances significantly improved resident and caregiver relationships as well as improving caregiver job satisfaction. However, their study was situated within a nursing home where it is possible to observe the same people and therefore note changes in relationships over a longer period of time. There is a gap in the current literature around live music in acute medical wards for patients living with dementia and their caregivers, where admission tends to be short-term, and structured participatory musical events such as the ones described above are not necessarily possible.

However, one such study which explores live music in acute medical wards Mogos et al. (2013), discovered that staff felt more relaxed, less tense and 'remembered to smile' following live music performances, and similarly the patients felt they received a more positive experience during their hospital admission as a result of the live music performances. Whilst the study was not situated within dementia care, it took place in cardiology care and orthopaedic wards in a US hospital, the findings do highlight the ways that live music affords more social opportunities than recorded music, as also demonstrated by Sherratt (2004).

Mogos et al's (2013) study consisted of 100 patients over an eight-week period, who were allocated to a Live Therapeutic Music (LTM) session group or control group (no music). The LTM group received a 10-30 minute performance at their bedside in their private single room performed by a certificated music practitioner (CMP). Both groups had to answer a short questionnaire, consisting of six questions rating their level of care and mood. The LTM group did this shortly after listening to the live music performance, comments and feedback were also collected from staff and patients over the duration of the study. Whilst the study

highlights the importance of working at an individual level, adapting live music performances to suit individual needs and preferences, we lack an understanding of the individuals and the ways that they engaged with the music. For instance, the authors do not say how often the patients heard the music, whether once or several times in the eight-week period, and whether their responses changed over time. Likewise, whilst we understand the ways in which the musicians delivered the music, as I shall go on to describe, we do not know how many musicians performed at the hospital, their instrumentation and the repertoire played; this leaves us with a lack of understanding of what 'worked' at an individual level.

The authors define live therapeutic music (LTM) as 'an adaption of the care environment offered to the patient, one which is intended to enhance comfort and relaxation or to stimulate and engage, depending on the needs of the patient.' (p189). My own study builds upon the work of Mogos (2013) looking at LTM within acute dementia care, providing a narrative for the ways that this type of music delivery can support the relational aspects of care, exploring micro interactions in this regard.

Preti (2009) discovered within paediatric wards, that provision of live music is generally valued by patients (and families) and has an overall positive impact on the patients and the hospital environment. Preti highlights that this is due to the live and spontaneous nature of the musical provision, the musician encouraging participation. Aasgard (2002) discovered similar findings in his ethnography of song creations within a paediatric ward for children with cancer. He demonstrates how engagement in the song creation fostered, even momentarily, a sense of expanding possibility for social roles for the children.

Through their phenomenological study of aesthetics and cultural pursuits of older people in one acute hospital in Dublin, Moss and O'Neill (2014) discovered that participatory arts activities (e.g., music making, playing percussion, structured movement to music sessions), may be more important during rehabilitation and recovery, whereas receptive arts may be more beneficial during the acute phase of an illness. Live music's power lies within this responsive nature; as Sloboda and O'Neill (2010, p.423) remark, the qualities of live music compared to recorded music are that it is 'live, improvisational, spontaneous, participatory and social.' Social in that it can create and sustain relationships, provide an activity to share with others, and support an understanding of one another. Small's concept of musicking (1998) is appropriate here; through the concept of musicking we understand how musicians, patients, staff, visitors intertwine with the music itself and the environment. Small (1998, p.13) explains:

'[Musicking] brings into existence among those present a set of relationships, and it is in those relationships that the meaning of the act of musicking lies. It lies not only in the relationships between the humanly organised sounds that are conventionally thought of as being the stuff of music, but also in the relationships that are established for the duration of the performance between the participants and the performing space.'

In this regard whilst live music may be considered as receptive arts, the music being provided *for* the patients, we might also consider that the live music performance is participatory in nature, the music being delivered *with* the patient through potential affordance for connection within the shared musical space.

2.5.5 Musicians' craft

The participatory and social nature of live music as Sloboda and O'Neill (2010) describe, may be in part due to the responsive and social nature of the musician themselves. We might consider Emotional Intelligence in this regard. Emotional Intelligence (EI), also known as Emotional-Social Intelligence (Cleary et al., 2018) is described by Salovey and Mayer (1990, p.189) as 'the ability to monitor one's own and other's emotions, to discriminate among them, and to use the information to guide one's own and other's emotions, and to use the information to guide one's thinking and actions.' There is a growing body of research to support EI in nursing (Štiglic et al., Cleary et al., 2018; Zysberg et al., 2011; Beauvais et al., 2011), suggesting that high EI 'enables nurses to make better decisions, manage their patients more effectively, improve relationships, and positively impacts the quality of care received by patients and families.' (Raghubir, 2018, p.127).

Furthermore, there is a clear value around empathy and the need for empathic caregivers within dementia care. Laurence (2017, p.12) remarks that 'empathy itself appears as synonymous with: mimicry; attunement; compassion; sympathy (and indeed even with kindness and helpfulness; moments of connection; feelings of mutual understanding.' According to Jütten et al (2019, p.13) 'empathy is often regarded as an important quality "good" doctors have and fundamental to good patient clinician relationships.' Likewise, Derksen et al (2013, p.76) discovered that 'patients consider empathy as a basic component of all therapeutic relationships and a key factor in their definitions of quality of care.'

However, whilst there is a breadth of research around empathy, emotional intelligence and emotional labour (Hochschild, 1983) within healthcare, there is

currently little research on EI in community musicians or even Music Therapists. Yet the crossovers between EI in nursing and EI in musicians are clearly apparent. For example, Bolton (2001) refers to nurses as 'emotional jugglers', and Preti (2009, p.173) describes the role of musicians in healthcare in a similar way, highlighting how the musician performing in hospital wards is equipped with skills such as 'empathy' 'intuition' and 'special sensitiveness', alongside delivering the musical performance itself. Whilst current literature touches upon the various social skills of musicians working in healthcare, there appears to be a gap in understanding the role of emotional intelligence within community music performances and engagement.

Goleman's (2009) model presents EI as consisting of four attributes: self-awareness, self-management, social awareness, and social/relationship management. The literature within the fields of music sociology, music psychology and music therapy show how musicians demonstrate the attributes described by Goleman. Preti (2009) reflects that the musicians alternate between two techniques whilst delivering live music performances in a hospital ward: firstly, playing *for* someone, and secondly playing *with* someone. Preti's research was conducted within a paediatric ward within a hospital in Florence, a site where Preti herself had worked as a community musician. The study took place over 4 weeks, drawing on a triangulation of data (observations, interviews, and quantitative methods) as well as a meta-analysis of existing findings to answer two main questions: what happens when live music occurs in a hospital context, and what is the value of offering a music programme in a hospital setting?

Each week her fieldwork focused on a particular group of participants (patients, family members, staff, and musicians). The findings through her observations of

the musicians, and reactions of the other social actors to the live music performances demonstrated that musicians needed to 'decode' emotional situations and 'translate' it into music' (p.173). In this regard the musicians in Preti's research were translating these emotions into active music making with the participants, playing together, at times engaging in spontaneous music making. Whilst this strategy for engagement differs from the live music typically offered within elderly care wards, the responsive nature of the music performance in this regard is still relevant. The emotionally intelligent musician adapts their performance in response to the individuals within the space, their emotional needs, mood and behaviour. We might consider the concept of emotional labour here. Coined by Hochschild (1983, p.7), she defined emotional labour as 'the management of feelings to create a publicly observable facial and bodily display.'

Preti considers this 'management' of feelings for the musicians delivering music in hospitals, highlighting how emotionally draining it can be at times to be performing in this way, giving so much of themselves to those within the shared musical space. The musicians within Preti's research perceived their role to facilitate a release of emotions (in this case often for the parents of the child participating in the live music session), through the music they performed. Whilst Preti's research was situated within paediatric hospital wards, the musicians who play in acute dementia care wards can be seen to draw upon similar skillsets, in terms in terms of the way that they adapt their performance to suit the needs of the 'audience', how they control the tempo, pitch and volume of the piece, and how they might facilitate an emotional connection with those they are performing to and/or with.

Moss and O'Neill (2014, p.127) also highlight the emotional needs of the patients as a major theme within their research on arts in healthcare, calling for arts and health programmes to take a 'sensitive curatorial role...in conjunction with patients, nursing professionals and those who design and shape the healthcare environment'. However, for the artists themselves, this curatorial or responsive nature of music making within healthcare is something that is rarely taught outside of the professional of Music Therapy, a challenge highlighted by Preti (2009) and Moss and O'Neill (2009).

In an evaluation report, Vella-Burrows (2017) presents a framework – The Goals Framework to support facilitators working with older adults by providing a guide to resources and activities which may support the wellbeing of participants. The report evaluated a project delivered by the community interest company Music 4 Wellbeing, called Carers Create, in collaboration with the Sidney deHaan Research Centre for Arts and Health. Covering the period May 2015 – July 2017, the Carers Create project delivered 205 creative activity sessions for people living with dementia and their caregivers, including singing rhythmic movement and dance amongst other arts-based participatory activities.

The author states that each facilitators delivery style was informed by Creech et al's (2012) handbook entitled 'facilitating music-making for older people: a facilitator's handbook', offering three interrelated elements to create safe and effective learning experiences for older adults. The 'gatekeeper' approach, with a hierarchical and transactional relationships, the 'midwife' approach, facilitating, open, learner-directed, and the 'fellow-traveller' approach, focused on empowering participants to utilise their inner resources to learn and achieve. The evaluation highlighted that facilitators felt they required further training in the

'fellow-traveller' approach, what we may consider the empathic element of artistic delivery, the participant-facilitator connection, demonstrating a potential need for additional support for musicians to deliver empathic performances and participatory activities.

2.6 Conclusion

Whilst there is now a great deal of literature on music's power within dementia care, considering a variety of musical activities including group participation, singing, recorded music, individual listening, background music, the number of studies which explore the role of live music within dementia care, and specifically acute medical care, is still limited. The literature shows that music can have a positive impact for people living with dementia, such as increased memory recall, improved mood, reduced agitation, and increased social interactions. However, music is often seen as an intervention still, with clear measurable outcomes. This approach has been shown to leave gaps in our understanding of music's role within dementia care, without considering the context and specific qualities of the music and its delivery.

Taking forward the idea of music as a medium for refurbishing of and a removal from social environments (DeNora, 2013), we can observe the ways that music is appropriated by individuals living with dementia, and their caregivers. Through considering the relational aspects of dementia care (Bartlett and O'Connor, 2010), an understanding of the ways in which music might support social relationships starts to emerge. Continuing with this theme, taking the concept of constructed emotion (Barrett, 2018), we can consider a main challenge in dementia care, agitation, looking at the relational and emotional aspects of

agitation, and the ways in which music might support a reduction in instances of agitation through intertwining with the relational aspects of care.

I propose that if we are to see music as a cultural event, considering the potential of music to promote social bonding and generate social capital, then we need to take a more ecologically grounded approach, observing how music plays a role within the culture of healthcare settings for people with dementia, and how one impacts the other. My own ethnographic study aims to contribute to the field of music sociology, inspired by a grounded theory approach, moving away from seeing music as an intervention with before and after measures, towards a deeper, holistic, understanding of the culture of hospital ward environments for patients with dementia and their caregivers, the relational aspects of dementia care, and the role of music within this. The methods of my ethnographic study are discussed in the following chapter.

3 Methodology - ethnography in a hospital setting

3.1 Introduction

The neuroscientific and medical paradigms predominate in the music and dementia arena, where music is regarded as an intervention with measurable and generalisable outcomes. Whilst the outcomes of such studies have appeared to show positive impacts of music on agitation, anxiety, depression, and wellbeing for example, as described within the literature review chapter, they leave gaps in our understanding of *how* people living with dementia and their caregivers interact and engage with music.

An ethnographic approach to exploring music's role within relational aspects of dementia care allows for an understanding of the individual experiences of music, exploring the nuances of the music itself and its delivery. In this regard, ethnographic research can provide a narrative to support the quantitative data.

There are key challenges involved in ethnographic studies of music in hospital environments and in relation to dementia care in particular. These include the logistical challenges of collecting data from people who may have difficulty communicating or expressing themselves verbally. They also include the ethical dilemma of involving vulnerable adults lacking capacity to consent in research. The difficulties of involving people living with dementia in qualitative research have been discussed by Featherstone and Northcott (2020), Reid et al. (2011) and Proctor (2001) who suggest that the ethics of involving people with dementia need to be considered, but that people living with dementia can and should be involved in research involving their experiences of their dementia. Beucscher and

Grando (2009, p.3) highlight the need for flexibility when involving people living with dementia in research, commenting that ‘researchers should be knowledgeable of communication challenges and need to develop strategies to address these concerns with the caveat that the same strategy may not work in all situations.’

In this regard, my research follows Aasgard’s (2002) approach, adopting a triangulation of methods. According to Aasgard, a triangulation of methods enables the researcher to *illuminate* the landscape, it creates a ‘security measure’, minimising misinterpretation and misunderstanding. Likewise, a triangulation of methods enables the researcher to still capture data such as participant observations if a participant is unable to take part in an interview due to communication difficulties, or medical issues, as can be the case in research in short-stay hospital wards.

In terms of my own research, these triangulated methods consisted of observational field notes, spontaneous discussions, musician reflective logs, focus groups and interviews. Whilst it was my original intention to include semi-structured interviews with patients and staff, this proved problematic, as I shall discuss further in this chapter. This triangulation approach to the methodology enabled me to gain an ecological perspective of the two wards observed, which then in turn illuminated (to use Aasgard’s terminology) the individual interactions and engagement with the music. I use the term ecology throughout as my study is interested in the interactions between individuals, the environment and music within this.

It must be highlighted that my research took place in 2017, pre-COVID-19, whilst outside musicians and visitors were able to enter the wards. During COVID-19

patients have been unable to see visitors unless they are at the very end of their life. All music performances have been stopped on the wards themselves with occasional performances played outdoors, only accessible to patients on the ground floor wards (of which Oak ward was one), who are able to see or hear the musician from their bed, and social interactions have been minimal.

In the following chapters I highlight the disconnect which can occur for people living with dementia when admitted to a hospital ward - the confusion and fear which is experienced from the lack of familiar faces, unfamiliar environment, and cultures of care which enforce restrictions and disempowerment (Featherstone and Northcott, 2020). This disconnect has been significantly heightened because of the further tightening of restrictions in response to COVID-19 as described above, and in addition the use of masks and minimised social interactions with staff and other patients. Whilst I walk us through these spaces, I ask you to consider my emphasis on the importance of relationship-centred care, social interactions, and the role of music within this. In some regards, my emphasis on the importance of such aspects of care inadvertently highlights the catastrophic impact COVID-19 has had and continues to have on this patient demographic whilst restrictions to relational care continue to be in place.

3.2 The study design

3.2.1 Why ethnography?

In the previous chapter I highlighted the ways in which music is often seen as an intervention within dementia care research, outcome rather than process focused. The complexity of music as a situational activity is often lost, along with the narrative and specificity of precisely *how* music plays a role in dementia care,

for the individual social actors within the space; it is here that the ethnographic method comes in.

In the broader field of dementia care research, the ethnographic method appeared to offer the tool I was looking for in order to capture micro shifts in terms of wellbeing, behaviour and social relationships, whilst also considering the wider environment of acute medical wards. Several studies have highlighted the use of ethnography within dementia care. Kontos (2004) adopted a long-term ethnographic approach to exploring embodiment within dementia care and the ways that people living with dementia maintain selfhood whilst living in a care home setting. Whilst the study was small, with 13 participants, the data was rich due to participant observations conducted over eight months for around eight hours per day, three days per week. The in-depth methodology enabled a deep exploration into embodied selfhood, and the ways that the individual participants experienced personhood, leading to the author's conclusions that personhood is embodied and must be 'embraced' in dementia care. Likewise, a more recent ethnographic study conducted by Featherstone et al. (2019) and following book (2020) considered the consequences of hospital care for people living with dementia, focusing in particular on 'resistiveness to care' and the ways that cultures of care within UK hospital wards, routines of care and everyday interactions demonstrate that hospital wards are not suitable for the social needs of patients living with dementia.

The two studies presented are indicative of the types of understanding that emerge from an ethnographic methodology. This qualitative methodology allows for a deeper understanding of the lived experience of dementia and of the individual's relationships with others, with their environment, and with

themselves. The ethnographic methodology appeared to provide the narrative that I was looking to capture in terms of music's role in dementia care, which I consider to be 'thick description' as described by Geertz (1973) as the ethnographer considering what the participants are doing, how they are doing it, as well as how these actions are perceived, interpreted by the individual, the ethnographer, and others.

A multisensory approach is perhaps required to provide a detailed way of understanding and experiencing how people living with dementia and their carers interact with their environments. In this regard, my research was influenced by the work of Sarah Pink (2015) in the emergent field of sensory ethnography, which recognises that researchers are not only learning about the things people do by observing and making notes but trying to understand that the things that people do and the way that they do them are not always things which can be expressed in words. Participants have ways of communicating that are not necessarily verbal, which as is known is particularly relevant for people living with dementia, where communication can be difficult, especially in the later stages.

We might naturally expect that music studies would be considered through sensory ethnography, music listening after all relies on the sense of hearing. However, with regards to my own research this is not the sole focus, rather I explore the role of live music in acute care as an embodied experience, considering the multisensory ways that people living with dementia engage through music. Inspired by Pink (2015) I consider how the senses can define space and place, and with reference to music the ways that meaningful, familiar music can help to connect people living with dementia to the healing environment by bringing the past into the present through sensory memories.

Likewise, I sought to capture not only what *was* happening, but also what was *not*; taking a cue from Clarke's (2003) emphasis that 'ethically accountable researchers... need to attempt to articulate what we see as the *sites of silence* in our data. What seems present but unarticulated?' To this end, my research demonstrates a consideration that the visual might not be the most important way of understanding, it is in the things that we do not see but *feel* that may be in some ways of equal importance.

3.3 Preparation for the research

Prior to my PhD research, I had worked as a Music Coordinator and Community Musician in various hospitals across the South of England, including the study site. Through this I first developed a curiosity around music's power within dementia care, having seen patients appear to remember long-lost memories, become more communicative and appear to experience increased joy during the musical interactions. I wanted to explore whether this was a result of the music itself, the musician, or indeed both. I developed a particular interest in agitation in patients living with dementia as my own experience had been that agitation was a main challenge for caregivers, and that it seemed to be experienced differently by each individual. Music appeared to reduce agitation, but I had little understanding of *how*, an area which has been a recurring theme throughout my research.

My PhD research builds upon a pilot study I conducted three years prior as part of my master's degree in Music Psychology, exploring the effects of live music for patients living with dementia, with a specific focus on agitation, anxiety and wellbeing. The study mainly used quantitative methods, including the Cohen-Mansfield Agitation Index (CMAI) and Likert scales to rate anxiety and wellbeing

before and after the live music performances. Whilst the results were promising on the surface – there was a significant improvement in wellbeing and a reduction in agitation and anxiety after the music, the data did not tell us *how* patients engaged with the music, and the various ways that music supported a reduction in agitation and improvement in wellbeing. The minute details of this were found through the observations.

It is for this reason that I consider the richest data of my pilot study to have been through the observations and interviews, as they provided a voice for the participants, giving meaning to their experiences, rather than reducing their emotions and behaviours to a number. I wanted to take this methodological framework further, to explore *how* patients living with dementia engage with music, and the interrelation between live music, healing environments and the wellbeing of patients living with dementia.

Bearing all this in mind, I chose to conduct an ethnographic study because it enabled me to take a wide lens approach, understanding the concept of musicking within the arena of healing environments, considering the nuances of such spaces and the ways the various social actors engage with music in terms of the environment and community of the space, whilst also capturing the micro changes that happen at an individual level in terms of wellbeing and social connections in relation to the music.

3.4 Research objectives

As originally envisioned, the specific research objectives were to:

1. Examine how the environment and particularly the soundscape of a hospital ward affects the ward culture and hospital experience for patients with dementia and care staff.
2. Explore how patients living with dementia respond to live music performances, and the 'spin off' effects of this for care staff.
3. Observe and understand what types of behaviours might be classified as agitation, and how they are manifested.

However, the more time I spent within the two hospital wards, the more I understood agitation to be a subjective and nuanced activity. Therefore, the final objective moved away from focusing solely on agitation as a set of behaviours, and instead agitation became one of the key recurring themes within the wider context of the affordances of music supporting relational-aspects of care. To this end, the research focused on the first two objectives, with the theme of agitation running through both.

3.5 The study site

The research was conducted at a major acute-care hospital in England, within two Elderly Care Units. Although these were not exclusively for patients living with dementia, they had a higher-than-average number of patients with dementia due to the age range of the patients on the wards (over 65 years of age). People living with dementia were admitted for reasons other than their diagnosis of dementia, including fractures (commonly hip fractures), urinary tract infections, chest infections, pneumonia, medical conditions requiring specialist treatment within an acute ward. Patients stay on average 11 days within the wards, often with delays in discharge whilst patients wait either for a package of care to ensure

continuing care and support in their own home, or instead waiting for an available space in a care home facility which can meet their specific needs.

The two wards studied were similar in size, Oak ward (ward one) caring for 26 patients arranged in four bays of five patients with six side rooms, and Beech ward (ward two) caring for 24 patients in four bays of five beds with four side rooms. Both Wards had undergone refurbishments to become dementia friendly, as part of the King's Fund Enhancing the Healing Environment. Dementia friendly in these contexts largely means aesthetic changes to the environment, with an aim to make hospital wards less disorientating for patients living with dementia. These changes in the two wards observed included removing the main nurses' station from the central corridor and instead placing individual nurse desks in each bay, clear signage, different coloured bays to help with orientation, artwork and photographs of local landscapes, and lighting set to imitate natural sunlight. The social aspects of the dementia friendly environment appeared to stem mainly from the occupational therapy team who provided occasional tea afternoons, the hospital's Musician in Residence, and visiting outside professional musicians.

The focus of the present study was on these live music performances. The hospital arts programme had a Musician in Residence, a community musician who sang popular music accompanied on the ukulele. She worked two days a week performing on the wards (mainly Elderly Care Units) and also coordinated outside musicians who visited the hospital. The outside musicians were from a national organisation who train and employ professional musicians (usually young musicians finishing or recently graduated from conservatoires) to deliver live music performances in a variety of settings including care homes, hospitals and schools. The organisation employs solo musicians, duos and small

ensembles consisting of a variety of instruments. However, in the present study I observed one male solo harpist, one female duo (violin and cello), and one all-male three-piece folk ensemble.

3.5.1 Importance of relationships

From previous knowledge of working in hospitals I have learned that having a good relationship with a 'gatekeeper' is key to gaining access to the study site. In this instance, my main contact was the Consultant Geriatrician at the hospital, Dr Myatt (pseudonym). I had worked at the hospital from 2009-2013 and had built a good relationship with the staff on the wards, and Dr Myatt had been the driving force behind the changes highlighted above, demonstrating his innovative approach to improving dementia care. He had a keen interest in the effects of activities for patients with dementia and was named as the Chief Investigator (CI) for my pilot study in 2013. Likewise, I had also established a relationship with the Research and Development (R&D) team within the hospital, the contact being made through my previous work at the hospital and close link with the head of department in both my administrative and research-based roles prior to the start of my PhD study.

In addition to the relationships built within the study site, I also discovered the importance of building a relationship with the study sponsor, who in this case was the Ethics and Governance Manager at the University of Exeter. This is the person who in terms of the NHS ethics procedure, provides authorisation on behalf of the University, and also provides copies of the various insurances needed in order to conduct the research at an NHS site.

Although I had successfully been through the NHS Research Ethics process previously, the process had changed significantly even in three years, and so I

found it invaluable to have the support of the Ethics and Governance Manager, who was able to guide me through the process and answer any questions I had along the way.

Incidentally, the study sponsor is also the one who decides whether any changes to the protocol are considered minor (able to approve in-house) or major (correspondence required with the Health Research Authority to approve the change). The implications of this restriction highlight a potential challenge when conducting ethnographic research within dementia care, particularly the concern that the research can become stifled as a result of the NHS ethics process, a point raised by Proctor. (2013). However, in terms of research involving vulnerable adults in healthcare settings all studies need to receive NHS ethical approval to commence, therefore this raises the question, how do ethnographic studies fit within such a bureaucratic system?

3.6 Ethical considerations

There are only a handful of studies exploring arts activities within acute hospitals in the UK compared with the growing research surrounding the same activities in residential care settings. I propose that this is largely since the ethics review process for research in NHS institutions is complicated, lengthy and appears daunting for many new or early career researchers. In the UK before a healthcare-based research study can commence, it must go through review by a Research Ethics Committee (REC) and also the Research and Development (R&D) office within the NHS trust(s) where the proposed research will take place.

Whilst this process may appear restrictive, in my own experience I found it to be useful when conducting the research as any potential challenges were raised prior to the start of the research, and as an early career researcher it provided

me with confidence in my research design and ethical considerations. Within the appendices I detail my own research ethics process and supporting documents.

The main ethical considerations raised by the REC for my research study were focused on involving patients living with dementia, who may have fluctuating capacity, and whether they should be included within the research. Although it is widely recognised that people living with dementia should have an active role in research focused on their condition, it is also acknowledged that this brings with it the difficulty of consent (Grout,2004). I intended to include people living with dementia who may lack capacity to consent, as from my own experience people with more severe dementia appeared to respond more to music than people in the earlier stages, and I did not want to exclude this participant group if they were able and willing to participate in an interview. My own motivation for the research stems from an expectation that it will contribute to the understanding of the lived experiences of people living with dementia. Therefore, it was my intention to include patients who were unable to consent for themselves, as the research may lead to a direct or indirect benefit to them or others with the same condition, with minimal risks.

Crow et al. (2006) produced a paper which 'sought to identify and disseminate best practice in relation to informed consent in research with six groups of "vulnerable" people.' (p.84). They interviewed 31 researchers about their experiences of conducting research with vulnerable people, and the process of informed consent. They determined that there are two schools of thought with regards consent - the 'optimistic' scenario – whereby the researcher feels that the process of informed consent helps to ensure a high-quality research project than perhaps unregulated predecessors, and the 'pessimistic' scenario – where

researchers believe that the process of informed consent actually hinders the quality of the research as it can mean low participant rates due to the difficulty in obtaining consent. As a result of my experience with the pilot study and low participant numbers due to difficulties in obtaining consent, this was a challenge I had foreseen in the present study and is one of the reasons I had chosen to focus on observations as my main source of data collection.

The REC had agreed that observing general interactions without knowing personal information did not require consent, as the observations were taking place in areas where people may have inadvertently been observed anyway. Although I did not have any personal information about the people on the wards, I knew if patients had a diagnosis of dementia due to the placing of a forget me not sticker above their bed (a now universal sign for dementia), and some patients would voluntarily offer information on why they were in hospital, and where they had been admitted from, for example own home, care home, or another ward in the hospital.

Any patients, members of staff or visitors who may have been mentioned in the field notes, did not require informed consent. However, it was important that everyone entering the wards was aware that observational research was taking place. I displayed posters in the information display cabinet on the ward and in the staff rooms, informing patients, visitors and staff of the research, and contact details should they have concerns about the study or if they did not want their observations to be included. Whilst this did not happen, had someone expressed that they did not want to take part, that person was excluded from any observation data that they were involved in. Whilst this was beneficial to my own research it does raise the question, how ethical is such a process particularly for involving

patients living with dementia? For example, the posters were displayed in prominent areas of the wards; however, they were not provided to each patient on an individual basis, and therefore I am not able to say for certain that every patient was aware of the research taking place. In hindsight this is a change I would have made, and I suggest that future research based on observations takes this into consideration.

3.7 On being a native ethnographer

A potential ethical challenge is that of being a 'native ethnographer' as Procter (2013) describes it - researching your own professional field, and in my case a setting I was very familiar with. Of course, it would be naïve to suggest that this would have no impact on my narrative; as explained previously I had worked at the study site for four years, coordinating their music programme. Whilst I had left the hospital three years prior to my PhD research commencing, I had kept in contact with the Consultant Geriatrician and Ward Manager of Oak ward. However, I interpret this insider role as a virtue, and I feel it contributed to the richness of the data I gathered. For example, being considered as an 'insider' meant that the staff appeared comfortable to chat with me as if I were another member of the team, and potentially the depth of the conversation was due to this existing relationship. Even if I did not know the member of staff personally, by way of association I was 'accepted' within the team.

To highlight this point further, my initial introduction on Oak ward was very different to Beech ward (where I had no previous associations). On Oak ward upon my first day of research the Ward Manager (and other members of staff) hugged me, found a locker I could use for my belongings, and welcomed me into the staff room to have my breaks. In contrast, I had no previous relationship with

Beech ward, in fact the ward was used for a different purpose (Medical Assessment Unit rather than Elderly Care) when I had previously worked at the hospital. Whilst it was Dr Myatt from Oak ward that introduced me to the Ward Manager on Beech ward, I still felt uncertainty from the Ward Manager, and a concern around my presence on the ward as a researcher observer, something the ward had not experienced before. As a result, I felt there was more apprehension from the staff in terms of chatting to me as they went about their work. Unlike Oak ward, on Beech ward I felt that I was very much considered an 'outsider', and as a result the spontaneous conversations were minimal, whereas staff on Oak ward would continually provide insights into my research. In this regard, I would argue that being a native ethnographer is what contributed to the depth of data I had collected over my study time. The key themes within my data emerged out of the conversations I was able to have with staff in particular, of being 'accepted' within the space as someone the staff could approach and converse with.

However, even having this insider knowledge of the ward and staff on Oak ward I still felt the insider/outsider paradigm which Procter (2013) talks of, in that whilst I was an insider with regards to my existing relationship with key staff members, in terms of my relationship with the patients I was an outsider; I had no previous experience with the patients, and nor they with me. Equally I had not undertaken ethnographic research before, and in this regard, I was seeing my own professional field through a very different lens, and therefore would argue that I was both an insider and outsider. Furthermore, I also switched between observer and participant-observer during the music performances, as I was equally sharing the experience with the patients, staff, musicians, and visitors, experiencing the

music for the first time together. Even if we had personally heard the piece previously, we had never experienced it performed by these musicians, in exactly the same way with the same people in the same context before. In this regard during the music performances, I considered myself a participant-observer. I try to share my own experiences as well as my observations of others, situating myself within the research as much as possible in the following data chapters.

3.8 Recruitment

Over a four-month period (November 2016 to March 2017) I undertook 104 hours of observations over 37 days, of 201 people consisting of patients (with and without dementia), staff and visitors, including 54 music sessions performed by six musicians. In addition, I conducted one focus group with five members of ward staff, and one-off interviews with four of the musicians.

3.8.1 Eligibility criteria

It was intended that participants who met the eligibility criteria (over 60 years of age, formal diagnosis of dementia, admitted to Oak or Beech ward) would be invited by the Ward Manager to participate in the study and be provided with a participant information sheet (PIS). Using Allan's Consent Procedure (2001) as a model, the participant information sheets and accompanying forms were colour coded and adapted depending on the intended audience. The information sheet for patients with dementia was written in clear language, in a large font, avoiding any unnecessary detail. However, in reality this process proved problematic in that there was a short window when I was in the hospital, and this did not always coincide with times when the Ward Manager was available to provide information to the patients, or would forget, due to the busy nature of their job. Likewise, on a couple of occasions the nominated consultees refused consent on behalf of a

patient as they felt that the individual would not be able to take part in an interview or were concerned that participation in the study would mean a delay to their discharge. Therefore, observational data became key within my study, as I describe later in this chapter.

I visited the hospital twice a week spending three hours on the wards, alternating each week between Oak ward and Beech ward, visiting at different times of day, mainly 10:00-13:00 and 13:00-16:00. On days when the musicians visited the hospital I would often observe on the day before the music performance and the day of the performance in order to capture the ward and the people in it prior to the music. In the middle of the study I conducted an intense research period, visiting Beech ward every day for seven days, observing two hours at a time. Due to the intense concentration required of observational field work such as this, I took a short break every hour, where I would leave the ward and take a short stroll down the hospital corridors.

3.9 Multi-method approach

3.9.1 Observations

General ward environment

Observations of the wards were written down in a field notebook (using anonymisation for anyone included in the notes). I wrote short-hand field notes into a small A5 notebook, and at the end of each observation period the field notes were typed up into a descriptive narrative. I positioned myself in different locations in the ward, generally starting with the communal area in the central corridor, allowing for a sense of the general ward environment, before sitting in individual bays either at the nurses' station or on a chair by the door. I chose

places to sit where patients would be used to seeing staff or outside visitors writing notes, in order to 'blend' into the environment. In the early days of research, I ensured that I visited each bay in the wards during my observation periods. As my analysis became more focused, I tended to visit the bays where I felt I would be able to capture observations relating to particular themes e.g. observing patients who the staff had indicated were agitated.

Observations of patients with dementia

Observations are considered a preferred method of data collection for patients with dementia who may have difficulties verbally communicating (Higgins, 2013; Beuscher and Grando, 2009; Bourgeois, 2002). It can also provide a 'live' account of how patients engage and interact with the music. Following the guidance from the European Commission (2015) observations are thought to be the least intrusive way of researching aspects of the lives of vulnerable people since it is less likely to challenge them emotionally and physically. As well as the general observations of patients outside of the musical events, observations of the patients were also conducted whilst the musicians performed on the ward and notes were taken of any changes within the ward and patient engagement. Observations were initially expected to include the following, during the music performance:

- Observation of exterior and physical signs – foot tapping, drumming fingers etc.
- Expressive movement – moving arm in time to the music, changing facial expressions etc.

- Physical location analysis – what is happening in the bay at the time of the performance?
- Observation of language behaviour – verbal and non-verbal communication.

However, as shown through the data chapters, as the research progressed, my focus moved away from the physical elements of musical engagement, to exploring music's affordances in terms of social relationships and what this meant for the individuals living with dementia.

3.9.2 Interviews

Whilst interviews were intended to be conducted with patients, staff and musicians, the research moved away from this method as a main focus considering the value in spontaneous discussions with staff and patients, as this felt a more natural means of understanding music's role within dementia care, and instead only used interviews with the musicians as well as one focus group of staff at the start of the research.

All interviews conducted with participants followed the episodic format developed by Flick (2000). This format was chosen as it provided a narrative voice for the participants, rooted in personal experiences – 'time, space, persons, events, situations (p.4). The Episodic interview schedule is based on 8 phases:

- 1) Introducing the episodic interview principle
- 2) The interviewee's concept of the issue and his/her biography in relation to the issue
- 3) The meaning of the issue for the interviewee's everyday life
- 4) Focussing the central parts of the issue under study

- 5) More general topics referring to the issue under study
- 6) Evaluation and small talk
- 7) Documentation
- 8) Analysis of episodic interview

(Flick, 2000, pp.6-13).

All interviews were recorded on a handheld recording device, and transcribed verbatim; participants were made aware of this in their Participant Information Sheet.

3.9.3 Interviews and spontaneous discussions with staff

I conducted one semi-structured focus group with the ward staff (Doctors, Nurses, therapy staff, Dementia Coordinators, administration staff etc.) exploring the impact of live music on the hospital ward and their working environment, using Preti's 2012 study "The Incidental Impact of Live Music on Hospital Staff" as a model for the interview guide. Using similar questions to Preti, the staff were asked about their experience of the music performances within the ward, how they felt this impacted patients with dementia, and any repercussions that such exposure had on their work.

A separate semi-structured interview was also designed for staff, to allow for an understanding of their experiences of agitation in patients with dementia, what impact this can have on the ward environment, and what behaviours they feel should be classified as 'agitation'. These were designed as two separate interviews, to allow staff the choice of topic (some may not have had experience of the music performances for example), and reducing the interview time required, therefore reducing staff burden. However, my own understanding of

agitation, seen through a needs-based approach, as subjective and episodic in nature, came about through spontaneous discussions with staff, and this became key. Whilst staff appeared reluctant to take part in interviews, they seemed happy to have spontaneous discussions with me even if they knew I would write the conversation in my field notes. My own findings in this regard are similar to that of Procter's (2013) who discovered that staff and service users had a negative association to the word 'interview', and from a researcher point of view he felt more formal and less comfortable in an interview situation than he did during spontaneous discussions. In my own experience staff found it difficult to make time to participate in the interviews, with the only time available seeming to be outside their work time, which for me was a concern that my research would cause a burden, something I had wanted to avoid. However, staff were very willing to chat about my research as they went about their work, and I was therefore able to capture small anecdotal data throughout the four months, potentially providing much richer information than I may have gained during a one-off interview with staff.

3.9.4 Interviews with musicians

Semi-structured interviews were conducted with the musicians to discuss their route into this profession, and how they deliver the music for patients with dementia. The topics included education and career path, any specific training they had received, how they chose their repertoire, how they engage the patients, the responses they have had to the music etc.

3.9.5 Reflective log

The Musician in Residence was asked to keep a reflective log (as in Aasgard's 2001 study), written soon after their performance, noting how patients and staff

responded, and how they felt whilst performing, and afterwards. I chose to use this form of data collection to form part of the triangulation of methods, adding validation to my own field notes, had I interpreted my observations of the musician 'in action' correctly?

3.9.6 Field notes

According to the standard wisdom, immersion in the field of study through observations allows the researcher to gain greater insight into the culture they are studying compared with interviews alone, and therefore enhances their understanding of the environment and social actors within. However, the difficulty lies in deciding what to observe, and how to depict this in the truest and most accurate form. Pink (2015) argues, sensory ethnography involves reflexive practice by the researcher, similarly Emerson et al. (1995) also suggests that 'substance ("data," "findings," "facts,") are products of the methods used, substance cannot be considered independently of the interactions and relations with others that comprise these methods; *what* the ethnographer finds out is inherently connected with *how* she finds it out.' With this in mind, I wrote detailed field notes considering not only what I was observing, but also how, through my own interpretations and personal reflections.

I undertook the writing of my field notes in this order: firstly, I took notes of my initial impressions of the ward, what I could see immediately as I entered, the volume, if it was noisy what was contributing to this noise? What could I feel (either a physical feeling or a sense), what if anything I could smell (pleasant or unpleasant). This provided me with a sense of the ward environment before observing individual participants in the ward culture. Secondly, I took note of my own opinion of what was significant on the ward, for example if a patient was

screaming out, or if I could see a patient wandering along the corridor. Thirdly, I noted what seemed significant for the people I was observing, as their opinion of significant events might be very different to my own.

I wrote my notes in an A5 notebook, creating jottings during my observations. These entailed words, phrases, conversations, reflections anything that would jog my mind later whilst I was writing up the field notes into a descriptive narrative. I decided to make these jottings at the time rather than making a mental note as I was concerned that I would miss important data or would misrepresent what I had seen if I were to rely on my memory alone. For this reason, I wrote up the notes into full descriptive pieces within 24 hours of writing the initial jottings whilst they were still fresh in my mind. Coding at the end of each day forced me to focus on certain areas as the research continued, which helped to shape my research focus.

3.10 Approaches to data analysis

The field notes were typed up in MS Word on my personal laptop, and likewise the interviews were recorded onto a handheld recording device and later transcribed into MS Word. All data was securely stored on the University's cloud system, and interview recordings were subsequently removed from the handheld device. Likewise, in order to follow each participant, I kept a log in an Excel spreadsheet, giving each participant a number (and noting defining features such as Oak ward, bay one, bed three, or staff nurse Beech ward, etc.) to enable me to later code and store all data on each participant to support my writing up of case studies which are included in the following data chapters.

My analysis was situated within the field work process; inspired by a grounded theory approach I started the analysis early on in my data collection as suggested

by Charmaz (2014) to allow themes to emerge and then to go back into the field to further explore these themes as my research progressed. I imported all data into NVIVO 11, and began with open coding, sticking closely to the data, coding line by line; this type of coding provided a detailed analysis that enabled me to deeply connect with the data and themes that were emerging.

Below is the initial list of top-level codes:

1	Activities of the body
2	Activities with objects
3	Acts of caring
4	Agitation Management
5	Agitation signs
6	Bringing the outside in
7	Call bell
8	Care interrupting music
9	Coding in the ward
10	Communal table
11	Community
12	Connectedness
13	Corridor

14	Dialogues with musicians
15	Discharge
16	Environment
17	Escapism
18	Frustration
19	Home
20	Hospital politics
21	Identity
22	Isolation
23	Material culture
24	Music as distraction
25	Music as transformational
26	Music integrated in care
27	Music interrupting care
28	Musical activities
29	Musicians' craft
30	Mutually beneficial music
31	My dialogue with patients

32	My involvement in care
33	Patient and staff interaction
34	Perception of performing for people
35	Physical environment
36	Privacy
37	Quality of life
38	Radio
39	Response to music
40	Responses to my presence
41	Role of the cleaner
42	Side room
43	Sleep
44	Smells
45	Soundscape
46	Spontaneous musical noises
47	Staff communication
48	Tea

49	Teamwork
50	Temperature
51	The performance
52	Visitors
53	Wandering

I then organised these codes into a structured coding system, using categories and subcategories, with no more than three levels in each hierarchy, as listed below. Structuring the data in this way has many potential benefits for data analysis – it allows the researcher to visualise any emerging themes; it reduces the ‘chaos’ that can ensue from open coding; it prompts the researcher to clarify their ideas and ensures a thoroughness of coding as the research progresses. (Bazeley and Jackson, 2013, p.97). For example, in my own analysis, the open coding enabled me to see the bigger picture of my data, capturing all the various elements of my research, and without this I would not have noticed more specific themes such as ‘connectedness’, ‘emotional intelligence’, and ‘social relationships’ which became key recurring themes within my research.

1.Musical Connections	a) familiar Music
	b) interactions

	c) musicians' craft
2. Healing Environment	a) soundscape
	b) agitation and environment
	c) bringing the outside in
3. Agitation	a) how it is manifested
	b) how it is managed
	c) perceptions of agitation
	d) music and agitation
4. Music and Care	a) soundscape before, during, after music
	b) responses to music
	c) Music as transformational
	d) when music did not 'work'
5. Community	a) communal areas
	b) how sense of community is created

	c) patient and staff interactions
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As the list above shows, four major themes emerged from this further coding: connections; role of music within the healing environment; agitation; and community in acute settings. Whilst writing the data chapters, these themes strengthened as I further explored the codes. For example, through repeated analysis of the codes I began to explore the relationship between instances of agitation and disconnection within the environment, viewing music within this theme and the ways that meaningful music appeared to support a reduction in agitation due to the ways it afforded moments of connection. The example highlights one way in which the codes and themes became intertwined, much in the same way that I had observed music intertwine with the care of patients living with dementia.

The challenge then was to turn these codes and themes which emerged from the data into a narrative, demonstrating music's role in dementia care. As Pink reflects, 'the task of the sensory ethnographer is in part to invite her or his reader or audience to imagine themselves into the places of both the ethnographer and the research participants represented.' (Pink, 2015, p.49).

Chapters four, five and six build upon the codes listed previously, exploring the four major themes identified – connections, music within the healing environment, agitation and community in acute settings. These data chapters consider the interrelations between live music, the ecology of acute short-stay environments, and relational aspects of dementia care.

Chapter four explores the environment of the two short-stay hospital wards observed, providing detailed descriptions of the soundscape, and the role of live music within this. Chapter five draws upon the theme of connection, looking at the ways in which live music may create and sustain moments of social connection in an otherwise disconnected, transient environment. Chapter six considers agitation in the context of social and emotional needs of individuals living with dementia, highlighting how live music, delivered by emotionally intelligent musicians may be one way to support a reduction in feelings of agitation.

3.11 Entering the wards

The hospital site occupies 52 acres set back from a busy residential road. Situated 1.5 miles from a small city in the South of England, the NHS Foundation Trust cares for a catchment population of around 500,000 people. The warm, honey coloured stone exterior of the main hospital is in keeping with other buildings in the city, and this provides a modern feel, unlike the redbrick style of most English based hospitals. Approaching the hospital grounds from the newly built main car park walking up to the main turning area, there are cars waiting on the left in the short stay 20-minute pick-up area, buses on the right, and directly in front is the most prominent building, the main atrium area of the hospital, with passenger transport ambulances lining the spaces in front. Under the main canopy of the entrance there are patients in wheelchairs wearing hospital branded pyjamas or holding drip stands, chatting with others, or on the phone. This used to be a main smoking area, but the trust has since become a completely smoke free site, meaning that only vaping is permitted, outdoors away from main entrances.

The main atrium area is a bright, airy, and modern space, with the main reception and hospital league of friends shop on the right, and a large coffee shop area directly in front, filled with light wood coloured round tables and chairs. An expansive sea-themed art installation hangs above the coffee shop serving area, this has been there for as long as I have known the hospital, with an art exhibition space on the left and right walls. Even from the first encounter with the hospital, the high-quality artwork features prominently.

Three corridors with light coloured flooring lead off from the main area, with large signs on the walls pointing to the various coloured areas and codes of the hospital. The walls are of a generic magnolia colour, but with each space lined with artwork, including artwork created by children, outside the paediatric ward, just down the corridor from Oak ward. During the day the corridors are lined with people and are noisy spaces, staff walking hurriedly to get to their destination, passing by confused visitors and patients asking for directions or staring at the map, figuring out the best route to their appointment or visit. Continuing straight down the central corridor, just before the double doors lead to the outside (where the estates facility offices are situated), you turn left into Oak ward. Beech ward is situated directly above Oak ward, accessed by a set of stairs next to the entrance of Oak ward.

Both wards are similar in design, although Beech ward is slightly smaller and does not have a day room space, which Oak ward does. Upon entering Oak ward, the modern style is striking, it is unlike other wards in the hospital. A buzzer system is in place, with the Ward Clerk allowing access to the space (staff including myself had swipe cards to allow entry). Straight in front is the Ward Clerk's desk, with the Consultant Geriatrician's office to the right, behind closed

blinds. The ward is brightly lit and surprisingly quiet, this is in stark contrast to other noisy and busy wards within the hospital, and in fact within most hospital wards as described by Featherstone and Northcott (2020). Past the Ward Clerk's desk and into the main corridor, to the left side of the corridor are four bays, each containing six occupied beds (it is extremely rare for patient beds to be empty), and to the right are four side rooms. In between the side rooms hang large photographs of local landscapes.

Each bay entrance is painted a different colour, bright orange, green, blue and purple, and there are large signs with pictures for the bathroom and shower. The dementia friendly design is prominent throughout. The bedframes are coated in cream plastic with remote controls to move the bed up or down, and the prominent bright orange button to request staff assistance. Above the bed is a whiteboard with the patient's name (and preferred name), Consultant name and any medical instructions such as nil by mouth, and for patients living with dementia the blue forget me not sticker, or maple leaf for falls risk, a symbol representing their dementia and mobility needs. To one side of the bed is a large wipe-clean armchair, next to a lockable bedside cabinet filled often with toiletries and clothing, and a long thin table which fits over the bed, set on four casters for easy movement. Patterned curtains hang by the side of each bed, ready to be drawn when privacy is required, however as I shall describe in the following chapter, this is merely a token gesture.

In each bay sits a single computer and chair for the nurse in charge of the area. Staff walk the corridors, dressed in different coloured uniform to denote their role and grade. Doctors wear their own clothes, men wearing shirts, sleeves rolled up

and chinos, while women wear office style clothes – neat skirts or chinos with a blouse in neutral colours.

In between the four bays on the left-hand side is a large day room area. This space is decorated in home-style design, a large TV is mounted above a fake fireplace, dark mahogany wooden bookshelves stand behind a faux leather sofa, in front of the steps and handrail used by the therapy team for patient rehabilitation, a reminder of the nature of the space. In front of the therapy team office stands the large dining table and six high backed black faux leather seats, a visual demonstration of social and physical care intertwining. However, this room is rarely used, and often sits empty or occupied by staff for meetings or writing notes.

The social interactions take place mainly in the individual bays and the central corridor, this is where my research is centred. In the chapters that follow, I have continued to recreate the 'ethnographic place' of the two hospital wards I observed, capturing the essence of the wards, the people, the sounds and sights, whilst also focusing on my own emplacement within these spaces. I invite you to walk the wards with me.

4 Music intertwined with soundscape

4.1 Introduction

The data findings are presented within this chapter and the two following chapters. Within this chapter I focus on the ecological considerations of the two elderly care wards observed, capturing the soundscape and the interactions between live music and environment. Chapter five draws on the theme of disconnection, exploring diminished sense of self as a common experience for patients living with dementia, and the ways that music may support social connections within such a transient, disconnected environment. Chapter six explores the role of musical connections within the wider context of relational aspects of care, and the ways that music can be one way of supporting a reduction in agitation when delivered in an emotionally sensitive way.

In this first findings chapter, I am going to offer a wide lens picture of the auditory landscape of the specific wards I studied in general, whilst also homing in on small, individual-level interactions which in turn contribute to the wider soundscape of the hospital ward environments. I am then going to look at the role of music within these soundscapes, in particular through the notion of 'paramusical' (DeNora and Ansdell, 2016), and the ways that music, care and soundscape are intertwined.

Featherstone and Northcott (2020) state that hospital wards are 'particularly unsuited for people living with dementia', as they are often noisy, busy and brightly lit environments, which can be confusing and at times frightening spaces for all patients, as previously discussed within the literature review. The two

wards I observed were dementia friendly, in that they had been adapted for patients living with dementia as mentioned in the previous chapter. However, the feelings of disconnection, disorientation and despair for patients living with dementia, could still be felt (as also discussed by Featherstone and Northcott, 2020; Reilly and Houghton, 2019; and Edvardsson et al., 2011). Therefore, considering hospital environments, and in particular the soundscape within these, is critical, and in light of what might ameliorate the sense of disconnection, music's role can be seen through its ability to afford reminiscence. Music which is meaningful to the individual, i.e. is familiar, and they already associate with positive memories, can recreate associated emotions, and within this chapter, I argue may in turn create positive associations with the present environment, and therefore support wellbeing.

Hospital wards are social and public places, yet deeply personal and private, with little space for social interaction within their tightly timetabled culture. As Featherstone and Northcott (2020) describe, the wards are 'so full of activity, yet also so full of invisibilities', and the more invisible a patient living with dementia feels, the more heightened their frustration can become (ibid). This frustration can manifest in shouting or screaming, their behaviour then labelled as 'challenging behaviour' rather than perhaps a perfectly normal emotional response to an abnormal situation. Within this chapter I describe these different sounds, and rather than seeing them as behavioural challenges, I invite us to consider these as potential sounds of communication, verbal and non-verbal, the challenges for patients who were not able to communicate their needs, and the ways that the live music performances afforded moments of communication. Through this we

begin to develop an understanding of music's role within the relational aspects of care, and the ways it can support the social experience of being in these wards.

I explore these interactions afforded by the musical performance through the concept of paramusical, which as DeNora and Ansdell (2016, p.35) describe, are 'any other "things" [outside the musicalized sounds] that are caused, initiated, influenced, modulated, or co-occurring with musicalized sounds.' Paramusical are the things that are not music themselves *per se*, but 'go with' music. In this regard, I look at how different paramusical matters come to be connected to the musical performances, and with what consequences. For example, I explore the changes in the soundscape and social environment during and after the music performances, with an increase in social activity and communication resulting in a ward environment which felt less chaotic, and more conducive to the social needs of the patients. I argue that it is through the understanding of these paramusical events that we can understand the affordances of music to support relational aspects of care for patients living with dementia.

I posit that we can understand music in an ecological sense, considering the intertextuality of music and environment within elderly care wards, one impacting the other. I will demonstrate how the use of live, familiar music in this context, anchored patients living with dementia, and afforded wellbeing, or least opened up the possibilities of such. This chapter begins by looking at the soundscape of the two dementia friendly wards observed, the particular sound sources that create the sonic environments within these spaces. I consider the social sounds of the wards, and the ways in which we can see sounds of communication to be at the heart of the ward soundscape, drawing in the ways in which music supported and at times increased communication and social activity which lasted

long after the music ended. In this regard, the chapter moves on to explore the intertextuality of music, soundscape and environment, considering the ways in which musical episodes are connected to paramusical things (DeNora and Ansdell, 2016), the things which 'go with' the music, but are not the music itself. Within this I draw our attention to the concept of musical asylums (DeNora, 2013), and the ways that familiar, meaningful music might afford a sense of removal for patients living with dementia whether figuratively or literally, and refurbishing, transforming and remaking the environment to support opportunities for wellbeing.

4.2 Soundscape of the healing environment

4.2.1 Order of the day

The structure of the day in the two elderly care wards I observed appeared marked by particular sound sources. For instance, the morning encompassed sounds of cleaning activities, preparing the ward for the day ahead – the sound of the cleaning trolley being wheeled down the corridor, the sound of the vacuum cleaner, the bin lids hitting the wall as they opened etc. Rice (2013, p.41) refers to these sounds as 'contaminating' the ward; this feels a fair description, with these sounds cutting through the quiet environment. The morning routines of the wards begin early, with monitoring beginning around 6 o'clock, when the lights are also turned up, and thus the sounds of the day begin.

The collection of sounds heard every morning appeared to depict the preparation of the ward, with the increase in sound sources linked with sounds of activity, which were heightened during the morning, preparing the ward for the day.

Mackrill and Jennings (2013) discovered similar findings in their observations of the soundscape within a cardiothoracic ward, remarking that early mornings were 'quiet' and 'relaxed', but between nine to eleven o'clock it became busy and subsequently noisier whilst staff undertook care tasks such as washing and dressing. These findings are in agreement with Preti (2009) who also discovered that the mornings were much busier than the afternoon, when the 'rhythm' of the hospital slowed down. (p.192).

Through my own observations, the preparation of the ward and patients took place concurrently, with the various associated sounds intertwining to create a distinct soundscape which appeared unique to the mornings. Increased sounds of conversation were heard as staff moved between bays assisting patients with washing, dressing, and changing the bed linen, the sound of the linen trolley moving down the corridor, occasionally bumping the wall, making a clattering sound. It almost felt that with eyes closed one would still be able to depict the time of day in each ward through the sounds heard. Likewise, every day at around the same time (ten o'clock in the morning), I listened to the sound of the medical notes trolley being wheeled from bay to bay; an auditory cue that the doctors were making their rounds. These sounds painted a picture of the order of the day within the hospital, this continuity and flow of the sound order being similar throughout the day every day.

As Rice (2013, p.4) comments, 'patients come to know the hospital and understand its routines and events through their ears.' In fact, often because patients are only able to see activity in their immediate vicinity, we might consider that they rely more on their auditory sense to tell them what is happening within the wider ward environment. For instance, one patient Mary, remarked "oh goody

lunch is here” when she heard the sound of the food trolley wheeled into the corridor (she couldn’t see the trolley from where she was positioned), in addition to the increase in staff conversation as they commented on the meals – “mmm smells nice today”, and the sound of the metal lids being lifted off the selection of dishes.

Despite the increase in ward activity however, the mornings still appeared relatively quiet in terms of the soundscape. In fact, the mornings were much quieter than they had been when I previously worked at the hospital; back when the nurses’ station was at the centre of the ward, and as a result generated a lot of noise and activity (which staff perceived as “chaotic”). As previously highlighted, both Beech and Oak wards had undergone dementia friendly refurbishments by the time I completed my PhD research. This included removing the main nurses’ station and placing individual desks within each bay, which acted to remove the biggest ‘noise’ within the wards. Instead of the loud sounds of conversation, telephones ringing, doors opening and closing, these dementia friendly environments brought with them significantly reduced sound levels, and if conversations took place in the corridors, staff would often talk in quiet and hushed tones. It must be noted that this new quiet environment is atypical, with general hospital wards considered to be challenged by noise pollution, with patients feeling ‘trapped in a stress inducing soundscape’ (Xyrichis et al., 2018).

The activity and therefore sounds heightened as the day continued, with increased volume connected with increased flow of traffic and activity on the wards. Likewise, new sounds became added to this symphony of the ward, patients being transported out of the ward often to medical appointments elsewhere in the hospital, visitors arriving, new voices etc. Every day this led to

a crescendo with staff rushing to complete their care tasks before lunch. Then, at the peak, when the lunch trolley arrived, a full sensorial cue, the ward would suddenly drop to a quiet volume again, activity diminished, doctors finished their ward rounds, nursing staff would finish washing/getting patients ready, cleaning activity stopped, and the ward became quiet once more.

The lunch period appeared to be the protected time where acts of caring were in flow on an individual basis – staff and visitors fed patients who needed assistance, whilst the remaining patients ate their lunch generally in silence. Staff talked with one another in quiet tones and there were no other visitors allowed on the wards except for those helping with feeding. This was a hospital wide policy, to protect mealtimes, and reduce distractions to allow patients to eat their meal in peace. Despite this, I was still allowed to observe during this period, again as previously mentioned, reconfirming my position as an extended member of the ward staff. Over the lunch period I mainly sat in the corridor to blend into the background, and not disturb or distract patients during this protected time.

The hour after lunch continued to be quiet; patients were often sleeping, the ward rounds had been completed, and nursing staff took it in turns to have their own lunch, often away from the ward. It felt as though the ward took a collective breath before activity and associated sounds picked up again; this was around two o'clock in the afternoon with an increase in visitors, ward moves, patient discharges etc. There was heightened activity at this time due to the increase in visitors and as a result early afternoon appeared to be when the sound levels were at their highest. The soundscape shifting from the sound sources of the morning, to incorporating sounds of social activity, arrival and exit of visitors, chairs moving, increased sounds of conversation. It appeared that staff, patients,

and visitors would all talk at a normal or louder than normal conversational level depending on the sound level of the ward in general – as the general sounds increased so did the volume of conversation. This is in stark contrast to the hushed silence of the ward at the start of the day. However, this increase in sounds was not a negative, rather it appeared to create a positive atmosphere on the ward, one of laughter, conversation, activity – social sounds, as I shall describe in more detail within the next section.

Similarly, Mackrill and Jennings (2013, p.2), through their observations in general hospital wards, remarked that ‘human generated sounds were reported most (67%) including conversations of patients, nurses, visitors, along with laughing and coughing.’ These social sounds were also typical in my observations and became a main focal point for my observations of the soundscapes in the two wards as I describe later in the chapter.

As with the lunch hour, so too at dinner, the ward reverted back to a sonic lull. However, unlike breakfast and lunch, the ward continued to be quiet in the evenings with fewer visitors, and medical activity generally kept to a minimum unless urgent. I was not able to observe overnight due to this reduction in ward activity, it was a concern that as a researcher I would not be able to blend in with the environment as intended. Therefore, I was not able to capture the soundscape overnight. However, through discussions with staff I understood that the soundscape of the ward continued typically to be quiet overnight and peaceful with reduced activity and therefore reduced sounds. Whilst the literature demonstrates that noise at night is a persistent problem, impacting on quality of sleep for patients (see Filliary et al., 2015), this did not appear to be the case

here, again highlighting the atypical nature of the two dementia friendly wards I observed.

It was my observation that at the weekends there was much less activity on the wards in the mornings – the Doctors did not do their ward rounds, only seeing specific patients who needed to be seen as a priority. However, the noise levels on the ward appeared to remain at the same quiet level. Even despite the notable increase in ward activity in the mornings during the week, the sound levels remained just as quiet during the weekends when there was a diminuendo in ward activity. We might consider this quiet atmosphere to stem from the dementia friendly design of the wards, the ‘calm’ and ‘quiet’ considered to be key features of the re-design according to the staff I spoke with. For example, in a focus group both Oak ward’s Ward Manager, Robert, and Consultant Geriatrician Dr Myatt, commented on the positive effect of this quieter soundscape:

[Robert]: There is a different feel [on the dementia friendly wards] you know. I dunno, again I think it might be to do with the buzzers that’s because the nurses are with the patients. You interact with the patients and therefore they don’t need to press the buzzer. It means that they [the bays] are much quieter, they’re quite tranquil in comparison to other wards.

[Dr Myatt]: It’s certainly more tranquil on those wards [dementia friendly wards], much more quiet, because the central nursing station is a hub, basically a noisy area, call bells going off and so it does make a difference.

Less noise.

We can see here that both Robert and Dr Myatt talk of the quiet of the ward soundscape as a positive, comparing it to the previous ‘noisy’ area of the nurses’ station with the sound of call bells and activity, whereas now they consider the

dementia friendly wards to be 'tranquil' due to this reduction in noise. However, we might question whether a reduction in sounds and noise levels also means a reduction in activity, and the resulting effects on social interaction, something I explore further in chapter six. Therefore, within the two wards I observed, I arrived at the understanding that the soundscape of the ward may not necessarily represent how busy the ward is, and the ward itself being busy might not necessarily be understood as a negative, rather it depends on the types of sounds contributing to the soundscape, and the ways that patients living with dementia understand and interact with these sounds. As Mackrill and Jennings (2013, p.2) remark, 'it may not necessarily be the absolute sound level that is important but the content and the interpretation'.

4.2.2 Social sounds – sounds of communication

We can consider social sounds and sounds of communication to be at the heart of the ward soundscape, as discussed previously, it is not necessarily the sounds themselves, but how they are perceived and interacted with. In this regard, it appeared that social sounds gave an opportunity for positive emotions for some, again depending on interpretation. For example, one Saturday morning I observed Joan, a volunteer at the hospital, taking the tea trolley around Beech ward. Prior to Joan's arrival the ward had been quiet, no conversations were heard, the majority of patients were either dozing or staring at the wall. Even sat at the other end of the corridor I could hear Joan wheel the tea trolley to each bay, asking each patient in a loud voice if they would like a cup of tea, making jokes as she went along, such as "sugar for you Mr Brown or are you sweet enough?" It was clear that other patients could hear Joan as she moved the tea trolley along the corridor. For example, I heard one patient, Moira, saying "oh

goody tea is here!", as she re-arranged the table which lay over her lap, presumably to make room for the cup of tea. This was a typical example of ways in which social sounds linked with social activity, in this instance the tea trolley, could support social interaction and as a result afford possibilities for emotional wellbeing.

Likewise, during visiting when social activity is in flow, there appeared to be a transformation in the environment. Even if a patient did not have a visitor themselves, they might smile at other patients and their visitors. However, we need to be mindful that this might have an element of performativity, the ward is a very public space and therefore social conventions such as smiling, being polite might continue.

As discussed previously, sounds of conversation were at their loudest during visiting times, and it appeared that patients were more engaged and interacted more with one another and their caregivers during this time compared with the silence of the ward beforehand. To this end, we might consider that social interactions and relationships are more important than the physical environment, an observation also made by Andrade et al. (2016), questioning whether it is the place or the people which support patient wellbeing during hospital admission.

When there was diminished social activity on the wards, outside of visitors, musical performances, and ward rounds, other forms of communication appeared to take place. For instance, call bells appeared to be rung more often outside of visiting times, likewise there seemed an increase in patients calling or shouting out, requesting attention, when they were alone compared with when they had a visitor or caregiver with them. With this in mind, we might consider the call bell

merely to be an extension of communication, a lifeline for patients, and a way to connect with their caregivers (as described by Duffy et al., 2005).

Within general hospitals the call bell is a universal sign for attracting attention; when someone was admitted to Beech or Oak ward one of the first things the nurse told them was where the call bell was, and to press it if they 'need anything'. Each patient had a control panel connected to their bed with a large orange call bell at the top (indicated by a bell picture), and up and down symbols to raise or lower their bed. In the central corridor there was a board with each bay and side room listed. When the call bell was rung an alarm sounded in the corridor and the board lit up above the bed number, as well as turning on an orange light above the door of the corresponding bay. As an alarm did not sound at the patient's bedside, they often pressed the bell repeatedly, although this did not change the sound in the corridor, the bell sounds on and off continuously until a button was pressed above the patient's bed, cancelling the request. Therefore, I am suggesting a recommendation for design, for a sign (audible or visible) for patients to know that the call bell has been rung and is waiting to be answered.

The call bell sounded on and off throughout the day, and this formed a large part of the soundscape in the two elderly care wards observed. It is the one sound which staff and patients talk most of, and generally in terms of negative associations, for instance staff would comment that a patient had rung their bell continuously, or patients remarking that their own or another patient's bell had been rung for a long time without being answered. These are also typical findings of other research exploring the use of call bells within general hospital wards.

For instance, Digby et al. (2011) discovered that on average in the small acute ward under observation, there were 320 call bell activations in one day, 2,240 a

week, with response rates ranging from two seconds to five minutes. I am providing this statistic to paint the picture of the soundscape; however, it is my intention not to consider the instances of call bell activation in isolation within the two wards I observed, rather through a social-ecological perspective I am exploring the dynamics of the call bell in relation to social activities and human-environment interactions.

To this end we could consider the sound of the call bell to be the keynote of the ward, which Schaffer (1977, p.9) describes as:

‘a musical term; it is the note that identifies the key or tonality of a particular composition. It is the anchor or fundamental tone and although the material may modulate around it, often obscuring its importance, it is in reference to this point that everything else takes on its special meaning.’

With this in mind, I am arguing that it is the symbolism of the call bell sound itself, the sound of communication, which is the fundamental core of the two elderly care wards I observed.

Through this we might also understand behaviours such as agitation manifested through screaming and shouting (often referred to as ‘vocally disruptive behaviour’) to be another form of communication. As Duffy et al (2005) state, cognitive impairments, visual loss and mobility issues can make it difficult for patients living with dementia to use a call bell or to understand its purpose. Therefore, it should be no surprise that we may hear more patients living with dementia calling out or shouting out to attract attention. For example, in my own observations I often observed patients vocally calling out, this was especially seen in patients in the side rooms where nurse visibility was limited due to their positioning on the wards. Consider this extract from my field notes:

I can hear Joan calling out from the side room, she's not using particular words, but her tone sounds strained and loud as if she is calling for attention, it sounds like she's calling "hey", but I can't be certain. She started with a low murmur, but as time passed this became louder and higher in pitch, it now sounds like she is screaming, loud and repeatedly. Two nurses enter her bay and Jean is now quiet.

This was a typical observation, patients living with dementia would often call out repeatedly as in the example of Joan, often repeating just one word, for example "no" or "nurse", calling out this word, over and over, each time increasing in volume until someone attended to them. Agitation and these sounds associated with agitation became part of the soundscape, human-environment interaction in full flow. Consider the example of Betty, I could hear Betty screaming on and off repeatedly like a siren from behind her closed curtain saying "nurse, nurse" over and over. This vocalising of agitation became an encompassing feature of the soundscape at that moment in time, it was impossible to escape, everyone could hear the sound although not everyone responded to it. In this regard, we can consider that sounds of agitation, particularly vocalising, can be seen through a socio-ecological perception as sounds of communication. These sounds become part of the rich tapestry of the soundscape itself as well as being a possible reaction to it, as I shall describe.

4.2.3 Perception of sound

The response to the various sound sources heard within the two elderly care wards I observed appeared to vary depending on the person listening to and engaging with the sound. As Mackrill and Jennings (2013, p.4) describe, 'these almost physical attributes [the sound sources] feed the subjective appraisal and

response of the individual.’ It is exactly this subjectivity with regards the soundscape which my own research looks at, opening the way to exploring music’s role within the soundscape, individual perceptions considered at a micro level. The different sounds of medical equipment within the two wards observed appeared to have different meanings for the various social actors on the wards, with different forms of listening appearing to take place for patients, staff and visitors, a finding also observed by Rice (2013). For instance, the medical equipment had different tones and metre of sounds which were evidently understood by the staff and responded to appropriately, either to ignore and carry on with the current task or to respond immediately if the sound was a code for urgent action.

One Tuesday afternoon whilst Oak ward was busy with visitors, noisy with conversation and resulting social sounds, I heard an alarm going off at John’s bedside. John and his visitors appeared alarmed by this sound and looked at the blood pressure monitoring equipment next to John, appearing puzzled by the screen, perhaps unfamiliar to them, although this is a mere assumption. Two nurses walked past John’s bay, and as his visitor put her hand out signalling for them to come over, one of the nurses, Tracey, said she would be over in “just one minute”. During the time that John and his visitors waited (around five minutes), John started to become visibly frustrated with the alarm sound as well as embarrassed, he kept looking at the screen with his family, trying to work out what the alarm was telling them, whilst also telling patients around “Oh this bally thing, I’m terribly sorry, nurse said she’ll be along in a minute”. Nurse Tracey arrived wheeling a new monitoring machine saying, “don’t worry John, it’s just a low battery, I’ve got a better machine here”.

Considering this example, we might assume that Nurse Tracey heard the sound source (the alarm) and responded by getting a new piece of equipment (and in no rush to do so), because she had perceived the alarm to be low priority from understanding the sound to mean low battery, or a fault in the system somehow. This supports Rice's (2013, p.25) findings, in which he compared this type of listening to stethoscopic listening: 'they [nurses] are trying to listen to the ward as if it were a body, making judgements as to which sounds are normal and which abnormal, diagnosing problems affecting patients.'

Whilst during my research I did not observe staff responding to abnormal sounds, in previous experiences of working in general hospitals over the past decade, I have observed staff attending to particular sounds over others. For example, falls alarms (also known as a tab alarm), are often connected to a cushion, whereby if a patient who is considered a falls risk stands up, an alarm sounds. Upon these occasions staff would always attend to the alarm immediately because it signalled that a patient was considered to be at risk of potential injury. In reality, the patient themselves would appear to become more agitated as a result which led to increased instances of the patient standing up, attempting to leave the space. However, this is not within the scope of this thesis, as it was not an observation I made during my PhD research; however, I feel it is an area of research worth highlighting with regards the soundscape, demonstrating the ways that staff understand and interact with the soundscape.

Mackrill and Jennings (2013) discovered that patients' negative perceptions of sound sources were generally focused on occupational sounds such as cleaning, machines, trolleys, loud conversation etc. Similarly, my own findings were that patients living with dementia in particular appeared to have negative perceptions

of sound sources from machines, particularly repetitive sounds, as demonstrated in the example of John and his visitors. However, other occupational sounds such as cleaning, conversations, and moving trolleys did not appear to produce negative responses, rather as described previously, these social sounds afforded positive emotions.

However, staff on the other hand, often remarked that the sounds of trolleys were “too loud”, or “the biggest noise on the ward”. Likewise, the sound of the medical notes trolley in the mornings, a sign of the Doctors’ rounds, appeared to provide different perceptions among patients and staff. For instance, one Monday morning whilst I was sat in bay two on Beech ward around half past ten, I could hear the doctors arriving on the wards, wheeling the medical notes trolley down to bay one, where they stood outside chatting between them about the patients they were about to see. Joan, a patient in bay two, could hear the Doctors talking and said, “oh thank goodness, the Doctors are here”. However, the response of the two HCAs in Joan’s bay contrasted with this positive response. The two members of staff commenting that the Doctors would be coming to their bay next so “we need to get Mrs Jacob’s ready”, with the activity of washing/dressing feeling like it increased, staff walking quicker, getting the bay and patients ready before the Doctors arrived. This is similar to the findings of Mackrill and Jennings (2013) that nurses regarded doctors’ ward rounds as an ‘intimidating sound’. This contrasting example demonstrates how patients and staff at times perceived and responded to sounds in differing ways.

In contrast to Mackrill and Jennings (2013), my own observations were that the patients did not respond negatively to occupational sounds generally, but rather did not respond at all; whether this was through habituation or disengagement it

is unclear. Rice (2003, p.4) considers the former to be the case, that patients soon became used to these hospital noises 'in the way the sound of a waterfall soon becomes an unheard sound to those who live near it.' It was my own observation that habituation may have occurred for patients without dementia, or rather if not habituation, they may have accepted the sounds, and it was certainly true for the staff that they became habituated to the soundscape and sound sources within. However, for patients with dementia they often appeared to be confused about where they were and why they were there, and it seemed that they perceived the variety of sounds as confusing, adding to this disorientating atmosphere.

For instance, one patient Doreen was staying in Beech Ward in bay one closest to the entrance to the ward. Each time the doorbell rang making a buzzing sound, she would jump and say something along the lines of "what's that?" or look around, eyes in panic. Likewise, she often asked the staff where she was, or requested that they point her in the direction of the bus stop. It was clear that she was confused and disorientated, and the sound sources such as call bells, door buzzer and monitoring equipment, did not help to orientate her within the space of the acute medical ward. Similarly, I observed Jack appear frightened when his monitoring equipment began beeping, shouting "stop...stop....Oh... how do I make it stop?" The staff appearing very shortly after to turn the sound off. Without speaking to Jack or Doreen about their experience we cannot understand for certain why they responded in this way, whether lack of understanding of the sound source or sheer frustration at the sound itself. However, their responses (and similar responses from other patients living with dementia), appeared

contrasting to the responses of patients without dementia, who did not respond in this confused, frightened state.

4.3 Music intertwined with soundscape

4.3.1 Physical and vocal responses to music

We can consider that if patients understand the sound sources, they might be better able to cope with the soundscape, and therefore have positive associations with it (Mackrill and Jennings, 2013). However, for patients living with dementia they may lack an understanding of the sounds within acute hospital wards, and this may cause disorientation and confusion. Therefore, for patients with dementia instead of considering positive emotional responses to be resulting from an *understanding* of the sound sources, we could consider that if sounds are *familiar* to patients with dementia this in turn will promote positive feelings towards the soundscape, through a connection with the environment. This is where live music can play an important role in improving the soundscape for patients with dementia. If there is an emphasis on the music being familiar, thereby creating positive associations with the ward soundscape, this might result in feelings of inclusion into their environment (DeNora, 2013, p.50) as I demonstrate within this and the following chapter.

We can understand the responses (both positive and negative) to the use of music within the two wards I observed through three categories: physical response; vocal response, and emotional response. Within this chapter I consider the physical and vocal responses and the ways these interrelated with the soundscape and environment, whilst touching upon the emotional responses, a theme I develop fully in Chapter six. Observed physical responses to the live music performances included patients living with dementia either moving a part

of their body, for example tapping their fingers or their feet, or moving their whole self to the music. Often this was in time, even observed in patients in the later stages of dementia, as if it were a natural sub-conscious response. As Bella (2018, p.378) remarks, 'rhythm and movement are profoundly linked and that music, due to its temporal regularity and predictability, is ideally suited to engage our body.... humans can naturally and effortlessly move along with a rhythmic auditory stimulus.'

To this end, consider Margaret, a patient who appeared to be in the later stages of dementia. Communication seemed difficult for Margaret, although it was clear she wanted to communicate, she would try to say words, and appeared frustrated when the words did not come. However, on one occasion whilst two violinists, Kate and Alice, were performing 'The Blue Danube', Margaret lifted her right arm and moved it in time to the music, as if she were conducting the musicians. The musicians in turn appeared to follow Margaret's lead, and for that moment Margaret was able to communicate. Without words she expressed her joy at hearing the music.

Likewise, I observed patients using their bodies as a percussion instrument, either tapping their hands on the side of their bed often with jewellery such as a wedding ring, making a 'ting' as it tapped the metal frame, or patting their hands on their table, and likewise tapping their feet on the floor, in time to the beat. These findings were also observed by McDermott et al. (2014), who discovered that residents living with dementia in residential care settings 'typically responded to familiar music by feet tapping, hand clapping, whistling, singing along or dancing.' (p.710).

Generally, in my own observations, patients did not appear to clap along during the performance in the two hospital wards, this was often reserved until the end of the piece. In this regard, there appeared to be a sense of confusion amongst patients (and staff) as to whether they should clap after each piece, for instance as we would after a concert. Some patients would apologetically point out reasons for not being able to clap – low mobility, cannula fitted, painful joints, and would be quick to say that their lack of clapping was not because of a lack of enjoyment of the performance. Whilst other patients and staff would clap loudly and enthusiastically at the end of a piece to communicate their enjoyment. The professional musicians commented that lack of clapping at the end of a piece was something they took a while to adjust to, the signs of enjoyment from patients can be very different to a concert hall audience for example. One musician reflected that “it feels so odd to not clap at the end, but it doesn’t mean anything does it, it also doesn’t mean that they didn’t enjoy it.”

The clapping that could be heard after a piece often caught the attention of other patients on the ward. For example, during one performance by Claire, the hospital’s Musician in Residence, I was sat in the corridor to hear how far the sound travelled. As Claire was setting up and talking with the patients in bay two, patients and staff in other areas of the ward did not respond to her presence, and perhaps it might be fair to say, were not aware of her presence on the ward. However, after the first piece ‘Paper Moon’ which Claire sang whilst playing her ukulele, the patients in bay two clapped loudly. Upon hearing this, Malcom a patient sitting beside his bed in bay three, got up and walked over to bay two. He too began clapping and said to the musician “I thought someone had the radio on, but when I heard the clapping, I thought that must be someone playing in

here, and you are!”. The music and the sound of clapping as a result, carried down the small corridor of Beech ward.

Likewise, vocal responses to the music equally altered the soundscape, including increased social sounds and positive emotions. The most common vocal response to music that I observed and perhaps the most obvious, was singing. However, it is not merely the act of singing upon which I wish to focus, rather it is on what the singing *afforded* for patients living with dementia. Often patients who were seemingly uncommunicative, withdrawn and disconnected from the ward appeared to ‘come to life’ through the music, starting to sing songs word for word, when prior to the performance they had been unable to have a conversation.

Consider for example Peggy, I had observed Peggy for a couple of days before the live music performance, she appeared withdrawn and distant. The staff would try to make conversation with Peggy, but her responses were delayed, and she appeared frustrated by this. For instance, on one occasion, I observed her trying to ask Nurse Jackie for something, it was clear she was struggling to find the right words. Nurse Jackie was very patient, saying “it’s OK Peggy take your time”, and each time Peggy moved her mouth and her hands, she uttered stuttered words, “please can I have a... a... hmmm” trying to find the right words but failing. Eventually Peggy dropped her shoulders and said, “never mind”.

However, I was sitting opposite Peggy one afternoon while Claire performed in Peggy’s bay, she started with Doris Day’s well-known song ‘Que Sera Sera’. Peggy’s eyes lit up, and she began singing – “when I was just a little girl...” singing loudly at the chorus “que sera sera, whatever will be will be”. Claire had clearly noticed Peggy’s engagement with the music, and walked over to her bed, both making eye contact with one another, singing together. The sound of this music

making together had also reached the staff in the corridor, who came into the bay, with wide smiles as they watched Peggy as she sang along. One HCA, Molly, commented to me “this is so unlike Peggy, she doesn’t communicate very well”. The staff seemed genuinely surprised by Peggy’s reaction to the music, here was a woman who was clearly singing the words to a song, and yet had been unable to communicate just moments before.

Although after the performance Peggy appeared to continue to have challenges with communication, for that moment in time the music had unlocked this restriction. This finding is supported by other research in the field, around the use of familiar music to support reminiscence, (for example Dassa et al., 2020; Sung et al., 2012; Cooke et al., 2010; Götell et al., 2000), with Moreira et al (2018, p.134) stating that in Alzheimer’s Disease ‘the ability to recognize music remains relatively preserved.’ In the case of Peggy, we can see how familiar music triggered memory for the lyrics, which Peggy was then able to communicate at an almost subconscious level.

Communication through vocal ‘disturbances’ (e.g., screaming, shouting) on the other hand, appeared to be heard less during and sometimes after the performance. For example, on Tuesday afternoon I was sitting quietly in bay one on Oak ward, when I heard Ted press his call bell. After waiting a minute or so he began shouting out, a pattern which I have previously discussed is typical. Ted became more and more frustrated by this situation and began shouting louder and louder “hey, hey, where are you?” Nurse Sarah entered bay one, turned off Ted’s call bell, and said in a calm voice “sorry Ted, what is it?” to which Ted replied, “oh there you are, I wondered where you were”. It appeared that Ted did not want anything in particular, and we might consider his shouting out to be a

sign for his need for social interaction, as discussed previously. However, around one hour after I had observed this interaction, and Ted's frustration, which became an ongoing pattern, the two female violinists arrived and began tuning up, just a few steps away from Ted's bed.

Ted appeared pleased to see the musicians, he smiled as they entered and said "ooh" as his eyes and his mouth lifted "what have we got here then?" For the duration of the performance (around 30 minutes) Ted sat smiling, he joined in every so often with singing along, and it was clear from his body language that he was experiencing joy from the performance. During this time, he did not call out or press his call bell, he was engaged in the music performance, and appeared to revel in the interactions with the musicians. This continued after the music performance; I observed Ted up to around one hour after the performance, and he appeared calmer and less agitated than he had been previously, pressing his call bell less. In turn, perhaps a result of the music performance and after seeing Ted's reaction to it, the staff appeared in his bay more often, having short conversations with Ted about the performance. These conversations were more natural compared with the interactions previously, with Ted pressing his call bell or shouting out for social interaction.

This example of Ted supports existing research which shows that agitated behaviours reduced after hearing familiar music (Park, 2009; Ziv, 2007; Jennings and Vance, 2002), and as Ted was singing along with some of the pieces, they were clearly familiar. As a result of the music performance reducing sound sources such as call bells, shouting, screaming etc., it was my observation that the soundscape changed, encompassing more social sounds – interactions between patients, staff and visitors, discussions, and laughter. Likewise,

emotional responses to the music performances observed included joy and delight, patients commenting what a nice surprise the music was, and how 'wonderful' it had been. As we saw in the example of Ted, it was a typical observation to see patients (and staff) smiling when the musicians arrived. Particularly the harpist, with patients remarking on the instrument of the harp itself, "you don't see this every day", "wow, what a sight to behold". I often observed patients smiling during the performance too, especially if they recognised a particular piece the musician was playing, and especially at the end of the piece as they showed their enjoyment, alongside clapping, and thanked the musicians. Laughter appeared to be heard more during the live performances than at any other time on the ward.

For instance, one Wednesday morning Oak ward had been quiet as usual, and only hushed conversations between staff could be heard. Claire arrived on the ward and positioned herself in bay three, a bay of female patients. During one particular piece, 'When the Red Red Robin Goes Bob Bob Bobbin' along' Claire made a mistake in the music and stopped for a moment as she found her place in the music. She laughed, not uncomfortably, but naturally, and said "oops, sorry!" a couple of patients laughed with her. Likewise, on another occasion, Claire played Morcombe and Wise's Bring Me Sunshine; halfway through the piece, two nurses, Jackie and Deanna, came into the bay and sang along with the song. One patient, Mary, turned to Jackie and Deanna and said, "go on, do the dance". Jackie and Deanna looked at one another, laughed and Jackie said to Deanna, "I will if you will", to which Deanna began hopping along the short length of the bay, arms and legs alternating as per the Morecombe and Wise dance, joined shortly by Jackie, doing the same movements. The bay erupted

with laughter, with patients and staff laughing together. Hearing laughter such as this within the ward changed the soundscape significantly, it made the ward feel light-hearted, and more sociable.

4.3.2 Paramusical

These knock-on effects arise when musical episodes or experiences are connected to para-musical things (DeNora and Ansdell, 2016). Paramusical are those things that are not the music *per se*, but 'go with' the music:

“any other “things” [outside of the musicalised sounds] that are caused, initiated, influenced, modulated, or co-occurring with musicalised sounds – things which are shaped-up (spatially, temporally, in terms of their trajectory, intent, or affect) either from/in-relation-to/alongside-with the musical track. Such paramusical things may be: actions (individual or relational), responses (individual or relational), thoughts, associations, emotions, verbal/non-verbal comments and elaborations etc.’ (DeNora and Ansdell, 2016, p.35).

Therefore, we can consider the role of music within dementia care and the resulting change of soundscape to not only be an effect of the live music performance itself, but rather these transformations for both the ward and social actors is afforded through the act of musicking. Music, care, and soundscape are intertwined to create the hospital environment, rather than acting as separate entities.

It was my observation that during the live music performances the perception of the environment and resulting soundscape appeared positive for patients living with dementia, providing a sense of transformation for both the patients

themselves as well as the ward environment. Consider Audrey, who appeared to be in the later stages of dementia. I had observed Audrey one morning showing visible and audible signs of agitation including screaming on and off, the words incoherent, but the sentiment clear, she was distressed. Later in the day, Kate and Alice visited Audrey's bay on Oak ward and began playing a repertoire of classical music and songs from the musicals on their violins. After the first piece Audrey called out "lovely. It was lovely". These were the first coherent words I had heard her speak all day. Audrey's enjoyment of the performance was clear, and for the duration of the performance she did not scream.

At one point she beckoned me over with the use of one finger and reached out for my hand. I gladly gave it to her, and I stood next to her bed, experiencing the music together. The main thought that struck me during the performance was the contrast of the soundscape compared to the previous sounds of Audrey's screams. During the music performance Audrey, and the ward as a collective, appeared calmer. One member of staff, Nurse Anthony, commented whilst I was with Audrey, that "the music made a world of difference, it really brightened Audrey's spirits. She needed that."

This perception of the importance of music within the care provision on the wards was also demonstrated through the way the staff accommodated the musicians, and the sense that they did not want to disturb the music performance in any way, perhaps because it may risk disturbing this positive transformation for patients and the environment. For example, on several occasions I observed staff bringing in noisy medical equipment into a bay, and either apologising to the musician, or waiting in the entrance until the musician had finished playing. Likewise, patients would often ask staff to come back after the performance as they did not wish to

be disturbed. For example, consider my field notes of an interaction between a patient John, and a Nurse Sarah, during a music performance:

Sarah came in to talk to John, he said to her “oh, I was enjoying the music, can you come back after?” to which Sarah replied, “don’t worry, I’ll be quick.” Claire the musician waits for a moment and then starts playing. She plays quiet chords and walks over to the other side of the room and starts to play “Tennessee Waltz” very quietly. Sarah listens to John’s heart with a stethoscope. I wonder if this is a difficult task with the music being played.

This was a typical example of the ways I observed music intertwining with care, with the musician Claire adapting her performance to suit the environment of the ward at the time, and likewise Nurse Sarah, perhaps spending less time with the patient John, than she might have done had Claire not been performing. Likewise, in terms of the soundscape, sometimes the sounds of music and care literally become one. For example, during one performance I observed Gareth playing his harp in time with the monitoring equipment as if it were a metronome, although I do not know whether this was a conscious or subconscious act. Likewise, at times seemingly by chance, the musician would play the same note within their performance as the tone of the monitoring equipment beeping, a momentary blending of music, care and environment. When either of these events did occur, the musician would often remark how ‘spooky’ this was, or similarly patients would laugh and comment that it was like the musician was playing a “duet” with the equipment.

There was of course a natural change in the soundscape during the music performance, with the music carrying down the corridor, resulting in other

patients', staff and visitors hearing the music, as previously mentioned. The performances I observed took place generally in the afternoon, during the busiest period with the previously discussed increase in visitors. However, instead of the usual increase in sounds – discussion, corridor activity, furniture being moved – there was a calmer feel, people were less rushed, they took their time to walk down the corridor often stopping to look into the bay where the musicians were playing. The paramusical features of the performance were very much evident in this regard. The feeling of calm continued after the performance had ended and the musicians had left. One patient commented that the ward felt more relaxed and calmer. Even when the musicians had not been playing particularly calm or gentle pieces of music, having the live music performance on the ward altered the soundscape and sound sources within it, appearing to leave behind a more tranquil perception of the ward than would normally be felt at that particular time of day. The transformation in this regard supports Preti's research (2007) whereby the staff, patients and relatives on a paediatric ward reported 'the positive effects of music in this setting in the creation of a friendly, distracting and relaxing atmosphere' (p.18).

4.3.3 Musical asylums

Considering music at a micro level, we might question how do patients living with dementia understand the soundscape of acute medical wards, the individual sound sources within the environment, and what music's role is within this? DeNora's (2013) work on musical asylums is useful here, through which we can see individuals connecting with their environment or escaping from it as a result of musical experiences. DeNora, putting Goffman's (1961) concept of asylum into a musical context, defines asylum as 'respite from distress and a place and time

in which it is possible to flourish' (DeNora, 2013, p.1). In the context of soundscape, the role of musical asylums within the wider medical environment is evident; for example, as previously demonstrated, patients who had appeared frustrated and agitated prior to the musical event (DeNora, 2017) appeared calmer and content as a result of the music performance. We can consider this through the concepts of refurnishing and removal. Defined by DeNora (2013), refurnishing *transforms* our surroundings and is more concerned with 'remaking the environment' (p.50), whereas removal moves the social actor out of the space, either physically or figuratively to somewhere more conducive to their wellbeing (p.49). I have explored refurnishing previously, in terms of the ways that the live music was perceived to be transformational for the environment as well as the patients themselves. Now my attention pivots to the concept of removal, and the ways in which the use of live music and resulting changes in soundscape affords acts of removal for patients living with dementia.

Consider Bob, I had observed Bob for a couple of days prior to the music performance. In this time, he appeared frustrated, he often requested to go home, and would spend most of his day walking the length of the corridor asking the staff when it was time to go. During one performance, the two musicians Kate and Alice performed swing style pieces, lively and upbeat, including Glen Miller's In the Mood. At the end of this particular piece Bob shouted out to the musicians "brilliant. Bloody brilliant", and then continued to tell them about how he used to go dancing when he was a "young lad" and he explained about the dance halls he went to, and the etiquette for choosing a girl to dance with.

The way that Bob spoke about this memory which had been prompted because of the music, it was clear that he was remembering a positive time in his life, his

eyes sparkled, he smiled, his cheekbones lifted. We might consider the main form of removal for individuals living with dementia to stem from music's ability to afford reminiscence as we saw in the example of Bob, which was a typical observation, with many patients interacting in this way during the music performances, reconnecting with past memories. Often patients would talk to the musicians about their memories linked with certain pieces, such as when they used to go dancing, where they met their first love, songs that were played during certain key events in their life such as school life, their wedding, their children growing up etc. With regards to patients who had appeared agitated before the music performance, this act of removal and taking themselves back to a time which was positive for them, may be considered to result in a more positive association with the environment.

Rice (2013) discovered that patients listened to the hospital radio station as an act of removal – 'as I went about my work it became apparent that one of the key reasons patients chose to listen to the station was that it gave them an opportunity to escape from the sounds of the ward.' (p.3). However, it could be considered that live music performances evokes a deeper sense of engagement and interaction, compared to listening to the radio. This is due to the live music performance affording moments of discussion and reminiscence (as we saw in the example of Bob), and a connection to those around us, a connection I did not observe whilst the radio was playing.

Within the individual bays, the sound of the radio formed part of the micro soundscape. Generally, each bay had a communal radio which would be turned on by a member of staff. It should be noted that not every bay had the radio on all day, it appeared to happen by chance whether a member of staff turned the

radio on. The staff member would often choose the radio station, which tended to be a current music station such as local Heart radio or BBC Radio One, playing chart music. I never observed a member of staff asking the patients what they would like to listen to, or what their musical preferences were. The patients could change the station if they wanted to, but again I never observed this happen. Perhaps conforming to/with the notion that we enact our patient-selves (Rice, 2013) whilst in hospital, with care and encompassing activities 'done to', rather than having agency over our care, to this end we can see this lack of agency taking place even through music listening. Perhaps even something as simple as changing a radio station appears to no longer be an option particularly if a member of staff has chosen the station. Generally, the patients did not respond to the communal radio, no matter how loud it was, and I never observed staff and patients discussing the music that was playing on the radio. It was as if the sound of the radio faded into the general sound sources within the ward, not particularly standing out against the backdrop of general ward noise that contributed to the ward soundscape.

In contrast, during the live music performances particularly those provided by the hospital's Musician in Residence Claire, patients appeared to be more engaged with the music, its sound appearing to be more notable, perhaps due to volume, but mainly due to the social interaction which the live music afforded. An observation which supports Sherratt et al's (2004) research on the subject, finding that individuals living with dementia experienced higher levels of wellbeing during live music performances due to the increased social interactions. Likewise, in my own research it appeared that there was greater engagement when the piece was familiar. For instance, during one performance a patient, Marick, had been

sitting looking out of the window, not appearing to engage with the performance. However, when Claire played one particular piece – ‘When You’re Smiling’ by Frank Sinatra, Marick began to sing with her, and afterwards said how that piece reminds him of his wife and their ‘courting days’.

The importance of familiar music and its potential affordances for opportunities of wellbeing and for providing acts of removal is supported by literature such as Chang’s meta-analysis (2005) which demonstrates that the use of preferred music decreased agitation in people living with dementia by introducing a sense of familiarity into an unfamiliar environment (p.1134).

With this in mind, we can understand how the use of familiar music can support this sense of familiarity in an unfamiliar space and create connections between patients living with dementia and the healing environment through sensorial memories brought into the present. We can see how familiar live music can help to bring back positive memories for the patient with dementia assisting with removal from the environment to somewhere more conducive to their wellbeing and preventing or reducing their agitation. This can in turn provide a type of refurbishing of the environment for the other patients and staff, creating a more positive environment and soundscape, a musical asylum not only for the patient with dementia, but also for those around them.

4.4 Conclusion

In the opening of this chapter, I set out an intention to explore *how* music intertwines with the auditory landscape of the two elderly care wards observed. I have demonstrated this through detailed descriptions of the dynamics of the live music performances in relation to the sonic and social environments, exploring how both are interconnected. An emphasis has been placed on the importance

of communication and social interaction within dementia care, and the ways that these sounds are part of the rich tapestry of the soundscape as well as being a possible reaction to it. The social and relational aspects of care and music's role within this, continues to be a developing theme in the following chapters.

It is through an understanding of the paramusical events (DeNora and Ansdell, 2016), the things which are not the music itself but happen alongside, where we can best understand the affordances of music to support relational aspects of acute dementia care. Through short vignettes I have demonstrated how the live music performances afforded a sense of 'transformation' for both the patients living with dementia, as well as the ward environment itself. It is through these small individual-level interactions where we can best see familiar, meaningful music affording possibilities for wellbeing. In this regard, it was discovered here that familiar music may bring back positive memories and, linking with the concept of musical asylums, (DeNora, 2013) therefore afford a sense of removal from the environment to somewhere more conducive to the individual's wellbeing.

In summary, music which is meaningful to the individual, i.e., that is familiar and already associated with positive memories, can in turn recreate feelings of positive emotions, and therefore positive associations with the present environment. Through exploring music in an ecological sense, considering the intertextuality of music and environment within elderly care wards, we can begin to form an understanding of how music intertwines with the both the auditory and social environment, paving the way for music's role within the relational aspects of dementia care.

5 Dis/connection

[When we are ill] 'we tend to forget our connection to the earth, to the sky, to each other, to the life that's constantly percolating in and around us. When we forget our connections, we wind up feeling drained and isolated. When we remember our connections, we become energized, inspired, and feel a part of all that's around us.' (Adair. As quoted in Biley, 1996, p.110).

5.1 Introduction

In this chapter I am going to demonstrate through my findings how a sense of disconnection is manifested in patients living with dementia whilst in acute short-stay medical wards, and the effect that this has on the patient, their environment, and other social actors in the space. The focus will then shift into exploring the ways that shared experiences in meaningful music can afford opportunities for social connections, introducing the term 'musical connectedness.' In this regard, I consider music's ability in supporting the relational aspects of care to lie in the ways that familiar music can create or strengthen social connections. Music is therefore seen as a tool for connection, which lasts long after the performance has ended.

As discussed in the literature review chapter, short-stay medical wards can be disorientating environments for people living with dementia. Even within the context of 'dementia friendly' wards, many things may still be disorientating, such as staff changes, lack of familiar faces, and difficulties with communication. Short-stay wards are transitory places, a stopping-off point for many patients, before being transferred elsewhere, for example to a care home or community hospital (for longer-term rehabilitation). Therefore, despite the efforts to make these

spaces dementia friendly (for example, clear signage, artwork, brightly coloured furniture, specialised lighting), it cannot fully overcome the inherent disconnectedness of a short-term stay ward.

It has been shown that clinical settings such as short-stay medical wards can create many challenges in caring for people living with dementia, as their capacity to function can be impeded within a hospital ward due to the unfamiliar environment, lack of privacy, and often chaotic nature of the ward (Featherstone and Northcott, 2020; Reily and Houghton, 2019; Hung et al., 2013; Nillson et al., 2012). Social interactions with nursing staff are often limited to task-based care activities such as washing, dressing, and serving meals (Edvarsson et al., 2011), and staff are often unable to learn about the social needs of the patients, the focus tending to be on medical needs (as discussed by Featherstone and Northcott, 2020). Challenges in communication as well as time constraints mean that staff may lack understanding of the individual's personal interests, abilities/inabilities and therefore may not be able to meet their social needs, creating disconnection through a lack of rewarding activities and social interactions.

I consider the concept of community within acute dementia care, exploring the ways that shared experiences in music can support inclusion into the environment (DeNora, 2013), and opportunities for re-connections with self-identity. Within this chapter I demonstrate how shared experiences of meaningful music can afford opportunities for social connections, potentially supporting caregivers to provide personalised care for patients living with dementia, which leads me to a wider argument concerning the importance of music to support relational aspects of dementia care.

5.2 Disconnect

5.2.1 Environmental disconnect

Often patient confusion stems from the fact that they do not understand where they are or why they are there (Featherstone and Northcott, 2020). I observed attempts to orientate patients, with staff repeatedly saying sentences such as “we are in a hospital bay”, “you are at [name of hospital];” and of course we see visual cues too, indicating that the patients are in hospital – white metal framed hospital beds, light blue pyjamas with the name of the hospital printed in blue and red, curtains around the beds, medical cabinets, staff in uniform etc. However, for some patients living with dementia they may not associate these visual and audio cues with a hospital environment, or even understand what it means to be in this environment. This can cause disorientation leading to agitation, if for example, they want to go home, not realising that they are in hospital and therefore cannot leave until they are formally discharged. As an aside, ‘home’ is a recurring theme which I cover in more detail later in this and the following chapter. The locked ward entrance, which is common in acute dementia care (Featherstone and Northcott, 2020), can create a sense of imprisonment and increases the disconnection between the patient and their environment, a seemingly common occurrence within the two wards observed.

Take for instance the example of Frank - when I entered Beech ward, Frank was stood at the door talking in a loud voice to the Ward Clerk at the desk, saying “but why can’t I leave? He has” (I presumed he was talking about a member of staff or a visitor). The Ward Clerk tried to distract Frank by offering him a chair to sit on in front of her desk, Frank shook his head and started to rattle the door, his face tightened, his eyes fixated on the door and his mouth turned into a grimace.

A Nurse, Joanna, appeared, put her hands around Frank's shoulders and suggested he might want to sit down for lunch - "if you go down and sit in the chair, we are going to have sausage and mash" Frank continued to stare at the door, not making eye contact with Nurse Joanna. She repeated herself, this time louder and clearer, and gently but firmly guided Frank away from the door.

In this example, I believe that Frank was exhibiting frustration: his face tightened, and his voice became raised, behaviours I had also observed in other patients who found barriers to their attempts to leave the space within which they found themselves, whether trying to get out of bed, or leave the ward entirely. These agitated behaviours may stem from the patient not understanding why they are in hospital, and when they will be discharged, resulting in frustration and disconnection. Consider this example of George, taken from my field notes:

George is sitting with three other male patients at the communal table, he asks the nurse why they are here. The nurse replies "you're going to have your lunch. George says "finally, an answer. But after my lunch I want to know how to get down there" [looks towards the entrance of the ward], the Nurse walks away.

Then George says to a passing Health Care Assistant: "why are we here?" He gets more irate, his tone is clipped and he raises his voice. A cleaner tries to help George by using lunch as a distraction – "you're going to have your yummy lunch." Meanwhile the HCA moves on and leaves the cleaner with George.

George tries to get the attention of a Doctor who is working at the desk close by; George calls out "can you tell me why we are here?" The Doctor responds without looking up, "I'll just be a minute." The other patients at

the table talk about how difficult it is to get an answer. They say this whilst laughing at the situation. Another patient, John says "it's like talking to a brick wall."

George becomes more annoyed, looking out for a member of staff to talk to, and drumming his fingers loudly on the table. He then moves his position so that he is sitting side on in his chair trying to get someone's attention. Sitting in this position he can view the length of the corridor. George looks up and down the corridor with a worried expression on his face, furrowed brow, he asks John - "has that lady [Nurse] got a stethoscope on? No one replies. Then George asks the other patients "why are we here?" Alan replies "to have lunch I think". George says, "we don't need lunch, we need to go home." The Physiotherapist comes over and tries to explain to George that he has been moved from another ward to this one and they are getting his paperwork together. Their conversation ends with the Physiotherapist saying, "I'll look into it." Alan scoffs. George says, "there's nothing we can do."

A short while later a Nurse walks past and calls out to George "I'm trying to get your notes to try and sort it out." George says to the other patients "are we all going home?" Alan who is sat in his pyjamas says, "I'm waiting to get dressed." The Nurse comes back and tells George "the Discharge Nurse is going to look into it. Now it's time for lunch, so I'm going to sort that". She asks each patient what they would like and starts pushing George's chair closer to the table.

As we see in this example, George repeatedly asks why he is here, and the longer this question goes unanswered the more frustrated he becomes. His utterance

typified something that I saw repeatedly on the wards, which was patients trying to understand the situation they are in and focussing on a central theme – going home. When the doctor tells George “I’ll just be a minute” without looking up, we see George become more frustrated, drumming his fingers on the table, looking up and down the corridor and like Frank, his face became tightened.

The examples of George and Frank are typical observations of the frustration that can be felt when the patient is unclear about where they are and what they ought to believe. The frustration can turn into and exacerbate agitation the longer this lack of clarity continues as shown in the example of George. In this regard, there is frustration felt on both sides, for the patients as we have seen, and for staff who are restricted in time and not always able to provide a full explanation.

There is a distinct sense of powerlessness both in terms of the patients and staff (Featherstone and Northcott, 2020; Dewing and Dijk, 2016). Patients may feel powerless in that they are reliant on external factors in order to be discharged from the hospital - their health needs to be in a good enough state, they may be waiting for a community care package to be arranged or for a home assessment to be undertaken etc. However, for patients with dementia this is even more challenging due to their lack of agency in their own affairs, in and outside of the hospital.

‘Going home’ becomes the focal point for patients, and for patients with dementia this desire to go home is even more heightened. Due to short-term memory loss, patients with dementia can become fixated on going home and often forget that they are in hospital, and therefore repeatedly ask staff when they are going home. For instance, Mary often asked the staff when she could go home (sometimes this would be every few minutes) and the answer would always be around the

fact that it would not be for a couple of days as she needed to “get better” first. Sometimes when the staff were busy Mary would be asking the same question “when am I going home?” and due to the staff focusing on other patients Mary would start shouting out louder and louder, repeating the same question. Other participants also displayed frustration in this situation, becoming more frustrated (displayed through their repetitive questions, raised voice, tightened facial expressions) the longer their request went unanswered, as seen in the previous example of George.

People living with dementia often have a distorted sense of time passing (Keage and Loetscher, 2015), and some may believe they are living in an earlier time period, for example when they were in their teenage years. Tom Kitwood (1997, p.56) remarks that ‘although primary dementia involves major losses in cognitive ability, it was well known that long-term memory often remains relatively intact.’ He goes on to explain that feelings connected with earlier parts of our life remain the same, and emotional memories can feel very real for someone living with dementia. This was a typical observation within the two wards in my research project.

For example, Mary told a HCA, Sally, that “you are all lovely here, but I really must be getting back to my mother as she will be worried where I have got to”. Likewise, John would often put his coat on and head to the locked ward entrance shouting “I’ve got to get the bus back home to my mother”. This became a typical interaction on the ward, with patients with dementia often appearing to be ‘frozen in time’ in their childhood years, and therefore the anxious feeling that their parents would worry where they were, was very real for them. From these examples we can see how patients living with dementia may become more

anxious about going home, particularly if they are experiencing feelings associated with past memories, lived in the present.

Whilst all patients mostly want to go home, for patients living with dementia this desire to go home is profound, as I shall explain in further detail in the following chapter. The potential lack of agency and desire to go home (which may not be the home the individual current lives in) may be seen to stem from a desire to feel a certain way, the possible feelings which 'home' affords, for example love, security, comfort, warmth. The very things which Kitwood (1997) regards as essential for supporting personhood.

Many patients are either discharged to a care home or back to their own home but with modifications from the support of the Occupational Therapy team. This often means that patients stay in hospital longer than they need to whilst a space becomes available in a local care home, or the necessary equipment is installed in their own home. This delay in discharge is known in a derogatory and culturally negative way as 'bed-blocking' and has become the focus of much social discourse about the cost of older people (Rojas-Garcia et al., 2018; Gaughan et al., 2017; Ekdahl et al., 2012), with the media often portraying older patients as 'choosing' to stay in hospital longer than they need to, therefore denying care to those whose need is greater.

However, the reality is not as simple. There may be frustration amongst the staff as well as patients when there is a reason beyond the hospital's control as to why a patient cannot be discharged, for example delays in packages of care or available care home spaces. Likewise, patients often must wait for their medications, which can take a long time especially at weekends and evenings when there is reduced staffing.

Patients who are not physically able to be taken home by their relatives will also have to wait for an ambulance to be ready which may not coincide with the time the patient is ready to be discharged. These are examples of the hurdles that all patients (not just those living with dementia) face when being discharged. This socially constructed problem results in beds that are often taken by patients who have no medical reason to be there, and do not want to be there either, which causes frustration for the patient, relatives, and staff, particularly during times when the bed capacity within a ward is pushed to the limit.

I was observing the study site over the winter months, a time when the NHS is at its most stretched. The year that I conducted my research (Winter 2016) is thought to have been the NHS' 'toughest Winter on record' (pre COVID-19) by the NHS Providers Briefing 2017. The NHS Providers Briefing shows the performance of the NHS over the winter months from 1st December 2016 to 26th February 2017; during this period daily performance data for 152 hospitals was collected and published weekly by NHS England. The briefing summarises the trends over this period, and it showed that 'the number of open escalation beds almost doubled in week 6 (2-8 Jan) to over 31,000. On average, a hospital has around 550 general and acute beds available per day (3,850 bed days per week) so this is the equivalent of opening an additional eight hospitals to cope with winter demand.' (NHS Providers Briefing. 2017:3).

Research has shown that bed occupancy levels above 85% can reduce quality of care, yet the briefing shows that bed occupancy levels in Winter 2016 over all weeks were above 85%, with occupancy levels rising to 96% in week 10 - 30th Jan to 5th Feb (ibid). The report also showed that delayed transfers of care were worse than ever as trusts struggled to find the appropriate care setting for patients

who continued to need support but who were medically fit to leave hospital (NHS Providers Briefing, 2017, p.6). This criteria would include but not be limited to patients with dementia. The report shows that for patients the tight pressures on the NHS can be distressing and potentially dangerous, and it can also be demoralising for the clinical workforce 'who sometimes feel they are struggling against all odds to provide the best possible care.' (ibid).

NHS trusts use Operational Pressures Escalation Levels (OPEL) figures to make judgements about the pressures they face; these are set out in levels, with level one being all is well, and level four (known within the NHS as black alert) requiring 'decisive action' for patient safety (NHS Providers Briefing, 2017, p.1). During my observations the hospital had a period of operating on black alert, indicated on a chart on the Ward Clerk's desk and in the touch down room. In the national news the picture was pretty bleak, with organisations such as the Red Cross warning that the NHS was facing a 'humanitarian crisis', and Senior Doctors calling the National Health Service 'broken' after two patients died after being left waiting on hospital trolleys at Worcestershire Royal Hospital (Campbell et al. 2017). I observed patients being transferred to the Elderly Care Units from other wards within the hospital, such as the Emergency Department, or Medical Assessment Unit. This results in the patients seeing different environments and faces potentially within the first 24 hours of admission to hospital, resulting in heightened disconnect.

During the winter months this disconnect is at its highest, staff are feeling the strain of the additional NHS-wide pressures, patients can often be left waiting for a long time for a diagnosis or to be discharged, visitors can be left without answers about their loved one's care, and there may be a heightened lack of

communication between the hospital and care in the community to discharge patients to the correct places to receive the best support and care for their medical or mental health (Rojas-García et al., 2017). There is a disconnect here at a structural level between the NHS hospital care, the community care of the NHS (GP, District Nurses etc.), and Local Authority Adult Social Care Services. Therefore, the sheer number of people needed to coordinate a patient's discharge is large, and consequently means more faces and meetings, which for a person living with dementia can be extremely confusing and worrying, causing increased disorientation (for more information, see Timmons et al., 2016; Mockford, C, 2015; Chenoweth et al., 2015).

This lack of communication can have a spiral effect, with patients left waiting for answers about their discharge, and hospital staff unable to provide an answer due to lack of information from the community care services. Naturally, this would make any patient frustrated, but for patients living with dementia who may already be confused and disorientated, this lack of communication can lead to an increase in agitated behaviours, which can cause a snowball effect. Featherstone and Northcott (2020) refer to this cyclical effect as looping; the patient living with dementia becomes distressed as a response to the structured and at times restrictive care practices, their heightened distress then leads to a further tightening of care practice and 'patterns of rigid and repetitive talk' (Featherstone and Northcott, 2020, p.9), exacerbating distress and reaction to care.

We can see this looping effect in one particular example. Fridays are often a busy day in hospital wards with many patients being discharged at this time so as to reduce the number of weekend discharges (when a smaller number of Doctors are working); consider the following extract from my field notes:

One Friday Beech ward was particularly busy and noisy, and a patient Jane started to shout out for a nurse. They passed by Jane's bay but due to the staff's limited time and a rise in discharge activities no one was able to stop in to see her. Jane continued to shout out "please please, help.... Hey..... Hey..." getting louder and louder. Peggy in the bed opposite started looking around as if she too was looking for someone, she then started to shout to Jane – "would you please just shut up". Jane continued to shout "hey....hey..." Peggy then shouts back, louder this time, "oh for goodness sake would you just shut up" and started repeatedly pressing her call bell. A member of staff came in holding a medical file, she turned Peggy's call bell off and told her someone would be along in a minute, as the nurse walked past Jane's bed Jane called out "hey... hey", the nurse looked at Jane as she hurriedly walked back out of the bay, face down, brow furrowed, she looked in my direction, sighed and smiled a weary smile.

Here we can see frustration for Jane, Peggy, and the nurse, all expressing their frustration in different ways. I saw this happen to other participants in this situation, this is a typical example of the snowball or 'looping' (Featherstone and Northcott, 2020) effect which I often observed within the two ward spaces - one patient becomes agitated, this makes other patients in their bay agitated, putting the staff under pressure, creating a tense environment which exacerbates the agitation, and so on.

5.2.2 Relational disconnect

We might consider this spiral effect to occur through relational disconnect and lack of social interaction as shown in the example above. In a hospital ward there

is a feeling of a fluid hierarchy, at times the staff are in control, for example telling patients to take their medication at a certain time or do their exercises, and at other times there is the perception of patient control particularly for patients displaying agitated behaviours, through acts such as pressing the call bell, wandering, shouting out etc., they are controlling the atmosphere of the ward, even though this may not be their intention. Therefore, we could consider this disconnection to occur through uneven power relations. Topo et al (2010, p.1683) says that 'the agency of patients in hospital care or of people living in a residential care environment is constructed through the power relations in the care institutes, the cultural and social norms, and each persons' own abilities, actions and intentions, through which she or he can also challenge or resist the social order of the hospital or residential care environment.' In this regard, we can see how the agency of patients living with dementia may be dependent on the relationships and interactions with staff, and those around them.

We could consider that patients living with dementia reconfigure the 'norm' of being a patient at times, by challenging and resisting the social order of the hospital due to a lack of understanding of the cultural and social norms of the environment and what it means to be a patient in this environment. Take the example of Jean:

When I first met Jean, she was sitting upright in her bed with her hands clasped and frowning, not looking at anyone specifically, staring at the wall as many patients do. She called me over to ask if I could find her phone in the kitchen, saying "I've just come home from hospital and I can't find it." I explained that she was still in the hospital, she looked at me, puzzled. She asked if I could call her sister, I explained that I couldn't, but the next time

a Nurse came in I would ask for her. Jane then tried to get the attention of the patient opposite her who was sleeping, calling out – “hey, you...you...”. No response. Jean talked to herself, still sitting in her bed, looking around her saying, “I think it’s over there, I’d better not get it though.”

Nurse Sarah walked past the bay, looking in. Jean called out “Karen” as she walked past; although Nurse Sarah looked at Jean she did not respond. Jean said out loud, not to anyone in particular “oh, she gets called away all the time.” When Nurse Sarah returned Jean called out again, “Karen...” no response, she says again “Karen... are you the one I saw earlier?” Nurse Sarah looked at Jean but again didn’t respond and went to see the patient in the bed opposite. Meanwhile Jean let out a loud sighing sound, picked up her call bell and pressed it repeatedly. No one came, and Nurse Sarah, seeing to the patient opposite, was unable to attend to Jean.

The sense of normlessness is heightened through this lack of communication between the patients and staff, when staff are time constrained and not able to have a conversation with patients or provide the attention they seek, as highlighted in the example above. This lack of communication can lead to a sense of social isolation. Alan commented to Geoff that the hospital ward is “like London”, and Geoff said, “it’s busy, so many people!” to which Alan replied “but they don’t stop to talk to you. That’s the problem. It’s like London, only people actually talk there.”

In a ward bay of six patients, days can go past without them talking to one another. Of course, for some patients this in itself may be a godsend, but for others this lack of interaction can result in social isolation. In terms of patients

with dementia, this social isolation may manifest itself in displayed agitated behaviours, which then go full circle – if their agitation is considered to be ‘disruptive’ they may be transferred to a side room, which I observed does not necessarily reduce agitation, it can often exacerbate the agitation. For example, one patient, Gladys, always shouted out whilst she was in the bay with other patients, constantly shouting “nurse” whenever a nurse walked past, getting louder if they did not stop to attend to her.

One day I noticed that Gladys had been moved to a side room and she was more vocally distressed; the way her bed was positioned she could not see people walking past, and as her door was shut, she resorted to attracting attention by screaming, long, loud deep screams repeatedly over and over. The result of this bed move to a side room was that the bay Joan had previously been in was much calmer and quieter, the patients and staff appeared less tense. However, for Gladys herself, her agitation had become exacerbated. This was seen in other patients, either ones where they had been moved to a side room for various reasons, or ones that had been admitted to the side room and stayed there for the duration of their admission.

Isolation in an acute setting is two-fold; firstly, patients may be physically isolated from the ward, moved to side rooms generally to stop the risk of infection if for example they have a virus such as MRSA, or in terms of the agitated patient, they are moved to a side room because their behaviours (mainly shouting and screaming) may be affecting other patients’ rest and recovery. Secondly, patients in the side rooms may become socially isolated, having minimal social interaction only through staff and visitors, but unable to participate in the ward community

and unable to interact with other patients. Of course, this could be a bonus if your companions are loud, snorers, or rude.

Existing research on adult patients' experiences of single room isolation (Knowles, 1993; Gammon, 1999; Rees et al., 2000) suggest that patients in side rooms experience 'loneliness, depression, stigma, a greater need for information, lack of social contact, less contact with healthcare professionals than the patients on the main open ward and perceptions that the physical environment was restrictive' (Austin, 2012, p.22). Some patients may consider side rooms to be a 'luxury', feeling more private than having a bed in a bay; however, through my observations and through discussions with staff the feeling was that the side rooms can represent a problem, in line with Austin's findings. As discussed previously with the example of Gladys, patients with dementia in the side rooms often screamed out more than they had done when they were in the bays, perhaps due to their restricted visibility (often the patients cannot see into the main ward area and may not have a window in their room), and the positioning of the side rooms often meant that staff and visitors did not pass by as often as they do in the main bay areas, therefore potentially resulting in disconnection both physically and socially.

5.2.3 Self-estrangement

There is a need within dementia care to provide person-centred care as previously discussed within the literature chapter, and this has become the 'gold standard' which care providers strive to achieve. Person-centred care was born out of Kitwood's theory of personhood (1997) in which the person living with dementia is the main focus, recognising their individuality, personal history and personality, seeking to understand the world from the individuals' perspective. A

person-centred care approach can empower the patient with dementia to be an active participant within their care, and promotes a sense of self, a reminder that beneath the dementia diagnosis is a *person*. Without this person-centred care patients with dementia can become alienated through the lack of rewarding activities and this sense of a lack of understanding of themselves, their personhood.

The hospital ward is separate from the normal world in which you (the patient) make sense, and there is an inability to find oneself and one's purpose as a person from within this environment. There is a sense that the person with dementia is unable to contribute to the ongoing 'furnishing' of the situation, a lack of ability to shape the social space in which they find themselves. The concept of self-estrangement can be best described as the antithesis to Kitwood's theory of personhood. Patients with dementia may find it difficult to communicate their likes and dislikes or abilities/inabilities, particularly in the later stages of the disease, and therefore staff might not know how to support them (as they care for all older patients not all staff are specifically dementia trained) and how to deliver care that meets their social needs, which in turn leads to self-estrangement, a lack of connection with oneself.

In this regard we can see self-estrangement through Goffman's (1959) concept of misrepresentation, an imposter providing a false performance, tricking the audience into believing that it is real. In a dementia context we can see this in particular in terms of confused behaviours associated with delirium and hallucinations, which are exacerbated due to the unfamiliarity of the space, faces and routines (Berry, 2014; Ryan et al., 2013). Whilst to an outsider the performance may seem removed from the present, e.g. an individual in their late

90s believing that their mother is at home waiting for them, it must be acknowledged that the associated feelings are real for the individual. The idea of the 'imposter' can be seen in two ways, firstly for individuals who no longer recognise their loved ones, they may be seen as imposters (Cohen et al., 2016). However, it should be noted that even if an individual no longer recognises their loved ones, this does not mean that they no longer feel love or experience love from those around them. Kitwood's model of personhood (1997) demonstrates a central need for love, to be loved and to give love.

Secondly the individual may also not recognise *themselves* at their current age and health state, and therefore may see themselves as an imposter (Brown et al., 2019). Take Derek for example, over a period of ten minutes I watched Derek look at the back of his hands, turn them over, study his palms as if studying each line in detail, turn them back over and again stare intently at his wrinkled, well worked hands, looking from his left hand to his right hand with a puzzled expression, almost as if he did not recognise these weathered, wrinkled hands connected to his body. This was a typical observation, and I saw other participants, male and female react in similar ways, with puzzlement. For example, sometimes patients would look in the mirror and stare into the face looking back at them, studying the lines, touching them, as if they did not recognise the face in the mirror.

If we are disconnected from ourselves then, can we create connections with our environment and those within it? Likewise, in an environment which is seemingly disconnected, can meaningful connections be made and if so how are they made, and by whom? In order to explore these questions further I will consider how the micro-community of a hospital ward is created and how the environment and

culture of the ward can afford connections for patients with dementia, as well as considering factors which may hinder these communal connections.

5.3 Community

A hospital community is an enforced community, unlike any other we experience, it is intimate yet transient. How then is a community created in an environment which is in a permanent state of flux, and what factors detract from a sense of community particularly for patients living with dementia? Before exploring this question further, we should first take a look at the construct of community and the symbolism of the concept. Cohen's demonstration of the *use* of community is appropriate here, I feel, describing rather than creating a new definition for the concept; he states that:

'a reasonable interpretation of the world's use [of community] would seem to imply two related suggestions: that the members of a group of people (a) have something in common with each other, which (b) distinguishes them in a significant way from the members of other putative groups. 'Community' thus seems to imply simultaneously both similarity and difference. The word thus expresses a *relational* idea: the opposition of one community to others or to other social entities.' (Cohen, 1985, p.12).

The two ward environments I observed fit this relational concept of community well. The individual patients within the space have something in common, they are being 'cared for' due to an acute medical condition which requires specialist care, in this regard they are part of the 'community' within the ward, each person bringing their individuality, medical and social needs to the space. These wards are unique communities, the very nature of them being dementia friendly means that their environments are atypical as previously discussed, with their members

entering for different reasons and a variety of temporal factors. As Cohen describes, the start and end of the community, its boundaries.

Within the ward environments I observed there was a definite feeling of this simultaneous interaction of both similarity and difference, communities within communities. These micro-communities within the wards were created through both physical location and embodied practices. In terms of physical location, boundaries were created through the segregated patient bays (grouped by sex), and restricted areas where only staff can go – kitchen, staff room and the touch down room.

Boundaries were also created within the wards through the use of clothing, creating a sense of ‘hierarchy’; uniforms are worn by all staff (and different colours according to job role), except the Doctors and Consultants who wear their own smart-style clothes. Some patients choose to wear their own clothes, whilst others opt for the hospital branded clothes. Gusfield highlights that ‘community must ...be viewed as a process by which individuals symbolically construct identities as members of a group.’ (Gusfield, 1979, referenced in Clifton and Peck, 2007, p.459). Therefore, we could consider clothing to be a symbol of the identities of the various agents on the ward, making it visually clear where the boundaries are between the two communities within the ward – staff and patients.

5.3.1 Embodied identity

There is a sense that whilst we are in hospital, we adopt a slightly different identity, that of our patient self which may be different to our usual selves. As I have previously described, patients create and confirm a particular experience of patient-hood, bringing the patients to recognise their ‘patient-selves’ as Rice (2013, p.22) describes. Topo et al (2010) considers this conformity to the social

role of a patient in terms of embodiment, which they refer to 'as being in the world and to the integration of body and self. A hospital stay offers a mental and practical experience of being a patient. In this situation, one projects and produces a particular self within a situation where health problems dominate.' (p.1683). I regularly observed patients in general taking on this role of patient-hood upon admission to the ward, and through listening to conversations with the patients and their families, it was clear that this varied from their usual identity.

Often families would express frustration towards the patient if they were not as mobile as they are usually, or not taking an interest in their usual hobbies such as reading or knitting. This appeared to be heightened in patients living with dementia. For example, a daughter visited her mum (living with dementia) the day after she was admitted to the ward and the first thing she said was "why are you still in your pyjamas? It's two o'clock in the afternoon;" and she pulled some clothes out of her mum's locker for her to wear. This example is quite typical and seemed to be more common for patients with dementia, which often added to their confusion, with patients regularly muddling times of day, despite the large LCD screen clocks at the end of each bay. This was a typical observation, and I observed other patients and their families having similar conversations. Whilst it is considered as previously discussed, that patients recognise their patient-selves, or experience a particular sense of patient-hood, it may be difficult for patients living with dementia to perform this social role, and to conform to the 'rules of the ward' (Featherstone and Northcott, 2020) due to a potential lack of understanding of the environment and social norms.

Twigg and Buse (2013) comment that 'clothes lie at the interface between the body and its social presentation' (p.3) and that people living with dementia are

often assumed to lack the capacity to express their individuality through their dress. They go on to say that the immediacy of clothing is significant for people living with dementia because they 'may experience episodes of greater mental clarity in which they are able to recognise close surroundings in the form of clothes, and these can thus help provide a sense of temporal and spatial orientation.' As highlighted in the example above, the interaction between the daughter and her mother, the opposite is also true in the case of wearing pyjamas all day, confusing this sense of temporality and embodiment.

Although patients are able (and encouraged) to wear their own clothes, many tend to choose to wear their pyjamas, and some wear the hospital branded pyjamas, usually the case if they were admitted with insufficient amounts of clothing, or due to incontinence need a regular change of clothes. Many patients attempt to stay in their pyjamas all day whilst in hospital or will lie in bed or sit next to their beds. This may stem from an understanding of the need for rest in order to make a full recovery, with pyjamas symbolising this. The NHS is set to turn this around; in March 2018 they launched a campaign to end 'PJ paralysis', which was aimed at getting older patients up, dressed into their own clothes and moving to support recovery. Professor Jane Cummings says, "for many wearing pyjamas reinforces feeling unwell and can prevent a speedy recovery. One of the most valuable resources is a patients' time and getting people up and dressed is a vital step in ensuring that they do not spend any longer than is clinically necessary in hospital." (NHS England, 2018).

The beginnings of this campaign were evident on the two wards I observed as well as in the wider hospital; posters with information and photos of various members of staff supporting the campaign were displayed around the hospital

corridors. In the bays themselves, during the morning care routine and throughout the day different members of staff could be heard encouraging patients to wear their own clothes. Male patients were also encouraged to have a shave if they wished; they were given an electric razor and a member of staff would sit with them, holding a mirror whilst they shaved. Female patients were asked if they would like to have their makeup and hair done, and they often commented on how much better, and more like themselves they felt by having their hair brushed and their makeup applied.

One patient, Betty, would often spend her day sitting in silence staring at the wall, she told me on many occasions that she was very bored, with the days feeling long and “lonely” with nothing to do. On one morning after all the usual care routine was complete, a nurse asked Betty if she would like her hair brushed. Betty’s initial response was that she did not want to be any trouble, to which the nurse replied “it would be no trouble at all. I could pop some makeup on for you too if you would like?” The nurse sat next to Betty and started brushing her hair. As she sat there the nurse and Betty talked about how nice it is to have a ‘bit of a pamper’ and this led onto a discussion about the nurse’s children and how difficult it is brushing their hair. Betty looked at the nurse and smiled; she touched her hair and commented “ah that feels better”. Afterwards the nurse applied Betty’s makeup – face powder and red lipstick (which the nurse found in Betty’s toiletry bag). The nurse held a mirror up so that Betty could see herself. Betty beamed into the mirror and said “thank you very very much. I feel like me!” Other participants responded in a similar way, I never observed a patient asking to have a shave or for their makeup to be applied, but when it was offered by a member of staff the patient gladly accepted it. During and afterwards they appeared

happier, they smiled more, and they interacted more with the staff and those around them. After one patient, Mary, had her hair brushed she told the tea-trolley volunteer how nice it was that the nurse had brushed her hair and how she felt much “smarter”.

This relationship-centred approach created a moment for the caregiver to stop and sit with the individual patient, providing care on a social level, the result being a more connected relationship. Twigg and Buse (2013) highlight that ‘maintaining individualised dress can be an important part of supporting identity in the context of care and can help create a benign interactional environment that supports embodied personhood.’ This was particularly evident when the care staff took time to assist patients with their appearance, supporting their identity and sense of self which can often become lost whilst in hospital. In terms of an interactional environment, the interactions between staff and patients continued after this personal level of care and played a role in creating a micro community in this transient world.

5.3.2 Social reciprocity

The notion of social reciprocity in this regard is in line with Cohen’s argument that ‘community... is where one learns and continues to practice how to ‘be social.’ (1985, p. 15). This follows Talcott Parsons’ (1951) definition of a social system: ‘a plurality of individual actors’ interaction with each other in a situation which has at least a physical or environmental aspect, actors who are motivated in terms of a tendency to the “optimization of gratification” and whose relation to their situations, including each other, is defined and mediated in terms of a system of culturally structured and shared symbols.’

In dementia care we can see this optimisation of gratification as the need for social reciprocity. Bosco et al. (2019, p.67) consider social reciprocity as a key element of personhood – ‘in this regard, personhood is promoted through the social interaction between the person with dementia, carers and other influential agents providing care. The person with dementia therefore plays an active role in promoting personhood through their own social behaviours (either verbal or non-verbal) enacted toward the other agents. As Bosco et al, (2019) remark, ‘social reciprocity becomes therefore instrumental in meeting what Kitwood defined “psychological needs, which include occupation, identity, inclusion, comfort and attachment”. These all culminate in the need for love and meaning, that is intrinsic to all human beings’ (p.67).

In terms of the two wards in the current research project, this idea of social reciprocity and sense of community on the wards often stemmed from the communal areas within the corridors, more so than within the individual bays. On Beech ward, this sense of community was particularly focused around the communal table, deliberately situated in the centre of the corridor with an aim of increasing social interaction, for instance the Occupational Therapy team used the table to encourage socialisation of small groups of patients (mainly those living with dementia) during mealtimes. Over the research period I observed this medium sized round table becoming the heart of the ward with different activities and social experiences taking place here. In the mornings Doctors would often sit at the table reading or discussing medical records, and later in the day patients would often sit here with their visitors, drinking tea and watching the activity of the ward together.

I often chose to sit on a chair opposite this communal table so as to observe the activities of the ward and the table with a slight distance between myself and those I was observing. Occasionally patients would sit at the table through choice (the Ward Manager commented that a patient sat at the table as she wanted a 'change of scenery') or they would be encouraged by the Occupational Therapy staff to join in with an activity at the table, either to have lunch, or to meet other patients. Often patients were moved to the table whilst the staff undertook a deep clean of their bay. I observed a pattern of behaviour whilst the patients were sat at the table, they often appeared more relaxed, and they communicated more with other patients and staff whilst sat at the communal table than when they had been in the bay.

Take for example bay two on Beech ward, I had spent a day observing the five male patients within this bay. The bay was generally quiet except for the usual morning activities. The patients did not talk to one another other, they generally sat staring at the wall opposite or in Peter's case reading his newspaper, until an activity took place in the bay such as the tea trolley, or meals arriving. When an activity occurred, they would normally chat with the member of staff serving (commenting that the food smelt good, or they were in need of a cup of tea) but they did not communicate with each other.

The day after I had observed the patients within bay two, they were moved to the communal table whilst their bay had a deep clean. An hour before they were moved, they were sat in silence in their beds, staring at the wall or looking down at the floor, as they had been the day before. I then observed them for around two hours whilst they sat at the communal table, and I saw a shift in terms of how

they connected with one another, something which developed over the period that they were sat at the table, as demonstrated in my field notes:

Three patients walk to the table and the other two are taken by wheelchair; one is assisted out of his wheelchair into a chair at the table, whilst the other remains in his wheelchair. A HCA brings their cups of tea from the bay and puts them in front of them on the table.

John holds up one side of the table cloth (it has pictures of cupcakes on it) and starts talking about food, how he used to live by the sea, where he ate many cockles, and how he remembered his mum giving him liquorice, which still remains his favourite sweet. The other patients don't respond, John continues to repeat himself, but it sounds as though he is talking to himself rather than anyone in particular.

Ron interrupts (John does not seem to mind) saying "are we all waiting to go home?" They start to talk about going home, George says that he feels like he has 'been in' [hospital] for ages, the others nod and make agreeing sounds. Out of the blue John says "...George Fornby... ever see him on that...?" Trevor says loudly "oh yeah!" and laughs. John continues, "my mum used to say, where you been? You've been out for bloody hours", they all laugh.

George asks, "what are we in for? A dram?" They all laugh again, this time louder. A couple of nurses standing close by look over at the table and smile at the patients then at each other.

The patients start talking about how long they have been in hospital, and how long they have been in previously, as if it is a competition. Peter is

sitting reading a local newspaper he has picked up from the table, he drops his glasses case and I pick it up. They all laugh “that was quick” says George, “that was like a fork lift.” John asks me “how often does this [implying the table] happen?” I explain that the table is always here, and the patients start to talk about how nice it is to have a place to come and sit and have a chat.

John asks the other patients “shall we play cards?” They talk about card games they like to play or had played in the past, including cribbage and rummy. The conversation naturally pauses and the men sit in silence for a few seconds.

A Phlebotomist walks past and says “good morning guys”. He has come to take bloods from Peter. The other four patients laugh about how bruised Peter’s arm was from the last blood sample taken, George says “he wants another fight” and they all laugh, including the Phlebotomist.

The Phlebotomist turns to his right and says “OK, Mr Smith your turn now” John watches Peter and smiles. He says to the Phlebotomist “while you’re there, you can give me a haircut like yours. Haircut and a shave.” George says “I should have shaved while I was in the shower.” He rubs the stubble on his chin. John says to the Phlebotomist “make sure you ration it.” To Peter he says “He’s having 3 pints!” Peter laughs.

Peter asks when he will get the blood test results back, and the Phlebotomist explains “there are hundreds of people looking after you, don’t you worry about that”. He gets up to leave, smiling, and says “nice talking with you guys, see you later.”

This general chit chat continued between the patients over lunchtime, with various members of staff joining in (although not to the same level of interaction as the Phlebotomist) over the duration.

As we can see, there was a sense of camaraderie in this example, the group were all experiencing being a patient in the same space at the same time, even though their health states varied, and other patients I had observed behaved in a similar way when sitting at this table. Considering these social interactions through relationship-centred care, we can see how a sense of community can be created through social reciprocity in this regard, building temporary relationships with strangers within the space, through empathy and understanding of one another. Through this sense of community, patients can play an important role in the relational aspects of care.

In terms of empathy, when Ron asked the others if they were waiting to go home, this opened up a conversation about how long they had all been in the hospital, which in turn led to a different topic of conversation resulting in them all laughing at John's comment. This was the first time I had seen the patients laughing together. There was a feeling that this type of social interaction and connection with others supported the patients' sense of self in an otherwise impersonal environment; particularly for Frank, who talked a lot about his personal memories whilst sat at the table.

The flow of conversation may be something we would expect to see in a local pub environment, a sense of the familiar, with various social agents coming and going, in fact even Trevor made a reference to a pub when he asked "what are we in for? A dram?". Again, prompting laughter in the group. Dunbar et al's (2017) study demonstrated that people 'who have a "local" that they visit on a regular

basis are more socially engaged, feel more contented in their lives, and are more likely to trust other members of their community.’ (p.126). We could observe the communal area of the two ward environments in my research project in much the same way, by providing this shared table where patients could be sitting closer to each other than in the bay, the patients appeared more socially engaged and socially at ease with one another, compared to their interactions whilst in the bay. In regard to these cultural and mediated connections we can see the affordances of music in similar ways; meaningful music offering opportunities for connections and social interactions.

5.4 Musical connectedness

A running theme throughout my research is how live music and the interaction between the social actors on the ward during and after the musical session might support refurbishing, inclusion *into* an environment (DeNora, 2013) through increasing social connections. Taking this concept further, I propose a new theme which has emerged out of my data, that of ‘musical connectedness’. At the heart of the theme lies the focus on music’s ability to support relational aspects of care, namely creating and sustaining relationships and connections between the patient and those around them.

5.4.1 Connecting with family

A large body of research shows that patients with dementia often perceive their level of care to be poor (Kelly et al., 2019; Featherstone et al., 2019; Porock et al., 2015; Cowdell, 2010). Hospital wards are often confusing and disorientating for people living with dementia, as discussed previously, and social interactions with nursing staff are often limited to task-based care activities such as washing,

dressing and serving meals; however, staff do try to make these social interactions count where they can.

Kelly et al. (2019) suggest that 'one approach through which hospital care for people living with dementia might be improved is the involvement of families in care planning and delivery' (p.2). In terms of bridging the gap between medical and social care families are key – 'the personal knowledge of families, and their expertise and involvement in care, could play numerous crucial roles in facilitating the connections required to provide more person-centred care.' (Kelly et al., 2019, p.6). The Ward Manager of Oak ward, Robert, explained the benefits from his point of view: "families are key. We haven't stuck to visiting hours, they can come and go as they please. For every minute a visitor is with a patient, it's another minute that a nurse can spend doing something else." However, this becomes problematic for those patients whose families do not live close by or able to visit on a regular basis, which can be the case for many patients.

Take Henry for example, I never observed a visitor with Henry, and he rarely spoke to other patients or members of staff unless he was spoken to. Days would go by, and Henry would stare into space, he did not engage in any other activity such as reading a book or watching a television. During the live music performance, he would often appear the same, staring at the wall, not actively engaging with the music. I noticed that he smiled at the musician when they looked at him, which I interpreted as a polite response to the music as his eyes did not sparkle in the same way other patients did. This 'sparkle' in the eyes seemed to appear more often for patients that were experiencing the music with a visitor or engaging with the music in some way with other agents on the ward. In this regard, we can see how families may play an important role in supporting

musical connections, often through supporting engagement and bringing previous musical experiences with their loved one, into the present situation.

To this end, consider the example of Margaret, I had observed Margaret twice on her own when the musicians performed, both times she stared out of the window with her arms folded as they performed, she did not make eye contact with the musicians and her posture and gaze did not change when the musicians left. However, I also observed two performances whilst Margaret's daughter was visiting; during these performances her daughter engaged with the music, singing along particularly with the songs from the Musicals, holding Margaret's hands and swaying to the music, she also requested pieces for the musicians to perform based on Margaret's own musical tastes.

During the performances with her daughter in attendance Margaret smiled, she had the sparkle in her eye, her face appeared more relaxed, her cheek bones raised, and the laughter lines wrinkled around her eyes. She watched the musicians perform, and they came over to her and played at her bedside. It was interesting to note that the musicians also engaged more with Margaret when her daughter was in attendance. A couple of nurses stood in the doorway watching this interaction, and afterwards spoke to Margaret's daughter about her musical tastes, and they learned that Margaret had been a dancer in London in her younger years and she loved going to the shows. The nurses seemed surprised to learn this about Margaret, who at this moment in time presented as an older woman with mobility difficulties, in the mid-late stages of dementia.

Through my observations of patients with dementia and their carers during the live music performances it became quite apparent how meaningful connections can be facilitated by the family members. Likewise, they can play a more active

role in their loved one's care, by providing personal insights into the patient's personal preferences and life history, such as the way Margaret's daughter supported Margaret's engagement with the music through her personal musical tastes. This in turn can support the nursing staff to provide better person-centred care due to a deeper understanding of the individual's interests and 'musical DNA' as a result of family involvement in their loved one's social care. Likewise, family visits can help to broaden the social interactions for the patient, often families would talk to other patients and engage them in a conversation, particularly with those who did not have regular visitors. As described, patients without regular visitors appeared less connected with their environment and with other patients, even during the live music performances the patients with visitors appeared more engaged, often encouraged by their visitors who remembered certain memories involving the patient associated with a particular piece of music or requesting a piece of music for the musician to play. The visitors in this sense were able to play an active role in their loved one's care through music, by placing them out as people.

During one performance in bay three on Oak ward, whilst Kate and Alice played 'White Christmas' on their violin and cello, a visitor stood in the doorway and filmed the performance. At the end of the piece, she came over and explained to the musicians that she filmed the performance to show her mother, Mavis, who was a patient in a side room down the corridor. Mavis' daughter told the musicians that her mother had been in the side room for two weeks and as a result was quite isolated; "it's a shame she can't see you play, she loves classical music."

The hospital's Musician in Residence, Claire, suggested that the musicians could play for Mavis in her side room. Whilst Mavis' daughter appeared embarrassed

at the suggestion, clearly not wanting to inconvenience the musicians, Claire was insistent that it was no trouble at all. We all (myself, Claire, Mavis' daughter and the two musicians, Kate and Alice) headed down to Mavis' room, with her daughter leading the way. The musicians positioned themselves outside Mavis' door (the cellist, Anna, sitting on a chair and the violinist, Katy, standing up), it soon became apparent that due to the positioning of her bed Mavis would not be able to see the musicians, and so two nurses standing close by offered to rotate her bed so that she was facing the doorway and therefore able to see the musicians.

Mavis' facial expression changed when she saw the musicians, her eyes sparkled, and she smiled at the musicians. Mavis did not use words to communicate, but her body language showed a clear appreciation of their visit, her shoulders were relaxed, she appeared comfortable within the space. The musicians played short classical pieces for Mavis, staying with her for around 10 minutes. During this time Mavis' daughter stood behind her bed, one hand holding a coffee cup to her lips (although not actually drinking from it), the other hand on Mavis' shoulder, tears forming in her eyes.

Here we can see how Mavis herself became connected to the environment. The music clearly created an engaging environment in otherwise unstimulating surroundings (as discussed earlier, patients in side rooms are more likely to feel isolated, and Mavis' daughter herself had confirmed this was the case for Mavis), and in a deeper sense the music connected Mavis with the main ward space and the agents within it. Mavis' bed was physically moved so that she could see the main corridor and those walking past (previously she was facing a blank wall, with no window and could not see through the door into the ward). Mavis also shared

this musical experience with other patients, staff and visitors on the ward who could also hear the music, even if they could not see one another. This idea of shared experiences through the music is something I will come back to later in this chapter.

However, I found the real interest to lie in the connection between Mavis and her daughter during the music performance. I had observed her daughter moments before talking with a Doctor about Mavis' care, and the conversation was very much what we would expect of the medical model, the Doctor telling Mavis' daughter about their diagnosis and plan of action to help Mavis get back to 'full health'. Whilst there was opportunity for her daughter to ask any questions; there was a definite sense that a decision had already been made about Mavis' care by her care team, and her daughter was merely being updated of the fact rather than playing an active decision-making role in her care. I am highlighting this not to undermine this approach, but to emphasise how families can find themselves playing an almost inactive role in their loved one's care. Through her interaction with the music however, we can see how Mavis' daughter was able to play an active role in her mother's care at that moment in time, taking care of her social needs.

When a loved one is admitted to hospital you bring all your family baggage with you, and the environment can expose your vulnerability as a carer. However, in the case of Mavis's daughter, I saw her whole demeanour shift during the music performance, from tense and worry during her discussion with the Doctor, to a more relaxed state, shoulders dropped, soft expression on her face, eyes bright. In this regard, we might see the music performance as a form of respite for

Mavis's daughter, a form of self-connection, as much as it was a meaningful experience for Mavis herself.

There is often a disconnect between the patient with dementia and their carers when they are admitted to hospital, something which Kelly et al. (2019) say is 'keenly felt by both parties.' (p.3), and this was certainly true in my own observations, often seeing this disconnect in terms of lack of communication (verbal or otherwise), frustration often felt by the carer in terms of frustration with the person with dementia for not functioning in the hospital as they do at home, and also frustration with themselves through a sense of helplessness, and lack of control of the situation.

I observed moments of re-connection and intimate moments between husbands and wives during the music performances. As DeNora and Ansdell (2021) say, 'intimacy is a life-long need' however, in such as public space such as a short-stay hospital ward, intimacy is rarely observed. Consider Jack, he was thought to be a falls risk (symbolised by the maple leaf above his bed) who regularly tried to climb out of bed, and so the staff had decided to put his mattress on the floor for his own safety. On one particular day Jack had been agitated for most of the morning, trying to get out of bed (although his legs were weak), shouting out in an aggressive tone, and swearing. The staff were clearly exasperated by this.

After lunch, Jack, clearly tired, lay down in his bed with his eyes open staring at the wall. His wife arrived at the same time as the musicians and sat in a chair next to Jack's bed as she did every day, this always struck me as unusual due to the height difference with Jack's bed on the floor and his wife above him on the chair, making any form of communication extremely difficult. Their

communication normally involved Jack's wife telling him about her day or passing on messages of love from friends and family to which Jack never responded.

The musicians played two or three pieces of music, Jack stayed in the same position eyes open, staring at the wall facing away from the musicians and his wife, who quietly clapped after each piece. When the musicians started playing Everybody Loves Somebody Sometimes, Jack's wife got down on the floor and climbed into bed with him, cradling him and stroking his hair. I had not seen her do this in the preceding days I had observed her visiting. Jack's mouth twitched, turning upwards at the corners, and he started to close his eyes.

Inspired by Goffman's presentation of self, presenting the idea that like actors we play roles depending on the situation in which we find ourselves; we might consider that we enact a different version of our relationships whilst in hospital, compared with any other public space we might encounter. Our behaviours are very much public within the medical environment, and we perform a version of our relationship in public view, which may differ from our normal relationship behind closed doors. I had not observed this intimacy between Jack and his wife before. She did not outwardly engage with the music, for instance she did not talk to anyone about the performance or whether it was a particularly poignant piece for her and Jack, but something about that piece of music at that moment in time meant that she wanted to be closer (or at least wanted to appear closer) to Jack than she had been previously. In this regard, we might understand music to afford possibilities of micro moments of intimacy, whether through familiarity (linked with memories), or a shared experience of being in the moment together through music.

Through reminiscence and sense of shared experience I often witnessed carers and patients with dementia re-connecting in this way through the music. Over my research period I got to know one couple very well. Derek would visit his wife Joan every day at two o'clock in the afternoon and stay for around an hour, I saw them on both wards as Joan was transferred from another ward to Oak ward halfway through my research period. Joan was in the later stages of dementia. Every time Derek visited, he would try to hold a conversation with her, but she never replied. Derek showed a clear appreciation of the music and had a good rapport with the musicians, teasing them if they played a wrong note or if they played the same music that they had played the week previously. He would always ensure the musicians acknowledged his wife, often commenting on Joan's state of mind, apologising if she was unable to communicate with the musicians or engage with the music - "sorry the wife's not with it today".

Derek would always try to engage Joan with the music, but she would not respond. However, on one occasion, the musicians played "oh I do like to be beside the seaside", Derek said to Joan "Can you hear the music? Remember when we went to..." and he started singing along with the song, Joan turned to him nodded her head and her mouth opened wide into a big smile. Derek continued to sing along with the song, "la la de de" singing to Joan. He positioned himself to face Joan with his back to the musicians and the rest of the bay. In a way I felt I was intruding by observing such a personal moment; it seemed deliberate that Derek had positioned himself in this way, blocking out the rest of the bay, purely focussing on his wife at that moment in time, together deeply connected through the music.

As demonstrated above, connection through the music can take many forms, it can be an active engagement as described in the previous example with Derek and Joan, or it can be a more subtle interaction of being in the moment together, experiencing the music at the same time, not talking but still connected through the music as seen in the relationship between Jack and his wife and Mavis and her daughter.

It should be noted that live music in a hospital environment will not always evoke positive connections. If we are to truly adopt a person-centred approach to the use of music in dementia care, we must be mindful that it will not be beneficial for all people all of the time. During one performance, the musicians were playing 'Oh I do Like to be Beside the Seaside' (the same piece that had formed a moment of connection between Derek and Joan); a visitor appeared from behind the curtain and told the musicians they must stop playing as his father was at the end of life and the music was 'completely inappropriate'. In this regard, music was seen to create a disconnect for this particular visitor at a vulnerable time in his life. The very nature of music as a personal experience means that it will not always 'work' for everyone or may in fact exacerbate conditions (for example brain injury), particularly in acute hospital ward environments where health states are in a state of flux and as such our interests in activities shift and change depending on this.

If we are to consider music as a subjective multi-faceted activity it is important to acknowledge the potential negative experiences of music listening. Existing research draws upon these negative experiences, with particular focus on the deliberate inhumane use of music, music used as a form of controlling behaviours (Cusick, G. 2012; Cusick, G. 2008; and Cusick, G. 2006). Likewise, there are

times where music has no impact, positive or negative, as DeNora and Asndell (2014) say, 'music can do nothing and everything' (p9). To understand music's role within relational aspects of care, we need to see it something that is fluid, dynamic and nuanced, intertwined with environment and social relationships within them.

End of life care in particular, might be a very sensitive time in which our interpretations of person-centred care, and what is 'appropriate' might be extremely different. For instance, on other occasions I observed visitors specifically requesting the musicians perform hymns (on their instruments) for loved ones in end-of-life care. Compared with quiet recorded music, live music might be seen as intrusive by some, not only the volume (which is not able to be controlled by the patient or their visitors), but also having extra people in the space might feel intrusive in the final hours. However, we might consider in longer-term palliative care such as hospice care, this type of activity might be more appropriate in the more prolonged dying period. Whilst my research does not focus specifically on palliative care, it opens up the question of music's usefulness in end-of-life care, and the importance of the emotional intelligence of the musicians delivering music within these spaces. Emotional intelligence in this regard considers the ways in which musicians respond to the emotional needs of those sharing the musical experience, how they adapt their performance, tempo and pitch responding both to their 'audience' and environment, a theme I develop further in the following chapter.

We should not consider music as an 'intervention' compared to a drug; this reductive approach does not allow for the complex nuanced experiences of music. Ruud (2008) suggests that we should stop thinking of music as a stimulus

leading to predictable responses in a person, and likewise DeNora (2013) suggests that music in itself does not contain all the necessary qualities to regulate someone's mood, rather 'music's powers are constituted by [the listener] herself; they derive from the way she interacts with them.' I have attempted to examine music at a micro level, exploring what musicking affords for the individual and connections with those around them. An understanding of the affordances of music at this level could contribute to supporting care staff and families of individuals living with dementia within hospitals to create and sustain meaningful connections, something which Kelly et al. (2019) highlights as an important aspect in delivering person-centred dementia care.

5.4.2 Reassembling the ward hierarchy

Connection through a shared experience between the various social actors on the ward (the ward community) appeared to be more prominent during the live music performances than at any other time. Before the music there was a definite sense of hierarchy due to the roles played out on the wards – Nurses and Doctors told patients what to do and when, they were very much the ones in 'charge', with the patients being the ones that were having things 'done' to them. Blass (2007) talks about a lack of a shared agenda, and the 'conflict' and 'challenges' felt by physicians when caring for patients with dementia, particularly the patients who lack capacity to consent to assessment, whilst Hynninen et al. (2015) discovered that 'some [patients with dementia] felt ignored and insufficiently informed' (p.3695). The sense of disconnect is felt on both sides.

However, during the live music performance this relationship changed. The staff and patients were experiencing something together on the same level. For some members of staff this may have been the first time they had heard live music on

the ward, even for others who had heard the performances a number of times, each performance provided a unique experience depending on the musicians, repertoire, patient responses etc. Therefore, they were sharing this experience at this particular moment in time with these particular patients, which we could assume would have been different from any other performance they had experienced previously.

I often saw what was possible during a live music performance for patients with dementia through the eyes of the nursing staff, and this was a running theme through my data. One HCA, Silvana, told me “I love it when the musicians come...when the other month the musicians played and a gentleman in the bay sat up and sang...” her eyes and mouth opened wide and she laughed loudly, giving me a real sense that this was a significant change in how the patient had been prior to the music performance, and the memory was still very much fresh in her mind. This was confirmed through talks with other members of staff on both wards; likewise, two musicians also reflected on this element of surprise for staff:

[Anna]: We’ve seen some lovely stuff. The very first time I came in here there was a guy who was like completely unresponsive when Claire came in and said to him “oh we’re going to play some music.” We played ‘Smoke Gets in your Eyes’...and he waltzed with the nurse.

[Katy]: he was dancing away

[Anna]: they [the nurses] were shocked

[Katy]: Yeah, they said he’d never done anything like that before.

Going back to Jack and his wife’s connection through touch not words, this is something that I repeatedly witnessed between patients and staff. One patient,

Jim, was fixated on going home and his agitation stemmed from this. He would often get his bag ready and put on his coat (no shoes), only to be told by the staff that he was not ready to go home yet, and they would help to take his coat off and put his bag back in his locker, assisting him back to his chair, sometimes placing his table in front of him acting as a physical barrier. This scenario could repeat itself two or three times in one morning, each time ending with Jim being encouraged to go back to his bedside, each time making him that bit more agitated. Jim demonstrated his agitation through resistance (refusing to sit down), frustration and wandering. He would often wander up and down the corridor trying to open the doors at each end, always to no avail.

Jim's agitation escalated over the period of one morning by the fact he could not leave, and it was clear that for his own mental wellbeing this cycle could not keep repeating. As appeared to be the standard procedure, the decision was made by the care team that one member of staff (usually a HCA) should sit with Jim, to 'de-escalate' his agitation. Every time Jim tried to stand up the HCA would encourage him to sit back down either by using a distraction technique ("it will be lunch soon") or by taking a firm voice ("sit down Jim"). This interaction would repeat itself over and over with each HCA that sat with Jim (staff would swap at breaks and shift changes). In between, the HCA and Jim would often sit in silence, or if they did communicate it would either be the HCA telling Jim to sit down, or otherwise asking if he would like a cup of tea, or Jim requesting to go to the toilet. Although Jim's agitation did reduce slightly, there were longer periods where Jim didn't ask to go home (which as I previously suggested was where his agitation stemmed from) I could not help but notice how withdrawn and apathetic he seemed. There was a real sense of disconnect in terms of disconnection with

the HCA, disconnection with the ward and disconnection for Jim with himself. It was clear that the HCA did not want to be there, they appeared relieved whenever another member of staff came in and they could have a conversation. Both seemed bored and fed up.

However, when the harpist arrived on the ward Jim's eyes lit up, he did not say anything, but it was clear in his relaxed face that this was something that gave him pleasure. I had not seen his face like this before, his mouth normally screwed up tightly and his brow furrowed. The HCA, Angela, commented "look at that Jim, you're going to have your own concert". Jim turned to her and smiled, eyes still wide. The harpist started with a few well-known classical pieces, during the third piece – 'O Sole Mio' Jim reached out his hand towards Angela, who then held it in her hand on her lap, stroking Jim's hand occasionally with her thumb. Both their appearances seemed more relaxed than they had been all day, every now and then they would smile at the musician or each other. They were clearly connected through this shared experience.

The notion of connection through shared experiences in the music performances was a common observation I made. For example, I often found that patients (particularly female) would reach out for my hand if I was standing near to their bed during a performance. At first this made me feel uncomfortable, not sure if I was overstepping a boundary as a researcher. However, after seeing the disconnect that can occur for patients with dementia in hospital, I realised that touch can be an incredibly important aspect of care, as Luke Tanner (2017) in his book *Embracing Touch in Dementia Care* highlights - 'since touch is also a form of non-verbal communication, someone with dementia may also be more reliant on how they are touched to make sense of their relationships' (p53). Tanner goes

on to talk about the importance of touch and attachment for people living with dementia: 'they can be extremely dependant on others to regulate their levels of stress and excitement, whatever their individual attachment style. In order to feel safe and secure they need to attach to others at times of under-stimulation and times of stress to find a comfortable place within themselves.' (p.71). On a daily basis nursing staff use touch with patients with dementia – assisting with dressing, washing, mobility etc. However, it was only during the music that I saw these moments of meaningful touch and they were always initiated by the patients, a physical 'reaching out' for connection. This allowed for the staff to break through the social norms of touch and touch in a more free way, in an egalitarian way, connectedness for all patients.

There appeared to be more of a need amongst patients with dementia to reach out to members of the ward staff rather than the patients in the same bay. This struck me as an interesting point; observing on numerous occasions the lack of social interaction between patients. Whilst a growing evidence base demonstrates the lack of connection between patients and staff (Reilly and Houghton, 2019; Hung et al., 2016; Hynninen et al., 2015; Clissett et al., 2013; Blass, 2007), very little research focuses on the lack of connection between patients. A hospital bay is an unusual community as discussed previously, here you live your private life in a very public way, nothing is truly private in a hospital ward, you are separated by flimsy curtains, the other patients can hear every noise you make, every bowel movement (if using a commode), every conversation you have about your medical condition, it is an extremely auditorily intrusive environment within a relatively small space (Rice, 2013).

Patients enact a sense of privacy creating a distance either physically or socially from other patients. We could consider that this distance might be formed through lack of opportunities for social interaction within this shared space, with the sense of disconnection forming naturally. Going back to this sense of shared experience which I discussed in terms of patients and staff, this concept is also true for the patients and one another. The live music performance, by creating a shared experience, can initiate forms of connection and a sense of being part of a communal group; 'co-patients' within this hospital space.

Betty, Mabel and Jean had been in the same bay for at least a couple of days, I never observed them talking to one another, instead they normally stared at the wall as seemed to be the natural default for patients. However, one afternoon whilst the harpist was playing 'Edelweiss' Betty and Jean started singing along together, Mabel joined in, singing loudly with tears in her eyes. A couple of nurses upon hearing this came and stood in the doorway watching in amazement. As we can see, the music elicited a sense of community with strangers, something which I hadn't observed in this group beforehand. After the performance the musician and staff clapped the three patients and said, "that was amazing" and "well done!" The patients laughed collectively. Later on in the day I heard the same group of patients talking about the music performance and how good they thought the musician was. This was the first time I had heard them talk to one another.

Reilly and Houghton (2019) discovered that some patients with dementia felt 'disempowered, and socially excluded' (p.17). Whilst I too generally observed this before the music, for example lack of social interaction, increased frustration at ward routines and restrictions, during the live music performance a shift often occurred such as the one described above. Patients would therefore emerge as

a collective, and this sense of social cohesion generally continued after the music had ended. Likewise, after the music had finished it was typical that the performance would provide a point of conversation between staff and patients after the performance, normally instigated by the staff. I overheard Angela talking to Jim about the performance, saying that she really enjoyed Edelweiss as *The Sound of Music* is one of her favourite films. Jim told her that he used to work in the local cinema and would get free tickets to see all the “big movies” at the time. This was the first time I had heard Jim talk to Angela or another HCA other than to ask if he could go to the toilet. This is a prime example of the paramusical, through this shared musical experience Angela and Jim had found a common ground, which resulted in Jim engaging in social interaction.

In this example, we can see how the music furnishes the environment with things that allow people to interact in new ways. Ruud (2008) suggests that instead of making assumptions over what music affords for people we should use an ontological lens placing more emphasis on how ‘interpretation and narrative help people construct meanings from aesthetic objects.’ (p.50). Therefore, with the example of Jim we can see how he constructed meaning from the musicking through reminiscence, recalling memories associated with the music, and finding a common ground with which to interact with the HCA. There is a growing recognition that a lack of meaningful connections can contribute to a patient living with dementia having a negative perception of the level of care they are receiving (Reilly and Houghton, 2019). Therefore, through this shared experience and deeper connection it may be easier to care for a patient who is feeling agitated, improving the patient’s perception of their care if their social needs as well as their medical needs are being met.

To this end, the implications of the live music performance can be much deeper than purely providing a form of entertainment for patients, it can be a way of 'mixing-up' the social hierarchies within the spaces, a means of social connections, and interactions which continue after the music had ended.

5.5 Conclusion

This second findings chapter has examined the ways that meaningful music might support relational aspects of care through affording opportunities for social connections, and moments of reconnection with self for patients living with dementia. Generally, it can be said, as mentioned at the beginning of this chapter short-stay medical wards are disorientating places for people living with dementia due to the unfamiliar environment, staff changes, and difficulties with communication. Even in 'dementia friendly' wards, they cannot escape the inherent disconnectedness that short-stay medical wards present for patients living with dementia.

I have demonstrated how feelings of frustration and agitation are experienced by patients living with dementia as a result of the disconnection with the environment and those around them. For instance, through the example of George we saw how feelings of frustration escalated due to a lack of understanding of the environment, and a desire to go home. In this regard, a sense of powerlessness appears to be felt by both patients and staff. Patients are powerless in that they are reliant on external factors to be discharged, and staff are restricted by time, with minimal time for social interactions outside of care-based tasks. Likewise, patients with dementia may find it difficult to communicate their likes and dislikes or abilities/inabilities, and therefore staff might not know how to deliver care that meets their social needs, increasing this sense of disconnection.

Shared experiences in meaningful music can afford opportunities for creating and sustaining relationships and connections between the patient living with dementia and those around them. In this regard, the relationship with families was explored, demonstrating how meaningful connections can be facilitated by the family members, for example by providing personal insights into the patient's personal preferences and social needs. This in turn can support nursing staff to have a deeper understanding of the individual's interests, and in a musical sense, understanding the music, which is particularly meaningful, as well as the memories associated with it. Therefore, shared experiences of music then might potentially support caregivers to provide better personalised care for patients living with dementia through creating and sustaining meaningful connections, something which Kelly et al. (2019) highlights as an important aspect in delivering person-centred dementia care, and likewise meeting many aspects of Kitwood's (1997) theory of personhood.

The wider implications of music supporting a deeper understanding of the individual living with dementia means that experiences of agitation may be decreased through an inclusion into the environment (DeNora, 2013) and a re-connection with sense of self, meeting social needs through increased social engagement. Considering the example of Jim, we developed an understanding of the ways in which shared experience in music can afford an opportunity for social reciprocity, with this increased social interaction lasting long after the music has ended.

It was discovered that music's ability to create connections in this regard lies in its familiarity, therefore creating a familiar environment by bringing the past into the present through sensorial memories, supporting connections between the

individual living with dementia, their environment, others around them, and a sense of reconnection with themselves. These results correspond with previous findings, for example Chang's meta-analysis (2005) demonstrating that the use of preferred music can help to decrease feelings of frustration and agitation by introducing a sense of familiarity into an unfamiliar environment (p.1134).

In summary, this chapter shows how shared experiences in music can create and sustain social connections, supporting person-centred care through providing a deeper understanding of the individual living with dementia, their life history, likes/dislikes, and social needs. Likewise, music can support aspects of relationship-centred care by providing a space for families to be involved in their loved one's care, through sharing their own personal knowledge of the individual's preferences, and as a result supporting care staff to provide better personalised care. In this regard, the ability to continue the benefits of live music performances lies in the support of staff and families to recreate and sustain positive emotions for people living with dementia. In the following chapter I shall explore this theme further, considering the ways that music can afford moments of empathic understanding supporting emotional care and therefore enhancing emotional wellbeing, and quality of life.

6 Relational aspects of caring for patients experiencing agitation

“What aspects of quality of life would you like to promote on the ward?”

“Feeling worth, feeling valued, having a satisfaction with life and one’s own self even if you are just ill or recovering from an illness, there can be something meaningful that you are a person of value and seem to be valued by other people in those interactions.” Dr Myatt – Consultant

Geriatrician – Oak ward

6.1 Introduction

In this final findings chapter I continue to explore how feelings of being unsettled within acute care are manifested in patients living with dementia, focusing specifically on agitation and apathy. Whilst chapter five explored disconnection and the ways that meaningful music can create or sustain meaningful social connections, this chapter focuses on the emotional aspects of dementia, providing an understanding of music as a meaningful sensory stimulation which supports the emotional wellbeing of people living with dementia, and therefore may provide a decrease in feelings of agitation and apathy.

Agitation is considered to be one of the main challenges of caring for individuals living with dementia (Featherstone et al., 2019), and it has been directly linked to caregiver burden and reduced quality of life (Park et al., 2009), as previously discussed in the literature review chapter. It is a common experience for people living with dementia, particularly in the later stages of the condition (Livingstone

et al., 2017). Whilst there is little research to suggest why this might be, more recent understanding is that one trigger for agitation stems from unmet needs (Bunn and Handley, 2019), whether physical, social, or emotional. This relational view of agitation may be seen to enhance the neuroscience research, that agitation is caused by dysfunctional neural networks involved in cognitive control and emotion regulation (Rosenburg et al., 2015). Whilst this research presents what may be occurring in the brain, it does not tell us how agitation is manifested and *felt* by someone living with dementia, as an emotional, embodied and situated experience.

To this end, within this chapter I consider the nuances of agitation and apathy, considering in particular how agitation stems from a combination of sociological and psychological factors, which is manifested in different ways for individuals living with dementia. I demonstrate how these can be conditioned by meeting certain emotional and social needs, however not always. Along with this, I am looking at how familiar, meaningful music is linked to changes between individuals living with dementia, and the environment, which might mean that even if instances of agitation continue, family and carers may be better equipped to deal with it and support the individual experiencing the agitation to perhaps notice these feelings less.

I draw upon DeNora's (2013) concept of musical asylums, as discussed previously in the literature review chapter, and chapter five, demonstrating how music can afford moments of refurnishing and removal. Refurnishing transforms our surroundings and is more concerned with 'remaking the environment' (p.50), whereas removal moves the individual out of the space either figuratively or physically to somewhere more conducive to their wellbeing, which may in turn as

I present within this chapter, be one way to reduce agitation for people living with dementia.

I consider the emotional needs of individuals living with dementia in acute short-stay medical wards, and the consequences for agitation if these emotional needs are not met. As Petty et al. (2019) remark, 'emotion is an important part of the internal world of people with dementia' (p.527); even when cognition and communication are diminished, individuals living with dementia still experience emotions, and still experience the need for emotional connections. However, the understanding and communication of these emotions is just one challenge for people living with dementia (Blair, 2003), in addition to neurological impairment, hallucinations, distress, and other people's behaviours which can also result in instances of agitation. It is my intention within this chapter to demonstrate how a social-emotional approach can lead us to understand agitation as a situated, subjective, embodied, and temporal experience.

Further to this, it is understood that there is a direct correlation between impoverished sensory environments (Malafouris, 2019) and poor mental health, and in particular for patients with dementia which is thought to lead to diminished communication and interaction (ibid). It is perhaps not surprising then, that apathy is likewise a common experience for people living with dementia. For instance, Da Silva Vasconcelos et al. (2019) discovered that apathy is experienced by nearly half of the people living with dementia in the UK; however, as it is less 'disruptive' than agitation it is often ignored. Apathy is considered a loss of motivation for goal-directed behaviours and is associated with reduced quality of life and caregiver frustration (Brodaty and Burns, 2012). Stuss et al. (2000) propose three categories of apathy: emotional, cognitive and behavioural. Within

this chapter I consider in particular emotional apathy, a common experience observed within the two wards I studied. To this end, I explore both agitation and apathy as experiences that exist within the gamut of life of individuals living with dementia.

I explore how connection with music may help to reduce agitation and apathy through providing possibilities to unlock and support feelings of emotions through the use of music which is meaningful to the individual living with dementia. This unlocking of emotions can be facilitated in some regard by the emotional intelligence of the musicians. Emotional Intelligence, also known as Emotional-Social Intelligence (Cleary et al., 2018) as described by Salovey and Mayer (1990): 'involves the ability to monitor one's own and others' feelings and emotions, to discriminate among them and to use this information to guide one's thinking and actions.' (p.189).

There is a growing body of research to support Emotional Intelligence in nursing (Štiglic et al., 2018; Cleary et al., 2018; Zysberg et al., 2011; Beauvais et al., 2011), suggesting that nurses who are in tune with their emotional intelligence make better decisions, build better relationships with patients, and positively impact the level of care received by patients and families (Raghubir, 2018, p.127). Whilst there is a plethora of literature around Emotional Intelligence in nursing, there is little research on this within community musicians or even Music Therapists working in clinical settings, yet there are clear overlaps in the ways in which healthcare staff demonstrate instances of Emotional Intelligence. I say healthcare staff, as the current literature focuses primarily on Nurses, whereas I am arguing that the craft of caring, and support for emotional care is and can be displayed by any social actor within the space. We could consider this through

the concept of Emotional Labour (Hochschild,1983) as described within the literature review. I explore the similarities between the ways in which the musicians and other social actors within the two wards supported emotional care at a micro level, focusing on individual emotional needs. Bolton (2001) says that nurses have become accomplished social actors, and multi-skilled emotion managers, able to portray a variety of faces: 'the professional face, the smiley face and humorous face, against the backdrop of structural changes affecting the British public sector.' (p.86). Whilst Bolton was writing two decades ago, the point he raises still stands today; in fact, in a more strained NHS we might consider that staff are required to do more emotional labour due to staff shortages and an increase in patients requiring additional social care alongside medical care. Therefore, additional social stimulation such as live music performances may support staff, through providing one way of meeting the social and emotional needs of patients living with dementia.

It must be noted that these emotional responses to music will not always be positive, the very nature of emotional associations with music means that it also has the possibility to be associated with negative emotions. To this end, I also demonstrate the times when I observed music bringing back negative emotions, and the resulting emotional responses to the music experienced by patients living with dementia.

I pull together the threads bringing the musical observations into care practice, by drawing upon the importance of empathy within emotional care both within and outside of the music. With this in mind, I use vignettes to describe the ways I observed the music performances affording empathic understanding in the caregivers, and the ways this supported the emotional wellbeing of patients living

with dementia after the music ended. The empathic and relationship-centred nature of these type of interactions is shown as one way to support the wellbeing of individuals living with dementia experiencing agitation.

6.2 Emotion regulation

6.2.1 Triggers of agitation

Various states of emotions are displayed during an acute hospital stay. For instance, I observed a multitude of emotional states in patients living with dementia and their families, including fear of routine care such as washing, anger from loss of control, joy during a loved one's visit, and sadness from the heart ache of seeing a loved one pass away, displayed either as subtle or overt expressions of emotion. These can be considered through Kemper's (1987) primary emotions: happiness, fear, anger, depression. In terms of agitation, we might consider the emotional aspects of agitation to be secondary emotions of fear, anger, and depression. As Turner and Stets (2019) remark, 'when people fail to confirm self, they can experience a variety of negative emotions.' (p.300). This failure to confirm self is central to my own research. As discussed in the previous chapter, the sense of disconnect from oneself appears to be heightened for people living with dementia whilst staying in hospital, and this diminished sense of self identity can lead to emotions which may exacerbate agitation and disconnection, as I shall demonstrate.

Clare et al. (2008) writing around residential care, discovered that people living with dementia experienced 'difficult and distressing emotions relating to loss, isolation, uncertainty, fear and a sense of worthlessness.' (p.711). Likewise, through my own observations in acute short-term care, triggers for agitation appeared to stem from situations in which the patient appeared lost, both

metaphorically and figuratively. For example, a common observation being the strong desire to go home. Going home is a key focus for the majority of patients, but for patients living with dementia there seems almost an obsession with the need to go home, a common observation; however, there is little research on the topic, as highlighted by Poole et al. (2014).

Consider the example of Arthur. Whenever I observed Arthur, he was wearing hospital branded pyjamas and bright red thick non-slip socks, a sign to the staff that he was a potential falls risk. Arthur's bed was the closest to the bay entrance, and during the busy mornings he would sit on his bed watching the comings and goings of the staff on their rounds. He would walk around his bed, going one way, look in his cupboard, and then walk back around the other way usually smoothing his bed sheets or moving his pillow a fraction. Through the lens of Goffman's asylums, we can see how Arthur was finding things to do whilst in hospital, in other words occupation.

During the morning's hustle and bustle of ward rounds and the constant coming and going of staff, Arthur would often tell staff he was going home. The staff would either not respond whilst they were occupied with another patient in the bay or would reply along the lines of "not just yet Arthur". During periods of inactivity on the ward, often after lunch when the ward went back to being still and quiet, Arthur's fixation on going home would continue, and consequently his agitation would begin to escalate.

Arthur would repeatedly press the call bell next to his bed, and if no one answered immediately he would start walking the length of the corridor, pacing up and down, telling staff "I'm going home, I've got to get home to my mum". Usually staff would tell Arthur to "sit down" and if Arthur continued to get up, a distraction would

be implemented – staff would give him jigsaws to complete, or picture books to look at with photographs of nature or local landscapes. Sometimes a member of staff, often a Healthcare Assistant or a Dementia Coordinator, would sit down with Arthur and talk to him about the puzzles or books, but usually he would be sitting on his own either next to his bed with his table pulled across, or on a chair in the corridor, as the stretched staff would not have the time to provide this level of individual, relationship-based support.

Considering this example then, we can see how this tightening of restrictions – locked door, the staff telling Arthur repeatedly to “sit down”, afforded various distressed emotions for Arthur and he appeared agitated, his face tight, his hands clenched, his posture stiff. We can consider this in terms of the ‘looping effect’ a term which Featherstone and Northcott (2020) introduce in their ethnography of dementia care in acute short-stay medical wards. Looping in this regard refers to the repeated cycles of ‘highly structured care practices at the bedside’ (p.9), which in turn heightens the individual’s distress. Their agitation is therefore seen as ‘behavioural’ features of the dementia (ibid) and these behaviours are then managed and restricted, escalating the agitation further. In this example we can see looping in action – Arthur presses his call bell and repeatedly asks to leave the ward, which means the staff direct him to sit back down, which in turn leads to further attempts to leave and increased agitation.

Consider another example, Donald. He often sat in the large armchair next to his bed, looking out of the window over the hospital carpark at the green hills beyond. He generally appeared contented; however, when the staff undertook care tasks such as washing, he would become distressed, shouting “no, no” repeatedly, each time getting louder. From the other side of the curtain, it was clear the staff

were becoming exasperated, having conversations amongst themselves about how “difficult” this was, often needing to call for another member of staff to assist them. This extra person appeared firmer, saying things to Donald such as “what’s all this fuss, Donald? You need to help us”. Once the curtains were pulled back it was clear both Donald and the staff were exasperated by this event, the staff sighing and rolling their eyes at each other, and for a while afterwards Donald pulled at his catheter and picked at the microtape holding his canula in place. This type of interaction appeared to happen frequently during the day-to-day care of Donald.

Likewise, Jean a patient staying in a side room, would often call out and press her call bell. Whilst a member of staff was in with Jean she would be quiet, but after they left she would call out “hey...hey” and begin pressing her call bell. At times I could hear staff saying to Jean “we’re just around the corner, Jean, I’ve just got to see another patient and I’ll be back”, but each time Jean would continue to shout when they left and repeatedly press her call bell. Her agitation escalated each time the member of staff came into her room and then left again. This type of interaction appeared to continue throughout the day.

Whilst I have chosen to highlight just three examples, this variation in agitation triggers and the ways in which agitation was manifested was typical across all patients I observed experiencing agitation - they each appeared to experience the emotions associated with agitation in different ways. Even if the triggers and manifestations were similar, no episode of agitation was the same. If we consider agitation in an emotional context then, recognising agitation to be made up of various emotions, we can understand agitation as a highly variable, subjective experience, much in the same way that we experience the emotions themselves.

As Feldman Barrett explains (2018) my feeling of joy and the way I display this might be *similar* to your experience of joy, but we will not experience it in *exactly* the same way. In this regard we can also understand how agitation does not have firm boundaries; by this I mean that it is not made up of a clear set of behaviours as has been the general understanding of agitation since Cohen-Mansfield (1986), rather it consists of a variety of emotional states, each unique to the individual. It should be noted here that whilst agitation was observed only in patients living dementia (it did not appear to occur in patients without dementia), agitation was not displayed in every patient living with dementia, again demonstrating the subjective nature of agitation, and indeed, of dementia itself.

6.2.2 Occupations and materiality

In the above examples we can see different triggers for agitation, and the ways in which agitation was manifested in different ways; from Arthur wandering in response to not being able to go home, to Donald repeatedly shouting whilst being washed, and finally Jean calling out and repeatedly pressing her call bell. As I got to know the individuals albeit over a short period of time, I got to understand their patterns in relation to agitation, noting their individual triggers. This pattern of agitation was almost episodic in nature, individuals did not seem to experience continually high agitative states, rather it came in waves. For example, agitation would be caused by a particular trigger or triggers and build (either suddenly or gradually) over a period of time, reaching its peak and then reducing, again either suddenly or gradually. We can also understand these 'waves' of agitation through the literature on the temporal variation of emotion; for example, Mattley (2002, p.375) remarks that 'emotions are temporally and relationally rooted in the social situation'. If we consider agitation to consist of a

variety of emotions then, we can see how agitation too may be considered to be temporal and a subjective occurrence relating to environment and social relationships.

I observed a break albeit sometimes short, before the next episode of agitation occurred, either by the same trigger or a different one. Continuing with the example of Arthur, he sat in his chair after being offered a jigsaw; whilst he did not put the pieces together, he looked at the pieces, turning them over one by one, opened and closed the lid, moving his fingers along the picture on the front. This exploration lasted around ten minutes before he began pacing once more, and again telling the staff he was “going home”, the next episode of agitation beginning. Here we can see how the sensory stimulation of the jigsaw became the focus of Arthur’s attention span, for a moment breaking the circuitry for the wave of agitation we had seen previously. Sensory stimulation such as this has been shown to support wellbeing (Mileski, et al., 2018; Cooney et al., 2014; Lykkeslet et al., 2001). For example, Mileski et al. (2018, p.967) state that ‘using non-pharmacological means such as sensory and memory stimulation... can promote both physical and emotional comfort in people living with dementia.’ The current research emphasises the importance of providing sensory activities that are meaningful to the individual and requires staff with a knowledge and understanding to deliver activities at the right time, in a way which is suitable for the individual. (Mileski et al., 2018, p.4).

Continuing with the example of Arthur then, we can see how the jigsaw chosen by the staff supported his emotional wellbeing, his agitation ceased. However, his agitation began to increase again after a short period of time, which considering Mileski’s (2018) research, we may assume to be triggered because he had been

left on his own to complete the jigsaw rather than a member of staff engaging in the activity with Arthur. I understand that this may sound a criticism of the staff, which is not my intention, rather I am highlighting that the nature of an acute medical ward is not conducive to the social and emotional needs of patients living with dementia, and therefore it is my understanding that this is why we see increased episodes of agitation in short-stay medical wards, sometimes with very few breaks in the circuitry.

If we are to understand agitation as episodic and subjective then, stemming from unmet social needs situated within an impoverished material environment (Malafouris, 2019, p.196), there is a need to understand individual triggers for agitation in order to reduce individual experiences of agitation and associated emotions. We need to understand what is typical for the individual rather than what is typical from a list of collective behaviours under the banner of agitation. Therefore, moving away from a behavioural model which sees agitation only as a pathological complication of dementia with a set of pre-determined behaviours, rather to a more sociological focus which sees agitation as relational, situated and subjective.

In line with this, consider my observations of Anne – Anne would sit in her chair behind her table, pulling at her bed sheets, putting them back on her bed and pulling them off again. She would also pluck the tissues out of their box, one by one and pile them on her table. These activities were enacted in a hurried, agitated manner. She appeared focused on the task, but emotionally she seemed concerned, brow furrowed as if looking for something she could not find. The nurses gave Anne a twiddle muff – a handmade muff with various accessories sewn on – ribbons, buttons etc. various things to twiddle, move, pull, stroke etc.

- and so Anne still sat in her chair, but instead of pulling at tissues, she held the twiddle muff, feeling the different textures and looking at the various colours. As a result, Anne appeared more contented, her movements were less frantic, her fingers slowed as she moved them over the different materials, feeling each bead, each piece of silk sewn on to the woollen muff. The twiddle muff appeared to 'work' for Anne and provided the stimulation she required at that moment in time, highlighting the need for 'fitting' sensory stimulation, that will meet the needs of the individual.

The literature on materiality and mental health is useful here (Malafouris, 2019; Ingold, 2012; Turkle, 2007). In relation to the importance of materiality in supporting the wellbeing of people living with dementia, Malafouris (2019) considering the transition from home to care home, remarks that loss of self occurs for people living with dementia when moving from the home environment to a care home due to the loss of material possessions and the memories and positive associations relating to said objects. In care home environments residents are allowed to bring personal possessions, although of course there is not enough space for all possessions. However, in an acute medical ward patients tend only to be admitted with a bag of clothes (at times not even this). There is a distinct lack of personal possessions or anything memorable to the individual, creating further diminishment of self. Providing sensory stimulation as seen in the example of Anne, can support positive emotions and a reduction of agitation, through the interrelation between materiality and what this affords for the individual in terms of an experience of positive emotions and a decrease of agitation. Whilst the material object in Anne's case was not personal to her, it did not have any previous memories associated, we can see how it afforded positive

emotions, and we can clearly see the link between the ecology of material objects with regards to reduction of agitation.

Likewise, continuing with the theme of materiality and occupation, consider the example of Phyllis, she would spend most of her day sitting in her chair slowly rocking back and forth; sometimes stopping to pick up the corner of her bedsheet, look at it and go back to rocking. Unlike Anne, her face was relaxed, her jaw soft, she did not appear distressed by this activity. However, under most agitation inventories both Anne and Phyllis would be understood to be displaying agitation due to repetitive mannerisms and in Phyllis' case, rocking. However, in Phyllis this repetitive activity did not appear to be causing her distress, in fact due to Phyllis' relaxed demeanour we might consider her actions to be providing her comfort, to be in 'flow' (DeNora, 2013), perhaps providing a means for comfort. Both of these examples demonstrate how agitation is a subjective and situated experience, one which cannot necessarily be determined through a behavioural checklist, but through observations, interactions and understanding of the individual's behaviours and experiences in relation to the environment and context.

In terms of agitation then, we may see the interrelation between materiality and flow to be the antitheses of agitation which can for some individuals stem from diminished sense of self, disconnection with others and dissociation with the situated environment. Rather, an embodied experience of material objects and occupation affords wellbeing. With this in mind, consider the following quote from Sandra, an Occupational Therapist now working as Dementia Coordinator across the whole hospital, she provides her experiences and understanding of agitation and relation with materiality and occupation:

“There’s a bit around productivity isn’t there, and when we think of productivity and the arts and the activities that go on are really important and provide that additional stimulation, but even someone in their own home they’re productive, you know they get up they make their cup of tea they might read the paper, so I suppose it’s providing some productivity that’s relevant to them, whether that’s some tidying their bed or you know getting their clothes organised, you know it’s about what makes their day meaningful to them.

And again I suppose it’s about knowing their history and their individual likes and dislikes, so for some people it might be really useful to come into the day room and have lunch and companionship and music and the television. But I had one gentleman recently and his productivity was he had been a mathematician, he liked to have his own space, he liked to write things down, to have an order to his day, so for him to have noise and other people would have been [makes a negative noise and screws up her face].”

Sandra reminds us of the importance of meaningful activity, considering activities as subjective, with the need for a sense of purpose for the individual. Taking this individual approach to agitation then, we may consider Anne and Phyllis not to be displaying agitated behaviours but rather participating in this sense of activity and occupation that is highly subjective. A lack of stimulation and occupation, diminished sense of self and purpose, is one way we see the wave of agitation begin, and through a sense of purpose and occupation with which we see it subside.

6.3 Emotional apathy

We can also see this diminished sense of self due to lack of stimulation and occupation through emotional apathy, a common narrative in dementia care literature (Perri et al., 2018; Ang et al., 2017; Domenico et al., 2016). Apathy is a common symptom of dementia, particularly Alzheimer's Disease (Theleritis et al., 2014; Tunnard et al., 2011; Esposito et al., 2009), defined as a lack of motivation for goal-directed activities (Domenico et al., 2016). Robert et al. (2006) remark that individuals with apathy 'do less, think less and feel less.' However, as I shall demonstrate, we might instead consider apathy to be an inability to express emotions, rather than to not feel emotions at all.

As Rujkumar et al. (2016) highlight, 'apathy is not merely a symptom, but a multidimensional syndrome affecting cognitive, emotional and behavioural domains...' (p.742). Unlike agitation, which we might consider to be a lack of emotional regulation and understanding, apathy as described by Rujkumar is considered through emotional experiences, or lack of. Likewise, Da Silva Vasconcelos et al. (2019) found that apathy is present in nearly half of all people living with dementia in the UK. They found that whilst it was a common symptom, apathy was often ignored as it was much less disruptive in settings such as care homes, than symptoms including agitation and aggression. We could assume then, that at least half of patients with dementia may have apathy, however there is little research around apathy within hospital patients with dementia, nor the relationship between apathy and environment - situational apathy.

Consider Norma, who I observed every day for a period of three days each at different times. She was in the middle bed of a six bedded bay, situated at the far end of the corridor. Norma would often sit in the high-backed armchair beside her

bed, staring at the blank wall opposite her. On her table sat a jug of water with a half-filled cup next to it alongside her glasses case. Norma's face displayed neither positive nor negative emotions, her jaw soft, her eyes flat. She did not make eye contact even when I attempted to catch her gaze with a smile. Staff would try to engage Norma in conversation – "it's beautiful weather outside today Norma", "soon be lunchtime Norma". She would look up at them with an unchanged expression and then continue to stare at the wall opposite, equally appearing not to notice the two patients either side of where she was staring; one lay in her bed with her eyes closed, the other sat in her chair looking down at her feet or out of the window, looking across to the older part of the hospital.

At mealtimes Norma would push her food around her plate, taking small mouthfuls, her face the same as I had seen previously, soft, neutral, unengaged. Norma never had any visitors and she appeared disconnected physically and metaphorically from the outside world. Considering the main definition of apathy as a lack of motivation and engagement, we might understand Norma to be experiencing apathy in that she did not engage with others or with her environment, she appeared withdrawn and disengaged. This was a typical observation in both male and female patients; where patients would sit and stare, appearing to display neither positive nor negative emotions, they appeared withdrawn.

The two hospital wards I observed were very quiet and generally calm, which is atypical within acute medical wards, this may be due to the 'dementia friendly' aesthetics and the removal of the main Nurses station as mentioned in previous chapters. Staff spoke of this peace and relaxation on the ward as a gold standard, something they strived for – "It means that they're [the dementia friendly wards]

quieter, they're quite tranquil in comparison to other wards. You go onto some other ones and there is something going on", "it's certainly more tranquil on those [dementia friendly] wards, much more quiet". There is a distinct avenue of exploration here, for future research to explore the relationship between presence of apathy (or lack of) and environment, how does a quiet dementia friendly ward or the busy, noisy nature of general acute wards in contrast impact apathy and agitation?

6.3.1 Music-induced emotions

Considering emotional apathy as an inability to display emotions then, we can consider the use of familiar music, particularly music with strong emotional memories, as a way of 'unlocking' these emotions which were previously difficult to express. Take the example of Jeff; when I observed Jeff before the music performance, I saw him as a tall man stooped in his chair, staring at the wall for hours on end. The nurses would ask if he would like anything, "cup of tea perhaps", but he just said "no" and continued to stare at the wall, displaying a similar 'apathetic' expression to the one that Norma had. Here was a man who may be presenting as emotionally apathetic. However, during the music performance I observed how Jeff was able to explore and express his emotions. Consider my field notes from one performance:

Whilst the musicians played Jeff continued to stare at the wall, as he had done for most of the afternoon before the musicians arrived. As the musicians were packing up, Jeff started to speak. He stared at his shoes and mumbled something about Christmas, one of the musicians came over to him and asked if he would like a particular piece, in a quiet voice he said, "White Christmas". The musicians smiled at each other and took

out their instruments again. While the musicians played, Jeff wiped a tear from his eye and he sang loudly with the chorus "I'm dreaming.... Of a White.... Christmas" the violinist played with the tempo, speeding up and slowing down to match Jeff singing. At the end of the piece Jeff laughed loudly with tears rolling down his face. The Musician said, "Oh I don't want to leave you sad." Jeff replied, "oh that was wonderful!" and laughed, a deep belly laugh.

The heightened emotional state that Jeff demonstrated immediately after White Christmas did not last, however. After about 20 minutes, Jeff returned to his previous apathetic state, staring at the wall. In all my observations of Jeff, his emotional engagement with music, and his heightened emotional orientation, was temporary. It lasted for a few minutes/seconds after the music stopped and then evaporated, a mere moment as Aasgard (2002) remarks. However, staff interaction afterwards provided a conversational reference back to the live music performance, prolonging this 'moment'.

The Nurse caring for Jeff's bay had seen his response to the performance and had presumably told other members of staff, they would talk to Jeff about it – "I heard you were serenaded by two beautiful women today Jeff?" which Jeff responded to by laughing. Each time the staff brought up the performance that day, Jeff would laugh. Through these discussions the staff were able to support a re-creation of the emotions which the performance afforded for Jeff. We can understand this through DeNora's (2013) musical asylums, the staff refurbishing the ward to make it more conducive to Jeff's wellbeing.

This instance of emotion may be assumed to also afford moments of the staff understanding the patient as an individual, having a glimpse of the personality of

patients such as Jeff, who may have previously been considered 'hard to reach.' What we may see is an understanding of each other afforded by the music, and an example of music intertwined with care, one supports the other. The music offers pretext for interaction before and after the music, prolonging the affordances of the music performance for both staff and patients.

To understand this mutual benefit of a shared musical experience, consider this interaction between Nurse Rosa and a patient, Joy. The musicians started playing *The Blue Danube* by Strauss while Rosa was monitoring Joy's blood pressure. Whilst she was setting up the equipment, Rosa stopped what she was doing, stood next to Joy and listened. Afterwards she said to Joy "Oh, that makes me sad, I miss my family," and continued to tell Joy about her family in Poland. She had come to England to work, but her family all still lived in Poland. This event happened a week before Christmas and Rosa explained that she would not be home for the holiday period. Joy looked at Rosa, put her head to one side, her mouth turned down at the corners, and nodded her head. At that moment in time, both showed almost a vulnerability, a mutual understanding potentially, of how the other was feeling.

We could consider this experience through Clarke et al's (2015) understanding of music as a 'medium for empathetic engagement.' Through sharing the musical experience there is an encounter for a 'mutual emotional calibration' (Smith as quoted in Clarke et al., 2015), opportunities for mutual understanding and connection afforded by engaging in music together. In the two examples above I believe we can see this empathetic engagement in action; the staff experiencing the music performance with Jeff and sharing in his feelings of elation at hearing the musicians play *White Christmas*. Likewise, Joy and those around her could

empathise with Nurse Rosa who was missing her family, as they too shared this experience of being away from home, mutual feelings which came to light through social opportunities afforded by the music.

This understanding of each other through the music links to the previous chapter in which I discussed the ways in which music afforded moments of mutual understanding and connection. Consider this example of Olga, I observed Olga over a period of three weeks, she was in Beech ward at the far end of a five-bedded bay next to the window; I always saw Olga in the afternoon. Unlike Oak ward, Beech ward always appeared busy in the afternoons, which may have been due to its smaller size, with the comings and goings of staff appearing more noticeable, and as a result the noise level was slightly higher. Olga's bay was in the middle, a light and spacious bay, with a bright orange doorway:

The first time I met Olga she was sat up in bed shouting out in what appeared to be Russian, she seemed upset, her face tight, her brow furrowed. The harpist, Gareth, positioned himself at the far end of the bay as he often did, in this case at the foot of Olga's bed. Gareth tried to engage Olga in conversation – "Hello, my name is Gareth and I'm going to play for you today." Olga continued to shout, Gareth smiled and began playing 'The Emperor Waltz' by Strauss. As he played Olga stopped shouting and started to wriggle her fingers in time to the music, she called out in English "oh yes". Her shoulders lowered, her face softened, and she let out a loud sustained laugh. She continued to talk in her own language, but this time it had a positive tone, almost song-like. At the end of each piece Olga shouted out "bravo Pasha" her smile wide, her cheek bones high.'

From this interaction we can clearly see that Olga was displaying an instance of positive emotion. The following week Gareth was requested by the Nurse in Charge (who had not been at the previous week's performance) to start in Olga's bay as Olga was "particularly agitated". The very nature of this request shows that the staff had learned of Olga's appreciation of the music, and this in turn set up the music performance based on the previous experience of the feelings of joy that the music afforded for Olga. The request from the Nurse in Charge is an example of one way that music aids learning about patients and can become incorporated as a strategy for supporting the wellbeing of the patient, the care staff, the whole ecology of the acute ward.

Olga appeared angry at the Healthcare Assistant who was trying to take her blood pressure. Olga kept trying to take the cuff off. As Gareth set himself up in the same position as the week before, the HCA said hopefully to me "maybe when the music starts she will calm", she looked over at Gareth almost eagerly waiting for him to play the first note. Gareth starts by playing a Viennese waltz a different one to the one he had played last week. The HCA appears disappointed, looking from Olga to Gareth and says "Oh, she doesn't recognise it." During the second piece – Claire De Lune by Debussy, Olga says "whatever you play, very nice." She says "dub dub dub" in time to the music and "give...give" then laughs. During Claire De Lune the HCA takes Olga's blood pressure, this time Olga doesn't appear distressed, she watches intently as Gareth plucks the strings on the harp. At the end of the piece Olga says "blip blip blip" and moves her hand, mimicking Gareth. She starts to laugh and so does the HCA.

Whilst Gareth plays Ain't Misbehavin' by Fats Waller, Olga says "Oh lovely. Like movie." Then she says to me "she like? She must love" and she smiles, her eyes sparkle. In the middle of the piece Olga says "oh yes" and clasps her hands tightly into her chest as if she is holding something close to her. At the end she claps loudly and says "bravo, bravo, bravo, oh thank you, bravo". The two other patients in the room continue to sleep in their beds, it is as though this performance has been solely for Olga.

The third week and the last time I observed Olga, she was sitting in her bed, her glasses upside down on her face. She appeared to be unengaged, she didn't recognise Gareth as she had done in the previous weeks. Gareth made attempts to recreate the connection they had before, playing the same pieces which had previously sparked joy. However, this time Olga had a glazed look, a stillness about her as if she wasn't present in the space. She wasn't agitated, she was sedate. Gareth and his music were unable to reach her.

The example of Olga highlights the complexity of music. Not all music works for all people all the time. Here we can see the staff's understanding of the role of music in the care of Olga, she clearly enjoyed the first week's performance and it afforded instances of positive emotion – Olga appeared to display more positive emotions and had appeared more animated and engaged than she had been. Therefore, the following week the staff used this understanding of Olga's appreciation of the music as a distraction whilst taking blood, an activity which had clearly been increasing Olga's agitation. However, we can see in the third example, that the music appeared to have no effect on Olga's emotional state, and even the music which before had been so powerful, this time could not reach

her. In these examples we can clearly see the complexities and nuances of the interplay between music and health/illness states, the music not always seeming to 'reach' Olga as it had in previous encounters.

It was typical to see patients engage more with pieces of music with which they had an associated memory, and this is a common discourse within music and dementia research, as discussed in the literature review (see Sung et al., 2012; Götell et al., 2000; Cuddy and Duffin, 2005). Take for example Vera; when I first saw Vera, she was lying in her bed with her eyes closed, facing away from the other beds towards the wall, and she stayed in this position when Gareth arrived in her bay and started playing. Vera remained in this position through the whole performance. At the end of the final piece, she called me over, grabbed my hand with both of hers and burst into tears, saying "that was beautiful. Tell him [Gareth] thank you so much, I wasn't asleep. All I could do was listen" and continued crying.

Gareth came over and talked to Vera about the music; he discovered that Vera's mother was Welsh like him and so they talked about this for a while and the fact that Vera's mother used to play many of the pieces that Gareth played during the performance. Vera continued to cry during this conversation but explained "these aren't sad tears, it's just that the music was such a surprise." Shater wrote (2000) 'memory's usefulness does not lie in its ability to replay the details of our lives with total accuracy, but in its power to recreate and sustain the important emotional experiences of our lives.' (p.163). We could consider music's usefulness and its affordances in terms of memory here.

As we saw in the example of Vera the music prompted a moment of emotion through memories associated with her mother. We might consider that music

created an asylum (DeNora, 2013) as described in the opening of this chapter. Within this Vera was able to express an emotional outpour, through the memories associated with the music and the nationality of the musician, Vera was able to explore her emotions, and to feel comfortable to do this.

Of course, moments of emotion induced by music were not always positive, for example there were certain pieces that would often remind people (patients and staff alike) of deceased loved ones, particularly pieces used at funerals – a Ward Clerk, Helen, asked the musicians to stop playing halfway through a rendition of the traditional Irish song, Danny Boy, as it was played at her father's funeral only the week before, and as she said this she started to cry. Similar examples have occurred with pieces such as You'll Never Walk Alone and Jerusalem. In terms of agitation, music-induced negative emotions can of course also exacerbate emotions associated with agitation.

Consider Graham, an individual who experienced frequent instances of agitation, mainly as a result of restrictions. Graham was considered a falls risk and so was in a bed with the side rails up to prevent him from climbing out, his bed was positioned at right angles to the bed next to him presumably to ensure one side of the bed was against the wall, again ensuring he did not fall out. He would often rattle the sides of the bed, call out, incoherently. We may consider from his tone of voice – loud, groaning- and his movements – twisted, tense and tight – that he was agitated. During one music performance he continued to shout out and press his call bell, it was clear that music was not useful for Graham at this moment in time and could have in fact been increasing his agitation.

The musicians had a mentor from their organisation visiting at the time, Sarah, she went and sat next to Graham. Sarah attempted to encourage Graham to

focus on the music – “look, the musicians are playing for you,” Graham turned his body away to face the wall, reaching for the call bell and pressed it repeatedly, hurriedly, calling out in the same way he had prior to the musicians’ arrival. The musicians began playing The Emperor Waltz by Strauss, a piece which had elicited positive emotions in other patients previously, Graham stopped calling out and started to cry. This was the first time I had seen him cry, he called out “oh...no...David... David...” Crying and an outpour of emotions should not always be taken as a negative as it may provide an opportunity to ‘unlock’ emotions which may have previously been difficult to express, as we saw in the example of Vera, she herself commented that she was crying but she was not sad.

However, in contrast, what we saw in the example of Graham was instead emotional distress displayed through an increase in the instance of agitation he was already experiencing. We can see this increase through his repeatedly pressing the call bell, continuation of calling out, and finally his outpour of distressing emotions through calling out loudly through tears for David, the music possibly prompting an emotional memory, and triggering what we may consider a negative emotional response. This demonstrates the complexity of music listening and engagement for people living with dementia, but it also transcends the field of music, and shows the need for an individualised approach towards agitation, understanding triggers for and exacerbators of agitation in patients living with dementia, in order to care for them in a holistic way, supporting emotional as well as physical care.

6.4 Emotional care

6.4.1 Empathy

In terms of emotional care, we can see the value of empathy and the need for empathic caregivers within dementia care. Going back to the theme of materiality, through understanding individual needs, providing stimulation, and supporting occupation as a subjective experience, staff can better support the wellbeing of patients living with dementia and potentially reduce some of the triggers for agitation. Derksen et al. (2013) suggests that 'patients consider empathy as a basic component of all therapeutic relationships and a key factor in their definitions of quality of care' (p.76). For patients living with dementia, they may not be able to express this need to be understood, nor the desire to feel emotionally connected, and therefore this inability to express emotions or communicate their needs may be seen through apathy or agitation as previously discussed.

In the two wards I observed, the empathic nature of caring for individuals living with dementia was at times almost palpable. Consider the example of Dr Smith, a Consultant Geriatrician; she came to examine Joan, a patient who frequently displayed instances of agitation. Joan's bed was at the near end of the bay next to a window looking out into the ward corridor. During one instance of agitation where Joan was screaming out "help, help" and throwing her bed covers off, a nurse closed the curtains around Joan's bed saying "oh dear Joan, you don't want everyone to see your bottom" and walked away, leaving Joan behind the closed curtain. Joan began shouting "Nurse, Nurse" and pressing her call bell. The other patients in the bay tutted and raised their eyebrows at each other, one shook her head saying, "she's at it again." The staff, busy with the morning's activities would

peek through Joan's curtains, turn her call bell off and continue to the next task, all the while Joan's agitation was escalating. We might consider here how the call bell became an occupational activity for Joan (a typical observation in both wards), through repeatedly pressing the call bell Joan might be communicating her needs for social interaction.

When Dr Smith came to see Joan, she was highly agitated, and the atmosphere was tense around her. Dr Smith opened Joan's curtain and sat down next to her bed, pulling up a chair at right angles to Joan. She asked Joan how she was feeling, to which she replied "not good. Not good" Dr Smith offered Joan a small cup of water which had been sitting on her table. She held the small plastic straw up to Joan's mouth and Joan took a long, deep sip, staring into Dr Smith's eyes as she did so. Dr Smith moved the straw away whilst Joan caught her breath, saying, "you were so thirsty. Alright, drink more my love." Joan sipped more water whilst Dr Smith gently held the straw to her lips.

We could consider this example as the 'craft' of caring, as well as a form of emotional care, or emotional support (Jeffrey, 2016; Weiner and Auster, 2007; Wenrich et al., 2003). The care task was that Joan needed to keep hydrated, the amount each patient drinks is recorded on their medical chart; however, the way in which the care task was delivered was gentle, kind, and we can see how Dr Smith was fully present with and empathetic to Joan's needs. Likewise, Joan seemed to respond in the same gentle at ease manner, almost mirroring Dr Smith. The result was that Joan was calmer and less agitated during Dr Smith's visit than she had been prior to Dr Smith's visit. Dr Smith left Joan with her curtains open, starting into the ward, able to see the staff walking past, not appearing to be in any emotional distress. Without this instance of empathic

caring, Joan may have continued to scream and shout, her agitation increasing, as we have already seen in other patients in similar situations.

In the example with Joan and Dr Smith what we are seeing is an instance of emotional contagion, Joan 'catching' the calm emotions displayed by Dr Smith. Likewise, in terms of empathy, we can see how Dr Smith took the time to be present with Joan before her examination, understanding how she was feeling at that moment in time, and how her thirst and need for connection may have been relating to these instances of agitation she was experiencing.

We can see both positive and negative effects of emotional contagion in the example of Joan; as her agitation escalated her screaming and shouting got louder the staff busy with the morning care activities, were unable to attend to her every time she requested attention, and when they did arrive it was often to rest her call alarm and tell her "we will be to you in a minute". Their short, clipped tone and their rushed actions displayed an air of exasperation. Joan 'caught' these emotions, which then in turn became a cycle - Joan's agitation would escalate, she would shout louder or repeatedly press the call bell, and as a result the staff would become more drained. Likewise, the other patients as we can see, also caught these emotions, telling Joan to "stop that racket" or "shut up", it became a "negative feedback loop" as the Ward Manager of Oak ward described typical instances of agitation such as this.

In the example of Dr Smith and Joan we can see empathic care in action; Dr Smith acting in a compassionate, empathic way, taking the time to understand how Joan was feeling and realising she was thirsty may have added more knowledge to Joan's individual emotional care needs. Robert, a Ward Manager on Oak ward reflected on this individual approach to agitation:

“...I think it is about the knowledge about the individual, so using the This is Me Document¹, so if the triggers are that they are hungry or need to go to the loo all you have to do is go through those things and think about why they might be agitated. Are they keen for their husband to get back from work? If you know some of that history about their family and the people they are talking about that can help to start to de-escalate perhaps some of their fears and anxieties because you can personalise your conversations with them.”

By understanding the individual’s needs as Robert points out, and providing the foundations needed to support personhood we may be able to support a de-escalation of these instances of agitation and an extension of these ‘pleasurable moments’ afforded by stimulating activities such as music (Asgaard, 2000).

6.4.2 Emotional intelligence and emotional labour

Existing research in care home settings shows that familiar live music elicits a greater sense of wellbeing and a reduction in agitation and apathy compared with recorded music (Holmes et al., 2006; Sherratt et al., 2004). Taking this further, my own research focuses only on live music, and takes a more holistic view of the affordances of live music within a hospital setting at a micro level for the individual actors on the ward. My research differs in that I am not only exploring the responses to the live music, but I have also considered the connections between the musicians and the ‘audience’ and how these connections are created through the emotional intelligence of the musicians, which as far as I am

¹ 'This is me' is a leaflet produced by the Alzheimer's Society to help hospital staff better understand the needs of people with dementia. The leaflet provides professionals with information about a person with dementia to help enhance the care and support they receive whilst in an unfamiliar environment. (Dementia Partnerships, 2010).

aware, has never previously been researched within the context of acute dementia care.

The musician performing live music is able to adapt their performance tempo and pitch if required to encourage engagement; for example, Claire playing the ukulele, would often create anticipation of a familiar chorus by slowing down towards the end of the verse and saying “ready?” and then playing the chorus louder and slower than she had been singing the verses. Inviting the ‘audience’ to participate in the musical space with her. However, the musician’s ‘craft’ is more finely tuned than just altering pitch and tempo, and it takes one with certain attributes (outside of their musical ability) to engage with patients with dementia through the music. In fact, the music itself often is not the focus at all, rather it is used as a tool by the musicians to create meaningful engagements (active and passive) for those within the musical space. How then do the musicians draw people into this musical space, and how does the music support affordances of empathic engagement? I consider this through the emotional intelligence of the musicians.

During their live performance the musician adapts their performance, tempo, and pitch, responding to the needs of their audience and environment. In an acute ward setting this can be of even greater value. Consider this interaction between Eva and Gareth:

Eva was quietly sat in the day room whilst the harpist, Gareth, set up his instrument. Eva didn't appear to notice him and seemed in her own world, staring at the wall. Whilst Gareth was playing in the first bay, Eva walked in halfway through a Handel concerto. She showed instant recognition of

the music, her eyes sparkled, her mouth opened and she hummed along with the music as she walked to her bed assisted by two physiotherapists.

At the end of the performance Gareth asked Eva if she knew that piece, she said "yes I do!" loudly with a big smile. She told Gareth that she was from Austria, and he initiated a conversation with her in German. Gareth reflected afterwards in our interview that "I felt like because I could speak German as well as play music that she recognised, there seemed to be a new bond". This bond continued throughout the performance, with Gareth continuing to play pieces by German composers, and conversing in German with Eva in between pieces.

At the end of the performance Eva asked Gareth for a signed photograph and for him to write her a note to remember the occasion. This photo and note provided a source of conversation between Eva, staff and visitors for days after the performance. The physical memento of the performance acting as a memory trigger, enabling the connection to last longer, whilst also drawing other agents into the musical space even if they had not experienced the music themselves; they were able to experience it through Eva.

In this example, we can see the interplay between music and care, in that Gareth is demonstrating the value of individual connection by understanding Eva's individual needs and using music as a means of starting a conversation. Likewise, the staff had a shared experience with Eva, had a more in-depth understanding of her as an individual, which then created a continuation of the positive emotions afforded by the music, through the physical memento of the signed photograph. We can see how a moment of emotional intelligence led to the music and care

intertwining. I believe we can see Gareth using Emotional Intelligence in this way, monitoring Eva's response to the music, enabling a conversation around her positive display of emotions, leading to a discussion around her personal history, which in turn meant Gareth played music that he felt would resonate with Eva.

Likewise, consider one instance when Claire was playing her ukulele in a female bay one morning during ward rounds – as Claire played 'It's Only a Paper Moon' a patient named Betty said "Oh lovely music. Will we have some more?" Claire smiled "your wish is my command!" and began playing Tennessee Waltz as a nurse appeared to see Betty. Betty with a disappointed tone said, "oh I was enjoying the music", to which the nurse replied with a faint smile "don't worry, I'll be quick." Meanwhile, Claire had moved to the far end of the bay playing quiet chords. Angela in the bed next to where Claire was stood caught her eye and smiled. Claire wandered over to her, starting to play Tennessee Waltz again from the beginning, this time quietly, softly, singing in a hushed tone whilst the nurse listened to Betty's chest with a stethoscope.

Here we can see Claire demonstrating elements of Emotional Intelligence, in terms of self-awareness and social awareness situated within the clinical environment. Claire played a style of music from a similar era to the original piece that had prompted a positive emotional response in Betty, she then shifted her playing style with the arrival of the nurse, followed by responding to the cue given by Angela, playing to her, creating a sense of a private performance by playing closely to her bed side, making eye contact with her the whole time, whilst the nurse was attending to Betty.

In a final example, we can see how Claire attempted to engage the patients in collective musicking:

Whilst Claire was playing “Que Sera Sera” a classic piece by Doris Day, she slowed down towards the chorus, saying “ready?” looking around the bay, and then playing the chorus louder and slower than the verses.

Here we can see Claire almost inviting the other social actors to participate in the musical space with her. One of the musicians, Hannah, provided her opinion of these type of skills needed to use music in acute environments for patients living with dementia, skills that we can see in the previous examples of Claire and Gareth, and ones which were typical observations in performances that afforded emotional responses in patients with dementia:

“What sort of skills do you think are needed to work in this environment?”

Hannah: Personable skills, social skills, intuition. I think... if...you have to know your audience quite quickly you have 15 minutes, and I think there were some wards that were quite quiet so you don't go in there and play a really loud piece flashy. The harp err the sound of the instrument can be quite overwhelming to begin with not matter what instrument it is whether it is harp, voice, piano, violin. So it's nice to erm err... how would I say... it's nice to warm them up into the sound get them used to it first if you want to play something a bit more lively. But sometimes the patients are quite lively already so erm... errr... you can start with something more chirpy, but still not loud.

In fact, the music itself was often not the focus during the performances, rather it was used as a tool by the musician to create moments of connection, reminiscence and induce positive emotions as discussed in chapter five, the musicians craft became less focused on the music itself and rather in the ways

that they used the music to engage and connect with patients, staff and visitors. Oak ward's Consultant Geriatrician Dr Myatt, remarked on the importance of the interpersonal skills of the musicians in this regard:

"I suppose the question isn't what is the difference between background music and live music; I think that's individual preference... the spontaneity and individual contact between the live musician and the people that makes it so special and different, that engagement really is key. And being able to alter it to the mood of the people at that time as well. That's the important thing I suppose, the emotional intelligence of the person delivering the live music can adjust to the mood she's experiencing. And I've always noticed they may have a repertoire that they will deliver but they will modify it because they're quick to pick up on if that's not appropriate."

Considering the disconnect which has been discussed at length in the previous chapter, we can see how disconnect can occur through a lack of understanding individual patients' social and emotional needs. Taking Dr Myatt's reflection of the role of music within Oak ward, we can see the emphasis on the importance of engagement through music at an individual level, this 'individual contact' made by the musician. Robert, the Ward Manager of Oak ward commented: "when someone plays live music people smile, it is uplifting for the patients, it's a different stimuli you know, if you are stuck in bed and can't move, nothing to do, if you've got someone coming in and they are prepared to play for you, to sing to you, that's pretty special." However, as Dr Myatt suggests, it goes beyond the music and personal preference to something which is potentially intertwined within the craft of emotional care.

We can see different social actors 'performing', in this Goffmanian sense. I particularly saw this in the cleaners, who appeared to provide a vital role in supporting emotional care. Consider the example of Tom, when I first met Tom, he was in a discussion with his Manager out in the corridor of Beech ward, he had just been told that another member of staff had called in sick and so he would be taking on extra responsibilities that day. His body language appeared tense, his body stiffened, he folded his arms as he asked if there was anyone else to cover, to which his supervisor laughed and replied that there wasn't. Tom walked down the corridor to bay one, when Gwen a patient who had been in the hospital for a couple of weeks, caught his eye Tom's demeanour changed, his shoulders dropped, he stood in front of where she was sitting next to her bed, in a relaxed stance leaning on his mop as he chatted with her. Tom asked how she was doing to which she replied, "well you know, me, can't complain". Tom replied, "oh I know, you're one of them Londoners, made of tough stock you are." They then talked about London, and how Gwen enjoys living in the countryside now, as Tom started to mop the bay, stopping every now and then to talk to Gwen or another patient.

In this example we can see aspects of emotional labour, Tom suppressing the feelings he had expressed just moments before whilst talking with his supervisor, instead showing the 'smiley and humorous face' which Bolton refers to, whilst talking with Gwen. This positive appearance was a typical observation of cleaners within the two wards, and whilst carrying out cleaning tasks they often sparked conversations, nurturing these connections with patients, embracing the extended caregiving 'role'. Goffman (1961, p.139) talks about social actors having 'multiple identities':

'I have argued that the individual does not embrace the situated role that he finds available to him while holding all his other selves in abeyance. I have argued that a situated activity system provides an arena for conduct and that in this arena the individual constantly twists, turns, and squirms, even while allowing himself to be carried along by the controlling definition of the situation. The image that emerges of the individual is that of a juggler and synthesizer, an accommodator and appeaser, who fulfils one function while he is apparently engaged in another; he stands guard at the door of the tent but lets all his friends and relatives crawl in under the flap.'

We can see this Goffmanian performance in the example of Tom, how he juggles different emotions and different acts. Likewise, we can see how Tom interacts with Goffman's concept of the front and backstage, in this example the backstage being the corridor space away from the bay, and the front stage being in the bay, 'performing' the different faces of his role. Few social actors appeared to have the time to be able engage with patients through emotional care in this way, the others being volunteers such as the volunteers that brought the tea trolley/newspapers onto the bay as well as the Chaplaincy team, providing spiritual support for patients in need.

Whilst Theodosius (2008) argues that emotional labour is an essential component of nursing care (p.143), due to time pressures acts of emotional care seemed to take place most during care tasks e.g., washing, dressing, monitoring etc, where the staff would engage patients in conversation during the care task. We could consider live music delivered by emotionally intelligent musicians then to be an additional way of supporting emotional care outside 'usual care tasks'; as Dr Myatt, Consultant Geriatrician on Oak ward, points out:

“it does give you a good sense of wellbeing on the ward for staff and a feeling that erm something is being done over and above the standard clinical care and thinking about the erm overall... you know...benefits to the patient group which needs to be well beyond just being well cared for well hydrated, and to personalising care and just thinking about those activities and entertainment that will be that will make a difference, it’s what staff aspire to have a little extra time to do more individual patient centred work, it helps to give that atmosphere to the ward.”

Here we can see the music performance supporting emotional care, almost an extension to the care that the patients receive. Of course, we should also consider when the music did not ‘work’ and more importantly, *why*. A typical observation was a clear battle between the musicians’ need to perform high quality music, and the patients’ needs for interaction; consider this example of two male musicians – John and Phil, who had visited the area for a local folk festival and had been booked to perform at the hospital:

When the musicians arrived on to the first bay in Beech ward it was particularly busy with lots of visitors and staff coming in and out; when they arrived on Beech ward they went onto the first bay which was particularly busy with a high level of activity occurring – visitors, staff going in and out – they quickly tuned their guitars, spoke between them, and began playing a folk style song, loud with heavy strumming, the vocals hard to hear over their playing.

During the piece the patients and visitors sat still, almost politely listening, as the volume got louder some of the patients made eye contact and raised their eyebrows. At the end of the piece the musicians kept a small

silence whilst they decided their next piece, which wasn't introduced, and started playing the next piece, again loud in a folk style. During this piece a visitor asked Claire who was responsible for the musicians if they could turn it down a bit. The third piece was quieter, but again unfamiliar, after which piece the musicians said "thank you, I'm afraid that's all the time we've got" and moved to the next bay, again going back to the original tempo and volume of the first piece they had played.

We can see from this example that there was a particular focus on the music rather than interaction, the musicians did not make eye contact with the patients or visitors during the performance and did not take time to engage with or support the emotional care of the patients. Likewise, the existing atmosphere was not taken into consideration in the ways we have seen previously, and therefore it appeared the music played didn't fit the environment, creating tension between musicians and 'audience'.

This was a typical observation when the focus was purely on the music and musicianship, moving away from Emotional Intelligence, the patients became disengaged, and I did not see instances of positive emotions in the same way as I saw during performances that were responsive to the emotional needs of the individual social actors. Existing research in care home settings shows that familiar *live* music elicits a greater sense of wellbeing and a reduction in agitation and apathy compared with recorded music (Holmes et al., 2006; Sherratt et al., 2004). However, I am suggesting that it is not purely the fact that the music is live, it is dependent on the way in which the music is delivered in line with the needs of the individuals within this shared musical space.

The collective musicking facilitated by the Emotionally Intelligent musician, could be considered in terms of social capital, the music forming a bridge between the patient and staff, as demonstrated, creating paramusical connections or 'music capital' (Proctor, 2011), as discussed in the literature review chapter. Music capital in terms of healthcare, is focused not only on the opportunities for social engagement during the collective musicking, but also how these social interactions intertwine with care, and continue after the music has ended, as previously discussed.

Consider this dialogue with the harpist, Gareth:

Gareth: I think sometimes one forgets that the loudest part of music can be the silence.

R: that's really interesting

Gareth: at the end, at the beginning, during. I think silence can be quite emotionally evoking.

R: ... and it's good to acknowledge the silence and not feel that you have to fill it?

Gareth: no but it's an event. And it's something that happens... I try to make it happen at the end of the piece that I control and just hold it, and I think it's quite a special moment if people do.

R: so that's a deliberate thing that you take a while to... what would you call it? To dampen? [strings]

Gareth: dampen yes to finish the music yeah. I don't just end the sound, I finish the music. The music doesn't end when you play the last note, it finishes when you end the silence, and it's part of the experience.

Here we can see an example of Gareth's emotional intelligence going further than playing the notation, rather he describes this 'controlling' of the environment of the space by holding the silence at the end. He physically holds this silence by keeping his posture in the same position, not sitting back on his stool until he decides to 'end the silence.' Whilst it may be assumed this is a literal meaning of the world silence, we could also consider the silencing of emotions, and in terms of music capital we could consider the musician's role finishing when the 'silence' of emotional care has ended, meaningful connections are made, affordances of empathy and mutual understanding take place, which last long after the musician plays the last note.

6.5 Conclusion

In this chapter I have demonstrated how agitation and apathy manifest in response to a range of factors but may also happen in regards to unmet emotional and social needs. Therefore, I have presented how occupation and emotional connection may be one way to break the circuitry for waves of agitation, and the ways that music can function to support an unlocking of emotions which may otherwise be difficult to express or regulate.

Agitation is considered to be one of the main challenges of caring for individuals living with dementia, as highlighted by Featherstone and Northcott (2020), Featherstone et al. (2019), and Park (2009). Cohen-Mansfield (1986) first defined agitation in people living with dementia as 'inappropriate verbal, vocal or motor activity that is not judged by an outside observer to result directly from the need

or confusion of the individual', and thereafter it has generally been considered through a behavioural model, seeing agitation as a pathological complication of dementia with a set of pre-determined behaviours. However, in more recent years the understanding has shifted to seeing agitation to encompass behavioural and social aspects, with one potential trigger being unmet needs, whether physical, social or emotional, as discussed by Bunn and Handley (2019).

It is through an emotional-social approach to agitation where we can begin to understand these feelings as relational, situated and embodied rather than just a pre-determined set of behaviours which can be objectively measured. With this in mind, my data presented within this chapter transcends the field of music in this regard, showing a need for an individualised approach to agitation, considering how emotional and social support may be one way to help reduce feelings of agitation for people living with dementia. I posit that it is through a lack of stimulation and occupation, a diminished sense of self and purpose that we might see one trigger for the beginning of the wave of agitation, and through a sense of purpose and occupation with which we may see it subside.

Drawing upon the concepts of musical asylums (DeNora, 2013), and Emotional Intelligence, I have demonstrated how the use of familiar, meaningful music with strong emotional memories, delivered by emotionally intelligent musicians may be one way of unlocking emotions which may otherwise be difficult for individuals living with dementia to express. Even if this musical interaction lasts only for a moment, as Aasgard (2002) remarks, staff interactions and conversational references back to the music can help to prolong this 'moment' as demonstrated in the observations of patients such as Jeff. In this regard, the music offers pretext for interaction before and after the music, continuing any opportunities for

emotional expression afforded by the music. Considering Clarke et al's (2015) description of music as a 'medium for empathetic engagement', I have built upon the data presented in chapter five, demonstrating how feelings of mutual understanding and connection can be afforded through shared experiences of music.

I have highlighted the typicality of increased emotional engagement in patients living with dementia and pieces of music with which they had an associated memory, which is in line with previous research around music in dementia care (Sung et al., 2012; Cuddy and Duffin, 2005; Götell et al., 2000). Likewise, through the shared experience of a live music performance, and its affordance for reminiscence, I have argued that staff can gain a deeper understanding of the individual(s) they care for, and therefore may be able to provide better relationship-centred care. Through the music affording moments of empathic caregiving, we can see how music intertwines with the craft of care and may provide potentially one way to support the wellbeing and quality of life of individuals living with dementia experiencing agitation.

7 Discussion and conclusion

7.1 Summary

Dementia is a worldwide public health issue. There is currently no cure for dementia; it is a terminal illness in which people decline over time. Likewise, people living with dementia are more likely to be admitted (and re-admitted) to hospital due to physical and mental deterioration, as well as general health issues related to older age. The focus in the UK has been on looking at ways that individuals living with dementia and their caregivers can 'live well' with the condition. This includes the creation of 'dementia friendly' environments, designed specifically to address some of the common issues experienced by people living with dementia. In hospital wards, dementia friendly environments tend to focus on aesthetic changes including artwork, colour coded bays, reminiscence photographs, natural-based lighting, in addition to social activities aimed to support wellbeing and quality of life.

One such activity is the use of recorded, live and participatory music sessions. Meaningful music, that is music which is familiar to an individual or connected with particular memories, has been shown to support a reduction in acute confusion, and significantly improve feelings of pleasure in individuals living with dementia (Cheong et al., 2016; McDermot et al., 2014; Götell et al., 2000; Gender and Swanson, 1993). The majority of the literature to date appears to be focused on the use of recorded music within long-term dementia care facilities, where changes can be seen over a longer time frame. Whilst the results have been promising, showing that music can have a positive impact on the wellbeing

of individuals living with dementia, it was my intention to explore whether similar findings could be seen within short-term, acute dementia care.

I situated my research within two dementia friendly wards within one hospital in the South of England. Through previous experiences of working at the hospital as Musician in Residence and later Music Programme Coordinator, I had seen first-hand how the use of live music could provide benefits for patients living with dementia, including improved communication, increased feelings of positivity, memory recall, and social interaction. Out of this personal experience came a curiosity to unpack music's potential to support wellbeing within acute dementia care.

In 2013 I undertook a pilot study as part of my master's degree in Music Psychology, specifically focusing on the effects of live music for patients living with dementia, exploring primarily its effects on agitation and anxiety. The study took place at the same site as my PhD research, and adopted a mixed methodology cross-over design, where the participants (n=16) listened to a 20 minute live music performance three times per week, for a period of five weeks. The Cohen-Mansfield Agitation Inventory (CMAI) was used to assess levels of agitation, and Likert scales were used to assess the impact of the live music on mood, anxiety, and wellbeing of patients living with dementia. A small amount of qualitative data was collected through interviews with and observations of the participants during and after the music performances.

The results showed that live music significantly reduced agitation and anxiety, and improved mood and wellbeing. However, what the results lacked was an understanding of *how* these opportunities were afforded by the music. Building on the pilot study, my PhD research aimed to unpack music's role within the daily

life of two dementia friendly wards. To this end, the primary intentions of my research were twofold: firstly, to examine how the environment and particularly the soundscape of an acute hospital ward affects the ward culture and hospital experience for patients living with dementia, and those that care for them. Secondly, to explore how patients living with dementia respond to live music performances, and the 'spin off' effects of this for care staff, with regards to social interactions and relatedness with the individuals in their care.

Originally the research proposed a third objective, to observe behaviours considered under the umbrella of agitation, with a view to creating a tool to capture changes in agitation in relation to stimulus such as music. However, the more time I spent within the two hospital wards, the more my understanding of agitation evolved, instead seeing it as a subjective, situated and temporal experience, which therefore does not lend itself to objective measures. With this in mind, my research shows the need for an individualised approach to agitation, considering how emotional and social support may be one way to reduce feelings of agitation for people living with dementia. To this end, rather than focusing solely on agitation, it became one of the key recurring themes within the wider context of the potential for music to support emotional wellbeing and relational aspects of dementia care.

The present ethnographic study sought to move away from seeing music as an intervention with before and after measures, more typical of the qualitative evaluation of health-care interventions, instead exploring the ways in which music intertwines with the care of individuals living with dementia. Ethnography was chosen as the primary method of data collection as it allows for an in-depth exploration of social and embodied processes of living and real-time events.

Through an ethnographic approach I was able to observe individual interactions with music, the sound ecology of the two wards observed, social relationships and engagement, and the intertwining of music with social care.

My analysis was situated within the fieldwork process, inspired by a grounded theory approach. Through the data analysis I discovered three main findings of the research:

- 1) Meaningful music can support relational aspects of care through affording opportunities for social connections with others, and for caregivers to have a deeper understanding of the individuals they are caring for.
- 2) Music may offer affordances to unlock the potential for people living with dementia to express emotions or reconnection, which may have positive impacts on wellbeing and/or reduce feelings of agitation in some instances.
- 3) Music's affordances for supporting the emotional wellbeing of people living with dementia potentially lies in the emotional intelligence of the musicians providing the live performance.

Within this concluding chapter I summarise my research in relation to these three findings, following with implications for practice and recommendations for future research.

7.2 Musical connectedness

Whilst person-centred care (Kitwood,1997) remains a gold standard within dementia care, my research has contributed to the wider literature which demonstrates the challenges of delivering such care in acute short-stay medical environments. Such challenges include disorientating layouts, noisy and

unfamiliar environments, ward moves, unfamiliar faces, lack of time to develop relationships and understanding the social needs of the individual and lack of time or resources to support occupation. As a result of a hospital admission, patients living with dementia can experience a variety of negative outcomes including increased confusion, heightened feelings of agitation, risk of delirium, increased length of stay, possible complications such as falls, and delayed discharge, as highlighted by the Royal College of Psychiatrists (2019, p.7). However, it is the impact on social interactions and relationships which I am arguing may be one contributing factor to increased confusion, social isolation and agitation, three main challenges for individuals living with dementia when admitted to hospital wards, as described by Featherstone and Northcott (2020).

The two wards observed had an average length of stay of 11 days, with patients admitted for a variety of reasons, including delirium, falls, or multiple medical conditions such as infections, heart failure or frailty. Patients living with dementia were not admitted because of their condition, but rather additional medical reasons such as those listed above. Patients were often discharged to a care home, or back to their own home with a package of care to ensure continuing care and support from community social/mental/medical care teams.

The wards were centred around specific routines such as medical observations, physiotherapy, occupational therapy assessments, Doctors' ward rounds, set mealtimes, and regular recreational activities (mainly the live music performances). In support of Featherstone and Northcott's research (2020), my own data also demonstrates how the routines of the two wards, the turnover of patients, restricted staff time, and focus on rapid discharge, presented many

challenges in terms of meeting the social and emotional needs of patients living with dementia.

Kelly et al. (2009) highlights the importance of meaningful connections in delivering person-centred care, and it is these meaningful connections between patients living with dementia and their caregivers, upon which my research is focused. The relational aspects of care centre around the relationships formed between staff and patients during their hospital admission, and can include communication, providing a space for patients to express their fears and concerns, and treating patients with dignity and respect. It was discovered through my research that the use of meaningful music (i.e., familiar with positive associations) can afford moments of social connection and empathic understanding in an otherwise disconnected environment of a short-stay hospital ward.

Exploring music in an ecological sense, through the intertextuality of music and environment, I have demonstrated how meaningful music may also create or encourage positive associations with the current environment, bringing the individual into the space through musicalised connections. Music in this regard intertwines with both the auditory *and* social environments.

The first research objective set out to explore how the environment and particularly the soundscape of a hospital ward affects the ward culture and hospital experiences for patients living with dementia and care staff. Through detailed descriptions of the dynamics of the live music performances I have shown the relationships between the sonic and social environments, demonstrating the interconnection between the two. Through an understanding of the paramusical (DeNora and Ansdell, 2016), and the concept of musical

asylums (DeNora, 2013), I have described the rich tapestry of the soundscape of the two wards observed, the things that happen outside of the music itself, and provided examples of the affordances of music to support relational aspects of acute dementia care, through these spin-off effects of live music performances, for both patients and staff.

In this regard, shared experiences of music can provide staff with a deeper understanding of the patient as an individual through knowing their musical preferences and associated memories. To this end, my original contribution to knowledge is that engagement in meaningful music such as this may make it easier to care for the social needs of patients living with dementia, through mutual understanding and connection.

7.3 Unlocking of emotions – alleviating experiences of agitation

It was my original objective to solely focus on agitation, which as the literature suggests, is considered to be a particular challenge when caring for individuals living with dementia (Featherstone and Northcott, 2020; Featherstone et al., 2019; Park, 2009). I had intended to create a measurement tool to capture changes in agitation in response to music, which could also be used for other stimulus and environmental changes. However, the more I observed agitation within dementia care, and the more I spoke to staff about their own experiences of caring for people experiencing agitation, I came to understand that agitation is not something that can necessarily be considered objectively, rather it is a subjective experience, at times almost episodic in nature, with variances in the ways it is manifested and experienced. Therefore, my research moved away from looking at agitation in terms of set, measurable behaviours, and therefore instead of becoming a sole focus of the research it became a recurring theme within the

wider context of the affordances of live music to support possibilities for emotional wellbeing in patients living with dementia.

Drawing on DeNora's (2013) concept of musical asylums, I have presented how music may be one way to reduce agitation, through affording moments of refurbishing or removal. Refurbishing, as DeNora describes, transforms our surroundings, whereas removal moves the individual out of the space either figuratively or physically to somewhere more conducive to their wellbeing. In this regard, we may see agitation subsiding in response to music through the use of pieces which are meaningful to the individual, providing positive memories and therefore transporting them away from the hospital ward, and at the same time transforming the acoustic environment of the ward through the various sounds and instrumentation.

Similar to Clare et al (2008), my own findings also showed that one of the main triggers for agitation appeared to stem from loss, isolation, uncertainty, fear and sense of worthlessness. Likewise, my research supports Featherstone and Northcott's (2020) concept of the 'looping effect', referring to repeated cycles of structured care practices which then heighten the agitation, which is then seen as behaviours which need to be managed or restricted, which further escalates the agitation.

Through my research I have demonstrated how music can be one way to break the circuitry of these waves of agitation, through bringing back memories and providing opportunities for unlocking emotions which may be otherwise difficult to express or regulate for individuals living with dementia. My findings in this regard support the literature on music and reminiscence (Baird et al., 2017; Sung et al., 2012; Cooke et al., 2010; Götell et al., 2000; Gernder and Swanson, 1993), as

well as music and emotions (Sloboda and O'Neill, 2010; Scherer and Zentner, 2001; Sloboda and Juslin, 2001), demonstrating a strong connection between music, memories, emotions and wellbeing. In the context of dementia care, my research has demonstrated how this link between music and emotions may be one way to reduce instances of agitation.

7.4 Importance of the emotional intelligence of the musicians

The research has demonstrated how the use of meaningful music is one such way of supporting the relational aspects of dementia care in hospital wards. It was discovered here that to best support the emotional wellbeing of individuals living with dementia through music, the attention needs to shift from music as the primary focus, to the ways that music can be used as a tool for various social outcomes, such as communication, connection and empathy.

To this end, I have demonstrated how the emotionally intelligent musician responds to the needs of the individual patient or collective group, as well as the environment of this shared space. In this regard, there is an emphasis on the interpersonal skills of the musician, an ability to connect with those around them, drawing them into the musical space and adapting performance (including tempo, pitch, and volume) to suit the needs of those they are performing *with*. The literature review highlights that there is a wide range of literature on emotional intelligence in nursing (Štiglic et al., 2018; Cleary et al., 2018; Zysberg et al., 2011; Beauvais et al., 2011); however, there appears to be little research within community music or even Music Therapy, yet as I have demonstrated there are clear overlaps in the ways that nursing staff and musicians utilise emotional intelligence. With this in mind, live music delivered by emotionally intelligent

musicians could be an additional way of supporting emotional and social care outside of medical care tasks, an extension to the care that patients receive.

Likewise, the research opens opportunities for further explorations of the ways that emotional intelligence in non-musicians may provide possibilities to support the emotional wellbeing of individuals living with dementia through careful delivery of familiar recorded music, and whether this might provide similar benefits as discovered through live performances. The potential for this could be a continuation of the benefits afforded by the live performances, offering an accessible way of providing meaningful music for individuals living with dementia as and when required, supported by care staff, families, and volunteers.

Current research demonstrates that live music may provide a greater sense of wellbeing and opportunities for social interaction compared to recorded music (see Van der Vleuten, 2012 and Sherratt et al., 2004). However, my own research has demonstrated that it may not necessarily be the live music itself, but rather that the benefits lie in the responsive nature of live music (as discussed by Sloboda and O'Neill, 2010), the interactions between musician and patient and the opportunity for conversations afforded through memories associated with the music. Music in this regard, connected with emotional intelligence can be seen as a nuanced activity, subtly intertwined with care, and which may produce different effects for people living with dementia, depending on the music delivery, personal associations with the music, the environment, and those sharing the musical space.

7.5 Conducting research in an acute hospital ward; evaluating the method

To my knowledge my research is the only study that has explored the role of music within acute dementia care using an ethnographic methodology. This

qualitative approach was used to gain a better understanding of the 'meaning of the individuals' actions and explanations' as explained by Savage (2000). By this I mean an understanding of the various ways people living with dementia and their caregivers interact with one another and their environment (with and without music), which is rooted in experience, told through narratives. It was for this reason that I chose an ethnographic methodology. Music is a complex and situational activity which is highly subjective in its interactions. In this regard, through the literature review it was highlighted that there is little research providing narratives around *how* music plays a role in dementia care, the micro interactions, and affordances of music with regards to wellbeing.

To this end, an ethnographic method offered the tools needed to capture micro shifts in wellbeing, behaviour, and social relationships, whilst also considering the wider environment of acute medical wards. Likewise, Featherstone and Northcott (2020) also adopted an ethnographic method in their study of the consequences of hospital care for people living with dementia for similar reasons, stating that it allows for an exploration of the interplay between social actors and the 'social world of these wards.' (p.xi)

The ethnographic methods used within this research allowed for a thick description as Geertz (1973) describes - the narrative to capture music's role within dementia care. In this regard I was able to consider the minute details of what the participants were doing, how they were doing it, as well as how these actions were perceived, interpreted by the individual (often in the case of the care staff) and others around them. In this regard I was able to immerse myself in the multiplicity of the culture of the two wards observed, understanding observed behaviours in relation to the environment, and music within this. As a result, I

have been able to present detailed vignettes of individual patients, demonstrating their interactions with live music, providing narratives to the existing research, which demonstrates the benefits of music for people living with dementia, but does not necessarily tell us *how*.

Ethical Considerations

A potential ethical challenge as described in the methodology chapter, is that of being a 'native ethnographer' as Proctor (2013) describes - researching your own professional field, and in my case a setting I had previously worked in. However, whilst I had previous knowledge of one ward (Oak ward) and had already built relationships with staff, this was not the case in the second ward (Beech ward). Although I had been introduced, I noticed that the staff on Beech ward appeared perhaps more reluctant to engage with me in my role as researcher, and there was a sense of apprehension whilst I was writing my field notes.

Whilst I spoke at the staff briefings on both wards on the first day of my study, it may have been of value to have spoken at every staff handover on the days I was conducting the study to ensure that every member of ward staff working on the ward that day understood my role and the purpose of the study. I found from my previous role within the hospital working on Oak ward, I had a good rapport with the staff, I felt that I was often considered part of the team, blending into this role. Therefore, the staff seemed to feel open to talk to me as if I were a co-worker rather than a researcher. Likewise, I felt comfortable wandering the ward and situating myself in different places throughout the day.

At the same time, due to my experience of working in the hospital, at times I found it difficult to observe, and would step in to support staff or patients if there was something I could do, for example when I overheard a conversation between a

patient named Alan, and a Nurse, John – Alan was getting frustrated because he was asking about his ‘lodge’, John (from Poland) said he did not understand what a lodge was, this conversation went back and forth as Alan was getting more and more frustrated. I assumed Alan may have been talking about Masonic Lodges and so I asked if this was what he meant, it was and therefore I was able to explain to John what a masonic lodge is, which may have then helped with future discussions with patients.

Likewise, there were multiple times when patients would stand up or attempt to walk; as I knew they were a falls risk (as indicated by a maple leaf symbol above their bed), I would seek the attention of a nurse, so as to protect the patient. At times like this it became difficult to maintain a position as an observer, demonstrating the natural shift from observer to participant-observer, a common experience in dementia care research as also highlighted by Featherstone and Northcott (2020).

Following on from this experience, a suggestion for future research may be that researchers immersing themselves in the field take the time to become familiar with the setting and staff before conducting the research, the result being a greater depth of data due to the increased likelihood of staff making conversation, which as I have demonstrated, enhance the narratives within the data. My own insights in this regard are in alignment with Swain and Spire (2020) who view informal conversations as ‘opportunities to add “context” and “authenticity” to data.’

Researching in an acute hospital setting means fitting around an already busy schedule for staff, and therefore it became apparent early in the fieldwork that it would be problematic to conduct interviews. Instead, informal discussions seemed to be preferred. I feel that this alteration was actually to the advantage

of the study, providing deeper information captured over a longer period of time, possibly in a more natural way than that of a recorded interview. Preti (2009) made a similar finding, discovering that familiarity with a context brings with it an element of trust between researcher and participants (ward staff). As a result, I was able to uncover the experiences of staff, particularly around their perceptions of agitation in patients living with dementia, the various ways it is manifested as well as the ways to reduce feelings and behaviours associated with agitation.

The study originally aimed to create an agitation tool, to measure levels of agitation in response to the environment. However, taking a grounded approach, as the theme of agitation became less of a sole focus and more of a recurring theme within the wider exploration of music and wellbeing within dementia care it was clear that the data was suggesting moving away from this type of objective measurement, towards a more holistic and subjective approach towards agitation. The implication of this meant that the scope of the study opened up to a more socio-emotional focus to consider the role of music to support positive emotional responses and within this, proving to be one way to diminish experiences of agitation.

Following on from the pilot study I conducted in 2013, I observed two elderly care wards rather than one to allow for a macro lens observation of the role of music within the social worlds of two hospital ward communities. The two wards observed were atypical of other general hospital wards due to their dementia friendly design. Likewise, other hospital wards do not have live musicians performing on a regular basis. In this regard in the concluding summary of this chapter I have made recommendations for implications of my research in practice in terms of wards that do not have access to regular live musical performances.

Therefore, it must be noted that working in two wards in this immersive way provided intrinsic details that were valid for the group of patients and staff I observed. With this in mind, it would be impossible to make generalised assumptions, keeping in mind every hospital ward and individual with dementia is different. Likewise, music itself is unique and its value lies in its adaptability, in the way it is delivered and received. Whilst we might not always see individuals living with dementia and staff members engage in music in the same way, it is likely that positive emotional responses will happen if the musician is emotionally sensitive to their surroundings and participants. More studies would be necessary to gain an understanding of music's role in a broader sense within acute dementia care e.g., to understand staff attitudes to music, and to see how this approach can be implemented in different hospitals or wards. Implications for practice and future research

A single researcher ethnographic study of course comes with its own limitations. I have focused on themes which appeared to be prominent within my own view and understanding of the two wards observed, for instance the theme of musical connections. Likewise, whilst I moved away from agitation as a sole focus, another researcher may have considered agitation as the main theme of the study, considering more specificity around the interactions between music and instances of agitation.

Furthermore, adopting a qualitative methodology means that the results are based on the interpretations of the researcher. Whilst another researcher may have made the same observations as I did, their interpretation may have been different. For instance, another observer may not have interpreted the responsiveness of the musicians as a sign of emotional intelligence, nor

concluded that there are crossovers in the ways the musicians and care staff demonstrate emotional intelligence.

In terms of my own interpretations of the data, of course we cannot ignore the fact that I run a not-for-profit organisation which supports the wellbeing of people living with dementia, and so I am personally invested in finding positive outcomes as I sincerely believe in the value of music for people living with dementia. However, I have also looked at counter-examples, in order to challenge my own data robustly. I have presented these examples as vignettes within the data chapters.

The study presents a multifaceted picture of music's role within dementia care, its power to connect people living with dementia with their surroundings, with each other and with themselves, reducing feelings of isolation and self-estrangement, and improving wellbeing and social interactions. I believe the results are meaningful in the fields of music therapy, community music, medical sociology, music sociology as well as having practical applications in nursing and healthcare. Whilst my research was conducted in acute healthcare it may also provide insights for care homes and domiciliary care of people living with dementia.

I have been writing up my thesis in 2020/2021 during the COVID-19 pandemic and experiencing the ways in which music has provided connection for so many. We have seen virtual choirs, virtual performances and virtual listening parties bringing people together during the pandemic, demonstrating a sense of connection through music in a digital space. This virtual form of shared music listening has opened new opportunities for engaging in shared experiences through music. With this in mind, we can see the potential for musicking even at

a distance. The implication for healthcare is that connections can still be created through music, being of the moment together even if not physically able to be in the same space. From my own experience, these musical moments need to be facilitated by staff and caregivers to ensure individuals living with dementia are supported to engage in music as they wish.

During the COVID-19 pandemic I have seen more than ever, the need for care staff to be supported to use meaningful music within dementia care specifically, due to restrictions which have meant that outside musicians were not able to visit to perform. Therefore, we might consider that the emotional intelligence needed to deliver meaningful music lies in the person delivering it, who may not solely be Community Musicians or Music Therapists. In response to this, and inspired by my research, I have created an online training programme for professional caregivers to understand how to embed meaningful music into daily dementia care.

The course covers key themes within my PhD research, including the importance of using meaningful music, how to hold conversations and involve family members to discover what music may be meaningful to the individual, using music as a possible way to reduce feelings of agitation, and how emotional intelligence plays an important role in delivering meaningful music within dementia care. The course is presented in four modules covering the theory behind why music is beneficial in dementia care, ways to adapt musical activities according to the individual needs of the participants, how to create meaningful personalised playlists, and ideas to support other members within the space (staff and family members) to utilise meaningful music within dementia care. Alongside this, over the 12 week period, each learner has access to fortnightly group

coaching with other learners, to share their successes and challenges around embedding music within their daily dementia care. The aim of the training is not to replace live musicians, but rather in response to limited budgets (and during COVID-19 the lack of live music), in order to support or prolong any benefits of music for wellbeing.

The training and group coaching has proven to be highly successful, with over 120 healthcare professionals completing the programme so far. In addition, my organisation has received a large grant from Music for Dementia and The National Institute for Social Prescribing, to train a further 400 care staff in 200 care homes in England, during 2021/2022.

Whilst the course has so far been aimed at care home staff, I am in discussion with two NHS trusts to explore how to adapt and deliver the course with staff on elderly care wards. Likewise, I have secured a place on the 2021 SPREAD academy course led by the Southwest Academic Health Science Network (SWAHSN) and The Billions Institute to access support to roll out my initiative within the healthcare sector.

Likewise, based on the literature review presenting a lack of training, support and resources for community musicians working in dementia care, I am also in the process of creating an online training and coaching programme for musicians looking to work in dementia care. The aim is that the course will focus on dementia awareness, the importance of emotional intelligence when delivering musical activities, how to adopt a responsive way of delivering musical activities, responding to the needs of the individuals and being in the moment through a shared experience of music, and the need to work collaboratively with care staff

to ensure that the conversations and engagement around music continue to happen once the musician has left.

There is a need for resources such as this to raise awareness of the power of music in dementia care, and to support care practitioners and community musicians to engage with individuals living with dementia through music which is meaningful to them. As the COVID-19 pandemic has shown, never has connectedness been more needed, and as I have demonstrated, shared experiences of music is one way to do this. I hope that this study will encourage more research on the role of music within acute hospital wards (not just within dementia friendly wards), considering the relationship between meaningful music and hospital ward environments to support mental wellbeing. It has shown that meaningful music delivered in an emotionally sensitive way can support the wellbeing of individuals living with dementia and support relational aspects of care within acute dementia care. Music has once again proven to be adaptable for people living with dementia, showing how much there is to gain from utilising it flexibly and in a way which is meaningful to the individual.

8 Appendices

Appendix 1 – NHS research process for the study

1. Started writing protocol and supporting documents, including information sheets, consent forms, interview schedules and observation guides.
2. Contact made with the R&D office at the NHS trust so that they were aware of the research
3. Registered on the IRAS system
4. Protocol written
5. Started completing the IRAS form based on the protocol
6. Made contact with the Sponsor at the University so that they were aware of the research
7. Peer review process – academic, clinical and lay people reviewed the protocol and documents. Amendments made as necessary.
8. Completed the Good clinical practice certificate online
9. Completed the taking consent certificate online
10. Completed IRAS form
11. Began DBS (Disclosure and Barring Service, previously CRB check) process – contacted the university's DBS and Admissions office for the DBS form. This took around 6 weeks to receive the DBS certificate.
12. Once IRAS form was complete, obtained electronic authorisations from the university sponsor, and academic supervisor(s). IRAS

form cannot be updated after this, or if it is updated the authorisations are invalid and need to be requested again.

13. Supporting documents uploaded to the IRAS system.
14. Authorisations received, and ready to submit. Phoned the central booking office to book place at the next available REC meeting. Researchers can attend any meeting across the UK; it needs to be a REC that has been authorised to review particular types of study, for example my study had to be reviewed by a REC that could review research involving adults that lacked capacity.
15. E-submission button enabled on the IRAS system allowing application to be submitted for review by the Research Ethics Committee.
16. The Research Ethics Committee Assistant reviewed protocol and supporting documents. informed me that they were unable to validate my application for REC review, and provided a list of amendments I needed to make on my application and protocol, mainly surrounding the fact that they felt I had not shown a clear understanding of the Mental Capacity Act surrounding patients unable to provide consent.
17. Necessary amendments made. Amended the IRAS form and uploaded the updated documents as required. As the IRAS form had been edited, I needed to obtain the authorisations again. Once ready to submit the assistant enabled the e-submission button. No need to call the central booking office, the assistant validated it internally and booked a space at the next meeting.

18. The HRA contacted me to remind me that my application was missing two key documents – Statement of Activities, and Schedule of Events.
19. Submitted documents to HRA
20. Received provisional approval from HRA dependent on approval from the REC.
21. Attended the REC meeting. Although this was not compulsory, it can help speed the process up if you can answer any questions that they might have there and then. For student researchers, the supervisor is expected to attend, or at least be available on the phone to answer any questions the REC has.
22. Obtained a research passport for working in the NHS. This is obtained through the NHS trust's R&D department.
23. Received a letter from the REC detailing the points of the REC meeting, and their decision. Unable to give approval; requested clarification of certain points (described later on).
24. Amendments made and highlighted, submitted through IRAS.
25. Favourable decision received by the Research Ethics Committee
26. Approval received from the HRA
27. Letter of access received from the R&D department at the study site
28. Completed Statement of Activities received from the R&D department at the study site.

Ongoing tasks:

29. Notify the university sponsor, REC and R&D department of any amendments to the protocol or documents.
30. Submit annual reports on the project and final report to the REC

Appendix 2 – Information sheet – patient



Title of Research Project

Live Music within a Hospital Ward for Patients with Dementia

Researcher: Rosanna Mead

Introduction and Invitation

We would like to invite you to take part in our research study. Before you decide, we would like to explain why the research is being done and what it would involve for you.

What is the purpose of the study?

This study is part of a PhD, looking at hospital ward environments and the effects of live music performances for patients with memory problems, and staff.

Why have I been invited?

You have been invited to take part in this study as our study involved patients with memory problems, and you have been admitted to either Combe or Waterhouse ward, where the study will be taking place.

Do I have to take part?

It is up to you to decide to join the study. We will go through this information sheet with you and answer any questions you might have. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This will not affect the standard of care you receive.

What will happen to me if I take part?

You will listen to live music on your bay, and will be asked to participate in a short interview (around 20 minutes long) with the researcher, talking about your experience of the music. The interview will be audio taped and typed up by the researcher later on.

The researcher will be observing the ward, and taking written notes. The researcher may write down direct quotes from the observations, and these may be used in the final thesis and publications; however, the quotes will be anonymised to ensure that you cannot be identified. Care will be taken not to record confidential information. Where possible, the researcher will check that you are happy with the quote as they have written it after the initial transcription. The notes will be stored in a secure place, and only the research team will have access to them. The notes will be destroyed in accordance with University regulations and/or

if you decide to withdraw from the study. You will not be identified by name or any other person specific details. The observations will be undertaken by Rosanna Mead.

What are the possible disadvantages or risks of taking part?

We cannot identify any risks to you in taking part. The disadvantage might be the time needed to take part in the interview.

What are the possible benefits of taking part?

We cannot promise that the study will help you, but listening to the live music may provide stimulation, improve your mood and reduce boredom.

Will taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all the information about you will be handled in confidence.

What will happen if I don't want to carry on with the study?

If you withdraw from the study, we will ask you if we can still use any data collected up to your withdrawal. We will comply with your wishes about this.

What if there is a problem?

If you have concerns about any aspect of this study, you should speak to the researcher, Rosanna Mead, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Tia DeNora (Academic Supervisor). Contact details on page 3.

Will my taking part in the study be kept confidential?

You will be given an anonymous participant number for the research and only the researcher and your medical team will have access to consent forms containing your personal information. The anonymous data will be securely stored on the University server. All information which is collected about you during the course of research will be kept confidential, in accordance with the Data Protection Act 1998.

What will happen to the results of the research?

We hope to publish the results of the study in peer reviewed clinical and scientific journals. You will not be identified in any published materials.

Who is organising the research?

Rosanna Mead is organising the research as part of her PhD in Sociology at the University of Exeter.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Central Hampshire A Research Ethics Committee.

Contact Details

For further information about the research please contact:

Name: Rosanna Mead (Researcher)
Telephone: 07983 670 678
Email: rsm214@exeter.ac.uk

Name: Professor Tia DeNora (Academic Supervisor)
Telephone: 01392 723280
Email: t.denora@exeter.ac.uk

If you need any advice about whether you should participate please ask a member of the study team, but also please feel free to discuss the study with your family and your GP.

Appendix 3 – Information sheet – staff



Title of Research Project

Live Music within a Hospital Ward for Patients with Dementia

Researcher: Rosanna Mead

Introduction and Invitation

We would like to invite you to take part in our research study. Before you decide, we would like to explain why the research is being done and what it would involve for you.

What is the purpose of the study?

This study is part of Rosanna Mead's PhD, looking at hospital ward environments and the role music can play within this for patients, and staff. We will be specifically looking at agitation in patients with dementia, and how the environment can affect levels of agitation.

Why have I been invited?

You have been invited to take part as you have been identified as a member of staff on Combe or Waterhouse ward

Do I have to take part?

It is up to you to decide to join the study. Rosanna Mead will go through this information sheet with you and answer any questions you might have. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

You will be invited to take part in an interview to discuss your experiences of live music for patients with dementia, and/or your experience of agitation in patients with dementia. These interviews will be audio taped and transcribed by the researcher afterwards.

The researcher will be observing the ward, and taking written notes. The researcher may write down direct quotes from the observations, and these may be used in the final thesis and publications; however, the quotes will be anonymised to ensure that you cannot be identified. Care will be taken not to record confidential information, and the researcher will check that you are happy with the quote as they have written it, after the initial transcription.

Observations do not judge your ability to deliver bedside care. Although, if unsafe/unprofessional practice is observed, the usual professional procedures will be followed. The notes will be stored in a secure place, and only the research team will have access to them. The notes will be destroyed in accordance with University regulations and/or if you decide to withdraw from the study. You will not be identified by name or any other person specific details. The observations will be undertaken by Rosanna Mead.

Alongside this we will be developing a tool to measure hospital ward environments and levels of agitation in patients with dementia. We would like your feedback on this tool as it develops, to ensure that it is user-friendly and suitable for its purpose.

What are the possible disadvantages or risks of taking part?

We cannot identify any risks to you taking part in the research, but a disadvantage may be the time taken for the interviews.

What are the possible benefits of taking part?

There will probably be no direct benefit to you. Indirectly, as this study will contribute to the profession's understanding about how hospital ward environments can affect patients with dementia and staff, you may benefit from changes to ward environments in the future.

Will taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all the information about you will be handled in confidence.

What will happen if I don't want to carry on with the study?

If you withdraw from the study, we will ask you if we can still use any data collected up to your withdrawal. We will comply with your wishes about this.

What if there is a problem?

If you have concerns about any aspect of this study, you should speak to the Rosanna Mead who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Tia DeNora (Academic Supervisor). Contact details on page 3.

Will my taking part in the study be kept confidential?

You will be given an anonymous participant number for the research and only the researcher will have access to consent forms containing your personal information. The anonymous data will be securely stored on the University server. All information which is collected about you during the course of research will be kept confidential, in accordance with the Data Protection Act 1998.

What will happen to the results of the research?

Anonymised findings will be used for the researcher's PhD thesis, academic papers and for dissemination via user networks.

Who is organising the research?

Rosanna Mead is organising the research as part of her PhD in Sociology at the University of Exeter.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the South Central – Hampshire A Research Ethics Committee.

Contact Details

For further information about the research please contact:

Name: Rosanna Mead (Researcher)
Telephone: 07983 670 678
Email: rsm214@exeter.ac.uk

Name: Professor Tia DeNora (Academic Supervisor)
Telephone: 01392 723280
Email: t.denora@exeter.ac.uk

If you need any advice about whether you should participate please ask a member of the study team, but also please feel free to discuss the study with your family and colleagues.

Appendix 4 – Information sheet – musician



Title of Research Project

Live Music within a Hospital Ward for Patients with Dementia

Researcher: Rosanna Mead

Introduction and Invitation

We would like to invite you to take part in our research study. Before you decide, we would like to explain why the research is being done and what it would involve for you.

What is the purpose of the study?

This study is part of Rosanna Mead's PhD, looking at hospital ward environments and the role music can play within this for patients, and staff.

Why have I been invited?

You have been invited to take part as you have been identified as a musician who has performed on either Combe or Waterhouse wards at the RUH.

Do I have to take part?

It is up to you to decide to join the study. Rosanna Mead will go through this information sheet with you and answer any questions you might have. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

You will be invited to take part in an interview to discuss your experiences of live music for patients with dementia. These interviews will be audio recorded, and transcribed by the researcher afterwards. You will be asked to write a reflective log after each performance on Combe or Waterhouse, and to discuss your log entries with the researcher.

The researcher will be observing the ward before, during and after your performance, taking written notes. The researcher may write down direct quotes from the observations, and these may be used in the final thesis and publications; however, the quotes will be anonymised to ensure that you cannot be identified. Care will be taken not to record confidential information, and the researcher will check that you are happy with the quote as they have written it after the initial transcription.

The notes will be stored in a secure place, and only the research team will have access to them. The notes will be destroyed in accordance with University regulations and/or if you decide to withdraw from the study. You will not be identified by name or any other person specific details. The observations will be undertaken by Rosanna Mead.

What are the possible disadvantages or risks of taking part?

We cannot identify any risks to you taking part in the research, but a disadvantage may be the time taken for the interview (around 30 minutes).

What are the possible benefits of taking part?

There will probably be no direct benefit to you. Indirectly, as this study will contribute to the profession's understanding about how music can play a role in hospital environments for patients with dementia, you may benefit from the rise in awareness in this field.

Will taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all the information about you will be handled in confidence.

What will happen if I don't want to carry on with the study?

If you withdraw from the study, we will ask you if we can still use any data collected up to your withdrawal. We will comply with your wishes about this.

What if there is a problem?

If you have concerns about any aspect of this study, you should speak to the Rosanna Mead who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Tia DeNora (Academic Supervisor). Contact details on page 3.

Will my taking part in the study be kept confidential?

You will be given an anonymous participant number for the research and only the researcher will have access to consent forms containing your personal information. The anonymous data will be securely stored on the University server. All information which is collected about you during the course of research will be kept confidential, in accordance with the Data Protection Act 1998.

What will happen to the results of the research?

Anonymised findings will be used for the researcher's PhD thesis, academic papers and for dissemination via user networks.

Who is organising the research?

Rosanna Mead is organising the research as part of her PhD in Sociology at the University of Exeter.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by South Central – Hampshire A Research Ethics Committee.

Contact Details

For further information about the research please contact:

Name: Rosanna Mead (Researcher)
Telephone: 07983 670 678
Email: rsm214@exeter.ac.uk

Name: Professor Tia DeNora (Academic Supervisor)
Telephone: 01392 723280
Email: t.denora@exeter.ac.uk

If you need any advice about whether you should participate please ask a member of the study team, but also please feel free to discuss the study with your family and colleagues.

Appendix 5 – Personal consultee letter



As someone who knows _____ (person's name) well / in an independent capacity (delete as appropriate), you are being invited to consider whether he/she would be willing to participate in a research study based on your knowledge of him/her.

Please read the Information Sheet that all participants read before deciding whether or not they would like to take part in this study. We will then ask you whether or not you think the person we are asking you about would have chosen to take part in the study, if they been able to read this Information Sheet and make that decision for themselves.

Further information is provided below about the provisions for people who lack capacity to consent to participate in research for themselves and explains your role as a consultee, if you agree to take on this role.

Capacity to give consent

Usually an adult must give their own informed consent before they can be entered into a research study. Some people however, may lack the mental capacity to make such a decision. For some research projects, including this one, it is important that adults lacking mental capacity can be included in the research because results obtained from them can be particularly important.

To protect both the person lacking capacity and the person providing advice about them, certain processes must be followed. Firstly, a formal assessment of mental capacity must be carried out by a doctor. If, after assessment, the person is deemed not to have the capacity to consent for themselves to being entered into the study, the researcher must appoint someone to provide advice, called a 'consultee'.

Consultees

Consultees can either be personal or nominated. A personal consultee is someone unconnected with the research who knows the potential research participant in a personal capacity and is able to advise on the person's wishes or feelings. This could be a friend or family member or someone appointed by the court.

A nominated consultee is someone unconnected with the research, who is appointed by the research team to advise the researcher about the person's wishes or feelings in relation to

the project. This could be another professional but they must not have any connection with the research study. A nominated consultee would only be appointed once the research team has taken reasonable steps to identify a personal consultee in the first instance.

The consultee's role

If you are prepared to act as a consultee, your role will be to advise the research team as to the individual's likely wishes/feelings with regard to taking part in the study. You are not being asked to consent on the individual's behalf, but rather to give advice about their wishes. However, your opinion will be respected in making a decision as to whether they take part in the study or not.

You will be given a copy of the participant information sheet and opportunity to discuss the project with the researcher so that you can form an opinion as to the individual's likely wishes/feelings in respect to the project. If, at the end of this process, you feel that the individual would be willing to take part in the project you will be asked to sign a form to that effect.

Further information

If you have any questions, please ask the person who provided this information sheet to you or address your questions to:

Name: Rosanna Mead (Researcher)

Telephone: 07983 670 678

Email: rsm214@exeter.ac.uk

Name: Professor Tia DeNora (Academic Supervisor)

Telephone: 01392 723280

Email: t.denora@exeter.ac.uk

Before you sign the consultee declaration form, you should ask questions about anything that you do not understand. The study staff will answer any questions before, during and after the study.

Thank you for taking the time to read this information.

As someone who knows _____ (person's name) well / in an independent capacity (delete as appropriate), you are being invited to consider whether he/she would be willing to participate in a research study based on your knowledge of him/her.

Please read the Information Sheet that all participants read before deciding whether or not they would like to take part in this study. We will then ask you whether or not you think the person we are asking you about would have chosen to take part in the study, if they been able to read this Information Sheet and make that decision for themselves.

Further information is provided below about the provisions for people who lack capacity to consent to participate in research for themselves and explains your role as a consultee, if you agree to take on this role.

Capacity to give consent

Usually an adult must give their own informed consent before they can be entered into a research study. Some people however, may lack the mental capacity to make such a decision. For some research projects, including this one, it is important that adults lacking mental capacity can be included in the research because results obtained from them can be particularly important.

To protect both the person lacking capacity and the person providing advice about them, certain processes must be followed. Firstly, a formal assessment of mental capacity must be carried out by a doctor. If, after assessment, the person is deemed not to have the capacity to consent for themselves to being entered into the study, the researcher must appoint someone to provide advice, called a 'consultee'.

Consultees

Consultees can either be personal or nominated. A personal consultee is someone unconnected with the research who knows the potential research participant in a personal capacity and is able to advise on the person's wishes or feelings. This could be a friend or family member or someone appointed by the court.

A nominated consultee is someone unconnected with the research, who is appointed by the research team to advise the researcher about the person's wishes or feelings in relation to

the project. This could be another professional but they must not have any connection with the research study. A nominated consultee would only be appointed once the research team has taken reasonable steps to identify a personal consultee in the first instance.

The consultee's role

If you are prepared to act as a consultee, your role will be to advise the research team as to the individual's likely wishes/feelings with regard to taking part in the study. You are not being asked to consent on the individual's behalf, but rather to give advice about their wishes. However, your opinion will be respected in making a decision as to whether they take part in the study or not.

You will be given a copy of the participant information sheet and opportunity to discuss the project with the researcher so that you can form an opinion as to the individual's likely wishes/feelings in respect to the project. If, at the end of this process, you feel that the individual would be willing to take part in the project you will be asked to sign a form to that effect.

Further information

If you have any questions, please ask the person who provided this information sheet to you or address your questions to:

Name: Rosanna Mead (Researcher)

Telephone: 07983 670 678

Email: rsm214@exeter.ac.uk

Name: Professor Tia DeNora (Academic Supervisor)

Telephone: 01392 723280

Email: t.denora@exeter.ac.uk

Before you sign the consultee declaration form, you should ask questions about anything that you do not understand. The study staff will answer any questions before, during and after the study.

Thank you for taking the time to read this information.

Appendix 6 – Information poster



This ward is participating in observational research

A researcher from the University of Exeter is currently conducting observational research on this ward, looking at hospital ward environments and the role of the music within this.

This study has been reviewed and given favourable opinion by South Central Hampshire A Research Ethics Committee. IRAS number: **206062**

The researcher will not have any personal information about you, but observations in which you are included may be mentioned in anonymised field notes.

The notes will be stored in a secure place, and only the research team will have access to these. The notes will be destroyed in accordance with University of Exeter regulations and/or if you request that observations in which you are included be removed from the research.

If you have any concerns about the research, or you would like to remove any observation notes in which you are included please contact either Rosanna Mead or Professor Tia DeNora.

Name: Rosanna Mead (Researcher)

Telephone: 07983 670 678

Email: rsm214@exeter.ac.uk

Name: Professor Tia DeNora (Academic Supervisor)

Telephone: 01392 723280

Email: t.denora@exeter.ac.uk

Appendix 7 – Consent form – patient



Participant Identification Number for this study:

PARTICIPANT CONSENT FORM

Title of Project: Live Music within a Hospital Ward for Patients with Dementia
Name of Researcher: Rosanna Mead

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I agree to my interviews with the researcher being audio-taped and typed up afterwards.
3. I understand that the researcher may write down direct quotations that they observe, and that these anonymised quotations may be used in the final thesis and publications.
4. I understand that my participation in the project is voluntary and I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
5. I agree to take part in the above study

.....
(Signature of Participant)

.....
(Printed name of Participant)

/ /
Date

.....
(Signature of Researcher)

.....
(Printed name of Researcher)

/ /
Date

When completed, one copy for participant, one copy for patient's medical record, one copy (personal information removed) for researcher's file.

Appendix 8 – Consent form – staff



Participant Identification Number for this study:

CONSENT FORM FOR STAFF

Title of Project: Live Music within a Hospital Ward for Patients with Dementia
Name of Researcher: Rosanna Mead

- Please initial box**
1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
 2. I agree to my interviews with the researcher being audio-taped and typed up afterwards.
 3. I understand that the researcher may write down direct quotations that they observe, and that these anonymised quotations may be used in the final thesis and publications.
 4. I understand that my participation in the project is voluntary and I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
 5. I agree to take part in the above study

..... / /
(Signature of Participant) (Printed name of Participant) Date

..... / /
(Signature of Researcher) (Printed name of Researcher) Date

When completed, one copy for participant; one copy (personal information removed) for researcher file.

Appendix 9 – Consent form – musician



Participant Identification Number for this study:

CONSENT FORM FOR MUSICIAN

Title of Project: Live Music within a Hospital Ward for Patients with Dementia
Name of Researcher: Rosanna Mead

- Please initial box**
1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
 2. I agree to my interviews with the researcher being audio-taped and typed up afterwards.
 3. I understand that the researcher may write down direct quotations that they observe, and that these anonymised quotations may be used in the final thesis and publications.
 4. I understand that my participation in the project is voluntary and I am free to withdraw at any time without giving any reason, without my legal rights being affected.
 5. I agree to take part in the above study

..... / /
(Signature of Participant) (Printed name of Participant) Date

..... / /
(Signature of Researcher) (Printed name of Researcher) Date

When completed, one copy for participant; one copy (personal information removed) for researcher file.

Appendix 10 - Nominated consultee declaration form



Participant Identification Number for this study:

NOMINATED CONSULTEE DECLARATION FORM

Title of Project: Live Music within a Hospital Ward for Patients with Dementia
Name of Researcher: Rosanna Mead

- | | | |
|----|--|---------------------------|
| | | Please initial box |
| 1. | I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. | I understand that the participant may take part in an interview with the researcher, which will be audio-taped and transcribed afterwards. | <input type="checkbox"/> |
| 3. | I understand that participation in the project is voluntary and that the participant would be withdrawn if they do not wish to continue participating without giving a reason, this would not affect their medical care or legal rights. | <input type="checkbox"/> |
| 4. | I understand that the researcher may write down direct quotations that they observe, and that these anonymised quotations may be used in the final thesis and publications. | <input type="checkbox"/> |
| 5. | In my opinion | <input type="checkbox"/> |
-[FULL NAME]
- Would have no objection to taking part in this study

..... (Signature of Consultee) (Printed name of Consultee) / .. / Date
..... (Signature of Researcher) (Printed name of Researcher) / .. / Date

When completed, one copy for consultee; one copy (personal information removed) for researcher file; one (original) to be kept in medical notes.

Appendix 11 – Interview guide – patient



Research study: Live Music within a Hospital Ward for Patients with Dementia

Semi-structured interviews for patients will be based around the following questions:

- 'What did you think of the performance you have just heard?'
- 'I would like to know more about the performance you have just heard, which parts did you enjoy the most?'
- 'Which parts did you dislike?'
- 'Can you describe how the performance made you feel?'
- 'Did you find the music brought back any memories for you? Can you tell me more?'
- 'What types of music do you like listening to?'
- 'Can you describe how you experience music in your everyday life?'

Appendix 12 – Interview guide – staff



Indicative Interview Schedule (Staff – Music)

Phases of Episodic Interview	Questions used in this study on the topic of agitation in patients with Dementia
<i>Phase One: Introducing the episodic interview principle</i>	<p>'In this interview I will ask you repeatedly to recount a situation, story or experience related to the use of live music for patients with dementia. Are you OK with what you are being asked to do?'</p> <p>The participant is then asked 'Can you tell me about a typical example or story or time when this happened to illustrate that?' after every question</p>
<i>Phase Two: Concept of topic</i>	
Subjective definition	'What comes to mind when you think of the use of live music on the ward?'
First experience	'Looking back, can you describe one of your first experiences of the music on the ward? What was your initial reaction?'
<i>Phase Three: Meaning in everyday life</i>	
Impact on ward environment	'Can you provide examples of how the music performances effect the ward environment?'
Impact on work	'How do the music performances affect your work?'
Negative impact	'Can you provide examples of any negative impact of the music performances?'
Recent event	'Think back to a recent music performance you have experienced on the ward; can you explain what happened?'
<i>Phase Four: Central focus on the topic</i>	
Benefits for Patients with Dementia	'In your experience, can you describe how the music affects patients with dementia?'
Negative impact	'Can you provide any examples where the music performances haven't worked? Why do you think this might be?'
<i>Phase 5: General opinions or attitudes towards topic</i>	
Why music has an impact on patients with dementia	'I'm interested to know your opinion on why music affects patients with dementia in a positive/negative way, and how it differs from other activities.' (question depends on their answers above).

Professionalism of the musicians	<p>'Can you tell me about the musician in residence and their role on the ward?'</p> <p>'How do you feel about other musicians visiting the hospital for one off performances?'</p>
<i>Repertoire and instrumentation</i>	<p>'What do you think of their selection of music?'</p> <p>'From your experience which instruments do you feel are more suitable to the hospital environment?'</p>
<i>Future</i>	'Can you describe how you see the future of live music performances in hospitals in general?'
<i>Phase 6,7,8 and 9</i>	Noting of small talk after interview, demographic information, feedback on method and analysis of interviews

Appendix 13 – Interview guide – staff (agitation)



Indicative Interview Guide (Staff – Agitation)

Phases of Episodic Interview	Questions used in this study on the topic of agitation in patients with Dementia
<i>Phase One: Introducing the episodic interview principle</i>	<p>'In this interview I will ask you repeatedly to recount a situation, story or experience related to agitation in patients with dementia. Are you OK with what you are being asked to do?'</p> <p>The participant is then asked 'Can you tell me about a typical example or story or time when this happened to illustrate that?' after every question</p>
<i>Phase Two: Concept of topic</i>	
Subjective definition	'What do you associate with the word agitation?'
Most significant experience	'Can you think about a significant experience you had had with a patient who was agitated?'
Experience of agitation	'In your experience can you tell me what measures are taken to reduce agitation in patients with dementia?'
<i>Phase Three: Meaning in everyday life</i>	
Recent Event	'I'd like you to think back to the last time you experienced caring for a patient with agitation. When was this? Can you please tell me about your experience?'
Impact on work	'How does an agitated patient affect your work?'
<i>Phase Four: Central focus on the topic</i>	
Impact on ward environment	'How is the ward environment affected by a patient who is agitated?'
Time	'In your experience, how do levels of agitation change over the course of the day?'
De-escalation	'Can you explain how agitation in patients with dementia is managed? How do you care for a person who is highly agitated?'
Measuring	'How is agitation in patients with dementia monitored?'
<i>Phase 5: General opinions or attitudes towards topic</i>	
<i>Why patients become agitated</i>	'In your opinion, what factors contribute to patients becoming agitated?'

<i>Reducing agitation</i>	'What measures can you see being used in the future to reduce agitation in patients with dementia?'
<i>Phase 6,7,8 and 9</i>	Noting of small talk after interview, demographic information, feedback on method and analysis of interviews

Appendix 14 – Interview guide – musician



Indicative Interview Schedule (Musicians)

Phases of Episodic Interview	Questions used in this study on the topic of agitation in patients with Dementia
<i>Phase One: Introducing the episodic interview principle</i>	<p>'In this interview I will ask you repeatedly to recount a situation, story or experience related to your performances with patients with dementia. Are you OK with what you are being asked to do?'</p> <p>The participant is then asked 'Can you tell me about a typical example or story or time when this happened to illustrate that?' after every question</p>
<i>Phase Two: Concept of topic</i>	
Subjective definition	'When you think of live music in a hospital, what comes to mind?'
Way into the field	'Can you describe how you got into this type of work?'
First experience	'When you look back, can you tell me about one of your first experiences of performing for patients with dementia. Could you please tell me about the situation?'
Training	<p>'Can you tell me about any training you have undertaken to learn how to perform in hospitals?'</p> <p>'Can you tell me about any training you have had to work with people with dementia?'</p>
Role	'Can you describe what you do in the hospital, and your role within the wards for patients with dementia.'
<i>Phase Three: Meaning in everyday life</i>	
Performing to patients with dementia	'How does it feel to perform to patients with dementia?'
Challenges	'Can you tell me about the challenges of performing in a hospital environment for patients with dementia?'
Preparation	'Can you tell me about how you prepare for your performances?'

During the performance	<p>'Can you describe your thought processes during your performance?'</p> <p>'Can you describe how the environment might affect your performance?'</p> <p>'How do you tailor your performances taking into consideration the environment?'</p>
Communication	'Can you tell me about how you communicate with patients with dementia?'
<i>Phase Four: Central focus on the topic</i>	
Benefits for Patients with Dementia	'In your experience, can you describe how the live music performances affect patients with dementia?'
Impact on ward	'In your experience, can you describe how the live music performances affect the ward environment in general?'
Agitation	'Can you describe any experience you have had with patients who appeared agitated? Describe the situation.'
Role of music in hospitals	'How do you feel music plays a role in hospital environments for patients with dementia?'
<i>Phase 5: General opinions or attitudes towards topic</i>	
Skills	'Can you describe the skills you feel a musician should have to be able to perform in hospital wards for patients with dementia?'
Benefits of music for patients with dementia	'I'm interested to know your own theories on how music is beneficial for patients with dementia. Please can you describe them?'
Future	'How do you see the future of music performances in hospitals for patients with dementia?'
<i>Phase 6,7,8 and 9</i>	Noting of small talk after interview, demographic information, feedback on method and analysis of interviews

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