

Enhancing Quality of Life through Singing:
A Music Therapy Study into Huntington's Disease

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ABSTRACT

This mixed methods study investigated whether the process of singing in music therapy can enhance the quality of life of patients with Huntington's Disease. It took place in New Zealand, over a two-month period, in a residential home dedicated to the rare condition. The research involved five participants: two residents diagnosed with Huntington's Disease who participated in individual music therapy sessions, two caregivers at the facility, and the music therapy student (MTS). The study endeavoured to answer the research question by triangulating three data sources. Data sources included; the MTS's clinical notes of the sessions, semi-structured interviews with the staff members and a short questionnaire developed by the researcher which involved gathering the personal self-rated scores from the resident participants. A thematic analysis was undertaken with the two text-based data sources (clinical notes and interview transcripts) and the questionnaire scores were collated for each case. However the questionnaire results were deemed predominantly invalid. The triangulation of findings found that participants observed the process of singing had contributed to areas of quality of life for both of the residents, by providing them with: 1) a stimulus for socialisation; 2) emotional and psychological support; and 3) support for their remaining cognitive and physical ability. The outcome of the study found that the process of singing stimulated the resident participants in two contrasting ways and their motivation to participate was not only the singing itself but also the music in the session, instrumental play and the relationship between the residents and the MTS. From the perspectives of the participants consulted in this study it was concluded that the results from this research added some rich detail to the current literature available. Findings also concluded that residents, caregivers and the MTS herself valued the process of singing in music therapy and regarded it as an important intervention when seeking to preserve the quality of life of Huntington's patients.

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This research study has received ethical approval from the;

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“The hereditary chorea, as I shall call it, is confined to certain and fortunately few families, and has been transmitted to them, an heirloom from generations away back in the dim past. It is spoken of by those in whose veins the seeds of the disease are known to exist, with a kind of horror, and not at all alluded to except through dire necessity when it is mentioned as, that disorder”.

Dr. George Huntington (1872, cited in Stevenson, 1934, p.4)

CHAPTER ONE

INTRODUCTION

Although it has been nearly 140 years since George Huntington penned these words, the challenge associated with preserving a reasonable quality of life for this group of people remains a preoccupation for health professionals and families alike. To date, scientists have yet to find a cure for Huntington's Disease (Maher *et al.*, 2011) and generation after generation are still being affected, either by inheriting the disease themselves or by losing a loved one to the disease. That said, it is imperative that we continue to provide research that looks for ways to alleviate some of the symptoms associated with the disease by finding ways to enhance overall quality of life for people diagnosed with Huntington's Disease.

This research was conducted in a residential home dedicated to the rare neurological degenerative disorder, Huntington's Disease (HD). This was where I worked as a music therapy student (MTS) in 2010, as part of clinical practice towards my Master of Music Therapy degree. From my own clinical notes and relevant literature I became acutely aware of how useful music therapy, in particular singing, could be in enhancing the quality of life (QOL) of people living with HD. Music therapy techniques used within the sessions such as; giving choice and control; encouraging participation; supporting self-expression; promoting communication and memory recall; responding to the client by 'holding' and 'matching'¹ provided a basis to enhance the residents well-being. These techniques enabled the residents to have independence, express themselves emotionally, reduce social isolation, communicate (verbal or non-verbal), support changes in mood and assist them in retaining some cognitive organisation. Prior to being diagnosed with HD, many of the residents would have had these natural abilities and would have been likely to function without any assistance. However due to the progressive nature of the

¹ Music therapy techniques used to match the patient's personal musical expression and support the patient's music (Wigram, Pederson & Ole Bonde, 2002).

disease, they were no longer able to do so easily and needed a lot of encouragement and stimulation to motivate them to become involved. It was hoped that by providing a focus on singing in music therapy sessions the residents might have been able to preserve some of the functions that were deteriorating to allow them to have a more positive outlook on life, and experience some freedom from the disease.

This study was therefore mixed methods research, which investigated whether the process of singing in music therapy could enhance the QOL of two residents, Frank and George².

1) Background

The residential home housed thirteen permanent residents, aged between 35-60, all in their mid-to late stages of the disease, four caregivers per shift and two nurse managers. The majority of the residents spent most of the day in the lounge, watching television, having their daily meals or participating in the odd recreational activity e.g. listening to the news being read out, bingo, cooking or occasional van outings.

Music therapy sessions were held in the facility's recreational room, a bright sunny room, which allowed the residents privacy away from the main lounge. During this time I conducted individual clinical sessions with a few residents who had shown an interest in music. I took note of their level of engagement, songs with which they had some personal connection, how well they could recall lyrics and melody, whether their communication increased between the songs or after the session, and whether there was a significant mood change within the session. The sessions also included the use of instruments (e.g. drums, xylophone, chimes, guitar and piano) and joint musical improvisation to encourage non-verbal forms of communication such as turn taking dialogues on instruments, body movement and free vocalising. It was through these daily observations, and conversations with my clinical liaison, manager and caregivers at the

² 'Frank' and 'George' are pseudonyms for the resident's real names to help protect privacy.

home that I began to understand the full extent of the disease and the critical importance of preserving residents' QOL.

When developing this research I took time to reflect over my clinical notes and observations and concluded that some of the residents appeared to become easily frustrated when using instruments. This seemed to be due to their inability to hold and play them effectively to create a satisfying sound. It also became apparent to me that the residents were primarily engaged when they were singing well-known songs and even though the majority of the clients suffered from dysarthria³ some were still able to vocalise a melody and/or remember the lyrics of songs, particularly from their own era.

1.1 Motivation for Research

Clinical sessions with the residents, as well as my experience being a professional vocalist and singing teacher, sparked my interest in the idea of using singing as a stimulus to enhance quality of life. There were also a limited number of studies linking singing, HD and QOL together. Magee's (2004) study which looked directly at the use of singing with people who have degenerative diseases, and Rainey Perry (1983) who used singing to maintain patients functionality by encouraging self-expression and relaxation, were the most closely related to this current study. Some music therapy studies mention singing as an effective tool for helping people with Huntington's Disease reduce psychological distress and aid relaxation (Hoskyns, 1982), stimulate speech through singing (Erdonmez, 1976) and song writing and song selection (Curtis, 1987) however none of them focused specifically on the singing process itself and the potential benefits of enhancing QOL. Therefore this study endeavors to contribute to this body of literature to assist therapists and researchers develop strategies using the process of singing to enhance QOL for people diagnosed with HD and other chronic degenerative diseases.

³ Speech that is characteristically slurred, slow, and difficult to produce (difficult to understand). A person with dysarthria may also have problems controlling the pitch, loudness, rhythm, and voice qualities of their speech. Refer to glossary for definitions (appendix 1, p.80).

1.2 My Personal Stance (as the researcher)

From my own experience as a singing teacher I am aware that students' moods tend to become more positive during singing sessions. While they are singing, they are opening their mouths, breathing in and exhaling more regularly, lifting up through their cheeks forming a smile, which may turn into a laugh if a note goes amiss or if they are happy with their performance. Levitin (2006) discusses the relationship of such behaviours with the release of endorphins, which act as mood enhancers.

My time at the residential home as a MTS was at times overwhelming. This was mainly due to witnessing the progressive nature of the disease and trying to remain positive and professional in what could be a depressing environment. On the positive side, music and singing was something that both the HD residents and the caregivers seemed to enjoy and get involved in. This in turn made me feel good about what I could contribute to the centre. Therefore I felt it was important to provide some more detailed study about what I, the staff, and the residents felt to be a valuable input to the facility's day programme. Further, I hoped this might influence charities and other investors to support further music therapy treatment in this field in the future.

2) Research question and aims

The research question and aims for this research were produced from my clinical notes, observations, personal experiences and the perceived need to provide more literature linking singing in music therapy, QOL and HD together.

2.1 Main Research Question

Can the process of singing in music therapy sessions enhance the quality of life of clients with Huntington's Disease?

2.2 Clinical Aim

The approach I used for singing in the sessions shared some similarities with a singing lesson. For example, as the MTS I provided one-to-one attention, supported the residents' voice with my own singing and accompaniment, created a warm friendly

environment, and complimented and encouraged participation. However, unlike a singing lesson I did not seek to improve the residents' singing voice, but instead sought to use the process of singing to stimulate and engage the residents with the aim of improving their QOL.

2.3 Aims of Research

- 1. To ascertain whether the process of singing in music therapy can enhance the QOL of clients with Huntington Disease.*
- 2. To identify themes from the MTS's clinical relative to quality of life of the residents.*
- 3. To establish whether quality of life (as measured by the Short Form Questionnaire (name, Y of publications) is increased over 16 sessions of music therapy.*
- 4. To explore staff participants perceptions about quality of life, singing and music and their ideas about music therapy with the residents during four interviews.*
- 5. To contribute to the body of music therapy literature for Huntington's Disease.*
- 6. To encourage health professionals, specialising in neurology, to incorporate music therapy into their treatment of Huntington's Disease and other neurological conditions.*

CHAPTER TWO

LITERATURE REVIEW

This literature review explores current research relating to the study and was drawn from a range of fields using online databases such as Medline, Web of Knowledge, PsycINFO and PubMed. Due to the lack of literature surrounding this topic the search was extended to explore literature related to singing in music therapy with other neurological conditions, and singing with the community for a general sense of well-being. Interestingly there has been a considerable amount of literature on HD and QOL. Within this literature there is a focus on various tools measuring QOL and their applicability when administering them to HD patients. This suggests that researchers are becoming more aware of how destructive this hereditary disease can be affecting not only the patient's physical, mental and emotional state but also their relationships with family, friends and ultimately their QOL.

1) Context of Huntington's Disease

Huntington's Disease (or 'Huntington's Chorea') was first described by Dr. George Huntington, in 1872, as a hereditary degenerative neurological condition that diminishes the affected individual's ability to walk, talk and reason.

HD affects men and women equally and is caused by a defective gene on chromosome four. This causes selective neuronal degeneration (reduction) within the basal ganglia and other areas in the brain such as the brainstem, cortex, cerebellum and spinal cord (Harper, 1996). The Diagnostic and Statistical Manual of Mental Disorder (DSM-IV) reports that there is a 50% chance of inheriting the defective gene from an affected parent and symptoms develop between the ages of 30-50yrs. Onset may occur as early as the age of four, however children who develop the juvenile form of the disease

rarely live to adulthood (American Psychiatric Association, 1994). If the onset is earlier the patient will contract a more severe form of the disease which will mean the CAG⁴ repeats are likely to be higher than 40+ which will cause more dystonia⁵, less chorea and a faster rate of motor, cognitive and functional progression (Mahant, McCusker, Byth & Graham 2003).

What makes HD so distressing is the period of which the disease is present (an average of 16yrs) and the symptoms which become progressively worse and eventually result in death (Davis & Magee, 2001). HD presents itself in varying degrees of physical, cognitive and psychiatric symptoms depending on the patient (Daveson, 2007).

1.1 Physical symptoms include:

Chorea (involuntary movement), dysphagia (difficulty swallowing), dysarthria (difficulty in sound production and articulation), gait that becomes ataxic, incontinence, clumsiness, dystonia and bradykinesia.

1.2 Cognitive symptoms are:

Dementia, difficulties with memory retrieval, difficulties organising thoughts associated with functioning, judgment, driving vehicles, making a decision and learning new information.

1.3 Psychiatric symptoms include:

Depression, anxiety, irritability, personality change, mood swings/emotional disturbance, obsessive-compulsive disorder (OCD)⁶ and inflexibility with routines.

It has only been since 1993 that the specific gene has been isolated and so now families can be tested for HD once they reach age eighteen (American Psychiatric

⁴ Within the HD gene there is a section where one codon (three molecules), containing the molecule sequence 'CAG', is repeated many times in tandem. As the number of repeats increases, the age when symptoms appear gets earlier and symptoms progress faster.

⁵ Symptom definitions on this page are defined in the glossary (appendix 1, p.80).

⁶ Obsessive-compulsive disorder is an anxiety disorder in which people have unwanted and repeated thoughts, feelings, ideas, sensations (obsessions), or behaviors that make them feel driven to do something (compulsions). Refer to glossary (appendix 1, p.80).

Association, 1994). Affected people will eventually be unable to take care of themselves and usually need support from a 24hr care facility. Patients may also have other conditions alongside the disease but death is usually due to infection (usually pneumonia), fall-related injuries, aspiration⁷ or suicide. In a study conducted in the department of neurology in Hungary, 96 family histories were studied and out of 396 deaths within the families, 40 people who were affected by HD had committed suicide (Baliko, Csala, & Czopf, 2004).

2) Music Therapy & Huntington's Disease

The voice provides the basic vehicle for human communication. Individuals living with a progressive illness may use singing, in the poetic idea of Magee and Davidson: *"...to defy the illness process, as an expression of life's breath running through the body"* (Magee & Davidson, 2004, p.65).

With the gradual degeneration of this innate ability to communicate there are also many physical, emotional and interpersonal ways of self-expression that are lost. As HD takes hold patients experience cognitive deficits in such areas as attention, memory, finding words, constructing sentences and general organisation of thought. This results in a decreased desire to socialise and interact, which inevitably causes some patients to stop talking altogether (Davis *et al.*, 2001). However, communication is not just transmitted through speech, it can be displayed through other forms of interaction such as eye contact and body and facial gestures which is of importance to music therapists.

Music has been seen as an effective way to help patients with HD develop meaningful communicative relationships, organise responses, and enhance positive interaction. It has also been shown to be a catalyst to increase arousal and motivate expressive responses. This is due to music being a non-verbal medium which involves elements of expressive communication i.e. pitch, rhythm, timbre, dynamic, tempo and phrasing (Aldridge 1996, cited in Davis *et al.*, 2001). Therefore by giving patients with

⁷ Choking on solids, which have caused blockages in the larynx or trachea. Refer to glossary (appendix 1, p.80).

HD a chance to express themselves through music, may in fact promote vocalisations, memory recall and reduce the patient's level of isolation.

Davis and Magee (2001) believed that despite growing isolation caused by the breakdown of communication associated with HD, music therapy could offer the opportunity to develop musical/therapeutic relationships between the music therapist and the patient. They looked into the effect of clinical improvisation on the expressive and interactive responses of a patient with HD and concluded that:

"...music-making within music therapy may offer an alternative means to communication, interaction and relationship development and may therefore be significant" (Davis & Magee, 2001, p.59).

Davis and Magee also noted that due to the unpredictable nature of HD the inherent fluctuation of response to musical stimuli was not always at a consistent level. However, Davis and Magee along with a multi-disciplinary team involved in the study observed that: *"the patients' participation in a musical and expressive experience unquestionably contributed to [their] overall quality of life"* (Davis & Magee, 2001, p.59). Erdonmez's (1976) study also stressed the importance of music and the need to maintain quality of life through self-expression and the importance of socialisation:

"The greatest contribution music can make to the treatment of Huntington's Disease is to enrich daily life, whether at home or in hospital. I believe music has a special role to play in the expression of feelings and the sharing of these feelings with those closest to the patient" (Erdonmez, 1976, cited in Hoskyns, 1982).

Research into the effect music therapy has on HD began to develop in the late 1970s and early 80's. Since then it has attracted specialist attention particularly at the Royal Hospital for Neuro-disability in London. Majority of the study specifically linking music therapy and HD together has been researched in the southern hemisphere, in particular Australia. Studies include: speech facilitation through singing (Erdonmez, 1976); music and movement programmes (Groom & Dawes, 1985); emotional expression by use of song-writing (Curtis, 1987); participation and communication (Rainey Perry, 1983) and a music therapy referral audit by Daveson (2007). The results from the audit concluded that patients with HD were most likely to be referred to a music therapist due to a need for emotional expression, and the maintenance of communication skills and

social relationships. All of these specific studies' explored the use of clinical improvisation and singing within the music therapy sessions.

Erdonmez conducted the first study into HD and music therapy in 1976. She explored whether the use of singing and musical play could affect the patients with HD abilities to communicate. She focused on the HD symptom of dysarthric speech and during a four-week period set out to determine whether expressive speech could be facilitated through stimulating music activities. Erdonmez found that out of the musical tasks: *"singing popular songs of the patient's choice was the most productive in terms of response"* (1976, p.62). The results were inconclusive, mainly due to the short research period, however she found that several patients were able to sing out words that they had previously had trouble articulating through speech and concluded that: *"the study supported the notion that singing in particular, is important in the facilitation of speech"* (1976, p.64).

Another study conducted by Hoskyns (1982), took information provided by Erdonmez (1976) and set out to counteract anxiety and frustration by encouraging relaxation and group participation, and reducing choreic movement by use of singing, playing and listening. It was hoped that the outcomes would include increased eye contact, interest, motivation, vocalisation (of any kind), independence and the ability to initiate interaction. The most significant findings were: *"Group singing seemed to be very beneficial... Concentration actually aids relaxation...Playing often increased the choreic movement"* (Hoskyns, 1982, p.17).

Rainey Perry (1983) conducted one of the most relevant studies to this current research. Although she did not focus on individual work Rainey Perry found that small music therapy groups where singing, self expression and relaxation were encouraged helped maintain and improve functioning in the following areas; participation; communication (both verbal and nonverbal); intellectual functioning (concentration and memory); relaxation; movement; self-esteem; self-expression; and social interaction. Rainey Perry (1983) concluded:

"It appears to me that receptive musicality may remain relatively intact despite diminished expressive musical abilities. Therefore, it is important that HD sufferers have the opportunity to participate in meaningful music activities, including music listening, in all stages of their illness" (p.9).

Magee's (1995) study recommended the use of highly organised musical tasks for patients who have HD and are in the mid-late stages of the disease due to their loss of information-organising capabilities. She highlights the importance of song structure to assist with the recall of information, and the preservation of vocal abilities through the singing of well-known songs.

Despite positive findings in the field, studies linking HD and music therapy together are scarce. Therefore a review of the wider field of neurological brain and movement disorders that share some similar symptoms to HD was essential to develop this study further.

3) Music Therapy & other neurological conditions

Huntington's Disease has some similarities to Alzheimer's Disease, Dementia, Multiple Sclerosis⁸, Parkinson's Disease and Motor Neurone Disease in which the disorder causes the brain to deteriorate progressively. Although these conditions have different impacts on the brain and central nervous system there has been more extensive music therapy research into these associated neurological disorders due to their more common occurrence in today's society.

The majority of the literature associating music therapy and neurological conditions together focused on dementia, particularly Alzheimers Disease (AD). Similar to HD, as dementia advances, participation and engagement in day-to-day activities diminishes. Concentration and the ability to communicate or contribute to group tasks become unattainable. As Sacks (2007) outlines:

“For those suffering with aphasia, the inability to communicate verbally may be almost unbearably frustrating and isolating...much of this can change with the discovery that such patients can sing...Suddenly their disability, their cut-offness, seems much less...” (p. 215-16).

Many music therapy studies have looked into the effect singing and music has on cognitive and physical functions and the patient's motivation for involvement. Studies

⁸ Definitions for the following disorders are defined in the glossary (appendix 1, p.80).

include: Pollack & Namazi (1992) who found an increase in conversational fluency and confidence in vocalisation among patients with AD after singing sessions; and Clair & Bernstein (1990), who concluded that patients with AD continued to show an interest in music and instruments despite a dramatic decline in physical and cognitive abilities. In later years Clair (2005) discovered music therapy could be used as an effective tool for dementia patients by improving alertness, and increasing engagement and participation. Music therapy treatment with dementia patients has also highlighted their ability to respond and retain music even when other cognitive abilities have diminished (Crystal, Grober & Masur, 1989). Prinsley (1986) concluded that music could assist with rehabilitation by ‘releasing motor skills’, enable a range of movement, vocalisation and maintain physical function. Further, Ruth Bright looked into the management of dementia where, social bridges were built between patients/families/caregivers by encouraging interaction, providing opportunities for decision making, emphasising the patients remaining positive attributes and strengths, and reinforcing awareness of time, person and place by positive affirmation (Jones & Meisen, 1992, p.169).

Literature specifically using singing and music to evoke memory recall with neurological conditions has also been explored in music therapy research. Carruth (1997) was interested in whether applying a music condition of singing to the spaced retrieval technique⁹ would increase the percentage of memory recall in name-face recognition with patients with AD. Due to a small sample size the data was not analysed statistically to determine a significant difference. However Carruth (1997) found that four of the seven participants demonstrated a greater memory recall for name recognition in the music condition than for a non-music condition. Prickett and Moore (1991) discovered that patients with AD recalled lyrics of well-known songs significantly better than new songs, information and spoken words. But even though the new material was unfamiliar to them they were still actively contributing within the sessions by attempting to sing, hum or keep time with the therapist. Aldridge (1995, cited in Rickson, 1998) recorded a similar phenomenon. He found that despite the onset of the language difficulty associated with

⁹ Spaced retrieval technique is described as “a method in which associations such as the names of to-be-remembered faces are repeatedly recalled at increasingly longer intervals of time” (Camp & Stevens, 1990, p.58).

aphasia and memory loss, patients with AD were able to sing well-known songs and even dance to tunes of their past. The music evoked not only emotional memories, but also verbal and physical memories, long thought forgotten.

Reminiscence focused music therapy sessions are often used as an activity in residential homes as they offer comfort, improvement with self-image, a stronger sense of self, social interaction, and a time to share memories with other residents and caregivers (Ashida, 2000). Lipe (1995) suggested that music therapy offers a real opportunity to communicate with dementia sufferers as the therapists are connecting with the person rather than the symptoms of the disease: *“As music is such a key way of communicating with Alzheimer’s sufferers, it must surely provide great scope to help them out of their isolation”* (Lipe, 1995, p.137).

Literature suggests that researchers need to focus on the remaining abilities of patients with neurological disorders and make use of these instead of focusing on the abilities that are diminishing. One study recommends using songwriting to help patients with dementia overcome their apparent cognitive, memory and language deficiencies. Silber & Hes (1995) found that creative song writing appeared to employ a section of the brain that compensated for deteriorated areas: *“For the patients who are emotionally withdrawn, songwriting provides the opportunity to express deep and repressed emotional feelings”* (p.33). Kota-Ewers (2000, cited in Aldridge, 2000) research which involved collecting the words spoken by dementia patients described it as a way of ‘holding’ the memories of the persons she worked with. Campbell’s (1986) research concluded that the more stimulation the brain receives, the larger the amount of neurons produced which therefore results in greater memory: *“...the more connections that can be made in the brain, the more integrated the experience is within the memory”* (p.14).

Behavioural issues are also a common component of degenerative diseases. As a result of positive engagement and participation in music therapy sessions, reports of reduced agitation, anxiety and other behavioural problems associated with dementia, have been discovered in many studies. Olderog-Millard and Smith (1989) found that singing in music therapy calmed the patient’s agitation and improved their orientation and sense of surroundings. Greone (1993) discovered a decrease in the directionless wandering, a common behavioural occurrence found with patients with AD, and observed that they were more likely to remain seated during music therapy group sessions than any other

form of treatment. Music therapy as a behavioural intervention has also decreased nonsocial behaviours occurring after the treatment session (Pollack *et al.*, 1992).

Sessions involving singing, instrument playing and dancing improved the QOL of dementia patients according to Koger (1999). Research by Nayak (2000), with patients who had suffered a stroke showed that music therapy is associated with a decrease in depression, improved mood, and a reduction in state anxiety. The results of this study showed that music therapy helped stroke victims recover faster by increasing the patient's positive emotions and motivation, allowing them to be more confident and driven to participate.

Sacks (2007) noticed a positive change in mood and an awareness of emotions when a patient, who had suffered extensive damage to his frontal lobe due to a brain aneurysm, began to sing. Although he retained his intellectual abilities, he was diagnosed as being severely emotionally impaired.

Sacks quoted: *“But all this would change, suddenly, when Harry sang...When he sang, he showed every emotion appropriate to the music – the jovial, the wistful, the tragic, the sublime. And this was astounding, because one saw no hint of this at any other time and might have thought his emotional capacity was entirely destroyed.”* (p. 303).

There is an increasing body of literature on the contribution of singing to well-being, and a growth in the use of choirs as a support for ageing. Group singing has been shown to be an emotionally positive activity, inducing feelings of improved health and personal well-being (Beck, Cesario, Yousefi & Enamoto, 2000). Presently, at the ‘Centre for Brain Research’ located at The University of Auckland, New Zealand, Laura Fogg (researcher) and Alison Talmage (music therapist) have set up the ‘*CeleBRation Choir*’ especially for people living with neurological conditions (Talmage & Fogg, 2010). Fogg was inspired by a London choir called ‘Sing for Joy’ and was interested in researching the affect singing has on the brain while developing a sense of community between these often somewhat isolated people. The authors of ‘Sing for Joy’ believe that singing songs allows us to understand each other as intentional and social beings:

“When we perform songs with others we share identifiable emotions within the musical structures of songs; performers are unified with a common goal; and understanding between group members is made possible through the shared intention of

singing. Thus, the performance of song helps us to develop a sense of 'self' and a sense of self in relation to others" (Magee, Temple, Grimes & Benson, 2008, p.1).

Bannan (2008) conducted a recent study in Australia involving patients with Alzheimer's and group singing. His results showed patients experienced a growth in confidence and alertness and the ability to learn a new song. The caregivers who observed this group felt that the sessions were of value and could foresee longer-term benefits. As Sacks (2007) suggests: *"Being able to sing words can be a great reassurance to such patients, showing them that their language capacities are not irretrievably lost, that the words are still 'in' them somewhere, even though it may take music to bring them out"* (p.216).

4) Singing in many societies

Singing is a popular cultural activity. It is something that many people enjoy and therefore is involved in many cultural events such as: church services, weddings and family gatherings, music festivals, parades, concerts and choirs. In Sweden it was reported that over 350,000 people participated in some form of music, in particular singing (Grape, Sandgren, Hansson, Ericson & Theorell, 2003). It has been regularly claimed that frequent participation in singing may prolong life although no quantitative studies have explored this (Konlaan 2000, cited in Grape *et al.*, 2003).

Why is singing such an integral part of our being and living? In addition to speaking, singing can be used to express ones thoughts, feelings and emotions (Chong, 2010). It is something that we are exposed to from an early age (Kohut & Levarie 1990). For example, mothers sing lullabies to alleviate their babies' anxiety, separation, and to help establish an emotional bond and develop communication. This links to Nordoff and Robbins (1983) suggestion that every child has a natural and spontaneous response to music, resulting in a concept they labelled as the 'music child'.

Studies show that singing enhances meaning in life (Chong 2010). Bailey and Davidson (2002) studied the benefits of singing in a choir and reported that singing promotes physical, emotional, social and spiritual health and has been used for clients that have a negative or low self-esteem. Southcott and Joseph (2010) studied The Bosnian

Behar Choir in Australia that was set up for older Bosnian immigrants to create a sense of community and to reduce social isolation. They interviewed the members and found out that singing in a choir enhanced the participants' perception of well-being, physical health, belonging and cultural identity. Singing has also been used with psychiatric patients to promote awareness of their emotional and physical states, as well as enhance their awareness of others (Tyson, 1982).

5) Quality of Life

Quality of life has been studied in a number of clinical fields and is particularly relevant for people who have life-threatening illness or those who experience disabling and degenerative symptoms where they are no longer able to care for themselves. QOL in this study is described as:

“The degree to which a person is able to function at a usual level of activity without, or with minimal, compromise of routine activities; QOL reflects overall enjoyment of life, sense of well-being, freedom from disease, comfort, and ability to pursue daily activities” (McGraw-Hill Concise Dictionary of Modern Medicine, 2002).

The World Health Organisation (WHO) specifically notes QOL in the definition of palliative care. The foundation of the approach of a dedicated Huntington's facility is to take responsibility for the palliative care of patients with this condition. Maintaining skills and a positive outlook can be really important for managing the illness.

5.1 WHO definition of Palliative Care:

1. Provides relief from pain and other distressing symptoms;
2. Affirms life and regards dying as a normal process;
3. Intends neither to hasten or postpone death;
4. Integrates the psychological and spiritual aspects of patient care;
5. Offers a support system to help patients live as actively as possible until death;
6. Offers a support system to help the family cope during the patients illness and in their own bereavement;

7. Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
8. Will enhance quality of life, and may also positively influence the course of illness.

6) Huntington's Disease & Quality of Life

Due to the growth in life prolonging medical interventions, QOL has become an important area to measure and it is specifically important for patients living with HD. One study conducted in Australia measured the mood and QOL of participants with progressive neurological illness including: Motor Neurone Disease, Huntington's Disease, Parkinson's Disease and Multiple Sclerosis. The results showed that people with HD compared to other illness groups experienced the most severe symptoms, poorest mood and lowest QOL (McCabe, Firth & O'Connor, 2009).

A range of studies assess the validity and practicality of various tools measuring QOL by considering patients with HD and carers needs. These measures include: the Huntington's Disease QOL life battery for carers (HDQol-C), (Aubeeluck & Buchanan 2007), which determines what aspects of quality of life directly related to HD are most important; the Health-related quality of life (HrQOL), (Mitchell, Kemp, Benito-Leon & Reuber, 2010), which is the sum of all sources of satisfaction and wellbeing minus all health-related threats (including anticipated threats); and the Unified Huntington's Disease Rating Scale (UHDRS), (Ho, Gilbert, Mason, Goodman & Barker, 2009), which is a rating system, that assesses the severity of the disease by measuring the patients motor, cognitive, behavioural and functional abilities.

In 2005, the Movement Disorder Society in England, published a study by Ho, Robbins and Barker (2006) that enlisted a group of participants with HD and their caregivers to examine their ability to perform self-rater assessments of their own behaviour to demonstrate whether they had selective problems with impulsiveness, lack of insight and disorganisation. The Dysexecutive Questionnaire (DEX) was used as it had

been validated in a general neurological population. The results showed that patients with HD did indeed have dysexecutive behaviours¹⁰ that were approximately twice that of very elderly rehabilitation patients with neurodegenerative disease. Specifically they lacked insight and an ability to make practical decisions regarding their vocational choices and treatment, and exhibited behaviours that were beyond the socially accepted norm or the norm of reality (Ho *et al.*, 2006).

Another study looking into the impact of HD on QOL used the Sickness Impact Profile (SIP) (Helder, Kaptein, van Kempen, van Houwelingen & Roos, 2001). The SIP has been proven to be a reliable and valid instrument and has been used to assess other chronic neurological disorders. The participants with HD were measured against a control sample of randomly selected Dutch subjects. The results showed that participants with HD scored significantly worse on every subscale of the SIP, particularly on the alertness, emotional and communicative subscales.

However although the SIP highlighted the importance of quality of life measures for people with HD, in 2004 the SIP and the Short Form (36) health survey (SF-36) were examined to validate the use of these two generic health related quality of life measures and to find out which best suited patients with HD (Ho, Robbins, Walters, Kaptoge, Sahakian & Barker, 2004). The researchers found an advantage in using the SF-36 because of its robust construction and test-retest reliability, the SF-36 was also shorter and quicker to administer and was easier for patients at various stages of the disease to complete. They reported that the SF-36 would be the recommended instrument of choice for assessing patients with HD (Ho *et al.*, 2004).

¹⁰ A disorder affecting the frontal lobe causing emotional, cognitive and behavioural symptoms.

7) Music Therapy & Quality of Life

A broad search on PyscINFO using the keywords music therapy and QOL came up with over a hundred different studies outlining the effectiveness of using music therapy with a range of illnesses. Most of the literature was aimed at elderly people with or without conditions such as dementia and AD, and the use of music in hospice and palliative care to aid in a reduction of anxiety, depression and other psychiatric symptoms. The studies addressed the effectiveness of music therapy on QOL in a number of settings. For example Nakayama, Kikuta and Hidekatsu (2009) found that the use of music therapy decreased anxiety and depression in patients in a hospice setting. In a community dwelling in Hong Kong, Lee, Chan and Mok (2010) found that being engaged in music activities stimulated the participants to become more social and connect with their life experiences. Grocke (2009) sought to enhance QOL by examining social anxiety with people living with severe mental illness. She concluded that music therapy gave joy and pleasure, working as a team was beneficial, participants were pleasantly surprised at their creativity and they took pride in their song writing. In 2010 a group of researchers formed a choir with elderly people in a residential home to counteract increased isolation and to improve QOL. The results showed the participants perceived their QOL to have improved due to the choir broadening their social network and they had learnt new knowledge (Carne, Mercadal-Brotons, Gallego & Riera, 2010).

One noteworthy study that specifically focused on the QOL of people diagnosed with cancer found research to clearly support the use of music therapy in hospice and palliative care for improving QOL. The Hospice Quality of Life Index-Revised (HQLI-R), a self-report tool administered to subjects, measured their QOL. Results showed significantly higher QOL scores in the experimental group rather than the control group, even when physical function declined (Hilliard 2003).

Overall, despite limited studies on HD and music therapy the relevant literature for this study appears to indicate the potential causal link between singing in music therapy and enhanced QOL. Singing with patients who have neurological conditions (as well as other conditions e.g. mental illness, and those in palliative care) is thought to enhance aspects of quality of life such as mood, participation, communication (memory recall), self-expression, general well-being, support movement, outlook on life, and to

reduce isolation, anxiety and depression. The QOL studies show that there is a need to assess QOL in patients with neurological conditions, especially those with HD, to highlight the patient's 'voice' and perceptions. Therefore this current study seeks to contribute to this body of literature to by examining the participants' perceptions of the process of singing within music therapy sessions and whether it can contribute to the QOL of patients diagnosed with HD.

CHAPTER THREE

METHODOLOGY

The music therapy studies covered in the literature review not only indicated the potential link between singing in music therapy and enhanced QOL but it also highlighted the importance of QOL for those living with neurological conditions. My previous experience with patients indicated the work was highly complex, individual, symptoms seemed to vary daily and there were many challenges faced within the residential environment. An exploratory study, which could document and interpret the rich and diverse experiences and perspectives of the participants, seemed to be appropriate for this study. The process of exploratory research, within the social sciences, is defined by Stebbins (2001);

“...a broad-ranging, purposive, systematic, prearranged undertaking designed to maximize the discovery of generalisations leading to description and understanding of an area of social or psychological life” (p.3).

However I was interested to use both qualitative and quantitative methods to find patterns and links within the perceptions of the participants and possible trends that were outlined in previous studies that might be further supported by the findings of this project. These objectives lead me to develop a mixed methods study.

1) Method

This research uses mixed methods to collect and analyse both qualitative and quantitative data in the context of a single study (Driscoll, Appiah-Yeboah, Salib & Rupert, 2007). This particular study has used a concurrent embedded qualitative design (Creswell & Plano, 2007), where the quantitative data has been subservient to the qualitative data. The process of concurrent embedding is described by Creswell (2007) as the supplemental data (quantitative in this case) is collected during the collection and

analysis of the dominant (qualitative) data type in a particular study.

Construct validity was sought by using three data sources to provide rich data about the participants' personal experiences, and responses about the role singing has to offer in an individual music therapy session (Wheeler & Kenny, 2005). Abrams (2005) and Bruscia (1995) endorse the importance of contextualising qualitative research by acknowledging the “...*many different frameworks, orientations, systems, environments and conditions*’ that co-exist in relation to the research study” (Bruscia 1995, p. 404). In this study consulting three varying perspectives, residents’ self-scores, therapist notes and staff interviews was one way to provide this contextualisation.

The three data sources have then been ‘triangulated’, which Abrams describes as adding to the grounded-ness of qualitative studies, through ‘consulting multiple perspectives’ and by drawing them closely together “...*the resulting constructions are grounded in the sense of being as well-informed and holistic as possible*” (Abrams, 2005, p 249). Fine, Weis, Weesen and Wong (2003) suggest that: “...*triangulation surfaces as a critical element in the practice of social science: ‘adding’ one layer of data to another to build a confirmatory edifice.*” However they recommend the importance of not just looking for a ‘*simple coherent synthesis of data or methods*’. They keenly suggest looking for diversity and difference having strong interest in multiple methods. They reported that after their data was collated: “...*we sought to cross over, converse within and tap into the different kinds of data; we searched for the very contradictions between methods that would most powerfully inform policy*” (p.187).

2) Participants

The participants in this study consisted of two residents at the centre, two members of staff who had detailed knowledge and experience of the resident participants, and myself as the MTS who wrote clinical notes detailing the regular practice within the music therapy sessions with the residents. The residents were ongoing clients in the music therapy service at the residential home, who had given consent to participate. The clinical notes were used for research purposes. The staff participated in semi-structured interviews.

3) Recruitment

The study was conducted at a private residential facility specifically for patients with HD. The thirteen residents residing at the facility have all been diagnosed with varying degrees of the disorder.

3.1 Resident recruitment

It was decided that the first two residents, out of a total pool of thirteen, who returned the consent forms and were verbally able to comprehend the questionnaire, would be chosen to be part of the research. This allowed room for residents or guardians to decline during the course of the study.

Two separate information forms were written for the residents due to the varied comprehension levels of potential participants. The simpler version was written with less formal wording and more emphasis on the idea that the researcher was writing a story about their singing and their time in the music therapy room. This was necessary to ensure they understood and could make an informed choice about consenting or declining participation.

The facility manager took time to explain the research individually with each of the 13 residents. Taking into account the residents' comprehension levels, she chose which information sheet and consent form¹¹ was most appropriate. The manager then gave the residents the opportunity to sign their own consent form. Some were unable to due to physical difficulties and so another information sheet and consent form was sent by post to their guardians¹². The information forms explained the aims of the research and stated that the research was entirely voluntary and the participants, staff or guardians on behalf of the residents could choose to withdraw from the study at anytime up until the end of the eight-week period.

¹¹ An example of both the residents' information sheets and consent forms can be viewed in appendix 2-5 (p.82-86).

¹² An example of the guardian information sheet and consent form can be viewed in appendix 6-7 (p.87-89).

3.2 Staff recruitment

All of the day staff members at the facility, 15, were provided with an information sheet and consent form¹³ and the facility's manager spoke with them about the nature of the study. It was decided that the first two staff members to return their signed consent form would be a part of the study.

4) Methods and procedures for data collection

Data was collected from three different sources and the procedure for each was as follows:

4.1 Clinical Notes

The clinical notes were documented by the MTS. These included an account of what occurred in the session and notes from the resident participants' case files. Each resident participant, if available and willing, received two individual music therapy sessions per week, over a period of eight weeks, lasting approximately 20-30 minutes. During the session the MTS gave particular attention to the use of singing, musical interaction, instrumental play, participation and changes in mood. At the end of each session, in accordance with usual clinical practice and if they chose to communicate, the MTS invited the resident participants to reflect on the overall session, what they enjoyed and how they felt on that particular day. Any comments were noted in the session record.

4.2 The Questionnaire for resident participants

Previous research on QOL and people living with Huntington's Disease suggested the use of the MOS Short Form 36-item health survey (SF-36)¹⁴ (Ho *et al.*, 2004), a measure for assessing patients own views of their QOL, and the World Health Organisation (WHO) questionnaire would be the most suitable for this study. However due to the fact that all of the potential participants were in the late stages of HD and a review of my clinical notes made prior to the research indicated that their ability to

¹³ An example of the staff information sheet and consent form can be viewed at appendix 8-9 (p.90-92).

¹⁴ Information regarding the MOS Short Form 36-item health survey (SF-36) can be viewed on the PubMed website. <http://www.ncbi.nlm.nih.gov/pubmed/1593914>

verbally respond, give full answers, complete the written form or remain focused for long periods of time was very challenged. Thus the supervisor of this study advised the MTS to adapt the Short Form (SF-36) questionnaire. In this instance it was simplified down to seven questions to be administered by the MTS so it would fit the design of this study. The brief set of questions appear quite simple and crude, (certainly much less subtle than the validated SF-36), but the MTS felt it important to invite residents viewpoints and it appeared that some idea of changes experienced by the residents could be mapped.

Once every two weeks, at the beginning of the session, an adapted quality of life questionnaire¹⁵ was administered. The seven questions¹⁶ formulated on a rating scale from 1-5 were then repeated at the end of the session to give participants a chance to provide scoring after being involved in music therapy and singing. The results were then collated and interpreted to determine whether any patterns or changes had occurred in participants' own scores. Over the eight-week period a total of 8 questionnaires, per participant, were administered by the MTS.

Although the study started with seven questions in the questionnaire during the study the MTS decided to erase the final question 'Have you had a conversation with another person today? YES/NO'¹⁷. At the time, while developing the questions it seemed appropriate as to possibly highlight social isolation, however when the MTS was required to repeat the questionnaire at the end of the session this question became irrelevant.

4.3 Interviews with staff members

Four short semi-structured interviews, all varied lengths depending on the staff members answers and time, took place two weeks into the study and at the end of the eight-week period with the two staff participants. During the interview the staff

¹⁵ Review of journal articles on quality of life measures suggested that MOS Short Form 36-item health survey (SF-36) (ref Ho, et al 2004) and the WHO QOL questionnaire could have been the most suitable for this project.

¹⁶ An example of the adapted questionnaire can be viewed in appendix 11 (p.94).

¹⁷ Refer to appendix 11.

participants observed a five-minute video extract of the two resident participants in their individual music therapy sessions. Footage was taken in the first and last week of the clinical sessions. The researcher selected specific video extracts where the resident participant was involved in singing, when they were responsive to musical stimuli and when they participated in conversations with the MTS.

The interview was designed so that they could give their own personal perspective on what quality of life and singing meant to them, reflections on what they observed in the video extracts of the resident participants and the connections between the resident's quality of life, singing and music therapy. It was anticipated that this would provide rich and in-depth discussions and plentiful qualitative data. However the staff participants involved in the study were unable to embellish on the questions asked and give much time to the study therefore the MTS found it difficult to gain the plentiful data predicted.

5) Data Analysis

5.1 Interview analysis

The four interviews were recorded onto a Dictaphone as both the interviewees could communicate verbally. The method of analysis went as follows:

1. The four interviews were recorded on a Dictaphone and transcribed verbatim. They were then posted back to the two staff participants for means of verification. At this time the participants were given the chance to delete, add to, or change any parts of the transcript.
2. Once the interviews were verified, the researcher read the transcript and listened to the recordings again to get an overall sense of the interviews.
3. The transcript was then analysed and organised into separate categories.
4. After cross checking, renaming and deleting categories, the main categories were chosen and themes that arose from the data were critically analysed and arranged into sub-groups.

5. Once the categories and subgroups were identified, the interviews were sent to a fellow music therapy student. She then read through the original unmarked transcripts to see if she agreed with the categories and subgroups discovered. Her thoughts were considered and adaptations were made when necessary.
6. The interview findings were then arranged into the finalised categories and further critical analyses was made.

5.2 Analysis for clinical notes

General clinical notes were made straight after each individual music therapy session and then typed up in full. The analysis of the clinical notes was similar to the data analysis of the interviews.

1. The researcher read the session notes and highlighted observations that were relevant to the research question.
2. These observations were then organised into separate categories.
3. Within each category, themes that arose from the data were critically analysed and arranged into sub-groups.
4. All of the session notes and themes found were given to another MTS for peer debriefing to guard against interpretive bias.

5.3 The Questionnaire analysis

The data from the questionnaires was formulated into simple line graphs to measure any changes in scores within the music therapy sessions. This data has been carefully considered due to bias that may have occurred due to the relationship between the MTS and resident participants and also due to the validity of the new design.

5.4 Triangulation of data

Following the analysis of the three data sources, I reviewed the findings and sort to triangulate the data into common categories and explored any new findings that arose from the data.

6) Ethical Considerations

Prior to the commencement of the study approval was sought and gained from the Central Regional Ethics Committee (Ref No: CEN/10/EXP/030). The study was also approved by the manager and reviewed by an appropriate Māori Kamatua¹⁸ connected with the facility.

Dedicated care for patients with HD is rare in New Zealand and as the residents had substantial challenges with their physical and cognitive functioning, particular care was needed to consider informed consent and to protect the identity of resident and staff participants. Care was taken to ensure that:

1. Due to this small community, the participants involved in the study would not be identified, however the participants were warned of the potential risk of identification in the information forms.
2. The use of names and revealing information was avoided to protect the rights of the participants involved and the risk of identification.
3. Informed consent was obtained from the client's themselves wherever possible or from an authorised family member or guardian.
4. Informed consent for the use of auditory and visual recordings of music therapy sessions for review by the therapist and interviewees was sought in writing before commencement of the study. After the study, the recordings were lodged at the residential setting, for use by resident or appropriate staff and family while the resident remained at the centre.
5. The participants were aware that their participation in the study was voluntary and they were able to withdraw at any time. If they chose to do so, they would not be denied the music therapy clinical service.

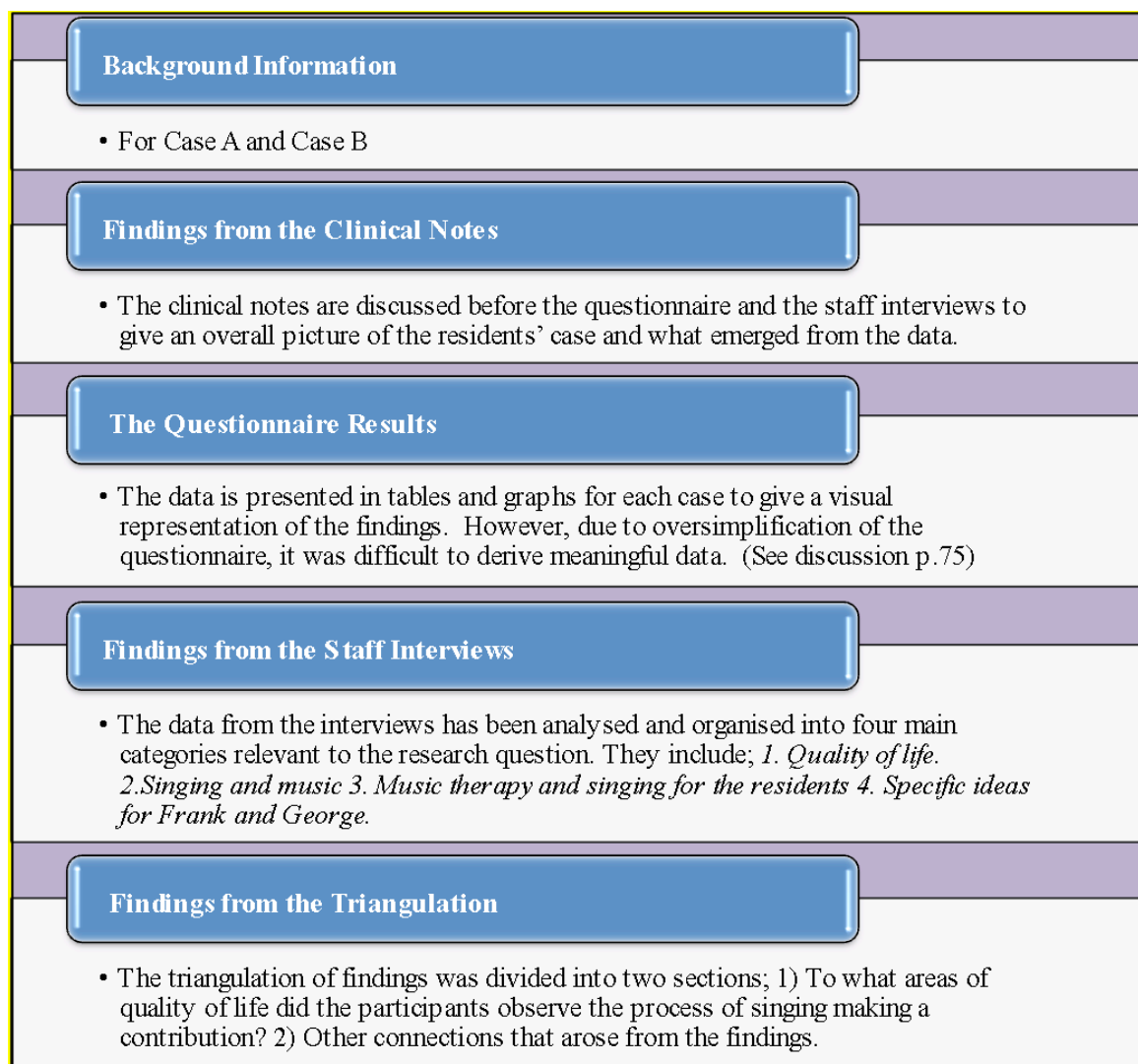
¹⁸ An example of the consent for the Maori Kamatua (Maori elder) can be viewed in appendix 10 (p.101).

CHAPTER FOUR

FINDINGS

In this section the findings from the clinical notes, questionnaire and the staff interviews are displayed as follows. The data was then triangulated to outline any similarities within the data and to present any new findings that arose due to the analysis.

FIGURE 1: DESIGN FOR PRESENTING CASE FINDINGS



1) Introducing the resident participants

1.1 Case A: Frank

Background Information

Frank¹⁹ is 53yrs and was diagnosed with Huntington's Disease, Scleroderma²⁰ and Raynaud's disease. He has a friendly nature and always greets me on arrival. He has lived with HD for over ten years and his symptoms include advanced chorea, aspiratory airbursts, dystharia and other physical conditions. He is still able to walk short distances, but at times feels weak and tired so spends most of the day in an armchair and uses a wheel chair to get to appointments. He is cognitively alert and is able to understand and participate in a conversation, however his shallow breathing and slurred speech all present communication challenges. Frank is married with three children and is very patient and caring of the other residents.

1.2 Case B: George

Background Information

George is 53yrs and was diagnosed with Huntington's Disease. He has lived with HD for approximately 10 years but is still able to walk. However, he has difficulty balancing at times and has endured a couple of falls in the past year which resulted in brain bleeds and has left him very weak and slumped on his left side. George is very dependant on the facility and needs support for other symptoms associated with the disease. Although at times he appears cognitively able, staff reports indicated that he is having more difficulties with future planning and was losing his short-term memory. Staff also report traits of Obsessive Compulsive Disorder (OCD)²¹ which manifests in the form of repetitive behavior such as asking for a drink or T.V. When his needs are not met he can become very agitated, noticeably grumpy and

¹⁹ 'Frank' is a pseudonym for his real name. All names have been changed for confidentiality purposes.

²⁰ Definitions for Scleroderma and Raynauds Disease can be found in (appendix 1, p.80).

²¹ HD comes with an overlay of psychiatric symptoms that are outlined on p.7.

volatile towards staff and the facility itself. The reports also mentioned he played drums in a band.

2) Findings from the Clinical Notes

The clinical notes from both cases were analysed through coding and then arranged into the eight categories below. Sub-categories were then identified from these categories.

Table 1: Categories found in the clinical notes

<u>Categories</u>
• <i>Therapist Technique</i>
• <i>Relationship with the MT student</i>
• <i>Relationship with family</i>
• <i>Changes in mood</i>
• <i>Communication changes during the process of the session</i>
• <i>Stimulation</i>
• <i>Changes in coordination & body control</i>
• <i>Deterioration</i>

2.1 Therapist Technique

Adapting to the resident's mood (frame of mind)

As a music therapy student it took a lot of mental and physical energy to work in this setting. Not only when it came to planning the sessions but mainly learning how to 'be' with the residents especially when they displayed unpredictable behaviour and uncontrollable movements (chorea). Upon arrival to the clinic, it was important to have a general conversation or re-introduce myself to the residents outside of the music therapy room before any sessions were conducted. This not only gave the residents time to adapt to who I was and why I was there but also gave me time, as the therapist to adapt to the clinical environment and allowed me to examine the residents mood and general feeling for the day.

For the majority of the sessions when I arrived at the clinic Frank would be seated in his special chair where he could view the whole room. He would greet most people with a nod or a 'hello' when they walked into the room but for the most part he remained quiet, occasionally gazing at the television. Frank's overall mood was generally calm and easy going. When I would approach Frank he greeted me with a smile and informed me of what had been happening. He was very aware of whom I was, what we would be doing and would patiently wait until the room was ready before he would enter.

George was very unpredictable. Sometimes he would greet me and other times he would stay focused on the television. A few times upon my arrival he would get up and start saying 'no' before I had even had time to speak to him. I had to learn very quickly to accept that George would most likely say 'no' to the session before he would say 'yes' so I had to adapt to his mood, become more flexible and not take his refusal as a personal reflection of my work. Over the 8 weeks I learnt to develop a technique of having a conversation with him before the session about drumming and our past 'band practices'. This would jolt his memory and get him enthusiastic about joining me in the music therapy room however I had to be very organised and ready to start his sessions at any moment. During session six when I finally managed to get George into the music room, I said to him: "...it's hard to get you in here..." and he started to laugh and put on a playful grin (25/08/10 - line 278). He seemed to acknowledge that he knew he was difficult to manage sometimes. I also noticed that he was more willing to come into the music therapy room in the afternoons and therefore half way through the research changed his morning session to an afternoon session. This made a considerable difference.

Changing the music therapy room to suit the resident

Frank's main objective to be in the music therapy room was to sing and therefore he was only interested in sitting on a chair facing the piano. However it could be said that if he had more confidence in his body control he may have enjoyed being surrounded by instruments.

For George, I realised quite early in the research that it was important to arrange the percussive instruments in a semi-circle around his chair. This kept his focus during the session and allowed him to reminisce, be stimulated and think like a drummer again.

Giving residents opportunities to make choices

For both Frank and George it was very important to allow opportunities for choice within the session. For example, choosing a song, instruments, tempo, cue to start and stop and the arrangement of the song. This gave the residents a sense of empowerment, that their 'voice is being heard' by simply giving them an opportunity to make a decision.

Giving awareness of surroundings through song

Due to experiencing the same routine everyday I noticed that the residents had become 'out of touch' with the world outside of the clinic. For Frank I was able to pick a subject, such as the weather and relate it to a song. This helped to maintain Frank's awareness of his surroundings. During session ten we sang 'Summer Holiday' as it was a sunny day. This helped Frank lift his mood and he became more relaxed and calm (08/09/10 – line 436). At times it appeared that Frank was able to stay in touch with some current affairs and give his own opinion. During session ten I asked Frank what he thought about the earthquake in Christchurch. He replied: "Yeah...It's shocking" (08/09/10 – line 439). We decided that 'Stand by Me' was an appropriate song to sing, as the lyrics related to the subject: 'If the sky, we look upon, should tumble and fall and the mountains should crumble to the sea.'

Highlighting and complimenting

Compliments encouraged participation and built the residents confidence during the session. During session three, Frank was singing 'What a Wonderful World', I commented on the character of his voice saying he sounded like Frank Sinatra. He

enjoyed this compliment very much and proceeded to try and imitate Frank Sinatra's deep warm voice (16/08/10 – line 182).

George also enjoyed compliments especially about his drumming. During the third session I complimented George on his use of percussive sounds making clear differences between the verse and the chorus. He replied '*It was cool*' and when I mentioned his sense of timing, he said '*It's amazing!*'. His response came across like he had surprised himself (16/08/10 – line 179).

Therapist singing and accompaniment supporting participation and physical movement.

Frank needed no encouragement to sing but felt more confident to sing louder when I joined in singing. Due to his dysphasia, at times it was important to adapt my playing to support his singing, give him more space to breathe and allow time for him to recall the lyrics.

Although it was very apparent that George was more interested in percussive instruments than singing, he became more encouraged to participate when I was singing a song. My singing enabled him to 'hold' a sense of rhythm and experiment using both arms. During session three he felt comfortable enough to reach out and explore different percussive sounds. He hardly ever went off the main beat and when he did, he tended to hit the djembe more lightly until he had found the right tempo again. During session two, while George explored the piano I supported his movement by improvising a song that followed his fingers ascending up the notes: "*Climbing up the stairs, George is climbing up the stairs, George is nearly there, George you made it there*" (11/08/10 – line 144-49).

Matching and responding to resident cues

As well as a positive change in mood, Frank's energy levels seemed to increase when he was singing. As I became more aware of matching and responding to his cues, I was able to support him when he put more emphasis on certain phrases within the song. In session five I commented that:

“As the session went on his energy levels lifted and while we were singing ‘Somewhere over the rainbow’ it turned into a rock tune. He was giving it punch and so I instinctively changed the style much to his delight...he left the session with a big smile and much more energy in his step” (23/08/09 – line 263).

His energy levels may have lifted due to his change in feelings of confidence by leading the style change and having me follow suit. These are emotions that he may not get to experience that often and it might have helped him to recapture some form of independence.

Therapist singing supporting memory recall

George would seldom sing without me singing along with him. In session three I wanted to assess whether he really knew the words of the song or whether he was just imitating the words I was singing. At one point while we were singing *‘Achey Breaky Heart’* I missed out some words e.g. ‘Don’t break my...my...heart’ and to my surprise George picked up on it immediately and filled in the gaps. This encouraged more participation as he saw it as a game: “ [George’s] *singing was very active...he filled in lots of words that I missed out on purpose and he really got into the song*” (16/08/10 - line 200).

2.2 Relationship with the MTS

Encouraged communication

Frank thrived on one on one attention. As our relationship grew within the sessions, I noticed our conversations became longer and he began to speak a lot about his family. Frank also began to start a conversation especially when a song had sparked a memory. During session seven he mentioned his daughters and told me proudly what each of them did for a job. Also as he became more comfortable with me, his singing became more spontaneous and creative and it was noted that his own improvisation provided him with a vehicle to express his feelings (01/09/10 – line 375-8).

George appeared to be more communicative towards the end of the sessions after singing and expressive play. This allowed me to access more of what he was feeling as he became relaxed enough to answer more in-depth questions. During session fifteen George and I had a conversation about his reaction to his diagnosis: ...I asked what emotion he had felt when he found out and he said, “angry” and “it was hard”. I then asked how are you dealing with it now? He replied, “good” (27/09/10 - line 543).

2.3 Relationship with family

Singing supported family involvement

During session two I invited Frank’s wife Mary²² to be involved in the session as she had come to visit him. Initially I felt nervous about having Mary there however, I was eager to find out how this session would evolve. Interestingly, singing supported family involvement in the session and it proved to be positive experience for Frank. I reported in my clinical notes that: “*Frank seemed very calm and relaxed after the song and had enjoyed singing in front of Mary. Her encouraging words definitely had a positive affect on him*” (11/08/10 – line 106). Her involvement also encouraged his participation, as he wanted to sing for her.

Life beyond Huntington’s Disease

Nearly every session I conducted with Frank he asked to sing his favourite song ‘Let it Be’. During the session that his wife was present it became evident how much the song meant to him and his wife. Singing the lyrics in the song gave Frank the determination to ‘push past’ his HD and carry on with life. His wife Mary commented: “*...that song sums you up eh [Frank]? Let it be and there will be an answer...especially when I was stressing out, you said not to worry, what will be, will be...take everything as it comes*” (11/08/10 – line 149-52).

²² ‘Mary’ is a pseudonym name for Frank’s wife.

2.4 Changes in mood

Positive change in mood

For Frank singing was something he felt confident doing and no matter what mood he was in, he never turned down the opportunity to come into the music therapy room. Sometimes he was in a lot of pain and appeared uncomfortable however this would quickly be forgotten when he started to sing. *“As soon as he started singing his mood changed and he became very cheerful and appeared to be in good spirits. He often gave me a playful smile and had a glint in his eye. His rosy cheeks and general enthusiasm shines through and I can’t help but smile back at him”* (09/08/10 – line 21-4). During session fourteen Frank commented: *“I feel good...always leave the room feeling good”* (22/09/10 – line 520).

Before the sessions, George would appear annoyed and agitated, not wanting to partake. Although he was more interested in being the ‘drummer’ rather than singing, after some positive one on one interaction George would become relaxed and happier and would often leave the session with a clear sense of achievement. I commented at the end of session twelve: *“He sat up right and gave me lots of eye contact. There were a lot of smiles and laughter and he seemed very contented”* (15/09/10 – line 461).

2.5 Changes in communication

Singing well-known songs

Both Frank and George preferred to participate in ‘well-known’ songs. They appeared more confident and relaxed and were able to sing with more conviction. There was a definite change in communication when George sung well-known songs. I noted: *“It is clear to see George enjoys singing and isn’t afraid to sing loudly when he knows the words”* (09/08/10 - line 18).

Singing aids in memory recall

Within the sessions it appeared that Frank was able to sing more words than he used in general conversations. This may be due to his dysphasia being more present when

he spoke rather than when he sang and his inability to use a bigger selection of words due to the memory deterioration associated with HD. Most of the time we would sing the songs together, which enabled Frank to have my support to remember the words but in fact, for the majority of the time, with some pauses, he was able to recall the lyrics. It also seemed that Frank's short-term memory was relatively intact as he was able to remember what we did in the previous session and was able to memorise the melody and the lyrics of the song we wrote during songwriting. In session nine: *"I encouraged [Frank] to sing the song by himself which he managed quite well with some prompting. It's lovely to see his reaction after the song and how he has a sense of achievement"* (06/09/10 – line 415-17).

Singing also seemed to support Frank's ability to reminisce about the past. In session three I asked Frank: *"What rate would you give singing out of 10?"* Frank replied, *"10...it helps me remember memories"* (16/08/10 – line 165). The well-known songs that he loves to sing triggered memories from times in his life when he was not ill and was able to function normally in everyday society.

Stimulating vocalisation through 'Call and response' singing

Frank responded well to the use of call and response when we were singing together. He especially liked to sing a deep 'oh yeah...' in a blues improvisation we made up together. He preferred to echo the words and sounds I was making rather than lead the song, which may have been because he felt more confident singing well-known songs. However this led to more spontaneous singing within the session and I would stimulate his improvisations by repeating phrases or sounds sung by Frank. This in turn encouraged Frank to explore his voice and provided a vehicle for him to feel confident enough to 'let go' and express his own feelings (01/09/10 – line 375-8).

Songwriting to express emotions

Singing and songwriting supported Frank's ability to communicate and express himself emotionally. During session two I suggested we start writing a song, which he was very relaxed about. In his wife's presence, Frank decided on the theme of 'love':

“He sang, ‘Oh you’re beautiful...’ [Then I remarked] ‘Oh you must be singing about [Mary]?’ [He responded with a smile]. ‘I offered, ‘you’re lovely’, and he said, ‘that’s it’. I said can you try and finish the phrase and he sang, ‘and you’re mine’” (11/08/10 – line 135-40). After singing the melody a few times Mary was overwhelmed and they turned to each other and shared a kiss. On reflection this was such an important moment for Frank’s QOL, as he is now in 24hour care, he rarely gets to the chance to see his wife let alone share intimate emotions with her. Mary also seemed to benefit from the session, as she was able to hear her husband express his love for her.

Eventually, over the next five sessions this phrase became a song that Frank proudly recorded for his wife²³. During session eight I asked Frank whether he had spoken to his wife about his song. He replied: *“I’ve told her, she asked me to sing it but I said she’ll have to wait” (01/09/10 – line 384).* This was followed by a playful smile.

During session four it became apparent in an improvisation that George had a love for the blues. Mindful of this I decided to try songwriting with George, using the blues progression and helping him make up lyrics. Although he seemed to enjoy the songwriting process about his ‘old blue car’ it appeared that he preferred to keep time on the djembe and listen to me sing the new lyrics and would smile and laugh along as he recalled his blue car (13/09/10 - line 415-18).

2.6 Stimulation

Singing vs Instrumental play

This study is focused on how singing can enhance quality of life, however it became evident throughout the sessions that although singing was Frank’s main motivation, it was not the main stimulus for George.

Frank was very aware of his lack of body control and because of that had little confidence when it came to playing an instrument. He would lose interest very quickly and became slightly irritated due to his inability to hold an instrument and make a

²³ The original score has been included in appendix 17 (p.104).

stimulating sound. The clinical notes reported that: *“I felt a strong sense of discomfort enter the room, and he would stop playing and lean back into his chair”* (18/08/10 – line 229-31). The only instrument he felt capable playing was the chimes. During session four, having noticed his lack of interest for instruments I asked him which instrument was his favourite? He said: *“The chimes...cause its easy to play”* (18/08/10 – line 232). The chimes are the most stimulating instrument for him to play as he can glide his hand through them easily and does not need to hold anything. However critical analysis leads me to question whether it was just his inability to play the instruments that made him enjoy singing more.

It was very clear that George’s motivation to enter the music therapy room was for the percussive instruments. At times George would sing along with me but it was the instruments that kept him focused on the music. However using the instruments did seem to increase his confidence and timing when he sang: *“...his drumming seemed to improve when he focused more attention on his singing”* (09/08/10 – line 37-9).

More than T.V.

The music therapy sessions gave both of the residents a ‘new hobby’ an alternative and a distraction to watching television.

2.7 Changes in coordination & body control

Singing supporting body awareness

It was reported in session nine that: *“[Frank] shows obvious enjoyment and tries to sit upright in his seat and sing as strong as he can”* (06/09/10 – line 397). This suggests that the stimulus of singing encourages Frank to become more conscious of his body position and prompts him to correct himself when he starts to slump into his chair.

HD causes some residents to be incapable of expressing physical emotions on their face and they often appear elusive, ‘not at home’ or unable to emotionally convey what the lyrics are saying. Frank would always be smiling no matter the song, sad or happy. However this changed when he sang the song he wrote about his wife. He

appeared to be much more aware of the lyrics and was desperately trying to convey his emotions. The emotional understanding that went into his songwriting and performance was observed on so many levels. After watching his recorded performance of the song during our videoed session, I reported that:

“There is so much joy and excitement in Frank’s eyes when he singing it. He produces so much energy and puts so much meaning into it that I know is completely genuine...This song means so much to him because he knows [Mary] and their daughters will treasure it like gold when he is gone” (20/09/10 – line 483-89).

Singing provokes changes in choreic symptoms

Although Frank seemed to be aware of his body his involuntary movement associated with HD became more prevalent when he was singing or playing an instrument. During session three I commented that: *“As he is singing I am aware that his choreic movements become more prominent and at times I was worried he was going to fall off his chair” (16/08/10 – line 169).*

George did not experience as much chorea, which allowed him to hold instruments and create stimulating sounds and rhythms.

Supporting coordination and body control

George understood musical terms and the concept of arrangement and dynamic placement. Because of this George appeared to calculate his moves with both sides of his body and coordinate changing instruments depending on the form, e.g. he often played the chimes between sections and at the end of the song and always ended with a drum roll on the djembe (11/08/10 – line 115). During another session in the middle of a song I called out ‘solo’ and as I supported him by keeping time, he appeared to know what I meant and his own drumming got louder and he started improvising more, rather than just holding the beat.

“At the end he gave a drum roll and when I had finished playing he hit the drums a couple more times, giving us a proper ending. The caregiver that was in the room was

very impressed with his drumming and gave him an encouraging compliment”
(16/08/10 – line 33).

2.8 Deterioration

Although 8 weeks would normally be considered not enough time to observe deterioration, HD is a progressive disease and accordingly, certain occurrences took place during the research.

Throughout the sessions I was acutely aware of Frank’s breathing. At times when he became overly excited while singing we would need to stop so he could catch his breath. Most of the time Frank would flex his voice up and down over his range and use a chest/spoken voice to sing (09/08/10 – line 20). This was due to the deterioration in his vocal box and his ability to control his breathing. This weakening became more apparent when he proudly played me a recording of himself singing the year prior. At the time I noted in my clinical notes that his voice in the recording was a lot stronger, there was less dysphasia and he was able to hold and control long notes (23/08/10 – line 248).

Although the sessions are unlikely to improve his breath control and vocal ability, the singing allows him to carry on using these important muscles associated with breathing and singing. Therefore this leads me to believe that with further music therapy sessions focused on singing may help in slowing down the deterioration. This area requires further research.

At the start of the research period George was giving lots of eye contact, sitting upright, playing the drums with both hands and singing and speaking words that were relatively comprehensible. Towards the end of the research period after suffering from a TIA I reported that:

“He [George] appeared very slumped and tired throughout the session today. Not like the usual George from previous sessions. There was very limited eye contact today and his head was hanging very far forward, so I only got a view of the top of his head. At times he did look up but that was only during a small amount of

communication...he tended to say one word answers that were very slurred (more than usual) at one tone and quite quietly today” (22/09/10 - line 500-7).

Due to HD being a progressive neurological disease it is hard to expect any improvement. However, the addition of a music therapy session to George’s day provided him not only with a new hobby and an alternative to watching TV, but it opened the door for a musical man. The music therapy sessions enabled George to reminisce over once being a drummer, it provided him with a safe environment to explore his emotions through self-expression, and it appeared to increase his vocalisation, raise his morale and reduce his agitation and social isolation.

3) The Questionnaire Results

Upon analysing the findings from the questionnaire I found that the results gathered were insignificant and did not add much information for the study. However I decided to include the results tables with a few explanations to display the reason why the data proved to be invalid.

Table 2: Table of results from Frank's questionnaire

	09/08/10		23/08/10		06/09/10		20/09/10		
Questions	T 1	T 2	T 1	T 2	T 1	T 2	T 1	T 2	
1 How would you rate your quality of life?	4	4	4	4	4	5	5	5	
2 What do you feel right now?	4	3	4	5	3	5	4	5	
3 How relaxed do you feel?	4	4	5	5	4	4	4	4	
4 How much energy do you have today?	2	2	3	5	4	5	4	5	
5 How much have you enjoyed your day so far?	4	4	5	5	4	5	5	5	
6 How well have you been able	3	4	4	4	5	4	5	4	
Personal Rating 1- 5		T 1= Time 1 T 2 = Time 2							
1	a very low level		not happy						
5	a very high level		very happy						

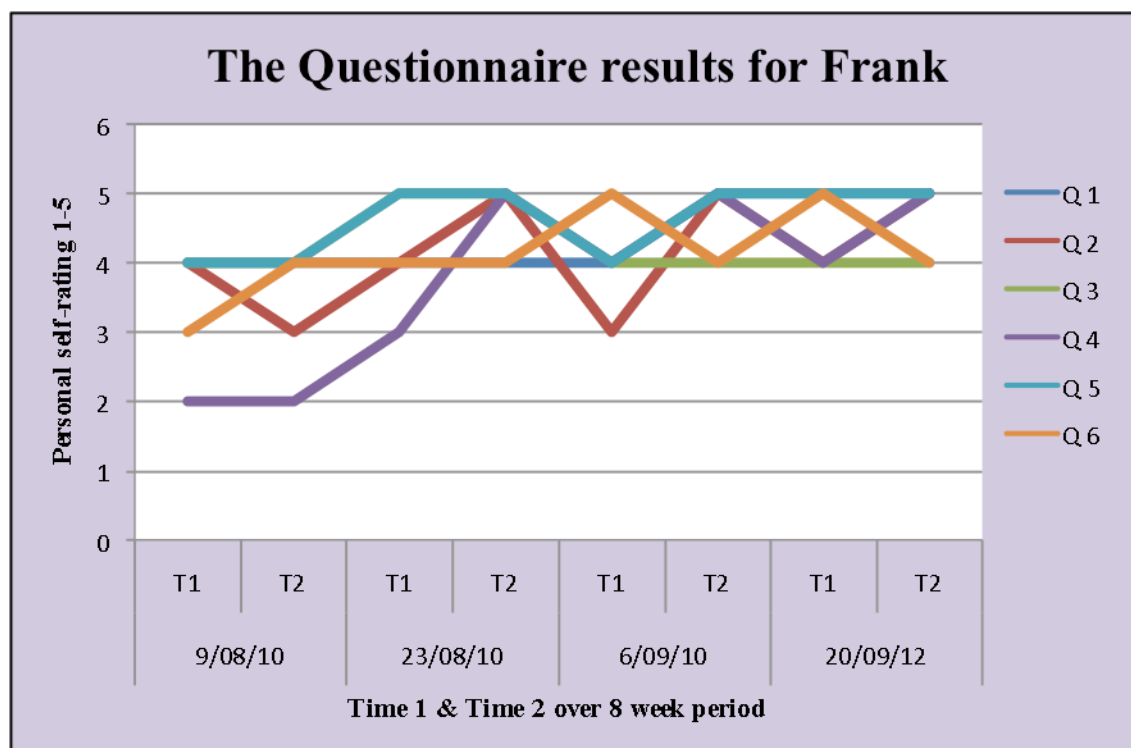
When analysing Frank's questionnaire results recorded over the eight-week research period, it was clear that there was little of no movement between the scores. For the majority of the time the scores did rise, but due to the first score being in the

upper limit it resulted in a small difference. The self-ratings are high and the variance is restricted so it can be said that these results have caused a ceiling effect²⁴.

Frank appeared to have understood the questions, given careful consideration to his answers and was aware of what QOL meant to him: When asked in session one, he replied: *“making choices”* (09/08/10 – line 80). Frank may have chosen high scores by coincidence, to please me or because that was exactly how he was feeling, therefore I can only interpret this as he is generally happy about his life. It was also hard to tell whether his answers specifically related to the music therapy sessions or whether other things had changed in his life that contributed to his positive outlook.

The only drop in score occurred in the first session documented on the 09/08/10 which may be explained by the clinical notes that reported Frank was suffering from a cold: *“...his general feeling had dropped and he said it was due to his cold and not feeling well”* (09/08/10 - line 82).

FIGURE 2: THE QUESTIONNAIRE RESULTS FOR FRANK



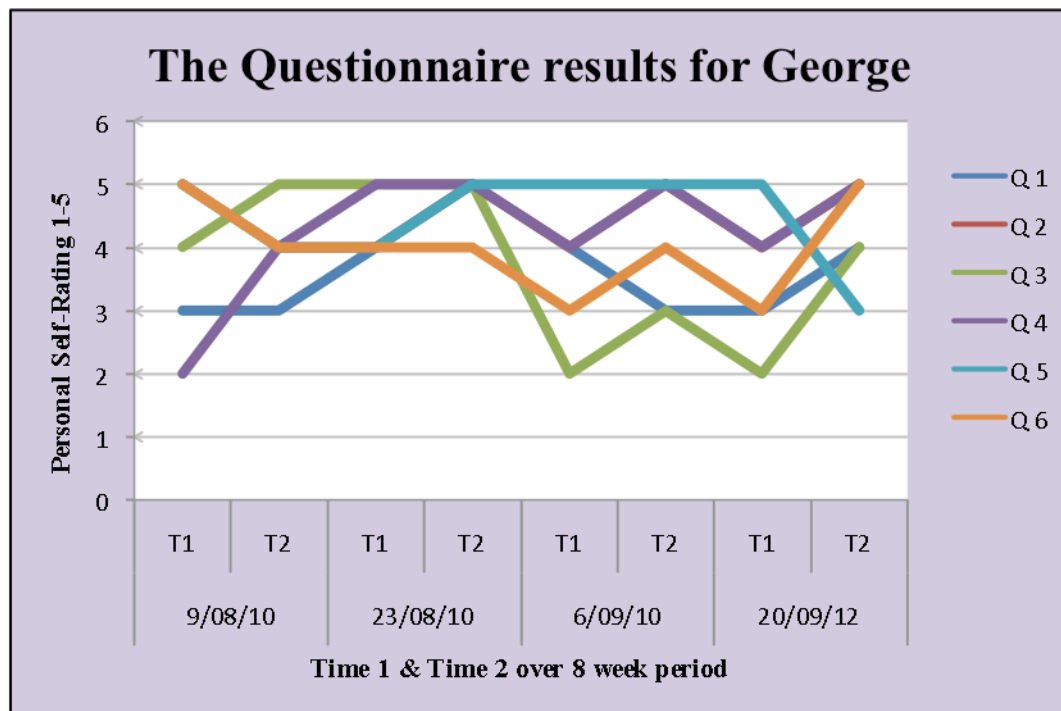
²⁴ Ceiling effect, refer to glossary for definition (appendix 1, p.80).

Table 3: Table of results from George's Questionnaire

		09/08/10		23/08/10		06/09/10		20/09/10	
Questions		T1	T2	T1	T2	T1	T2	T1	T2
1	How would you rate your quality of life?	3	3	4	5	4	3	3	4
2	What do you feel right now?	5	4	4	5	4	5	4	5
3	How relaxed do you feel?	4	5	5	5	2	3	2	4
4	How much energy do you have today?	2	4	5	5	4	5	4	5
5	How much have you enjoyed your day so far?	5	4	4	5	5	5	5	3
6	How well have you been able to concentrate today?	5	4	4	4	3	4	3	5
Personal Rating 1- 5		T 1= Time 1 T 2 = Time 2							
1	a very low level	not happy							
5	a very high level	very happy							

When analysing George's questionnaire results, it appears the same ceiling effect occurred as it did in Franks results but for different reasons. George did seem to have some understanding of what QOL meant, "...that I get looked after good" (25/08/10 - line 293) but at times I observed that he would "...quickly pick a number and sometimes jumped between two" (09/08/10 - line 25). Sometimes the number he picked did not reflect the way he presented in the session. For example: "When I asked George, 'How relaxed do you feel?' George responded with a self-rating of, 'lots...5', when externally he appeared to be really agitated and grumpy" (25/08/10 - line -298).

George's results appear jumbled and there is no overall increase. I did make note of how fast I read the questions the first time it was administered and this may have caused some comprehension difficulties. The graph below shows no overall progression and clearly displays the disorderly nature of the way in which George answered the questions.

FIGURE 3: THE QUESTIONNAIRE RESULTS FOR GEORGE

However I can conclude that both Frank and George were happy to participate in the questionnaire and the clinical notes state there was an increase in communication during this period in the session.

4) Staff Participant Interviews

The interviews with the two staff participants²⁵ focused on their own QOL beliefs, what they perceived as being important for the resident participants, thoughts about singing and music therapy and observations from the video extracts of the two resident participants. Ideas and responses were analysed and put into four main categories (displayed in table below). Sub-categories appeared under each category, depending on what findings emerged from the data.

Two individual interviews were conducted with Helen and Petra during the second week of the study and after the sessions were completed, four in total. All of the interviews were held during or after their daily shifts at the residential home. Although it was hoped that the interviews would provide plentiful data it was very difficult to gain full answers from the interviewees, as they were unable to give much time to the study due to their heavy work schedule and family commitments.

Table 4: Summary of the four main categories and sub-groups

Quality of Life	Singing and Music	Music therapy and singing for the residents	Specific ideas for Frank & George
<ul style="list-style-type: none"> • <i>Relationships give meaning</i> • <i>Independence</i> • <i>More than TV</i> 	<ul style="list-style-type: none"> • <i>Part of life</i> • <i>Music is for everybody</i> 	<ul style="list-style-type: none"> • <i>Enjoyable experience</i> • <i>Aids Relaxation</i> • <i>Enhance their quality of life</i> • <i>Involvement with other people</i> • <i>Supports independence and abilities</i> 	<ul style="list-style-type: none"> • <i>Increases participation</i> • <i>Aids communication & memory recall</i> • <i>Self-expression</i> • <i>Aids body movement and control</i> • <i>Reduces OCD, chorea & aids relaxation</i> • <i>Positive change in mood</i> • <i>Deterioration</i>

²⁵ Interview extracts can be viewed in appendix 15 and 16 (p.99-103) as an example of the data.

4.1 Findings from the interviews with Helen²⁶ and Petra

4.1.1 Quality of life

Relationships give meaning

Helen was very quick to respond that to her QOL meant to: “...*be happy, be valued*” to have: “...*respect for each other*” and: “...*to be able to communicate with people and to have a good outlook on life*” (1st: line 14-18)²⁷. She referred to the importance of respect and felt that for the residents to have a good QOL they needed to feel like they: “...*have got meaning in their lives and they are part of the community*” (1st: line 8).

Petra was very clear about what QOL meant to her: “...*the people in my life, how important they are to me.*” She mentions family and how much focus she gives that part of her life. Petra was a lot more philosophical in the second interview and suggested that the environment and the people around you were important for: “...*an all-round psychological, emotional, physical well-being.*” Therefore relationships with those around her seemed to be an integral part of what QOL meant to her.

Independence

Helen seemed to have a heightened awareness and understanding of what QOL meant to her in the second interview. Instead of focusing on general terms such as, the people in her life she focused more on the idea of having independence: “*Being able to do things without any restrictions, doing things individually...still ‘being able’ to make my own choices...*” (2nd: line 6). This implies that she may be aware of the residents’ inability to be independent and experience control in their daily lives.

²⁶ ‘Helen’ is a pseudonym for confidential reasons.

²⁷ References were used for Helen’s interviews to show credibility. 1st - First Interview (18/08/10) and 2nd - Second Interview (27/09/10).

Within Petra's thoughts about the meaning of QOL she referred to the importance of maintaining her independence by partaking in hobbies and activities: *"The things I'm able to do, get out and play my sports."* This suggests that she is conscious about remaining active and independent and not having to rely on anyone.

More than T.V.

Watching television is a common theme that occurred a lot in both interviews with Helen. Helen refers to Frank as: *"he's just sitting there watching T.V, he's not really interacting"* (2nd: line 73) and to George as: *"he is pretty quiet, he just sits there and watches T.V...he doesn't say a lot"* (1st: line 87). For Helen it seems as if the television is limiting. The word 'just' that accompanies each statement suggests that there might be more to life than T.V. and that other possible opportunities and a feeling of regret or sadness was being communicated. Her observations in the second interview outlined the difference in the residents mood when they are in music therapy and not watching television: *"Just watching them...their love for music is really out there it's really obvious... There's no joyful expressions on their face when they're watching T.V."* (2nd: line 83-88).

Petra is also aware that watching television is limiting the resident's ability to socialise, build relationships and share emotions compared to when the residents are in the music therapy room. The reoccurring theme of "just" and "watching T.V." also appeared in Petra's first interview. Petra notes that one of the resident's appears to be a lot happier in the music therapy room. She remarks: *"...out in the lounge room, he's just left to sit and watch T.V...he's not getting the chance to actually communicate or be able to share that happiness or to express himself"*.

4.1.2 Singing and music

Part of life

Helen recalled that singing and music was very much apart of her upbringing *"...singing has always been a big part of my life"* (2nd: line 19). She explained that her

family considered it to be “...*a pleasurable hobby for anybody to have*” (2nd: line 14) and insisted on her joining the local church choir. She also believes that singing helped her to express her emotions “...*it’s good to know that you can express yourself*” (2nd: line 21).

Petra commented that she also comes from a: “*family of people who always sing*”. She takes great pleasure in singing and music and comments that: “*I sing all the time, its good therapy for me*”. The words ‘good therapy’ suggests she finds singing a good way to relax.

Music is for everybody

In the second interview, Petra commented that music is for everybody and believes that: “...*music is something that we’re born with, doesn’t matter if you don’t come from a musical family...it’s there...it’s all around us...we hear it and we all have special memories, special songs...*” Since the first interview Petra seemed to reflect on how much singing and music meant to her. She comments that singing is something that happens naturally for her in her day-to-day life but especially when she’s happy: “...*we sing when we’re happy, we sing in the shower...music around us just makes us feel good.*”

4.1.3 Music therapy and singing for the residents

Enjoyable experience

Helen supports the idea of singing and music therapy at the facility. “*I think it’s wonderful, because you can see that the people really do enjoy it*” (1st: line 48). In the first and second interview Helen commented on how music therapy is such an enjoyable experience for both Frank and George. In Frank’s video extract she observed that he gets a lot of enjoyment out of going to the music therapy sessions: “*Frank’s obvious enjoyment...you can see that Frank’s really giving it his all and that’s wonderful for Frank to be more active...*” (1st: line 119). This implies that Frank does not often participate in daily activities and that singing is more of a stimulating activity

for him. Helen also observed the same for George. She noted his: “...*eagerness to take part and the enjoyment he was getting out of it...*” (1st: line 84).

Aids relaxation

Helen observed that the residents appeared calmer in music therapy and made reference to words associated with relaxation such as, ‘calm’, ‘soothing’, ‘relaxed’ and ‘therapeutic’ throughout the first interview. Helen is very observant of the residents and knows them well enough to determine whether singing in music therapy can aid in their ability to relax.

Petra also made comments about relaxation during the first interview referring to the residents: “*I’ve never seen both of them so relaxed in a music session.*”

Enhance their quality of life

After observing the residents in the sessions and having some more understanding of what music therapy is and the specific goals, Helen seemed convinced about how singing and music therapy might enhance their QOL:

“I think it can because there are a lot of things, physical things that they can’t do. Whereas with music they are able to...get into the rhythm, listen to the beat and sing...it’s good to see that they are enjoying something that they can do and they can make choices and that they are individuals and that they can express themselves” (2nd: line 98-109).

In the second interview Petra had reflected on what she observed in the music therapy sessions and concluded: “*I think it enhances their life and you make them feel better.*” Petra went onto say: “*Huntington’s or not, [music is] bringing life to maybe a sad day.*”

Involvement with other people

Petra believes that singing in music therapy is really important for the residents involvement with others because they are able to: “*sing with people and be involved with other people*” and it: “*makes them feel good about themselves, good about others.*” This implies that singing is a good way to get involved within the community. It is something that is accessible for them, non-restricting and non-judgmental, a ‘feel good’ activity.

Supports independence and abilities

Petra made comments about how singing in music therapy encouraged the residents to try things independently with support on hand if needed. She observed that the residents were: “*...being made to feel that they can do it...*” She went on to say: “*...I think a lot of that gets lacked, because we do it for them. So this was saying, you can do this, give this a go, would you like to try it and they were doing it...it was like wow!*”

One reoccurring theme throughout the interview were the words ‘be able’: “*To be able to use instruments, so they’re able to control and learn the control*” and: “*To be able to be happy*” and “*...being able to sing*”.

4.1.4 Specific ideas for Frank and George*Increases participation*

Helen enjoyed watching Frank and George on the video extracts and made reference to the fact that they both seem to be much more interactive and communicatively involved in the music therapy sessions than in other daily activities. Helen commented that: “*Franks a pretty quiet fellow, not doing any activity... so to see Frank participating like that, it’s good because he’s not just getting involved in the musical path but he’s interacting and talking as well and I think that’s wonderful*” (1st: line 130 – 133). Helen also made reference to George saying he: “*...is pretty quiet...he*

doesn't say a lot...he seems more active when he's participating in the music room" (1st: line 87).

In the second interview Helen observed that there had been an increase in participation: *"...they are getting more involved now and more confident in what they do and participating"* (2nd: line 38). Helen observed that their confidence and motivation to join in was sustained over time: *"At the beginning they weren't [always involved] ...now when you come...you can see just by watching them that they're always happy to participate in music therapy"* (2nd: line 42-45).

Petra observed the positive interaction between George and I and noticed that this caused an increase in his participation. She commented: *"...he was picking up on what you did, so if you banged it hard he was trying to imitate it...which I thought was pretty cool."* Petra observed that George is still very much aware of how to play the drums, how to listen, and when to respond.

By the end of the research Petra was able to highlight the positive outcomes from the music therapy sessions and mentioned the positive relationship that had formed between Frank and I. Observing Frank in the second interview, Petra commented that: *"I think there's more of an input...he loved it anyway, he loves you and he loves being involved and he loves music, so you've got some awesome things happening."*

Aids communication and memory recall

In the first interview Petra seemed to be surprised about George's ability to recall lyrics when singing the songs in the session: *"I didn't realise he knew so many words...He was really communicating through the music."* This suggests that in general conversation George does not use a lot of words. She believes singing to be beneficial for maintaining communicative skills and memory recall in Georges case: *"... you having music [with George] is making him use his vocal chords, making him think, making him aware of music and he is enjoying it, so either way it's going to be a plus."*

In the second interview Petra mentioned how Frank was able to communicate a lot of feelings through a small amount of words. She stated that she knew Frank well enough to know that: *“he’s a typical male”* and he does not choose to say a lot but what he does say is: *“what he needs to say”*. She commented about three words Frank used in one of the video extracts and explained what the three words meant to her:

“His words...energy, memory, happiness...those three words will always stick with me...those were three words that he wasn’t prompted. Those were three feelings and what huge, huge feelings. So that’s the difference that music is making...”

Self-expression

Petra commented emotionally on the art of songwriting and how useful it was for Frank to be able to express himself: *“...the song that he made for [Mary] that just about had me in tears that’s just beautiful, that’s another form of communicating, expressing and being able too.”* This suggests that she understands how important it was for Frank to have had the opportunity and encouragement to express his emotions through his own personal song.

In the second interview Petra watched Frank perform his song for the camera and went into more detail about Frank’s ability to express himself through his song: *“...you could see it in his eyes he was thinking about every word, the love he has, the journey that he’s taken...it’s just amazing.”* Petra observed that Frank was able to comprehend the words he was singing enough to physically display the appropriate emotions during the song. This shows he was able to make links between his cognitive and emotive abilities, between the words and emotions.

Aids body movement and control

Helen observed that music therapy is able to motivate the residents to move, even if it is only slightly. Helen observed *“...little movements...sometimes they are just tapping their feet on the floor”* (1st: line 63).

Petra was aware that George was a drummer before he was diagnosed with HD, but was unaware of his ability to still play them with a degree of control: *“Wow, he’s got quite a*

bit of rhythm”. This suggests that before I started sessions George may not have wanted to or been given the opportunity to play and interact with someone on the drums. Since he has been encouraged to play the drums in the session he has been able to show his underlying drumming ability and sense of rhythm.

During the second interview she was impressed by Franks control over his facial muscles. She commented: “...*he [Frank] is controlling and understanding his movements because he’s smiling the whole way through...*” As an HD caregiver Petra has some understanding of how difficult it can be for people with HD to control their movements so that they are able to focus on a physical action such as smiling.

Reduces OCD, chorea and aids relaxation

Helen made reference to George’s OCD behaviors and how he seems less anxious and repetitive after his music therapy sessions. She commented that: “...*he’s a lot more settled because he is not always up and down asking for a drink or anything, straight away after the sessions he is fairly mellowed out...*” (1st: line 112-114).

After watching the video extracts of Frank in the first interview Petra commented on the decrease of his chorea in music therapy. Petra commented that: “...*his movements...they were definitely calmer, that’s the first thing that struck me.*” This implies that the singing and creative play in music therapy helped Frank control his chorea and increase his relaxation. In the second interview she observed that both George and Frank were more relaxed during the session, which suggests that there was an increase in relaxation.

Positive change in mood

In both of the interviews, Petra noticed that music and singing evoked a positive change in mood in Frank. She commented: “...*he’s definitely happy because he is singing away.*” She was fascinated by his smile, something that she may not have seen enough during her time at the residential home. She commented emotionally: “*Oh his smile...oh (emotional sigh)...it didn’t stop the whole way through.*” This

implies that Frank enjoys singing and the well-known songs evoke happiness within, and a chance for him to reflect on memories that may arise. It also highlights the warm encouraging atmosphere within the music therapy room that enabled Frank to feel comfortable enough to sing and smile throughout the song.

Deterioration

After viewing the video extracts of George in the second interview Helen observed his overall deterioration and commented that: *“He seemed...not really like he used to be”* (2nd: line 54). She observed George’s alertness within the session appeared to be very inconsistent: *“...some of it he was right up there and alert and other parts of it he wasn’t.”* She noticed that there was no eye contact and he: *“...wasn’t up straight and alert”* (2nd: line 54-61).

This may have been the first time that Helen was able to observe George participating in an activity since he experienced his TIA²⁸. This footage showed him slumped to one side and imbalanced which was very different to how he appeared in the previous video where he was more upright. Her comment brought out some sadness and reiterated the fact that HD is a progressive neurological condition and the residents are deteriorating everyday.

Petra observed George’s deterioration in the second interview and commented that: *“Compared to last time he has definitely deteriorated. The information is definitely not going in as fast. He is only using one side. It was sad...I know that George has had two brain bleeds, so that won’t be helping.”*

Petra seemed interested by the fact that despite his weakened physical state and reduction in communication George was still motivated enough by the singing and music to participate during the session: *“He’s trying, he’s wanting to be involved...and the music is still making a difference and even if it makes a slight difference then that*

²⁸ A transient ischemic attack (TIA) is an episode in which a person has stroke-like symptoms for up to 1-2 hours.

is a plus...music is still communicating isn't it?" This suggests that regardless of his reduced state, Petra believes that music is stimulating enough to engage George and give him an expressive and physical outlet.

The comments from both of the interviewees suggest that it was physical deterioration rather than boredom, which reduced George's participation during the last few sessions.

Summary of similar themes found within the clinical notes, staff interviews and the questionnaire.

Table 5: Common themes found in the data

(F and G = Frank and George. Y = Yes)

Themes in the data	MTS Clinical notes		The Questionnaire		Staff interviews	
	F	G	F	G	F	G
(Frank and George)						
Life beyond HD/enhancing QOL	Y	Y			Y	Y
Increased participation	Y	Y	Y	Y	Y	Y
Increased communication	Y	Y	Y	Y	Y	Y
Supported choice and control/Independence	Y	Y			Y	Y
Relationships give meaning	Y	Y			Y	Y
Positive change in mood	Y	Y			Y	Y
Increased confidence	Y	Y			Y	Y
Enjoyable experience	Y	Y			Y	Y
More than TV	Y	Y			Y	Y
Increased energy levels	Y					
Self- Expression	Y	Y			Y	Y
Reduced anxiety/OCD		Y				Y
Aids relaxation		Y			Y	Y
Reduces Chorea					Y	
Supported cognitive ability / Emotional understanding	Y	Y			Y	
Stimulation through singing	Y				Y	Y
Stimulation through instruments		Y				Y
Memory recall	Y	Y			Y	Y
Increased alertness/ awareness	Y				Y	Y
Supported coordination and body control	Y	Y			Y	Y
Deterioration	Y	Y				Y

5) Triangulation of Findings

The triangulated findings cover a number of themes that arose in at least two of the data sources, and sometimes all three. They include some areas that confirm hunches I had about the value of singing and also surprises and interesting connections. The triangulated findings are divided into two sections; 1) To what areas of quality of life did the participants observe the process of singing making a contribution? And 2) Other connections that arose from the findings.

5.1 To what areas of quality of life did the participants observe the process of singing making a contribution?

In this section I discuss the central themes that were shared strongly across the clinical notes and the staff interviews interlinked with the residents 'voice' by including findings from the questionnaire. The data can be categorised into three main areas.

The process of singing provided: 1) a stimulus for socialisation; 2) emotional and psychological support; and, 3) support for remaining cognitive and physical ability.

5.1.1 A stimulus for socialisation

Participation

Participation and staying active is an important part of maintaining QOL. The findings from this study suggest that it was not only the process of singing that motivated the residents' to participate in the sessions. It was also the music itself, the instruments and the one on one interaction from the therapist.

It was very clear from the analysis that George and Frank were affected by the singing in two contrasting ways. George was more stimulated by the drums than his own singing, so it was the process of my singing that motivated him to participate.

Whereas for Frank it was the enjoyment he gained from the process of his own singing and my reaction to it that stimulated his participation.

The findings from the clinical notes and the staff interviews also suggest that both Frank and George needed the presence of a well-known song, preferably of their own choice, to be stimulated enough to participate.

Relationship between the therapist and residents

The findings suggest that the positive interaction between the resident participants and myself helped to increase levels of participation. In the clinical notes I observed how both Frank and George seemed to be more relaxed and motivated by the music as our relationship grew. Petra also made reference to the positive relationship between Frank and I and noticed an increase in participation: *“I think there’s more of an input...he loves you and he loves being involved”*.

To ‘be able’(independence)

To ‘be able’ and ‘being able to’ was referred to a lot over the clinical notes and the interviews. Petra observed that although there are a lot of physical activities they cannot participate in ‘*being able to sing*’ was something that they could do. She believed that singing was an activity that the residents could participate in and thus helped to retain some feelings of independence. Helen valued the idea of *“still ‘being able’ to make my own choices...”* (2nd: line 6).

The clinical notes indicated that by giving the residents opportunities, it ‘enabled’ them to choose songs, instruments, remember past memories through song and therefore experience an increase in energy levels, enjoyment and participation. The questionnaire also gave the resident participants the opportunity to give their own ‘voice’ to the study. It also displayed their remaining capability of ‘being able to’ choose a rating that reflected their mood at the time, thus giving the residents independence.

Communication

Using singing to communicate was an important aspect within the music therapy sessions as it not only allowed me to observe and learn from the residents verbal and non-verbal responses but it also provided a vehicle to enable positive social interaction.

The findings suggest that both the resident participants became more conversational as the sessions progressed. This allowed me to ask them more in-depth questions about their feelings surrounding their disease, and to prompt them to participate in songwriting. The interviews discuss a noticeable increase in communication from being in the lounge room to being in the music therapy room. Petra commented about George, *“I didn’t realise he knew so many words...he was really communicating through the music”*. Petra noted that special interaction between Frank and I allowed Frank to increase his communicative skills and Helen made reference to QOL stating that, *“to be able to communicate with people and to have a good outlook on life”*.

The clinical findings suggest that Frank may have been communicating his feelings through a song with lyrics that reflect his own current emotions. Almost every session Frank would ask for ‘Let it be’. His wife referred to Frank’s thoughts as, *‘what will be, will be’* and mentioned the emotional relief and courage she gains from these words knowing that Frank has learnt to accept his condition.

5.1.2 Emotional/psychological support

Life beyond HD

During the research the staff and residents were asked what QOL meant to them. On reflection it is a difficult question for anybody to answer, as it is not something you would encounter that often and it requires some personal thought. Helen and Petra considered ideas such as independence, participation, and maintaining relationships with friends and family to be important for QOL. The questionnaire results also indicated that both Frank and George might have had some idea of what QOL meant to them. Like the staff participants, Frank also shared a common view of independence and commented

that “*making choices*”, was essential for his QOL and George commented that ‘*I get looked after good*’.

Positive change in mood - Enjoyable experience

Participation, communication and a positive change in mood were strongly evident across the interviews and clinical notes. Findings from the clinical notes suggest due to an enjoyable experience there was a noticeable change in mood as soon as the singing started within the session. George’s agitation and irritability decreased and Frank immediately became engaged and showed signs of enjoyment through facial expressiveness. Observations in the clinical notes identified that the expression on their faces was considerably different to when they were in the lounge room. Frank commented in session fourteen: “*I feel good...always leave the room feeling good*”. Findings from the interviews also suggest a positive change in mood due to singing. Petra observed Frank’s change in mood commenting that, “*he’s definitely happy because he is singing away*”.

A positive change in mood led to an increase in energy levels due to the enjoyment the residents were getting out of the sessions. Clinical notes reported spirits being ‘lifted’ and Frank leaving the session with “*much more energy in his step*”.

Self- expression and emotional understanding

It was noticeable in this research that the singing in the music therapy session provided a medium for self-expression both vocally and through instrumental play. The clinical findings indicate that the use of a ‘call and response’ improvisation supported Frank and led to “*more spontaneous singing within the session*”. Whereas George became more expressive with his percussive play when I added vocal improvisation to well-known songs. The staff participants also believed that singing was a good way to express yourself. Petra especially finds singing to be a ‘good therapy’, a good way to relax and experience an emotional release.

Songwriting proved to be a good way to encourage emotional expression. The findings suggest that Frank in particular found this musical activity to be rewarding and useful in expressing feelings that he may never have been able to say in a conversation. Through his original song, Frank was 'able to' sing the words he wanted to say to his wife. The clinical findings indicated the poignant effect this had on Frank's wife and the emotional understanding they shared between each other. I reported that, "...*there is so much joy and excitement in Frank's eyes when he is singing it...this song means so much to him*". It was evident Frank took pride in his songwriting. Petra also commented emotionally on the art of songwriting and how useful it was for Frank to express himself. She noted that he was able to comprehend the lyrics he was singing and reflect on memories. She commented that, "...*you could see it in his eyes he was thinking about every word, the love he has, the journey that he's taken*".

Reduced anxiety and aids relaxation

The clinical findings and Helen suggest George displayed a decrease in anxiety after he left the music therapy sessions. Helen also commented that his OCD behaviours decreased. This may also be due to the positive change in mood discussed above and the observed increase in relaxation.

Helen and Petra indicated that both George and Frank seemed to be more relaxed and 'calmer' in the music therapy session and Petra observed a reduction in Frank's chorea while he was singing. However although some relaxation was observed in the clinical notes, there was no indication that there was a decrease in Frank's chorea, rather an increase was noticeable while he was singing.

5.1.3 Support in remaining cognitive and physical ability

Increased alertness – awareness of surroundings

Helen findings suggested that Frank was “*more alert, more aware*” in the music therapy sessions. The clinical notes also mention the use of singing songs relating to topics in the present, to orientate Frank’s sense of surroundings.

Memory recall

The clinical notes and Petra’s interview findings suggest that singing facilitated speech within the sessions with George (for example, ‘Achey Breaky Heart’). The clinical notes and Petra observed that with some prompting Frank and George were able to recall lyrics of well-known songs. The clinical findings also suggest that Frank was able to recall the lyrics of his new song.

Singing reminiscence songs helped to evoke emotional memories which was highlighted in clinical findings when Frank referred to the reason why he liked singing, “*...it helps me to remember memories*”.

Processing physical coordination

The clinical notes indicated that my singing supported George’s sense of timing and remaining rhythmic ability. The findings also suggested that the addition of his own singing also supported his coordination. Petra was surprised by the fact that George still had “*quite a bit of rhythm*” and noted how Frank was able to coordinate a number of musical tasks at the same time, something she recalls as very difficult when executing other tasks.

Deterioration

All three data sources observe cognitive and physical deterioration in George over the research period. The clinical findings and interview findings suggested that George appeared to be more slumped, displayed limited eye contact, and slurred speech, and was unable to put as much energy into verbal communication. The questionnaire findings displayed George's declining cognitive ability when choosing a rating that reflected how he felt. However the findings did suggest that despite his deterioration he was still engaged and wanted to participate.

5.2 Other connections that arose from the triangulated findings

5.2.1 Music therapy vs Television

The theme of 'more to life than T.V.' was something that occurred quite frequently throughout the staff interviews and the clinical notes. It was generally referred to as the activity the residents did on a daily basis for long periods of time. It is quite an interesting issue as many people without chronic diseases also choose to watch television for hours on end as it is an accessible activity that does not highlight difficulties or distress and can be engaging and stimulating. However, I personally felt that the television was too much of a focal point at the facility, and it did not necessarily encourage interaction. In the findings the staff participants suggest that there may be more to life than T.V. and Petra commented that by watching television "...*he's not getting the chance to actually communicate or be able to share that happiness or to express himself*". Helen outlined the difference in the resident's mood when they are in music therapy and not watching television: "*Just watching them...their love for music is really out there it's really obvious... There's no joyful expressions on their face when they're watching T.V.*" (2nd: line 83-88).

5.2.2 Persuading the residents to come into the session

Psychological and cognitive symptoms associated with HD made it difficult to persuade George to come into the music therapy room. He needed time to remember

who I was and adjust to the idea of doing something different, other than watching television or asking for a coffee. At first a caregiver helped me to persuade him. This developed into conversations about singing and drumming to help him remember his last session and to motivate him to come into the music therapy room. However, at times I felt ethically challenged. Before the session he was very stubborn and definitely made it clear to me that he did not want to participate, so was I imposing the music therapy session on him? The findings indicated that overtime, once our relationship was established it took less time to persuade George to join me. The interview findings also suggested George experienced a positive change in mood, an enjoyable experience and a reduction in anxiety. Therefore I can only assume that it was his psychological symptoms such as anxiety, dislike of routine change, and a lack of motivation that initially stopped him from participating in an activity that he actually enjoyed and gained some satisfaction from.

5.2.3 Breathing difficulties

The clinical findings and Petra indicated that Frank experienced some breathing difficulties while he was singing in the sessions. Due to the deterioration caused by HD increased voice production was not expected. However, with the adaption of the accompaniment and my increased awareness of supporting him at his level, I was able to assist him in the maintenance of his remaining vocal ability and overall sense of physical health. Petra also commented that she believed that singing may strengthen their vocal cords and therefore assist in maintaining their ability to swallow.

5.2.4 Caregiver burden

Another subject that arose from the data was related to caregiver burden and responsibility to “*keep them active...keep them happy*”. Staff workload, scant resources, and the fact that it is very hard to coordinate and create stimulating activities for residents with HD, can all create a burden for caregivers who may be underpaid and inexperienced in the field of recreational activities. This in turn may create stress and an unhappy work environment that can then impact on overall quality care for the

residents. In this study, music therapy was seen as a welcomed relief for the staff participants because it was something that ‘...*occupied*’ the residents and didn’t leave them to just sit ‘*around doing nothing*’. Therefore giving the caregivers time to continue their work and not feel the ‘responsibility’ to entertain the residents. The clinical notes also observed caregiver burden by the mere fact they were unable to give enough time to the interviews. However the staff participants did realise the importance of music therapy as Helen mentioned in her interview: “*I want to see it as ongoing because I think it is very beneficial for them...we appreciate your visits very much.*”

CHAPTER FIVE

DISCUSSION

This study has focused on some particular issues in neurological care: the process of singing, music therapy, quality of life and Huntington's Disease. This was expressed in the research question:

Can the process of singing in music therapy sessions enhance the quality of life of clients with Huntington's Disease?

In this discussion chapter I will concentrate on five areas: firstly, connections to the literature; secondly, methodological considerations in this research; thirdly, limitations of the study; fourthly, implications for future music therapy practice; and finally, recommendations for future research.

1) Connections to the literature

In discussing the synthesis of findings I have also drawn in connections that are observed within the music therapy literature, as outlined in chapter two to provide an integration of thinking.

1.1 Importance of participation and 'being able to'

The health viewpoint '*...ability to pursue daily activities*' (McGraw-Hill Concise Dictionary of Modern Medicine, 2002) reflects similar perspectives, which relate to the staff participants' thoughts about participation. '*Being able to*' was a reoccurring theme throughout this study. All of the findings highlighted the importance of independence and participation, "*Being able to do things without any restrictions, doing things individually....still 'being able' to make my own choices...*" (2nd: line 6). Music therapy can provide opportunities for independence through decision making (Jones *et al.*, 1992). The WHO definition of palliative care also indicates the importance of participation, stating that '*a support system to help patients live as actively as possible*' is vital to improve QOL (World Health Organization, 2011). Other literature also suggests that it is

important for HD patients ‘*to have the opportunity to participate in meaningful music activities*’ (Rainey Perry, 1983. p.9).

The clinical notes and the interviews provided rich data suggesting that there was a positive change in mood when participating in music therapy compared to when the residents were not in the sessions. Sacks (2007) experienced a similar phenomenon with a patient that spent most of his day lifeless and flat, “*...but all this would change...when Harry sang*” (p.303).

Participation in music therapy also provides a vehicle to enable positive social interaction (Bailey & Davidson, 2002), and the increase in positive emotions drives participants to participate (Nayak, 2000). Positive interaction can also help to develop a meaningful communicative relationship and motivate participation (Aldridge 1996, cited in Davis & Magee, 2001). This was indicated in the findings as the relationship grew between the therapist and the residents this motivated both George and Frank to communicate and an increase in participation was observed.

As outlined in the clinical notes it was very difficult to determine George’s mood and persuade him to come into the music therapy room. Davis (2001) referred to the unpredictable nature of HD and concluded that despite some inconsistency, “*the patients participation in a musical and expressive experience, unquestionably contributed to [their] overall quality of life*” (p.59).

1.2 Singing vs. instruments

It was very evident in the findings that Frank was more stimulated by the singing rather than the instruments in the session. He had the opportunity to explore and play different instruments but as the clinical findings suggest the MTS: “*...felt a strong sense of discomfort enter the room and he would stop playing...*”. This suggests that due to his awareness of his extreme Chorea and the concentration involved in controlling his body, he much preferred to sing. These findings were coherent with the research by Mellhuish (1996) and Hoskyns (1982). Mellhuish (1996) found that elderly clients were difficult to engage in clinical improvisations using instruments because it often caused anxiety and resistance and Hoskyns (1982) observed that instrumental play and singing increased chorea.

George on the other hand seemed to prefer to play the percussive instruments, especially the drums, rather than to sing. Findings showed the MTS did the majority of the singing in the session, becoming the voice for him and he supported the MTS voice by playing the drums. He did sing along in parts that he remembered but he was mainly focused on providing the beat and other percussive elements. This may be due to his past experience as a drummer, always playing the supportive role to the singer. Findings suggest that by enabling him to have some control and responsibility as the drummer it may have aided his motivation to participate and allowed him to relax and enjoy the session. Also by providing musical terms and a song structure it aided his remaining cognitive ability and he was able to follow instructions, calculate movements as well as add some creative flair to his playing. Therefore, for George the music therapy sessions may have resembled something more like a band rehearsal from his early years.

1.3 Watching television

Literature associated with watching television seemed to address issues such as: child obesity (Hancox & Poulton, 2006) and increased risk of heart disease and diabetes (Hu *et al.*, 2003). However another study raises a valid point about watching television within a residential home. The study involved older people in geriatric care and findings suggested that watching television helped to structure daily life, satisfy the residents need for reflection, remain socially integrated, contribute to their capacity to cope, and was a way to promote communication and well-being (Ostlund, 2010). Relating these findings back to this current study HD is a challenging condition to manage and from experience with the HD residents, other than group music therapy, it was hard to find activities that they could all participate in and gain some positive experience. Therefore watching television could be considered beneficial for this client base.

1.4 Caregiver burden

The staff at this facility appeared to be stressed and overworked and during the interview Helen mentioned her feelings of responsibility to ‘keep them’ happy and occupied. McCabe (2009) study reported that caregivers working with HD had the lowest mood and QOL compared to other neurological illnesses. She suggested that interventional programs needed to be developed to help caregivers adjust and cope with HD.

1.5 Singing supporting coordination and increased alertness

Singing can assist in coordinating and supporting movement (Rainey Perry, 1983). The clinical notes indicated that the MTS singing supported George’s sense of timing and remaining rhythmic ability. The findings also suggested that the addition of his own singing also supported his coordination. George’s ability to navigate himself a range of instruments using both sides of his body supports the literature that states that music may assist in the rehabilitation of maintaining physical function (Prinsley, 1986; Groom *et al.*, 1985).

Singing and music therapy can be used as an effective tool to improve alertness (Clair, 2005; Bannan, 2008). Helen findings suggested that Frank was “*more alert, more aware*” in the music therapy sessions. The clinical notes also mention the use of singing songs relating to topics in the present to orientate Frank’s sense of surroundings.

1.6 Singing in music therapy supporting communication and memory recall

Singing and music making may offer an alternative means to the growing isolation caused by the breakdown of communication associated with HD (Davis *et al.*, 2001). Sacks (2007), suggests that “*the inability to communicate verbally may be almost unbearably frustrating and isolating...much of this can change with the discovery that such patients can sing...*” (p.215-16). The findings in this study very much support the literature available outlining the importance of the residences ‘voice being heard’ and the chance to develop a meaningful relationship using singing and music making.

The literature states that singing can be used to facilitate speech (Erdonmez, 1976) and increase conversational fluency (Pollack *et al.*, 1992). The literature also suggests that patients with AD are able to recall well-known songs better than new songs (Prickett *et al.*, 1991). This finding is present in this study as Frank and George were both more confident singing well-known songs. Erdonmez (1976) suggested that: “*singing popular songs of the patient’s choice was the most productive in terms of response*” (p.62). The incentive of singing a well-known song can also preserve vocal abilities (Magee, 1995).

The findings in this study also suggest that singing evokes memories (Aldridge, 1995 cited in Rickson, 1998).

1.7 Reduction in anxiety and OCD

Singing in music therapy can aid in the reduction of anxiety (Nayak, 2000; Hoskyns, 1982; Olderog-Millard *et al.*, 1989; Nakayama *et al.*, 2009). As literature suggests evidence of this may be found in early childhood and the effect singing lullabies has on the alleviation of babies’ symptoms, involving stress and anxiety (Kohut *et al.*, 1990). Both the clinical notes and the interview findings suggested that George displayed a reduction in anxiety after the music therapy sessions and there was a decrease in OCD behaviours (Pollack *et al.*, 1992).

1.8 Emotional expression

Singing in music therapy can provide a medium for self-expression (Rainey Perry, 1983). This finding was very present in the current research. Both Frank and George were able to express themselves either by singing or with instrumental play supported by my singing. During the sessions Frank was also able to emotionally express himself by singing his own words by through the facilitation of songwriting. Silber (*et al.*, 1995) commented that, “*For patients who are emotionally withdrawn, songwriting provides the opportunity to express deep and repressed emotional feelings*” (p.33). As well as being able to express himself through his own song, Frank

displayed immense pride in his songwriting (Grocke, 2009) and was very excited and anxious to record the song for his wife and daughters.

1.9 Deterioration

Although both Frank and George displayed signs of deterioration they were still interested in participating in the music therapy sessions. This also reflects the literature regarding the deterioration in neurological conditions stating that there was continued interest in singing and musical activities despite dramatic decline (Clair *et al.*, 1990; Magee, 1995).

1.10 Summary of the connections to the literature

As well as feelings of improved well-being due to singing (Beck *et al.*, 2000; Southcott *et al.*, 2010; Nayak, 2000), the greatest contribution music can make to the treatment of HD is to enrich daily life (Erdonmez, 1976). The findings from this study suggest that process of music therapy enabled the residents to have the opportunity to participate and engage in an activity that they are 'able to' do, something which causes them no distress or discomfort, instead allows them to express themselves, have more choice and control and enhance their mood. This all effectively gives them more meaning to their life (Chong, 2010), adds more enjoyment to their day, a reason to carry on and ultimately might even prolong life (Konlaan, 2000).

2) Methodological considerations in this research

Collecting data from different sources helped to create an overall picture of the current research. However triangulating different perspectives, although worthwhile proved to be very challenging. The interviews and the clinical notes appeared to be more relevant to the question than the questionnaire. This has propelled me to rethink whether it was even necessary to add in this third data source. Also although the questionnaire appeared to be useful for gaining Frank's perspective, due to George's cognitive decline

the results appeared to be inconsistent and in effect unreliable. However this did give me some insight into the level at which he was functioning cognitively. In hindsight it may have been more reliable to use the full official SF-36 QOL questionnaire to give more credibility to the study, however due to the resident participants level of cognitive function I made a decision with my supervisor at the start of the study to design a shorter version that would allow for the residents lack of concentration and ability to process information. Another design for the questionnaire could have involved happy and sad faces, which may have enabled the residents to visually comprehend the questions with more ease. However, despite some flaws, the questionnaire did add the residents' voice to the study, which adds value to this research. I would feel uncomfortable judging people's QOL without consulting them. With some insightful adjustments to the questionnaire it could potentially add richer information for future studies.

The interviews were intended to create meaningful data and add another perspective to the study. As the interviewer I was rather inexperienced and though I was intending to be open, sometimes I asked leading questions, which in retrospect created rather closed replies rather than full independent answers. Perhaps more open-ness would have allowed richer data. The semi-structured interviews were not planned to be a specific length however due to the caregivers concise answers and the fact they were on duty at the time meant that the interviews tended to only last between 15-20 minutes. Therefore you could argue this was not enough time to gather 'meaningful' data however given the chance to interview the caregiver participants outside of work, the same result may have occurred.

Although short, the interviews did reveal how insightful staff members can be, and how well they know the client base and the residents individually. At times the interviews elicited differing themes to the clinical notes. For example the staff participants' felt strongly about how the singing in music therapy sessions aided the residents' relaxation. They also observed a decrease in chorea, which was not captured in the clinical notes. This could be due to the fact that it can be challenging for clinicians to observe and measure some of the benefits a person may experience. Therefore observations from staff members can play a major part in informing professionals of insightful perspectives on their work.

As the researcher it took a long time to understand what I meant by the process of singing. At times I found it hard to interpret my own proposed question, as singing with people diagnosed with HD was not necessarily about the act of singing itself. Rather, the data exposed themes that related more to the ‘process which enabled them to sing’, i.e. persuading the residents to come into the room, building a strong relationship with the participants’, using my voice, using instruments (or not) and providing songs (or writing songs) which meant something to them.

3) Limitations of the study

This study had a very small number of participants. More may have created richer data and a greater overview of the participant’s reactions in the clinical sessions and answers in the questionnaire. Therefore it does not represent the views and experiences of the overall population of this group of residents or staff members group. It was also the first time the adapted questionnaire had been used in a study, which implies care should be taken in the use of the findings. Another limitation of this study was the fact that I as researcher had multiple roles. I was at different times the music therapy student on placement, the interviewer, and the researcher analysing, collating and writing up the data. Although having a range of roles allowed me to develop trust and helpful relationships in the setting, I am aware that my perspective has the potential to strongly influence the viewpoint of the study. I have however done my best to remain very objective and have analysed the data with careful consideration to all views.

There were some other issues that may have affected the findings and the outcome of the study. These were:

- The researcher shared a bond with the participants before the research started. Therefore in hindsight it may have been better for the questionnaire to have been filled out by another member of staff. However due to staff workload and the questionnaire itself this was not possible.
- There was not a sufficient recreational programme at the facility to compare the music therapy programme against.

- During the research some sessions were unable to commence due to sickness, unforeseen appointments, and how the clients were feeling and their willingness to be involved on that particular day.
- No one was observing the music therapy sessions so this study relies on the precision and care taken by the MTS and interviewer in gathering the data. However video data shared with staff at interviews provided some balance and witness here for the process.

Despite the limitations this study highlights the importance of QOL and singing with this client base. The data was collected from several sources, which provided multiple perspectives and interesting outcomes. Member checking of transcriptions and peer debriefing with a student colleague, was also employed during the compiling of this thesis to help enhance the credibility and integrity of this research.

4) Implications for future music therapy practice

This research points to the following practice recommendations:

- Practitioners should provide the opportunity for family members to be involved within the music therapy sessions if this is possible and appropriate. Work with Frank showed that when his wife was present in the music therapy session she raised his morale and confidence.
- Thought and care should be taken when putting together clinical sessions with this particular client group. It is important to observe and assess the client and their needs before planning for music therapy, as a HD diagnosis affects clients differently. Frank displayed more physical symptoms whereas George presented with more cognitive delay and psychiatric symptoms.
- The practitioner should have some understanding of HD and the symptoms that cause the clients to be unpredictable and frustrated at times, and be guided by the caregivers approach to the patients. It was particularly valuable to gain staff insights in the research interviews.

- Practitioners should have an awareness of previous studies in this area and the benefits and factors that contribute to the use of singing in music therapy. Literature on HD is growing, and there are indications that the use of singing in neurological care has some very specific benefits that warrant further investigation. Practitioners can contribute very helpfully to the knowledge base.

5) Recommendations for future research

The findings in this study suggest that singing in music therapy can help to enhance aspects of QOL with patients who are diagnosed with HD. The current literature linking singing, music therapy and HD together is limited therefore more experimental studies with a bigger sample size, exploring the physical act of singing, facilitation of speech and vocal production, engagement levels, participation, and the possibility of reducing psychiatric symptoms without medication would be beneficial to this client base. The enjoyment Frank got from having his wife present in the room also suggests that research into family involvement during singing could be valuable.

Another finding regarding caregiver burden suggests that investigations in caregivers and residents integrated work in music therapy might be valuable to develop relationships between staff and residents. There needs to be more research into the importance of providing recreational programs with this client group. Also providing more resources and training for caregivers so that they can be more aware of the psychological needs of HD patients as well as their physical needs in the hope to maintain their quality of life.

A final outcome from the study was that the interviewees discussed how beneficial music therapy was for the facility, how much they appreciated my work with the residents, and their desire for the service to continue. This relates to Bannan (2008) research suggesting that caregivers saw the longer-term benefits of singing. It suggests that further research could be developed looking into perspectives surrounding the value of music therapy in neurological facilities in New Zealand as this may support the possibility of future jobs for music therapists in this area.

CONCLUSION

From the perspectives of the participants involved in this study, the process of singing in music therapy can be effective in contributing to aspects of QOL for both participants by providing them with; 1) a stimulus for socialisation; 2) emotional and psychological support; and 3) support for their remaining cognitive and physical ability.

Although the initial aim was to find out whether the process of singing can specifically enhance QOL it appears that it was not only the stimulus of singing which encouraged participation but also the relationship with the MTS and the use of instruments within the session. Also it was very apparent that singing was beneficial for the residents in two different ways. Frank was specifically stimulated by singing, either by himself, together with the MTS or during songwriting. Conversely, George's motivation to join in was stimulated by his initial interest in percussive instruments, which was then increased by the support the MTS gave him by her singing.

In conclusion, this research has not only considerably helped my professional practice and understanding of the process of music therapy but it has also contributed to an area of music therapy literature that needs some more attention and consideration. It has also highlighted the value of making music therapy available to those who have declining abilities to care for themselves. With no likely cure on the horizon, people living with HD need to be provided with not only the best of care but also a rich daily programme that provides them with opportunities to 'be able to' socialise, to retain some of their cognitive and physical abilities, to express emotions, to support feelings of control and independence all of which I believe will lead to an enhanced quality of life.

APPENDIX 1: Glossary of Definitions²⁹

Ataxic – The loss of muscle control. Patients often stop walking or move in peculiar positions without showing any discomfort.

Bradykinesia - Slowed ability to start and continue movements, and impaired ability to adjust the body's position. Rigidity can occur in facial muscles reducing facial movement.

Ceiling effect - The ceiling effect is the failure of a test to fully measure the outcome due to a very high average. This can be an indication of the ceiling effect because the test failed to distinguish much variation between scores.

Chorea - is an irregular, rapid, uncontrolled, involuntary, excessive movement that seems to move randomly from one part of the body to another.

Dysphagia - People with dysphagia have difficulty swallowing and may even experience pain while swallowing (odynophagia). Some people may be completely unable to swallow or may have trouble safely swallowing liquids, foods, or saliva.

Dysarthria - Speech that is characteristically slurred, slow, and difficult to produce (difficult to understand). A person with dysarthria may also have problems controlling the pitch, loudness, rhythm, and voice qualities of their speech.

Dystonia - is a neurological movement disorder characterised by inappropriate and involuntary muscle movements.

Motor Neurone disease - is a neurological condition that causes the progressive degeneration of specialised nerve cells, called motor neurons, in the brain and spinal cord. It can cause generalised muscle spasms, exaggerated reflexes and a progressive wasting and weakness of muscles responsible for speech, chewing and swallowing. As the condition progresses, sufferers may be unable to walk, speak, use their arms and hands or hold up their head.

Multiple Sclerosis - is a nervous system disease that affects your brain and spinal cord. It damages the myelin sheath, the material that surrounds and protects your nerve cells. This damage slows down or blocks messages between your brain and your body. Symptoms include; visual disturbances, muscle weakness, trouble with coordination and balance, sensations such as numbness, prickling, or "pins and needles" and thinking and memory problems.

Obsessive-Compulsive Disorder (OCD) - is an anxiety disorder and is characterized by recurrent, unwanted thoughts (obsessions) and/or repetitive behaviors (compulsions). Repetitive behaviors such as handwashing, counting, checking, or cleaning are often performed with the hope of preventing obsessive thoughts or making them go away.

Palliative Care - is a specialised area of healthcare that focuses on relieving and preventing the suffering of patients. Unlike hospice care, palliative medicine is appropriate for patients in all

²⁹ Reference for all medical terms: Medical Encyclopaedia. (2011). *MedlinePlus*. Retrieved March 15, 2011, from <http://www.nlm.nih.gov/medlineplus/encyclopedia.html>

disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients who are nearing the end of life.

Parkinson's Disease - Parkinson's disease is a disorder of the brain that leads to shaking (tremors) and difficulty with walking, movement, and coordination.

Pneumonia - is a respiratory condition in which there is infection of the lung.

APPENDIX 2: Information sheet (Full Resident)



Topic: Enhancing quality of life through singing: a music therapy study into Huntington's Disease.

Researcher:

Sacha van Beek
Music therapy student

Ph: XXXXXXXX

04- 9779945

sach.vanbeek@gmail.com

Supervisor:

Sarah Hoskyns (Director of Music Therapy)
New Zealand School of Music (NZSM)
PO Box 2332

Wellington

04- 801 2794 extn 6410

sarah.hoskyns@nzsm.ac.nz

You have been invited to take part in a research project that will explore how singing in music therapy can enhance quality of life for people living with Huntington's Disease (HD). I am writing to ask for your consent to participate in this research.

Quality of life is an important issue facing patients with degenerative diseases and due to the progressive nature of the disease it is important to find ways to support and value all aspects of people's health - including psychological, sociological and physiological aspects. As you might imagine, singing can be a very integrating experience – helping to stimulate breathing, joint activity with others and promoting a sense of hope, laughter and reflection about valuable times in our lives. It is hoped that this project will benefit you, 'the facility' and the Huntington's Disease community to provide more detailed information and evaluation of the place of music therapy in patient care, and to possibly enable a continuous music therapy service to take place in the future. This project is being undertaken as part of a Master of Music Therapy under the supervision of Sarah Hoskyns, Director of Music Therapy at the New Zealand School of Music in Wellington.

What will the research involve for participants?

As part of the research, I would like to conduct and study two music therapy sessions per week for two months for two residents. The sessions will last for approximately 20-30mins and will involve my usual approach to music therapy – that is, singing and playing instruments. I would like to use my clinical notes from these sessions in the study to write two in-depth case studies about my work. At four points in the two-month period I will ask you seven questions relating to your quality of life at the beginning and end of the session, and invite you to rate how you feel in a rating scale of 1-5. I would also – with your permission - like to videotape the first and the last session of the study to be used in interviews with two staff participants to give their perspectives on your quality of life. No one other than the researcher, my supervisor and the two staff participants will view the video-recordings. My research analysis will integrate the data from

your perspective, from staff members, and from my own case studies to answer the question about how singing can enhance quality of life for people living with HD.

How will Sacha decide about participation in the project ?

I will need two participants for this study, and eight residents are regularly and willingly receiving music therapy input. The Centre Manager is sending this letter to the eight potential residents and I will invite the first two residents who respond (or who's families respond) and who are able verbally to complete the questionnaire, to this invitation to participate. Other people will continue to receive music therapy as normal.

Your rights

No material, which could personally identify you, will be used in any reports on this study. Your name will not be used in the thesis to ensure privacy and confidentiality. Also, 'the facility' and its location will not be named or identified in the written documentation. However, as dedicated care for patients with HD is rare in New Zealand, there is a slight risk that you could be identified through association with this specialised service. It is important that you know this before giving consent. The records will be stored in a secure room at the New Zealand School of Music for a period of ten years. Only my supervisor and myself will have access to the data. A copy of the thesis will be in libraries of Massey University and Victoria University of Wellington. Participation in this project is entirely voluntary and you will be able to withdraw from the project at anytime, up to the point at which I begin analysis of the data. Please be assured that residents at 'the facility' will continue to receive music therapy sessions in the usual way whether or not they are involved in this particular study. You will have up to two weeks to decide. The results of the research are available upon request. Please note that the results may not be ready for publication until midway through 2011. A copy of the results will be available from me at the research site. If you prefer, a copy of the results can be mailed to an address supplied. I will be willing to discuss outcomes relevant to you after the study.

This study has been approved by the Central Regional Health and Disability Ethics Committee by expedited review. If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a Health and Disability advocate:

(04) 496 2053/ Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

If you require more information regarding the above project, please contact my supervisor or myself, Sacha van Beek, with the contact number provided on the first page.

Kind Regards,

Sacha van Beek

APPENDIX 3: Full Consent Form (Resident)**For:**

Research Title: Enhancing quality of life through singing: a music therapy study into Huntington's Disease.

1. I have read the information sheet dated _____ for me to take part in this project to investigate how music therapy may help to enhance my quality of life.
2. I understand that it is my choice to be part of this study and that I can withdraw from the study at anytime up to the analysis of the data, and this will not affect my eligibility to receive music therapy sessions outside the project.
3. I understand that any information relating to my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
4. I have had time to consider whether I will take part in this study.
5. I understand that the research will cease if it should appear harmful to me.
6. I know whom to contact if I have any questions or concerns regarding this study.
7. I understand that the study will be presented by the researcher as a project towards the qualification of Master of Music Therapy, New Zealand School of Music.
8. I give consent for the first and last session to be video-taped: YES / NO
9. I give consent for the researcher's session notes to be used: YES / NO
10. I wish to receive a copy of the results: YES / NO

I _____ (full name of resident), hereby give consent to participate in this research project.

Signature: _____ Date: _____

Signature of witness: _____

Name of witness: _____

APPENDIX 4: Information sheet for Residents



Topic: Enhancing quality of life through singing: a music therapy study into Huntington's Disease.

Researcher:

Sacha van Beek
Music therapy student

Ph: XXXXXXXX

04- 9779945

sach.vanbeek@gmail.com

Supervisor:

Sarah Hoskyns (Director of Music Therapy)
New Zealand School of Music (NZSM)
PO Box 2332

Wellington

04- 801 2794 extn 6410

sarah.hoskyns@nzsm.ac.nz

Sacha is going to offer music sessions to some of the residents in our home. She will then write about the sessions and the music so her university teacher can mark it. The information from the sessions and interviews with staff members will then be made into a book for other people to read. The book will not have our names in it. The book will be about how music and singing makes us feel and how it may make our daily lives better.

You have been invited to take part in this project. You will have music sessions with Sacha, twice a week for two months. The music sessions will only be approximately 20minutes long. We will be mainly singing songs and playing instruments in the session, as per usual. Sacha will write about what happened during music and this will be included in the book. At four points in the two months of music sessions, you will also be asked 7 questions about how you feel (before the session starts and after). To do this Sacha will use a rating scale, 1 means, not good and 5 means, great. The first and last music session will be visually recorded for Sacha and other staff members involved in the project to look at.

You do not have to participate in this project if you don't want to and you may decide not to do the music with Sacha at anytime. You can have some time to think about whether you would like to help Sacha with this project so that she can help other people, therapists, doctors, caregivers and nurses understand how music makes you feel. You can also continue to have your usual music sessions without taking part in the project. You will have two weeks to decide. If you have any questions you are welcome to talk to XXX or to Sacha before you sign this paper. If you would like to be a part of this music project, please sign the 'assent' page.

Read and explained to: _____ (resident) Signed by: _____

APPENDIX 5: Assent Form (Resident)**For:**

Research Title: Enhancing quality of life through singing: a music therapy study into Huntington's Disease.

1. I understand what has been explained to me about having two music sessions with Sacha a week for two months and the information from the sessions will be shared in her book.
2. I know that the book will be available for other people to read.
3. I have had a chance to ask questions and am happy with the answers.
4. I know that I don't have to have music with Sacha and I can say no at anytime.
5. I know that my real name will not be used in the book.
6. I have had enough time to think about whether to take part in the music sessions.
7. I know I can talk to Sacha or XXX about my feelings about the music sessions and can ask them any questions, at anytime, during the two months.
8. I understand that the study will be presented by the researcher as a project towards the qualification of Master of Music Therapy, New Zealand School of Music.
9. I give consent for the first and last session to be video-taped: YES / NO
10. I give consent for the researchers session notes to be used: YES / NO

I _____ (resident), hereby give consent to participate in this research project.

Resident signature: _____

Date: _____

Project explained by: _____

APPENDIX 6: Information sheet (Guardian)



Topic: Enhancing quality of life through singing: a music therapy study into Huntington's Disease.

Researcher:

Sacha van Beek
Music therapy student

Ph: XXXXXXXX

04- 9779945

sach.vanbeek@gmail.com

Supervisor:

Sarah Hoskyns (Director of Music Therapy)
New Zealand School of Music (NZSM)
PO Box 2332

Wellington

04- 801 2794 extn 6410

sarah.hoskyns@nzsm.ac.nz

Your family member has been invited to take part in a research project that will explore how singing in music therapy can enhance quality of life for people living with Huntington's Disease (HD). I am writing to ask for your consent for your family member to participate in this research.

Quality of life is an important issue facing patients with degenerative diseases and due to the progressive nature of the disease it is important to find ways to support and value all aspects of people's health - including psychological, sociological and physiological aspects. As you might imagine, singing can be a very integrating experience – helping to stimulate breathing, joint activity with others and promoting a sense of hope, laughter and reflection about valuable times in our lives. It is hoped that this project will benefit your family member, 'the facility' and the Huntington's Disease community to provide more detailed information and evaluation of the place of music therapy in patient care, and to possibly enable a continuous music therapy service to take place in the future. This project is being undertaken as part of a Master of Music Therapy under the supervision of Sarah Hoskyns, Director of Music Therapy at the New Zealand School of Music in Wellington.

What will the research involve for participants?

As part of the research, I would like to conduct and study two music therapy sessions per week for two months for two residents. The sessions will last for approximately 20-30mins and will involve my usual approach to music therapy – that is, singing and playing instruments. I would like to use my clinical notes from these sessions in the study to write two in-depth case studies about my work.

At four points in the two month period I will ask your family member seven questions relating to their quality of life at the beginning and end of the session, and invite them to rate how they feel in a rating scale of 1-5. I would also – with your permission - like to videotape the first and the last session of the study to be used in interviews with two staff participants to give their

perspectives on the residents quality of life. No one other than the researcher, my supervisor and the two staff participants will view the video-recordings. My research analysis will integrate the data from your family member's perspective, from staff members, and from my own case studies to answer the question about how singing can enhance quality of life for people living with HD.

No material, which could personally identify your family member, will be used in any reports on this study. Their name will not be used in the thesis to ensure privacy and confidentiality. Also, 'the facility' and its location will not be named or identified in the written documentation. However, as dedicated care for patients with HD is rare in New Zealand, there is a slight risk that your family member could be identified through association with this specialised service. It is important that you know this before giving consent. The records will be stored in a secure room at the New Zealand School of Music for a period of ten years. Only my supervisor and myself will have access to the data. A copy of the thesis will be in libraries of Massey University and Victoria University of Wellington.

Participation in this project is entirely voluntary and you will be able to withdraw your family member from the project at anytime, up to the point at which I begin analysis of the data. Please be assured that residents at 'the facility' will continue to receive music therapy sessions in the usual way whether or not they are involved in this particular study. You will have up to two weeks to decide. The results of the research are available upon request. Please note that the results may not be ready for publication until midway through 2011. A copy of the results will be available from me at the research site. If you prefer, a copy of the results can be mailed to an address supplied. I will be willing to discuss outcomes relevant to you after the study.

This study has been approved by the Central Regional Health and Disability Ethics Committee by expedited review. If you have any queries or concerns regarding your family members rights as a participant in this study, you may wish to contact a Health and Disability advocate:

(04) 496 2053/ Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

If you require more information regarding the above project, please contact my supervisor or myself, Sacha van Beek, with the contact number provided on the first page.

Kind Regards,

Sacha van Beek
Researcher

APPENDIX 7: Consent Form (Guardian)



For:

Research Title: Enhancing quality of life through singing: a music therapy study into Huntington's Disease.

1. I have read the information sheet dated _____ for my family member to take part in this project to investigate how music therapy may help to enhance his/her quality of life.
2. I understand that it is my choice for my family member to be part of this study and that we can withdraw from the study at anytime up to the analysis of the data, and this will not affect my family member's eligibility to receive music therapy sessions outside the project.
3. I understand that any information relating to my family member's participation in this study is confidential and that no material that could identify him/her will be used in any reports on this study.
4. I have had time to consider whether my family member will take part in this study.
5. I understand that the research will cease if it should appear harmful to my family member.
6. I know whom to contact if I have any questions or concerns regarding this study.
7. I understand that the study will be presented by the researcher as a project towards the qualification of Master of Music Therapy, New Zealand School of Music.
8. I give consent for the first and last session to be video-taped: YES / NO
9. I give consent for the researchers session notes to be used: YES / NO
10. I wish to receive a copy of the results: YES / NO

I _____ (full name of guardian), hereby give consent to participate in this research project.

Signature: _____ Date: _____

Signature of witness: _____ Name of witness: _____

APPENDIX 8: Information sheet for member of Staff



Topic: Enhancing quality of life through singing: a music therapy study into Huntington's Disease.

Researcher:

Sacha van Beek
Music therapy student

Ph: XXXXXXXX

04- 9779945

sach.vanbeek@gmail.com

Supervisor:

Sarah Hoskyns (Director of Music Therapy)
New Zealand School of Music (NZSM)
PO Box 2332

Wellington

04- 801 2794 extn 6410

sarah.hoskyns@nzsm.ac.nz

You have been invited to take part in a project that will explore how singing in music therapy can enhance quality of life in Huntington's Disease patients.

Quality of life is an important issue facing patients with degenerative diseases and due to the progressive nature of the disease it is important to find ways to support and value all aspects of people's health - including psychological, sociological and physiological aspects. As you might imagine, singing can be a very integrating experience – helping to stimulate breathing, joint activity with others and promoting a sense of hope, laughter and reflection about valuable times in our lives. It is hoped that this project will benefit the residents, 'the facility' and the Huntington's Disease community to provide more detailed information and evaluation of the place of music therapy in patient care, and to possibly enable a continuous music therapy service to take place in the future.

This project is being undertaken as part of a Master in Music Therapy under the supervision of Sarah Hoskyns, Director of Music Therapy at the New Zealand School of Music in Wellington.

As part of the research, I would like to engage with a staff member in a short unstructured interview about their views on the quality of life of the nominated resident participants and their perspectives on how music therapy may be able to contribute and enhance their daily lives. If you decide to take part in this study, you will be involved in an interview process, which will last for approximately 20-30 minutes, at a time suitable for you. At the start of the interview you will view short video segments of a music therapy session with both of the resident participants, to act as a prompt, to discuss what has been observed. This process will be repeated two months later after the last music therapy session has been completed.

The interview will be audio recorded in order to get an accurate transcript. I will provide you with a copy of the transcript, before it is analysed, and you may correct, edit or add to it. You may also request to have the recording of the interview after it has been transcribed.

No material, which could personally identify you, will be used in any reports on this study. The records will be stored in a secure room at the New Zealand School of Music for a period of ten years. Only the researcher and her supervisor will have access to the data. Your name will not be used in the thesis to ensure privacy and confidentiality. A copy of the thesis will be in the libraries of Massey University and Victoria University of Wellington.

Participation in this project is entirely voluntary and you will be able to withdraw from the project at anytime, up to my analysis of the data. You will have up to two weeks to decide.

The results of the research are available upon request. Please note that the results may not be ready for publication until midway through 2011. A copy of the results will be available from the researcher at the research site. If you prefer, a copy of the results can be mailed to an address supplied. The researcher will be willing to discuss outcomes relevant to you after the study.

This study has been approved by the Central Regional Health and Disability Ethics Committee by expedited review. If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a Health and Disability advocate:

(04) 496 2053/ Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

If you require any more information regarding the research above, please contact my supervisor or myself with the contact number provided on the first page.

Sacha van Beek
Researcher

APPENDIX 9: Consent Form (staff member)



For:

Research Title: Enhancing quality of life through singing: a music therapy study into Huntington's Disease.

1. I have read the information sheet dated _____ for a staff member volunteer to take part in this project to investigate how music therapy may help to enhance the quality of life of a patient with Huntington's disease.
2. I understand that it is my choice to be part of this study and that I can withdraw from the study at anytime up to the researcher's analysis of the data.
3. I understand that any information relating to my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
4. I have had time to consider whether I will take part in this study.
5. I know whom to contact if I have any questions or concerns regarding this study.
6. I understand that the study will be presented by the researcher as a project towards the qualification of Master of Music Therapy, New Zealand School of Music.
7. I give consent for the interview to be audio-taped: YES / NO
8. I understand that I will receive a copy of the interview transcript for checking and editing.
9. I wish to receive the audio-recording from the interview after it has been transcribed: YES / NO
10. I wish to receive a copy of the results: YES / NO

I _____ (full name of staff member),

hereby give consent to participate in this research project.

Signature: _____ Date: _____

Signature of witness: _____ Name of witness: _____

APPENDIX 10: Letter to Kaumatua

To whom it may concern,

1. I have had an opportunity to read and discuss Sacha van Beek's research proposal; Enhancing quality of life through singing: a music therapy study into Huntington's Disease.
2. I believe that the research as outlined is appropriate and meets the needs of Maori.

I _____ (full name), hereby give consent for this research project to go ahead.

Signature : _____ Date: _____

Signature of witness: _____

Name of witness: _____

APPENDIX 11: The Questionnaire

This questionnaire has been adapted from The World Health Organisation Quality of Life (WHOQOL) and Short Form – 36 (SF-36) questionnaires.

Questions:

1. How would you rate your quality of life?

Very poor	Poor	Neither poor	Good	Very good
		Nor good		
1	2	3	4	5

2. What do you feel right now?

Not happy	Could be better	OK	Happy	Great
1	2	3	4	5

3. How relaxed do you feel?

Not at all	A little	A moderate	Very much	An extreme
		amount		amount
1	2	3	4	5

4. How much energy do you have today?

1	2	3	4	5
----------	----------	----------	----------	----------

5. How much have you enjoyed your day so far?

1	2	3	4	5
----------	----------	----------	----------	----------

6. How well have you been able to concentrate today?

1	2	3	4	5
----------	----------	----------	----------	----------

7. Have you had a conversation with another person today? **YES / NO**

APPENDIX 12: A section from Frank's clinical notes

Clinical Notes 9/08/10

3 Overall XXX mood was relaxed and he was very aware of what was going on.
4 He had remembered from the previous week that he would be part of a research project and
5 he was to have individual sessions with me on Monday and wed.
6
7 When it was time to go into the session, XXX had already participated in the end of a group
8 MT session and so it didn't seem necessary to greet him with a hello song again. Instead, I
9 just struck up a general conversation about what we would be doing for the session and how
10 his weekend was. He responded with upbeat comments.
11 I then asked the questions from the questionnaire. He answered the questions with what
12 rating he saw fit and seemed to cognitively comprehend the questions well.
13 While answering these questions he came across as very positive, happy go lucky attitude
14 but also answered them truthfully, e.g. have you had a conversation with somebody today?
15 Being 1.30pm it seemed likely...but he answered 'no'.
16
17 The first song was his choice, between three songs, he chose 'Let it Be'. He appears to love
18 this song and knows all the words. Sometimes singing in tune but mostly he flexes his voice
19 up and down over his range in a chest/spoken word voice. As soon as he starts singing his
20 mood changes and he becomes very cheerful and appears to be in good spirits. He often
21 gives me a cheeky smile and has a glint in his eye. His rosy cheeks and general enthusiasm
22 shines through and as his MT you can't help but smile back at him. This creates a lovely
23 warm atmosphere in the room and a sense of calm.
24 However I did notice that his involuntary movement seems to deteriorate when he starts to
25 sing, he tends to move around a lot more. This may be due to focusing on something else.
26 Something I'd like to observe on the coming weeks.
27
28 From previous sessions with XXX I am aware that due to his condition he prefers not to play
29 certain instruments he can't hold well. However he always gives them ago and then politely
30 looks at me when he has finished. In today's session I wanted to try some rhythmic work. He
31 used the Djembe and I was on the bongos. Due to his condition, his involuntary movement, I
32 was acutely aware of when and how he hit the drum. It all depended on when he could
33 control his body or not. You can see that a lot of cognitive power is taken up controlling his
34 movements, so when you add in something else it becomes increasingly harder for him to
35 control. Next I added in a song, 'Day Oh', he seemed to enjoy this more, he obviously enjoys
36 singing and feels the most comfortable and confident doing so. When he started singing, he
37 wasn't able to keep up hitting the drum, making few attempts, more concentrating on the
38 singing and controlling his body movements.
39
40 Next was another song choice – 'Hey Jude' (which I need to learn properly!). Hi memory
41 recall is very apparent but he became a bit flustered and needed the words.
42 - Need to bring in music stand and print out words bigger.
43 Xylophone improvisation involved XXX coming up with a pattern, and then myself and then
44 we had to put them together. Unlike XXX who didn't get the gist of this he played a simple
45 note with the beat and swopped it up along all the notes. Listened for my pattern and then we

46 put it together. I asked him to try another one and this time I asked him to explore a few
 47 different notes. This time it was a bit longer, still involving a swop up the notes. Alongside
 48 my pattern it sounded really interesting and he seemed content with it.
 49 One thing that really restricts mark from fully getting involved is his chorea. He is aware of
 50 it but after years of dealing with it seems to have become used to the jerking. He just deals
 51 with and moves on. Due to this he could only hold one beater and use his other hand for
 52 balance, this may have held him back from more creative play.

53

54 Final song – his choice – ‘I can see clearly now’. It became obvious during this song that he
 55 was struggling for breath and I slowed the song down to meet his pace. He had been
 56 coughing a bit through the other songs but it became more apparent that he wasn’t coping
 57 that well. I stopped the song to give him a rest and that’s when he told me his a bit unwell
 58 from a cold. I hadn’t noticed it before then. We took some deep breaths in together and
 59 found his sense of calm again and tried again but he seemed to become a bit frustrated and
 60 annoyed that he couldn’t sing his best, we ended the song.

61

62 I sparked a conversation about what he enjoy about music therapy?

63 He responded – ‘*expressing yourself*’

64 Just before I asked the questions from the questionnaire again, I asked him what do you
 65 consider important when it comes to your QOL?

66 ‘*making choices*’.

67

68 I noted that the 2nd time I asked him the questions, his ability to focus came up one but his
 69 general feeling had dropped and he said it was due to his cold, not feeling very well

APPENDIX 13: A section from George's clinical notes

Clinical notes 29/09/10

571 Initially when I asked XXX to come in for his session, he said a firm 'No'. Now after
 572 2months of experience when XXX says no, sometimes he doesn't mean it he is just
 573 processing what you are asking him to do, trying to remember whether he knows what
 574 happens, whether he knows who I am or whether he can be motivated to do so or not.
 575 Once again, I knelt down and spoke about a few musical things, he still said 'no', so
 576 I said do I have to tell yah another joke? He laughed and then promptly stood up and
 578 came in.

579 Today was different than usual. XXX felt a lot more relaxed and interactive today.
 580 His head remained up majority of the time and he participated more in singing. He
 581 straight away asked to play the guitar, so this showed he remembered his last session
 582 playing it and he shows his obvious enjoyment. It's very far from the fact that the first
 583 time I asked him whether he would like to have a go.

584 We chose 'heard it through' and after a few verses XXX started singing the lyrics as
 585 well as strumming the guitar. His execution of his words were a lot more clear and his
 586 memory recall seemed to come in and out as he remembered the lyrics. He was able to
 587 focus on strumming and singing at the same time. As the song went on it felt like we
 588 started to play as one, but this only became apparent when XXX started to sing. As he
 589 sang more he got more and more into the song and started saying 'cool' throughout the
 590 piece.

591 When the song finished it seemed like he didn't want to finish with the guitar so I
 592 turned it over and placed it on my knees for us to explore a bit more. This turned into
 593 improvisation by tapping the strings and holding a beat on the body of the guitar.
 594 Although the therapist very much held it together, XXX came in and out with different
 595 parts and even picked up on the rhythmic singing and was able to join in on the
 596 repetitive rhythm. He seemed very satisfied after the improve had come to an end.
 597 After this I asked him what he would like to play next? He said 'just sing'; I was
 598 surprised at this but very happy at the same time. He moved his chair forward without
 599 prompting so we were both closer to the piano. He chose 'It had to be you' which we
 600 played for a bit and then moved onto 'the way you look tonight'. XXX does mumble
 601 lyrics at times but then comes out with the right ones when you least expect. It's like
 602 he participates and mumbles along with the singing and then when he knows the lyrics
 603 he will get louder. He may do this to stay in time. Rhythm is an important part of XXX;
 604 this is where as a therapist I have been able to bond with him.

605 Before the last song I asked him about what he had enjoyed about our sessions
 606 together...he said 'making music and singing'. The last song we sang together was
 607 'Rock around the clock', XXX left our session with a smile on his face and repeating
 608 the word 'cool'.

APPENDIX 14: Interview guidelines (Staff Member)



(Semi –structured interview)

Note: This will be the general structure consisting of questions from which the interviewer diverged or adapted when it was important to do so.

QUESTIONS

1. What does 'quality of life' mean to you?
2. What aspects of QOL would you consider important to be maintained for the residents?
3. Do you enjoy singing? What kind of memories do you associate with singing?
4. How do you think singing and music therapy contributes to this facility?
5. In the group sessions, do you think singing and music therapy enhance the resident's physical and mental wellbeing? What have you noticed?
- 6. 5min video**
7. What stands out for you after watching these video extracts?
8. How does the resident's mood compare to when he/she are not in the music session?
9. How do the residents communication levels compare to when he/she are not in the music session?
10. How often do you see this resident communicating with other residents? Other staff members?
11. After watching the video extracts, in what ways do you think singing can enhance people with Huntington's disease QOL?
12. Is there anything else you would like to discuss regarding music therapy as a service at this facility?

APPENDIX 15: A section from Helen's first interview (18/08/10)

6 S: The first question I am going to ask you is what does QOL mean to you?

7 H: QOL means to me that our people have got meaning in their lives and they are part of the
8 community and...they are happy and comfortable.

9 S: As in for you specifically, what do you believe is important for your QOL?

10 H: To be happy, to...be valued...to do the best that I can to help our people to have a good
11 quality of life.

12 S: Yes,

13 H: To...be able to communicate with people and to have a good outlook on life. To have a
14 sincere, calming approach.

15 S: Hmm,

16 H: And...to treat people the way I would like to be treated myself. Respect for each other.

17 S: That's really important. So what aspects of QOL, what you just named, would you
18 consider important to be maintained for the residents here?

19 H: To keep them happy and to keep them active and contented so they are not board or
20 lonely or just sitting with nothing to do. Yeah, keep them occupied, and yeah...keep them
21 happy, yeah not...not just sitting around doing nothing. To make life meaningful.

22 S: Do you find that happens a lot here at the moment?

23 H: No, not a lot but sometimes there's gaps where it is good to interact with them and to
24 keep them happy. They participate in passive exercises, quizzes, bingo, go out for van rides
25 to the movies or a concert when able to. They also go out to lunches sometimes.

26 S: So Norah do you enjoy singing?

27 H: Oh yes I do, I love music, yes I do very much so.

28 S: You personally enjoy it?

29 H: Our family is a musical family you know we all enjoy music.

30 S: So what memories would you associate with singing?

31 H: We were a church going family so we were taught how to play the Ukulele and we sang a
32 lot at church and went to different youth groups...so there was always music in the family.

33 S: Yes.

34 H: Even when we went to visit other relations, other members, extended family. We had sing
35 alongs. We are very happy and outgoing.

36 S: Yes

- 37 H: That was a most important thing, to family members is to...sing along...yeah...join in.
38 We are a very happy close family unit and even including extended whanau.
- 39 S: So how do you think singing and music therapy contribute to this facility?
- 40 H: I think its wonderful, because you can see that the people really do enjoy it, they're
41 always keen to participate...yeah...and I love seeing the different reactions from them to,
42 even, even the ones that don't communicate as such that don't speak the special expressions
43 that you can see, that you that you know that they are enjoying it.
- 44 S: Do you think singing and music therapy enhances the resident's physical and mental
45 wellbeing?
- 46 H: You can see that they are very...very interested in it you know they are, sometimes you
47 have sessions and they are a lot calmer their movements are not always extreme, they seem
48 more still, yeah... more relaxed.
- 49 S: Yes
- 50 H: yeah, like 'Molly', she'll sit there and she is not moving around like she normally does
51 and you know that it must have some calming therapeutic effect on them. Just listening to
52 music...I think it is...I think its very soothing for them.
- 53 S: Ok.
- 54 *(pause to watch video)*
- 55 S: So we just watched a few video extracts from a session with 'George', what stood out for
56 you when you watched these extracts?
- 57 H: 'George's' eagerness to take part and the enjoyment he was getting out of it you can see
58 that he was really, really getting involved.
- 59 S: And how does 'George's' mood compare to when he is not in the music session?
- 60 H: 'George' is pretty quiet and he just sits there and watches T.V and he doesn't say a lot, he
61 seems more active when he's participating in the music room.
- 62 S: Yes...
- 63 H: 'George'...doesn't do a lot, its just watching T.V or going out for outings I think he is
64 more involved showing more involvement more activity.
- 65 S: Yeah. How often do you see 'George' communicating with other residents and other staff
66 members? On his own accord?
- 67 H: No, not a lot...'George' doesn't always communicate willingly but if you speak to him he
68 will communicate, he usually just sits there and watches T.V. or a lot of the time he is asking
69 for a cup of coffee!

APPENDIX 16: A section from Petra's second interview (24/09/10)

53 S: We just watched some video segments from 'George's' session, what stood out for you?

54 P: Compared to last time he has definitely deteriorated. The information is definitely not
55 going in as fast. He is only using one side. It was sad...I know that George has had two brain
56 bleeds since then, so that won't be helping, so the information with Huntington's doesn't get
57 there, well that's not getting there. It's making it harder. He's trying, he's wanting to be
58 involved, especially on the guitar and on the piano, he's singing away a little bit to himself,
59 so the involvements there...he's gone down hill since I last saw him.

60 S: What did you notice about his singing?

61 P: He was slurring and very one tone...very low...just like he is just managing to get it out
62 and very repetitive of whatever your saying, he's hanging on every word, if you said low,
63 "low" you know its just a repetitive motion...which is good, but...

64 S: Did you notice anything about his eye contact?

65 P: Well I mentioned it to you while we were watching it, there was none at all...I don't think
66 he looked up...but maybe near the end...he was very slumped, favouring the left side but
67 still trying to participate, you know, I mentioned it at the start as I watching, I was impressed
68 that he's actually using the three drums instead of just one. So he is trying to extend himself,
69 it's just taking that little while, you know, for the information to get there.

70 S: How does 'Georges' mood compared to when you see him in the lounge area and also the
71 last time you saw him?

72 P: From what I saw on the video, there's definitely no eye contact and he's favouring the left
73 side. But he is still communicating and the music is still making a difference and even if it
74 makes a slight difference then that is a plus, so that's how I see it. That music is still
75 communicating isn't it?

76 S: Yes

77 P: And so communication is so important, so he'd have to walk away feeling good.

78 S: Yes absolutely, I think his communication, although I have to ask him the questions he is
79 still willing to participate. Do you think he is more relaxed this time?

80 P: I would of thought he was more relaxed from the video I saw last time, yeah definitely
81 more relaxed.

82 S: So we were talking about communication levels, how does communication levels compare
83 to his last video?

84 P: I think he is finding it a lot harder to talk now, because of the slurring and it's just coming
85 out the way he wants it too, and everything's been processed a little bit slower and so I think

86 communication maybe just that little bit harder. But you having music is making him use
87 his vocal chords, making him think, making him aware of the music and he is enjoying it, so
88 either way its going to be a plus.

89 *(pause to watch video)*

90 S: So we are just reflecting on what we saw of 'Frank' in the video and him singing anne's
91 song...

92 P: ohh *(emotional sigh)* Yup I'm tough...but I've got one little tear sitting on the right hand
93 side. That was just beautiful, that was with his heart and the look on his face and you could
94 see him contemplating every single word he sung...that's just so touching...

95 S: And the expression that he showed...

96 P: Oh yeah absolutely. Its just...being able to physically watch him not just hear him, you
97 could see it in his eyes he was thinking about every word, it came out in every word, that he
98 sung, the love that he has, the journey that he's taken...its just amazing...

99 S: Do you think it's affecting his quality of life?

100 P: Oh absolutely, yeah that's what's I said at the start. It's the psychological, physical,
101 emotional all that makes your well-being of who you are, so all that affects you.

102 S: What stood out for the most in this video segment?

103 P: His words...energy, memory, happiness...those three words will always stick with me
104 because those are the three things, if he's saying that's how he feels, and its what it's about,
105 it's about how he feels. And those were three words that he wasn't prompted. Those were
106 three feelings and what huge, huge feelings. So that's the difference that music is making...

107 S: Absolutely. Comparing that video to the previous video you saw, do you notice anything
108 different?

109 P: I think there's more of an input, 'Franks'...even from the first video, he love it anyway,
110 he loves you, and he loves being involved and he loves music so you've got some awesome
111 things happening. But I think he was probably more relaxed this time and maybe
112 participating and given a bit more...he let himself go a bit more...yeah.

113 S: Especially on that communication level...

114 P: Well we talk about communication and he's a typical male, he's not letting it all out there
115 but he's saying what he needs to say. And going back to those words... energy, memory,
116 happiness...so it was short but he was getting his point across.

117 S: Especially the energy in the song...

118 P: Oh his smile...oh...it didn't stop the whole way through.

119 S: Yes cause from what I have observed from Huntington's disease they find it hard to use
120 their facial muscles to show expression...

121 P: And showing that he is controlling and understanding his movements because he's
 122 smiling the whole way through and when he got to 'Mary's' song and that smile was in his
 123 eyes but his facial movement...you could just feel the heart and love that was going into
 124 it...so you know his knowing...that's just not a smile which quite often is with Huntington's
 125 as well it can either be a smile or just you know fairly straight...he's showing all his
 126 emotions...its just out there.

127 S: Are there any other reflections you have around singing and music therapy and how it can
 128 directly enhance Huntington's disease patients QOL?

129 P: I think it directly changes them, that involvement, and motivation, all of them because its
 130 something that we've had, music something that we're born with, doesn't matter where we
 131 were, doesn't matter if you don't come from a musical family...it's there...it's all around
 132 us...we hear it and we all have special memories, special songs just like 'Frank' said, so to
 133 put all that and to make it happen, those groups and your work with them is so important,
 134 because this is memories, this is energy and this is happiness and I think those three words
 135 will stick with me for a long time. 'Frank' just summed it up for everybody for all of us,
 136 Huntington's or not, but especially Huntington's, that's just bringing life to maybe a sad day.

137 S: Well thank you 'Petra', it was great to hear your wisdom and your reflections.

138 P: Well your doing an awesome job and this paper that your doing...its awesome, its just
 139 going to make such a difference, its making a difference already...so good on you.

140 S: Thank you.

APPENDIX 17: The original score of Frank's song for his wife.

'MARY'S SONG'

FRANK

6 OH YOUR BEAU-TI-FUL YOUR LOVE-LY AND YOUR MINE OH YOUR

10 BEAU-TI-FUL YOUR LOVE-LY AND YOUR MINE

14 WE'VE BEEN TO-GE-THER-FOR MAN-Y A YEAR

18 SEEN THE SUN RISE AND FALL OH YOUR

22 BEAU-TI-FUL YOUR LOVE-LY AND YOUR MINE OH WE

26 FELL IN LOVE THE FIRST TIME THAT WE MET OH I

30 SAW YOUR LIPS (SPOKEN) AND THAT WAS IT! (GRIN APPEARS ON FRANK'S FACE)

34 WE HAVE THREE LOVE-LY GIRLS

38 AND I LOVE YOUR OH YOUR

BEAU-TI-FUL YOUR LOVE-LY AND YOUR MINE

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