

“THE MUSIC IS STILL THERE”:
HEARING FROM INDIVIDUALS WITH DEMENTIA WHO SING TOGETHER

A Thesis Submitted to the College of Graduate and Postdoctoral Research
In Partial Fulfillment of the Requirements For the Degree of Master of Education
In the Department of Educational Psychology and Special Education
School and Counselling Psychology
University of Saskatchewan
Saskatoon

By
Stephanie L. Danger

UNIVERSITY OF SASKATCHEWAN PERMISSION TO USE

In presenting this thesis in partial fulfillment of the requirements for a graduate degree from the University of Saskatchewan, I agree that the libraries of this university may make it freely available for inspection. I further agree that permission for copying of this thesis in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis work, or in their absence, by the head of the department or the dean of the college in which my thesis work was done. It is understood that any copying or publication or use of this thesis or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my thesis. Request for permission to copy or to make other use of material in this thesis in whole or in part should be addressed to:

Department Head
Educational Psychology and Special Education
College of Education
University of Saskatchewan
28 Campus Drive
Saskatoon, SK
S7N 0X1

ABSTRACT

Music therapy is increasingly recognized as a valuable component of dementia care, yet research on group singing with this population is relatively limited, as is qualitative research that uses this population's firsthand accounts to understand their experiences. The current study provided a means for individuals with dementia to express how they experienced music therapist-led group singing in a residential care home. The guiding research question was: What is the experience of music therapist-led singing group for individuals with dementia living in a residential care home? Six male residents, diagnosed with moderate to advanced dementia and ranging in age from 78 to 92 years, participated in six 30-minute group singing sessions facilitated by a music therapist who also played the piano. Data was collected in a community-based setting through observation, field notes, video recording, and individual interviews (fully recorded and transcribed), which were analyzed using an observational checklist (Davidson & Fedele, 2011) and Interpretive Phenomenological Analysis (Smith & Osborn, 2003). Six themes were produced: (1) *Self as a Performer*; (2) *Self as Part of a Group*; (3) *Live Music is Special*; (4) *Music is a Gift*; (5) *Gaps in Time, Memory and Ability*; and (6) *The Music Is Still There*. Conclusions included support about the value and appropriateness of engaging individuals with dementia in research, as well as in group singing led by a music therapist; and evidence supporting group singing as an aspect of dementia care that contributes to well-being.

Keywords: Qualitative Research, dementia, music therapy, group singing, well-being, personhood

ACKNOWLEDGEMENTS

The journey of completing a thesis is not an easy one and many people walked with me along the way. I owe a great debt of gratitude to my supervisor, Dr. Jennifer Nicol. Your direction, feedback, contributions, and encouragement helped me to create research that was valuable and meaningful. I am also grateful to my committee member, Dr. Shelley Peacock; your passion and enthusiasm for my research was truly a gift. Thank you to my work supervisor and mentor, Heather, and all the staff at Christian Counselling Services. Your grace, compassion, encouragement, and prayer supported me through this process. I am also thankful to my SCP cohort and for our shared journey in this program.

Thank you to my parents, family and friends who were incredibly patient with me over the past few years as I worked on my thesis, I am looking forward to spending quality time with each one of you! Thank you to my husband, Brook, who was by my side through every high and low in this journey, and always supported, encouraged, and believed in me.

Thank you to Candace, the music therapist who facilitated the group singing sessions and allowed me to experience music therapy. You are an incredibly gifted therapist, and it was a privilege to see your passion, dedication and excellence transform the lives of all who interact with you. Of course, this research would not have been possible without the beautiful individuals who sang in the group. Meeting and singing with each one of you was by far the highlight of the entire research process. I am deeply humbled to have the privilege of sharing your stories.

Finally, thank you to my Lord and Savior, Jesus Christ. Knowing and following you has been my most important journey.

I will sing to the LORD as long as I live; I will sing praise to my God while I have my being.

Psalm 104:33

TABLE OF CONTENTS

PERMISSION TO USE	i
ABSTRACT	ii
ACKNOWLEDGMENTS.....	iii
TABLE OF CONTENTS	iv
LIST OF TABLES	viii
LIST OF FIGURES.....	ix
CHAPTER ONE: INTRODUCTION	1
Background of the Study.....	1
Purpose of the Study	2
Researcher Background.....	2
Definition of Key Terms	4
Thesis Organization.....	5
CHAPTER TWO: LITERATURE REVIEW	7
Dementia	7
Personhood as a Framework for Dementia Care.....	8
Well-being Theory (WBT).....	11
The PERMA Model	12
Music and Music Therapy.....	15
Promotion of Personhood Through Music Therapy.....	16
Music Interventions in Dementia Care.....	17
Dementia Research.....	18
IPA Studies Involving Individuals with Dementia	21

Rationale for the Current Study	23
CHAPTER THREE: METHODOLOGY	25
Qualitative Inquiry	25
Interpretive Phenomenological Analysis	26
Phenomenology.....	26
Hermeneutics.....	27
Idiography	28
Research Site	30
Ethics Approval.....	30
Ethical Considerations	31
Singer Recruitment and Selection.....	33
Group Singing Sessions	34
Data Collection.....	35
Data Analysis	37
Establishing the Quality of the Research	40
Sensitivity to Context.....	40
Commitment and Rigor.....	41
Transparency and Coherence	42
Impact and Importance	43
CHAPTER FOUR: FINDINGS	45
Introduction to the Singers	45
Louis.....	46
Leonard	46

Gord.....	47
Johnny	47
Jerry.....	47
Tony	48
How individuals with Dementia Experience Group Singing	48
How They Experience Themselves.....	50
Self as a Performer	50
Self as Part of Group	52
How They Experience Music.....	54
Live Music is Special	54
Music is a Gift.....	57
How They Experience Dementia	59
Gaps in Time, Memory, and Ability	59
The Music is Still There.....	61
Identity	62
Memory	64
Ability	65
Summary	68
CHAPTER FIVE: DISCUSSION	71
Enhancing Well-being and Promoting Personhood Through Group Singing.....	72
Self as a Performer	73
Self as Part of Group.....	74
Live Music is Special	76
Music is a Gift.....	77

Gaps in Time, Memory, and Ability	78
The Music is Still There: Identity	79
The Music is Still There: Memory	81
The Music is Still There: Ability	81
Enhancing Well-being.....	82
Promoting Personhood	83
Strengths of the Research.....	85
Delimitations of the Research	88
Implications of the Research.....	89
Future Research.....	93
Reflections.....	95
Conclusion.....	97
References	100
Appendix A: Consent Form	112
Appendix B: Background Information Form.....	114
Appendix C: Assent Log.....	116
Appendix D: Song List.....	117
Appendix E: Semi-Structured Interview Guide	118
Appendix F: Observation Data Checklist	119

LIST OF TABLES

Table 1. Interpretative Phenomenological Studies (IPA) Involving Individuals with Dementia

..... 22

LIST OF FIGURES

Figure 4-1. Experience of Group Singing: Summary of Themes and Sub-Themes49

CHAPTER ONE: INTRODUCTION

Although music therapy is frequently used in the care of individuals with dementia, there have been critiques regarding the lack of conclusive research demonstrating the positive impact in well-being and personhood (Vink et al., 2013) and commentary that standardized quantitative measures cannot completely capture the positive outcomes that have been described anecdotally and qualitatively (Davidson & Fedele, 2011). There is a small amount of qualitative research relative to existing quantitative research on the topic of music therapy and dementia. There is even less research examining the unique role of group singing to enhance well-being and personhood. The current study adds to the dearth of literature exploring the first-hand accounts of individuals with dementia and their experience of music therapist-led group singing.

Background to the Study

Music has a unique ability to positively impact that quality of life for individuals with dementia because the ability to engage with music remains intact late into the disease process (Maguire, Wanschura, Battaglia, Howell, & Flinn, 2015). Music therapists have used music to help this population with communication, memory recall, reduction of agitation, and improved physical coordination (Chang et al., 2015). More recently, researchers from various disciplines have focused on group singing to enhance well-being and promote personhood in this population (Ahonen-Eerikainen, Rippin, Sibille, Koch, & Dalby, 2007; Clements-Cortés, 2014; McDermott, Orrell & Ridder, 2014). However, the amount of literature that explores the perspectives and experiences of those with dementia who participate in the group singing is not large, and much of the literature is quantitative in nature.

The quantitative research involving individuals with dementia participating in singing primarily examines the impact of group singing on cognition and memory (Oostendorp & Montel, 2014), quality of life (Camic, Williams, & Meeten, 2013), and negative mood and behaviours (Lesta & Petocz, 2006). While quantitative research provides valuable information and insight, it cannot capture the specific experience and perspectives of the participants. This gap can be addressed by qualitative research, which structures the research process in such a manner that rich and contextualized descriptions and representations can be drawn from the data that is generated (Mason, 2002). This process allows for the exploration of individual experiences, meanings, interpretations, and perspectives.

Purpose of the Study

The purpose of the study was to address this gap by using Interpretative Phenomenological Analysis (Smith, 1996) to explore the lived experiences and perspectives of individuals with dementia participating in group singing in a special care home, to understand how they experience group singing and the perceived impact of group singing on their well-being.

Researcher Background

My training in psychology and undergraduate courses in neuropsychology gave me an early interest of the etiology and impact of dementia. As I progressed in my education and training as a counsellor, I became interested in the ways that those with dementia can be supported. Although I do not have any family members living with dementia, I have many friends, colleagues and neighbours who have been directly affected, and their stories and experiences have encouraged me to explore this area of research. Exploring literature related to the topic prompted a desire to focus on the perspectives of individuals with dementia, both

because of their absence in the literature, as well as my existential counselling orientation, which emphasizes the importance of freedom, responsibility, relationship, purpose and meaning (Corey, 2009). This orientation emphasizes the importance of finding meaning in human experiences, both the negative and the positive, as a vital part of well-being. Existential psychology posits that creating meaning provides the purpose that makes life worthwhile (van Deurzen, 2002).

But what does this mean for individuals who have cognitive deterioration? Since meaning is created and not implicitly present, how does an individual with dementia experience and make meaning? There is an alignment between interpretive phenomenology and existentialism as ways to investigate the experience of living with dementia. The research question stemmed from my desire to address the lack of qualitative research on singing and dementia, to explore the narratives of participants, and to understand their lived experience and perceptions of group singing and the impact on well-being.

My belief and assumption was that music could have a significant impact on the social, emotional, and intellectual well-being of individuals with dementia. I expected that through participation in group singing there would be some sort of effect on the singer's overall well-being and that they would have insights regarding these effects that cannot be completely understood through external measures (e.g., observation or caregiver ratings). I believed that to understand more fully their experiences of group singing, a phenomenological approach was needed. This approach acknowledges the importance of the meanings and interpretations everyone creates through their experiences and the need to hear directly from them to best understand their experiences.

Another assumption I have is that individuals with dementia maintain personhood and research involving this population should reflect that status. All people should be viewed as a whole person, worthy of dignity and respect, regardless of their health status. In the specific context of dementia, Bright (1997) noted that personhood meant that the essential core of the individual remained intact despite limitations resulting from illness. The term personhood was first applied to dementia care by Kitwood (1997b) and supports the thought that people with dementia are still whole people capable of living fulfilling lives and a primary goal of dementia care and research should be to maintain personhood. It is my goal that this research acknowledges and promotes personhood and that this view be evident in the methodology, analysis, and writing.

Another assumption is that an individual's verbal dialogues can reflect their internal cognitions (Smith, 2004) and by analyzing this data by engaging individuals with dementia, I can gain insight into individual perspectives, thoughts, and feelings. A related assumption is that individuals with dementia can participate in group singing and communicate about their experiences in a rich and meaningful way. Previous studies have found that individuals with moderate to severe dementia can reliably communicate, both verbally and non-verbally about personal experiences such as mood or quality of life (Clare, Rowlands, Bruce, Surr, & Downs, 2008).

Definition of Key Terms

Below is a list of key terms that appear throughout this document. For the purposes of the current study the following definitions are used:

Dementia. Dementia is an umbrella term for a class of chronic and progressive neurodegenerative disorders, including Alzheimer's disease, that result in a disturbance of

higher cortical and subcortical functions. These functions include memory, thinking, orientation, comprehension, calculation, language, and judgment, but degree and breadth of impact is highly variable across the different disorders (World Health Organization, 2012).

Group Singing. Group singing defined here refers to a group of individuals being led in singing activities by a music therapist.

Music Therapy. Music therapy is the skilled and trained use of music and its elements to enhance personal well-being through a therapeutic relationship with a music therapist (Canadian Association of Music Therapy, 2014).

Personhood. Personhood as defined by Kitwood (1997b) is ‘the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being’ (p. 8)

Well-being. Well-being is a multi-dimensional construct consisting of five measurable elements: positive emotion, engagement, relationships, meaning, and accomplishment (Seligman, 2011). A state of well-being can also be thought of as *flourishing*.

Thesis Organization

This thesis contains five distinct chapters. Chapter one provides a brief overview of the current research on music as a therapy for people with dementia, the purpose of the current study, researcher background and definitions of key terms. Chapter two reviews the research literature on the impact of dementia, both on a personal and societal level, the importance of promoting personhood through care practises and research, the PERMA model of well-being, PERMA being an abbreviation for positive emotions, engagement, relationships, meaning, and accomplishment (Seligman, 2011), the use of music therapy in dementia care, and qualitative research involving first hand accounts of individuals with dementia. Chapter three describes

the methodological approach of IPA, the research site, data collection procedures, data analysis, and how the quality of the research was established. Chapter four presents the findings: introduces the singers, reports on the themes that emerged from the data analysis and interpretations, supported by direct quotes from the singers. Finally, chapter five integrates the findings from the current study into the existing body of literature, comments on how and why group singing enhances well-being and promotes personhood, reviews the strengths and limitations of the study, and finally concludes with suggestions for future research and my personal reflection of the research process.

CHAPTER TWO: LITERATURE REVIEW

To explore the literature in a structured way, the following chapter begins with a discussion dementia, the impact on those diagnosed, caregivers and society as well as the state of dementia research. A description of personhood and its use as a research framework is then presented. Next, Seligman's Well-being Theory (2011) is introduced and described. Following this, there is an overview and definition of music therapy and the music interventions typically used in dementia care. Next is a review of the literature focused specifically on dementia research and research that applies IPA to a dementia context. Finally, the chapter is concluded with a section detailing the current gaps in the literature and the rationale for the current study.

Dementia

Dementia is currently the leading cause of disability for individuals over 65 years of age and an estimated 500,000 Canadians are living with this disease (Alzheimer Society of Canada, 2010). Dementia is a term used to describe a large class of disorders characterized by progressive, irreversible degeneration of the brain causing impairment in cognitive, memory and social-emotional functioning (Alzheimer Society of Canada, 2012). These impairments can have a significant impact on the ability of an individual to function in work, relationships, and everyday life. The economic cost of dementia is also significant, with numbers ranging in the billions of dollars (Alzheimer Society of Canada, 2010). The rate of dementia is also expected to increase twofold over the next twenty years and researchers have been prompted to take targeted action lest the Canadian health care system be completely overwhelmed by this increase (Alzheimer Society of Canada, 2010).

One of the actions recommended by the Alzheimer Society of Canada (2010) is the creation of support programs for individuals with dementia and the use of evidence-based care

plans. Many such programs are already in place or are in the process of being implemented, including the use of non-pharmacological interventions; e.g., music or music therapy, touch, and physical activity/exercise (Hulme, Wright, Crocker, Oluboyede, & House, 2010). The use of music as an intervention has been growing in popularity in dementia care, perhaps because musical ability and music appreciation are some of the most enduring abilities in individuals with severe dementia (Maguire et al., 2015).

The success of using music in dementia care has generated interest amongst researchers. Historically, much of the research has been quantitative (Skingley & Vella-Burrows, 2010) and has focused on managing challenging dementia-related behaviours such as agitation, aggression, wandering, restlessness, irritability, social and emotional difficulties (Hulme et al., 2010). Kitwood and Bredin (1992) commented that the focus of dementia research has “been technical rather than personal” (p. 270). However, more recently, some researchers (e.g., Heggstad, Nortvedt, & Slettebø, 2013; Higgins, 2014; Phinney & Chesla, 2003) are turning their attention to the experiences of patient or the client, focusing on understanding their inner world and perceptions of the use of music therapy in care.

Personhood as a Framework for Dementia Research

Dementia has traditionally been viewed through a biomedical lens that attributed the decline in cognitive abilities primarily to neurodegeneration (Franssen, Kluger, Torossian, Reisberg, 1993; Franssen & Reisberg, 1997; Mitnitski, Graham, Mogliner, & Rockwood, 1999). Since the late 1980’s there have been new frameworks and theoretical conceptualizations emerging that interpret dementia through social psychology (Kitwood & Bredin, 1992) and social gerontology (Bond, 1993) lenses. These new frameworks provided researchers and practitioners alike with alternative interpretations that contrasted significantly

with decline and deficiency models common within the biomedical view (Innes & Manthorpe, 2013).

The pioneering work of Tom Kitwood, a social psychologist, commented that the biomedical focus on physiology resulted in a deep understanding of the medical side of dementia, but importantly, also resulted in a poor theoretical understanding of care practices. Kitwood and Bredin (1992) suggested that the dementia disease process was not the result of neurodegeneration alone, but also the interplay between neurological impairment and personal and social psychology of a person. Kitwood and Bredin (1992) identified inappropriate care practices (e.g., infantilizing, labelling, outpacing, ignoring, and withholding) as having a negative impact on the development of dementia care. He drew attention to the fact that some care practices reflected a negative, *less-than* view, of individuals with dementia and “managing their challenging behaviour” (p. 272) was the central focus of care. It is important to note that while Kitwood critiqued the medicalization of dementia he did not deny the physiological basis of dementia (Innes & Manthorpe, 2013).

Aside from identifying the shortcomings of narrow medical models of dementia, Kitwood (1997b) also further developed the concept of personhood, which he defined as “a status or standing bestowed upon one human being, by others, in the context of a social relationship and social being. It implies recognition, respect and trust” (p. 8). Kitwood asserted that because personhood is relational in nature, it can be both promoted and diminished by the care practices of practitioners working with individuals with dementia. He emphasized that maintaining personhood was both a neurological and a psychological task, emphasising the need to expand care practices beyond physical care and medications to “enabling the exercise

of choice, use of abilities, expression of feelings, and living in the context of relationship” for those with dementia (p. 60).

These ideas all contributed to the development of person-centered care, which is a care philosophy and practise that maintains personhood (Dewing, 2008). This is done in part by promoting identity and worth through interactions and communications (Innes & Manthorpe, 2013). On a social-psychological level, personhood is maintained by enabling the person with dementia to retain relationships, to use their abilities, and to enjoy a variety of experiences (Kitwood, 1997a).

While the philosophy of personhood has been guiding the progression of care practises for the past 25 years, it has been used only more recently to develop a research framework. The use of this framework has in part been developed to address critiques that only anecdotal accounts of the benefits of person-centered care practise exist and that there is little evidence to support the benefits and efficacy of these practises (Dewing, 2008). To address the limited empirical evidence for person-centered care, O’Connor et al. have developed a new research framework (2007). This framework has two broad objectives that include (1) understanding personhood and (2) supporting personhood (O’Connor et al., 2007).

Given new perspectives that suggest the prognosis of dementia is influenced by neurodegenerative changes, as well as personal histories, interpersonal interactions and perceptions within social contexts, dementia care is being reframed to support an individual’s personhood by focusing on facilitating the transitions that occur in the progression of dementia (O’Connor et al., 2007). For example, a review by McGilton (2004) described and advocated the use of relational care, a care practice designed to increase meaningful connection and relationship between formal caregivers and individuals with dementia.

According to O'Connor et al. (2007), research adopting this perspective of personhood in dementia should contain one or more of three domains of inquiry. The first is *subjective experience*, understanding the subjective experiences of individuals with dementia. The second is *the interactional environment*, understanding the interactions individuals with dementia have with other people as well as their physical environment. The third is *the socio-cultural context*, recognizing and exploring how broader society and culture shapes individuals with dementia and personhood.

Using the framework presented by O'Connor et al. (2007), the present study contained all three of the abovementioned themes, however the domain of *subjective experience* was primary in the study. As IPA is concerned with the idiographic, the IPA methodology of this study supports the theme of *subjective experience*. This focus on group singing and meaningful interactions in the study illustrate the domain of *the interactional environment*. Finally, the *socio-cultural context* of the study is discussed in relation to the model of care used by the care home and the gender dynamics of the group.

Well-being Theory (WBT)

Well-being theory (WBT) suggests that well-being is not a unidimensional entity, but instead is a construct consisting of five measurable elements: positive emotion, engagement, relationships, meaning, and accomplishment (abbreviated as: PERMA) (Seligman, 2011). These five elements were identified by Seligman, an American psychologist and founder of the positive psychology movement, because he found that people universally pursue them, even across differences in age, culture, and geography. Seligman believes that people are drawn to experience these five elements because they are naturally rewarding and contribute to flourishing (Coffey, Wray-Lake, Mashek, & Branand, 2014).

The precursor to WBT was Seligman's Authentic Happiness Framework of Well-Being (AHF; Seligman, 2011), which identified three pathways to happiness: pleasure, engagement, and meaning. These three pathways reflected both hedonic and eudemonic orientations. The pleasure pathway aligns with the hedonic tradition in that it focuses on the maximization of positive emotions. The engagement and meaning pathways compliment the first pathway with a eudemonic focus on making life worth living through growth, understanding and the realization of potential (Lambert, Passmore, & Holder, 2015).

After much critical analysis, input, testing and reflection, Seligman (2011) determined a new theory was needed that built on the foundations of the authentic happiness framework. He noted that in his research he was unsuccessfully trying to measure a real thing (happiness) as defined by life satisfaction. However, life satisfaction was just one way to measure happiness and thus did not give a comprehensive representation of happiness. Seligman determined that the focus should be on measuring constructs rather than real things. He further concluded that several measurable elements contributed to well-being and that none of the elements independently defined well-being itself. This new emphasis on construct measurement gave way to a new theory, WBT, which contains five psychosocial elements of well-being, abbreviated as PERMA.

The PERMA Model. To be considered in the new iteration of Seligman's Well-being Theory, contributing elements had to meet three criteria: (1) the element must demonstrably and positively contribute to well-being; (2) the element must be pursued for its own merit, not just to gain another element; (3) the element must be able to be measured independently from the other elements. Seligman (2011) started with three elements from the original AHF – positive emotions, engagement, and meaning – and identified two additional important

elements – relationship and accomplishment. These elements were added to reflect the need of humans to achieve goals for their own sake as well as the need for connection with other humans. In addition to these changes, the new framework referred to well-being/flourishing rather than happiness/life satisfaction.

The first element of WBT is Positive Emotions, which are the pleasant or pleasurable feelings such as satisfaction, contentment, pride, serenity, fulfillment, hope, optimism, confidence, and joy (Jayawickreme, Forgeard, & Seligman, 2012). This element of WBT represents a hedonic approach to well-being and is not only about pursuing positive emotions, but also about learning the skills needed to amplify and prolong the experience of positive emotions.

Engagement is the second element of WBT and is a reference to the concept of *flow*, which is a state of concentration that requires all cognitive and emotional resources, and results in loss of self-consciousness and time-stopping (Seligman, 2011). Engagement can occur when we are completely absorbed in an activity such as listening to music or playing soccer. Since engagement requires all an individual's mental and emotional resources, those who enter this state infrequently experience emotions in the moment. In this regard, Seligman (2011) noted that engagement is the opposite of the first element, positive emotions. It is not until an individual exits the state of engagement and reflects that they express emotions.

Positive Relationships is the third element and involves the connections that individuals make with others. Humans need connection, love and contact with others. When positive networks form between individuals, they have the potential to enhance and contribute to well-being. Positive relationships often fuel the creation of the other elements such as positive emotion or meaning.

Meaning, the fourth element, is about belonging to and serving something that is beyond the immediate self, something that is transcendent. Meaning can also be thought of as purpose or the *why* of living. Victor Frankl (2014), in his book *Man's Search for Meaning*, wrote that “people have enough to live by but nothing to live for; they have the means but no meaning” (Frankl, 2014, p. 132). Meaning was central to Frankl's logotherapy and the importance of meaning in life is similarly acknowledged in Seligman's PERMA model. Seligman also noted that meaning can change over time and that what may be meaningful at one time may, upon recall years later, not retain that same meaning.

The final element, Accomplishment, was added to the model after Seligman (2011) had a conversation with a work colleague about how setting and achieving goals for their own sake was an important part of well-being. Setting and working towards goals helps to create a sense of anticipation of the future and accomplishing goals contributes to overall well-being in life.

Seligman's PERMA model posits that positive emotions, engagement, relationships, meaning, and accomplishment all contribute individual well-being. As the PERMA model is new to the research community, empirical support for the model is limited. However, the initial results of several studies are promising. Huppert and So (2013) tested a representative sample of 43,000 Europeans in 23 different countries on ten different constructs related to well-being. The constructs were identified based on the determination that well-being was opposite to common mental health disorders such as anxiety and depression. Using the definitions and characteristics of these disorders, they created a list of opposing characteristics to generate a list of well-being factors, such as engagement, positive relationships, and self-esteem. The authors noted that their deductively created list included the five elements described by Seligman in the PERMA model. The authors also agreed that measuring well-

being by looking at life satisfaction alone is too simplistic and suggested that well-being should be conceptualized and measured as a multi-dimensional construct. Both conclusions give support to using the PERMA model to measure well-being.

A more recent study by Coffey et al. (2014) evaluated the PERMA model directly in two different samples, one with Australian college students and the other with a diverse community sample. The study examined the higher-order factor structure of the five elements and the model's utility in predicting concurrent and prospective well-being outcomes such as physical health or college success. Results from both studies indicated that there was cross-sectional and longitudinal support that the PERMA model has good utility in predicting well-being.

The PERMA model appears to have promise as a measure of well-being. In the present study, it provided a conceptual framework for considering the impact of music therapy, specifically group singing, in promoting well-being and personhood.

Music and Music Therapy

Music is a universal and pervasive phenomenon that permeates everyday lives (MacDonald, Kreutz & Mitchell, 2012). Humans experience music in a variety of ways and value music for a variety of reasons, both therapeutic and non-therapeutic. For example, music offers entertainment, enjoyment, relaxation, worship, meditation, a means to create connection, as well as something to sing along with, to dance to, and so on. The use of music as a therapeutic tool by credentialed music therapists is increasingly recognized as a valued therapy, in part through the development and establishment of the profession of music therapy.

The idea of using music as a healing influence traces back to the writings of Aristotle and Plato, but the profession itself began in the early twentieth century when community

musicians visited veteran's hospitals and played music for the thousands of veterans wounded physically and psychologically during World War I and II (American Music Therapy Association, 2015). Since the formal beginning of the profession, music therapists have continued to create, deliver, and evaluate music interventions in a wide range of clinical and non-clinical settings (Bunt & Hoskyns, 2002).

According to the Canadian Association for Music Therapy (2014, para. 1), music therapy is “the skillful use of music and musical elements by an accredited music therapist to promote, maintain, and restore mental, physical, emotional, and spiritual health” and music interventions can be used to “facilitate contact, interaction, self-awareness, learning, self-expression, communication, and personal development”). The American Association of Music Therapy (2013) further specifies that music therapy can “address physical, emotional, cognitive, and social needs of individuals of all ages” (para. 2).

Music has been increasingly utilized in dementia care over the past two decades (McDermott et al., 2014). Music (e.g., music listening, music making, singing) is known as a “non-pharmacological intervention” in health care, because methods other than pharmacological treatment are used to provide therapeutic benefits (Clift, 2012). Several positive outcomes associated with music therapy include mood enhancement, social support, identity formation, self-esteem development and stress reduction (Clift, 2012).

Promotion of Personhood through Music Therapy

In using personhood as a research framework, it is important that the intervention used in the research itself promotes personhood. Music therapy is widely accepted as an activity that contributes positively to well-being in individuals with dementia and is one of the most popular care home activities in Europe and North America (McDermott et al., 2014). Kitwood

(1997b) wrote specifically about the ability of music to promote personhood, suggesting that music may help to protect an individual's identity or help individuals in process of redefining their identity. Individuals can show who they are through musical interaction, and meaningful musical experiences have the potential to increase emotional connectedness and intimacy with the other individuals involved (Kitwood, 1997b).

Music Interventions in Dementia Care

The therapeutic use of music for individuals with dementia has primarily focused on the benefits of music listening and formal caregiver singing. According to Skingley and Vella-Burrows (2010), there was a convincing research base indicating numerous positive effects for these activities. These positive effects included reduced agitation, positive mood, enhanced feelings of well-being, increased social interaction and a sense of empowerment. The use of group singing however has generated mixed results and some authors (Brown, Götell, & Ekman, 2001) propose that the cognitive decline associated with late-stage dementia impedes one's ability to engage in beneficial coordinated group singing.

Despite this possibility, other researchers have reported beneficial effects of group singing for individuals with dementia. For example, Myskja and Nord (2008) found that after two months of twice-weekly group sing, individuals with dementia had a statistically significant reduction in depression. Positive benefits found in other studies included: reductions in activity disturbances, aggressiveness, and anxiety (Svansdottir & Snaedel, 2006); increases in mood, energy and happiness and decreases in pain (Clements-Cortés, 2014); increases in lucidity and social interactions (Davidson & Fedele, 2011); and increased conversation, positive feelings and belonging (Dassa & Amir, 2014).

Dementia Research

O'Connor et al. (2007) suggested that researchers using a personhood research framework develop innovative data collection techniques to gather data with individuals with moderate to severe dementia, as research using first-hand accounts of this population is limited. Skingley and Vella-Burrows (2010) also noted an overall lack of qualitative studies on this topic. McDermott et al. (2014) observed that although music-based interventions are popular in dementia care, there is "a limited knowledge of how and why individuals with dementia find music beneficial for their well-being" (p. 706). Much of the previous dementia research also focused on diagnosis, pathology, behaviour management and caregiver strain rather than the perspective of those with dementia, which aligns with an underlying assumption of dwindling personhood (Moore & Hollett, 2003). Fortunately, in response to this gap in the literature as well as with the development and increased use of qualitative methods, there has been an increase in recent years of qualitative studies with individuals with dementia. I located three qualitative studies that specifically examined the impact of music (Ahonen-Eerikainen et al., 2007; Clements-Cortés, 2014; McDermott et al., 2014).

Ahonen-Eerikainen et al. (2007) studied six women, between the ages of 77 to 90, with varying degrees and types of dementia. The women participated in structured instrumental music therapy group led by a certified music therapist. The group met for a total of 12 sessions over a four-month period. Data collection included field notes by the music therapist, session comments by observers, and video recording of the music sessions. Data were analyzed, coded and categorized according to grounded theory guidelines. The analysis process produced three hierarchical descriptive categories describing the role of music and therapeutic factors of music therapy group. The first category was *dealing with difficult feelings within the*

therapeutic music group process; singers expressed that the group was a safe place to deal with frustration, irritation, sadness, and worthlessness. The group provided participants with a sense of safety, support, assurance, positive feedback, validation, and encouragement. The music served to improve self-esteem through the process of creating. The second category was *the empowering experiences*; the group led to increases in self-confidence, self-esteem, and feelings of worth and provided occupation and a sense of identity. The last category was *the joyful moments*; the group provided fun, energy, excitement and facilitated trust and relaxation. Ahonen-Eerikainen et al. concluded that participating in the instrumental music therapy group provided participants with a beneficial therapeutic process, which ultimately improved their quality of life.

Clements-Cortés (2014) interviewed 16 residents of a long-term care home of whom 14 had mild to moderate dementia or cognitive impairments, and two had physical impairments. Four staff were also interviewed. All of the participants attended 10-16 sixty-minute choir sessions held over 16 weeks that were led by two music therapists, the choir leader and the choir pianist. The study employed mixed methods to examine the impact of group singing on well-being of individuals with dementia by conducting interviews, having participants complete self-report questionnaires, and observing singing sessions. Findings showed statistically significant increases in mood, energy and happiness, and a decrease in pain. Thematic analysis of the transcribed interviews generated themes that included: (a) community building; (b) special moments; (c) climate of positivity; (d) music as therapy; (e) singing makes me feel well; (f) increases mood, energy, and alertness; (g) I can do it; and (h) I love to sing. Clements-Cortés concluded that the choir group provided participants with a sense of community, and increased confidence, sense of purpose, mood, energy, and alertness. She also

noted the important role of the choir leader, who created a positive environment and helped participants to recognize their significance and value.

Kirkland, Fortuna, Kelson, and Phinney (2014) studied nine residents of a long-term care home with moderate to advanced dementia, ranging from 52 to 99 years of age. The participants took part in a weekly music and spiritual care group, co-led by an accredited music therapist and the resident chaplain. Each session had a different theme, such as hope, peace, or childhood. Session elements included song, prayer, reading inspirational passages, poems, and visual presentations on PowerPoint. A mixed method approach was used to explore the experience of music therapy as a spiritual care method for individuals with dementia. Quantitative data were collected using Dementia Care Mapping (DMC; Kitwood & Bredin, 1992), which is a tool used to assess quality of person-centered care and quality of life for individuals with dementia. DMC is based on the belief that well-being is observable through external indicators such as bodily relaxation, initiation of social contact, and creative self-expression. Sessions were video recorded and then analyzed and coded using DMC. Qualitative data were collected in the form of observation, videotaping and interviews. Results from the DMC analysis indicated that co-facilitators supported participants' well-being and maintained personhood by meeting their core psychological needs for: identity, through respect and celebration: attachment, through acknowledgment and validation: and occupation, through enabling and collaboration.

Analysis of the interviews revealed that participants felt music group provided them with social connection and opportunities that were rarely available to them. They also emphasised that the group was spiritually fulfilling to them.

Interpretative Phenomenological Analysis Studies Involving Individuals with

Dementia. Since 2007, there have been a few studies employing IPA to investigate the experiences of individuals with dementia. Research utilizing IPA often focuses on personal meaning and sense-making in specific contexts (Smith, Flowers & Larkin, 2009). Data collection tools best suited to IPA are those that can provide rich and detailed first-person accounts of experience, such as in-depth interviews or diaries (Smith et al., 2009). Given the cognitive and linguistic impairments associated with dementia, obtaining detailed first-person accounts with this population presents some challenges and the research is limited. Nevertheless, I located five studies that utilized IPA to analyze interviews with individuals with dementia.

The studies included in Table 1 all involve individuals with varying severity of dementia, and four of the five studies include individuals with moderate dementia. These studies' thematic accounts provide valuable interpretations of participants' experiences and support the idea presented by Clare et al. (2008) that individuals with dementia can describe their experiences in a meaningful way, participate in qualitative research, and ultimately contribute deeper understanding of their experiences and inform care practices. It is important to note that from a humanistic human science perspective, memory change, confusion or confabulation are not problematic in the data since individual experience and perceptions are of most importance, not objective truth (Moore & Hollett, 2003).

Interpretative Phenomenological Studies Involving Individuals with Dementia

Reference	Number of participants	Dementia Severity/ Rating	Area of study	Data Collection Tool	Findings
Clare et al. (2008)	n = 80	Moderate to severe dementia Mean MMSE score m = 7.58	Explored subjective experiences of life with dementia for those living in residential care	Unstructured conversations	Themes identified included distressing emotions such as loss, isolation, uncertainty, fear. Residents coped through acceptance and affirming their past sense of self
Clemerson, Walsh, & Isaac (2013)	n = 8	Moderate dementia Mean MMSE score m = 18.9	Experience of living and coping with Alzheimer's disease in younger life	Semi-structured interviews	Themes identified included disruption of the life cycle, identity, social orientation, and agency
Frazer, Oyeboode, & Cleary (2012)	n = 8	Moderate dementia Mean MMSE score m = 20	How women living alone with dementia manage their identities and cope with day-to-day living	Semi-structured interviews	Themes identified included loss, embodiment, adapting, awareness, safety, relationships, exclusion, and loneliness. Coping strategies included building relationships with friends and neighbors and attending memory clubs
Higgins (2014)	n = 10	Moderate dementia Mean MMSE score	The importance of Christian faith to individuals with dementia living in care homes	Semi-structured interviews	Themes identified included faith as an integral part of their identity, the centrality of their relationship with God, and faith as a consolation

Rationale for the Current Study

Dementia presents a significant economic, social, and emotional cost to Canadian society and various agencies have made calls for evidence-based care practices to minimize the progression and impact of the disease (Alzheimer Society of Canada, 2010). Traditionally dementia has been viewed and researched using a biomedical lens, leading to studies that focused on the technical, rather than the personal (Franssen et al., 1993; Kitwood & Bredin, 1992). New frameworks, incorporating theoretical perspectives from social psychology and social gerontology, have provided alternative interpretations, which suggest that the dementia disease process is an interplay between neurological impairment and the personal and social psychology of a person (Kitwood & Bredin, 1992). This alternative view calls for care practices that attend to the social aspects of the individual with dementia and that ultimately promote personhood by enabling them to engage in meaningful relationships, use their abilities, exercise choice and participate in a variety of experiences (Kitwood, 1997a). Further research is needed to demonstrate the efficacy of person-centered care practices, as critiques of these practices have noted a lack of scientific evidence to support benefits (Dewing, 2008).

Although there is much research on the topic of dementia, the research designs have been primarily quantitative, relying on objective measures and caregiver ratings. O'Connor et al. (2007), in their personhood research framework, advocate for research that focuses on understanding the subjective experiences of individuals with dementia. Another shortcoming of the current qualitative research with this population is that participants typically have mild to moderate dementia, no doubt due to the challenges in accessing the experiences of those with later stage dementia. Nevertheless, there is an ethical responsibility to include all

individuals with dementia in research, regardless of their disease stage (Alzheimer Society of Canada, 1997).

In the context of music therapy research, studies involving individuals with dementia have focused more on the benefits of music listening rather than participatory practices such as singing or music making (Skingley & Vella-Burrows, 2010). More research on participatory music experiences is needed. There is also a need for more investigation of the benefits of group singing for individuals with late stage dementia, given the mixed results of previous work (Brown et al., 2001). Finally, there is a need for research that conveys the perspectives of individuals with dementia, and their experiences of music and well-being (McDermott et al., 2014).

Given the current gaps in the literature described above, the present study was designed with the intent of using qualitative research to explore the experiences of individuals with dementia participating in group singing, and gain an understanding about how group singing affected their well-being and maintained personhood. Reflecting these interests, the research question was:

What is the experience of music therapist led group singing for individuals with dementia living in a special care home?

CHAPTER THREE: METHODOLOGY

The methodology chapter begins with an introduction to qualitative inquiry, followed by a description of the interpretive phenomenological analysis (IPA). The focus then moves to topics related to the study's implementation and data collection, which include ethical considerations, research site description, participant recruitment criteria and selection procedures, a description of the group singing session and a description of the data collection procedures. Following this is a description of the data analysis. This chapter concludes with a section on how the quality of the research was established using Yardley's (2000) criteria for good qualitative research.

Qualitative Inquiry

Qualitative inquiry is the study of social phenomena in context and employs a multimethod, interpretative, and naturalistic approach (Denzin & Lincoln, 2011; Hays & Singh, 2012). The aim is to create rich and contextualized descriptions and representations drawn from nuanced and detailed data (Mason, 2002). Emphasized in these descriptions are processes and meanings described those participating in the research (Denzin & Lincoln, 2011). The research traditions belonging to qualitative inquiry are numerous and varied (e.g., case study, grounded theory, narratology, or phenomenology) and each has unique characteristics, foci, and data collection methods. While the different traditions are diverse, Bogdan and Biklen (2003) described three commonalities of qualitative inquiry: (1) data are collected in natural settings and the researcher is the key instrument; (2) inductive reasoning is employed, the notion that data drive the creation of deeper understanding of phenomenon; and (3) meaning created by the research participants is emphasized.

Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) examines in detail how people make sense of their experiences (Smith et al., 2009). Belonging to the phenomenological research tradition, IPA is concerned with exploring participants' perceptions and interpretations, rather than objective descriptions of lived experiences, objects, and events (Smith & Osborn, 2003). While understanding the perspective of participants is central, IPA also acknowledges the active role of the researcher in the process and that the researcher cannot directly or completely experience the insider perspective of the participant (Smith & Osborn, 2003). Since the researcher cannot fully access the participant's experience, they must engage in their own interpretations based on what the participant has shared with them. This multi-stage interpretative process is referred to as a double hermeneutic, a parallel process where the researcher is making sense of the participant making sense of their world (Smith & Osborn, 2003).

IPA was first developed and utilized by Johnathan Smith, a British psychologist, as a new approach that would capture both the experiential and qualitative, but could still be situated within mainstream psychology (Smith et al., 2009). Early IPA primarily focused on lived experiences of health and disease, but is now also prominent in clinical, counselling, social and educational psychology (Smith et al., 2009). While IPA is a newer approach, the philosophical foundations that it is based on are much older. IPA draws on key concepts from three different philosophies of knowledge: phenomenology, hermeneutics, and ideography (Smith et al., 2009).

Phenomenology. Phenomenology is concerned with how one examines and comprehends lived experience (Smith et al., 2009). The primary task of phenomenology is “to

capture the essence and essentials of the experience that make it what it is” (Saldña, 2011, p. 8). The ideas and developments associated with four leading figures of phenomenological philosophy – Husserl, Heidegger, Merleau-Ponty and Sartre – have shaped the phenomenological aspects of IPA (Smith et al., 2009). Husserl believed that to achieve the task of phenomenology, one must step outside of the *natural attitude* or one’s everyday experience and instead adopt a *phenomenological attitude*, by turning one’s gaze reflexively inward to the perceptions of the experience. *Bracketing* is necessary to achieve this attitude. Bracketing is “the means by which researchers endeavor not to allow their assumptions to shape the data collection process and the persistent effort not to impose their own understanding and constructions on the data” (Ahern, 1999, p.407). Husserl suggested that bracketing shuts out the taken-for-granted world by separating it from one’s perceptions of the world (Smith et al., 2009). Heidegger, Merleau-Ponty and Sartre also contributed to the view that people are in and relating to a world of objects, relationships, languages, and cultures (Smith et al., 2009). Distilled from these ideas is a major goal of IPA: to interpret others as they relate to and create meaning from their everyday activities and experiences. The idea of interpretation leads to the next philosophical foundation of IPA, hermeneutics.

Hermeneutics. Hermeneutics is essentially the study of interpretation and theorists associated with this philosophy are concerned with the methods and purposes of interpretation, determining if it is possible to uncover the original meanings or intentions of the author and the relationship between past and present contexts (Smith et al., 2009). The hermeneutic philosopher Schleiermacher believed that each writer brings different technique and intention to their work, thus impressing a unique meaning on what they create. The main goal of the writer should be to create an interpretation so detailed, holistic, and complete that it allows a

reader to understand the writer and the text better than they understand themselves (Smith et al., 2009). While IPA theory does not fully endorse this thought, IPA borrows from it, acknowledging that the IPA research's analysis may provide meaningful insight that exceeds those of the participants. This is accomplished through a methodical and thorough analysis of the data, connections created within larger data sets and discourse with psychological theory (Smith et al., 2009).

The hermeneutic circle is another concept relevant to IPA. It refers to the dynamic relationship between the different levels or parts of some whole. Understanding is iterative in that to understand the whole, each separate part must be understood and vice versa. This concept informs the methods of IPA, where there are no sequential steps in analysis but instead responsive and recursive movements between levels of interpretation (Smith et al., 2009).

Idiography. Idiography pertains to the description or explication of particular cases or events ("Idiographic", 2015, para. 1). It is important to note that in the pursuit of the individual or particular, idiography does not renounce generalizations, but instead uses generalizations with careful consideration (Harré, 1979). While idiography is concerned with individual experience, people are also immersed and embedded in the world, so experience occurs in context of the surrounding environment. People are *in-relation-to* phenomena, but they also offer a unique perspective to those phenomena (Smith et al., 2009).

IPA operates as idiographic on two different levels. The first level is the depth of analysis prescribed in IPA and the amount of detail that depth brings about. The second level is the focus on understanding how a person or group of people experiences an event, process, or relationship in a particular context (Smith et al., 2009). These operations provide a partial

rationale for the small, purposively selected samples recommended for IPA research (Smith & Osbourn, 2003).

IPA was chosen as the methodological approach for the present study because of its strengths and alignment with the purpose and context of the study. The focus of IPA on individual's subjective experiences fits well with the theoretical framework of personhood, as well as with the Eden Alternative care model, the research site's care model, because both acknowledge the importance of individual perspectives and contributions, regardless of ability or health status. IPA also provides a clear practical framework to guide the inquiry, from the research questions to analysis to data representation. This was helpful to me as a novice researcher because it gave structure and direction to the entire research process, and Smith himself suggested that IPA was a useful research approach for new researchers, for those same reasons (2004).

IPA also has limitations that are important to acknowledge and discuss. IPA, as indicated by its name, is interpretative in nature. The use of interpretation means that the written document cannot be a true presentation of an individual's lifeworld and experience but rather is what is referred to as a *double hermeneutic*, the intersecting interpretations that occur in IPA. The first is the participant themselves interpreting their world and the second is the researcher making interpretations of the participant's interpretation (Smith, 2004). Although the intent is to represent the perspective of the participants with as much fidelity as possible, it is important to acknowledge that I am interpreting the participant's perspectives, not presenting them at face value. This is not necessarily a weakness but rather a characteristic of the approach that must be described for the reader to fully understand exactly what is being represented in the text.

Research Site

The study was conducted at a special care home in a midsize Canadian prairie city. The research site delivers care based on the Eden Alternative care model (Eden alternative: It can be different, n.d.). Dr. Bill Thomas, an American physician, developed the Eden Alternative model of care in response to three factors he observed occurring in some traditional “institutional model” care homes. These factors included loneliness, helplessness, and boredom and Thomas believed they contributed negatively to the experiences of older adults in long-term care (Eden alternative: It can be different, n.d.). The principles that guide the Eden philosophy are directed toward the goal of mitigating these three factors and emphasize social connection, creation of meaning and belonging, older adults as decision makers, facilitating new and familiar experiences and ongoing personal growth (Eden alternative: It can be different, n.d.).

As part of the Eden Alternative care model, the research site has specialized memory care residences designed specifically to meet the unique needs of residents living with dementia. Residents live in small communities designed to provide specialized support and care to individuals with dementia. In these communities, they are supported by the same care staff to facilitate familiarity and friendship. The Eden Alternative also emphasizes the importance of meaningful activity and the research site has many programs to promote this, including a resident music therapist, resident artist, art studio, gardens, animal areas, and a chapel.

Ethics Approval

Three different levels of ethics approval were necessary for this study. The first level was the University of Saskatchewan Behavioural Ethics Review Board (U of S beh-REB),

which focused on ethical considerations for each part of the study: informed consent, confidentiality, anonymity, storage of data, recruitment materials, consent forms, intervention materials, interview guide and follow-up procedures. The application was approved on May 5, 2016 (BEH approval #16-134) after which I completed an operational cost analysis for the city's Health Region Authority to determine potential costs to the health region. The third and final level of ethics approval involved working with the ethics board of the special care home to ensure that the proposed research aligned with the care practices they employed. They also provided helpful insights and recommendations regarding the best way to conduct research with individuals with dementia.

Ethical Considerations. Two main ethical elements were of primary importance in this study. The first was ensuring that the research design aligned with the care practices of the research site. In designing this study, I researched and reviewed the Eden Alternative model of care, which is the model employed by the care home. I was also invited to join the care home's music therapist as she engaged in music therapy with residents in a dementia care community, which allowed me to observe how she interacted with the residents and delivered the music therapy. We also met to discuss how the principles of the Eden Alternative care model were applied to everyday care activities and therapy at the care home. With this knowledge in mind, I endeavoured to find a research framework that would align with the Eden philosophies and I believe this objective was achieved in the employment of the personhood framework chosen. Additionally, I believe that IPA is a methodology that values the perspectives of individuals with dementia and affirms both their value and personhood.

The other main ethical consideration was that of consent. Considering the unique care needs and potential vulnerability of individuals with dementia, I used a specially structured

consent process described by Dewing (2007) to obtain consent. This consent process consists of five steps and requires that consent be continually evaluated and re-established.

The first step was to gain permission to invite the singers to participate from the unit managers of the care communities as well as the singers' appointed decision makers. Consent forms (see Appendix A) were sent to the appointed decision makers and returned to the music therapist at the special care home. Biographical information about the singers was gathered through history forms (see Appendix B), which were completed by the music therapist and care staff.

The second step required establishing a basis for consent with the understanding that the capacity to consent is not a global ability but is situational and variable. It was determined that appointed decision makers would grant consent and that ongoing assent would be elicited from the singers themselves.

The third step required providing the singers with appropriate information needed for them to understand the study and ask for their assent to participate. In this step, it was important to gain an understanding of how each singer typically consented in his daily activities. I gathered information through the history forms and through discussions with the music therapist. The music therapist initially asked each singer if he would like to join a singing group and participate in interviews with a researcher who would explore how they experienced the group.

The fourth step required continually re-establishing assent with the singers at the beginning of each singing group, throughout the group time and prior to each interview. Before each singing group, the music therapist would invite each singer by asking if they wanted to come sing with the group that day. As the music therapist invited the singers, I

would record their answer in my notes and following the group, both she and I would initial an assent log (see Appendix C). If a singer did not wish to join the group that week, the music therapist would honour that choice and invite them again at the beginning of the next session. Following the session, I would invite one singer and ask if they would like to talk with me about their experience of the singing group that day. Their answer was recorded in the assent log and witnessed by the music therapist.

The final step involved seeking feedback and support from the singers, staff, and appointed decision makers to ensure that assent was re-established throughout the study. This was primarily achieved through the music therapist checking in with the singers during the group sessions and interviews and continually assessing the impact of the music therapy or discussion on the singers.

Singer Recruitment and Selection

Singers were recruited from two separate communities in the care home. Recruitment and selection was facilitated by the care home's music therapist who also delivered the group singing intervention. Convenience sampling was used to identify six singers who had a background or enjoyment of music and were familiar to the music therapist. This sample number was guided by Smith's (2004) IPA sample size recommendations and a more detailed rationale can be found in the section below titled *Data Collection*. Singers included in the study were (a) residents of the care home, (b) were willing to participate in six half-hour choir sessions and one half-hour interview, (c) were diagnosed with moderate to severe dementia as confirmed by a qualified health professional in their health records (d) could communicate verbally to answer interview questions, (e) and were fluent in English.

Group Singing Sessions

The group singing sessions were developed in partnership with the resident music therapist and six half-hour sessions were carried out over four weeks at the research site. Four of the sessions took place in the early afternoon and two occurred in the late morning, as the music therapist recommended those times as the most suitable for the singers.

At the beginning of each session the music therapist would invite the singers, who were usually gathered in a living room/dining room area, to join and would walk with them to the piano room. The piano room was a small, sunny lounge area with a white console piano and comfortable chairs. The chairs and piano were arranged in a circle in such a way that the music therapist would look outwards to the singers as she played standing behind the piano. This allowed her to engage in direct eye contact with each of the singer as she led the group.

She would begin the sessions by welcoming the singers and taking them through a vocal range exercise. Following this, she would lead the singers through 15 to 20 songs on the piano. She selected songs that would have been widely known to the singers in their early adult years or songs that were classic hymns (See Appendix D for a complete song list). She also knew each singer's favourite songs and would call out to a singer that she was about to sing their favourite song, encouraging engagement within the group. As she led the group, she would take time to sing directly to each singer, smiling, making eye contact, and commenting on their singing. If a singer was quiet or disengaged, she would happily invite him to sing or begin to play a song she knew he enjoyed.

The piano/lounge room did not have a door and was directly off a main hallway. Many times, staff or residents would be drawn to the sound of music and stop by to listen. Residents would often come into the room to sing with the group or just listen and watch the singers. The

sessions would end with two or three closing songs, such as “Good Night Ladies” (Christy, 1847) or “Till We Meet Again” (Whiting & Egan, 1918) and then the music therapist would congratulate the singers and thank each one for their singing. Next, the music therapist and sometimes the staff would walk back with the singers to their rooms or the living room area.

Data Collection

Three methods of data collection were utilized: participant observation, video recording and individual semi-structured interviews with the singers. Throughout the singing sessions, I observed the singers and took informal notes. These notes included who was present at the sessions, salient interactions between singers or the music therapist, verbal and physical actions of the singers, and impressions of the general mood of the group. At the beginning of each group singing session I also set up a video camera to focus on and record one specific singer, although the recording was framed so that interactions with other singers were captured as well. The use of videotape observation in dementia research has been encouraged by O’Connor et al. (2007) to facilitate the contribution of individuals with moderate to severe dementia.

Following the group singing session I interviewed the singer that I had also video recorded for that session. The music therapist also assisted in portions of the interviews, especially in cases where the singer needed additional assistance verbalizing their thoughts. The interviews took place in the same room that the sessions had occurred in. The rationale for this was to provide a familiar context and to potentially aid the singer in their recall of reactions, thoughts and feelings regarding the group singing.

The interviews included general open-ended questions relating to the research question with the opportunity for responsive follow-up questions. I also included some more specific

closed questions to focus in on certain topics (See Appendix E for the interview guide). The loose structure of the open-ended questions allowed for more in-depth responses and was recommended by Smith (2004) for use with children and adults who may have difficulty with language. Smith also suggested that the researcher may need to take a more primary role in guiding interviews with these populations and must be flexible enough to modify protocols as the interview progresses and develops. This was certainly true in my experience given the wide range of language abilities possessed by the singers. Some singers could express and articulate their feelings while others required more support and very specific questions. I found I often repeated the singers' words back to them and asked "I heard you say [repeated words of singer] is that correct?" Sometimes I would reflect meaning or feeling to the singers and check with them to ensure I had interpreted them correctly.

In total, I conducted interviews with all six of the singers in the group. This was an ideal number. Too many individuals participating in group singing could potentially cause over stimulation and distress for those with dementia and thus small group numbers are recommended (Moore & Hollett, 2003). As well, the in-depth and nuanced analysis of the transcripts needed for IPA requires smaller samples numbers, typically between five and ten cases (Smith, 2004).

There were also special considerations required for conducting interviews with individuals with dementia. According to Moore and Hollett (2003), it is important to monitor these individuals for signs of distress, fatigue, and desire to withdraw assent from participating; however, this must be balanced with the desires of individuals to speak about their experiences even when they become overwhelmed with emotion or feel distressed (Moore & Hollett, 2003). The music therapist and myself both monitored the singers

throughout the singing group and interviews to assess for any of these signs. I believe that my training as a counsellor was helpful in being attuned to the emotional states of the singers, as I engage in that practice daily in counselling sessions. I also endeavored to follow the specific recommendations from Goldsmith (1996) that were designed to help facilitate interviews with people with dementia. These recommendations include listening attentively, accepting the person as they are and approaching the interview with openness to understanding the person and what they are trying to share. I also received helpful direction and instruction from the music therapist, especially regarding the singers' memory difficulties. She shared with me the importance of accepting their understanding of what happened or where they were, even when it was different from my own. For example, when a singer commented that he had missed part of the singing group, even though he had attended the whole session, the music therapist simply reassured the singer that was "okay" and that he had done a wonderful job of singing.

Observations and interviews were chosen because both are data collection methods prescribed for use with IPA (Smith, 2004). The observations were important because they helped to describe and understand the context in the study was situated with and provided integration between my perspective and those of the singers. The interviews provided the medium through which the experience and perspectives of the singers were explored. The interviews also allowed the singers to verbally express their feelings, impressions and thoughts about their experiences and were flexible enough to allow for new directions to emerge as the interview progressed.

Data Analysis

IPA does not have a single prescribed method for analyzing data but is instead characterized by a set of common practices and principles (Smith et al., 2009). Smith (2007)

described the entire analytic process as an iterative and inductive cycle, where one step or level of analysis often results in a reflexive return to a previous step or level with new understanding or insight.

For the data analysis, I followed a six-step process recommended by Smith et al. (2009) for IPA. The first step included a detailed examination of each transcript with analysis focused on the experiential claims, concerns, and insights of that participant (Larkin, Watts & Clifton, 2006). Each transcript was read twice, including listening to the audio recording while reading the transcript. This purpose of this step was to immerse myself in the world of the participant, to understand the overall flow and structure of the interview, and to begin to locate the rich and detailed portions of the transcripts.

The second step included an initial examination and analysis of language and semantic content in the transcripts. A detailed commentary was created for each interview, with descriptive, phenomenologically focused comments that endeavored to stay as close as possible to the singers' explicit meaning. Three different categories of comments were recorded: (a) descriptive comments that described the content of what the singer had said, (b) linguistic comments that analyzed the specific use of language by the singer, and (c) conceptual comments that engaged with the transcript at a more interpretative and abstract level.

The third step involved expanding and establishing the themes that had begun to develop from the data. This required re-organizing and grouping portions of the transcript into coded theme groups, accompanied by their exploratory comments.

The fourth step included searching for connections across the emergent themes within each individual transcript and grouping similar themes together. I used several strategies to

identify these patterns and connections including abstraction, subsumption, polarization, contextualization, and numeration. Abstraction involved creating new super-ordinate themes and grouping others under that title. Subsumption occurred when one emergent theme became a super-ordinate theme itself and other emergent themes were grouped under it. Polarization involved examining the transcripts for opposing themes or looking for the differences between themes. Contextualization involved connecting themes to a particular context, narrative moment in the transcript. Numeration represents the number of times a theme occurred in the data and helped to uncover major themes or those most relevant to the singers.

Steps one through four were completed for one transcript prior to moving on to the next. This allowed bracketing by limiting the influence of themes identified from previous transcripts. In the final step of the process, I grouped recurring or similar themes across the six transcripts to create super-ordinate themes.

The videotaped sessions were then analyzed using the observation data checklist adapted from Davidson and Fedele (2011) (Appendix F). The checklist was developed specifically for use with individuals with dementia participating in a singing group and focuses on positive elements such as engagement, interaction, participation, and mood. The observational data gathered from the videos was then integrated into the theme descriptions described in chapter four. Often, the observation data provided powerful illustrations of the themes created from the analysis.

The analysis was then written up with two purposes in mind. The first purpose was to give an account of the data, to help the reader get a sense of what the data were like. The second purpose was to offer my interpretation of the data, representing each man and his

experiences to the best of my ability in an expressive text and providing explanations of my interpretations.

Establishing the Quality of the Research

Yardley (2000) provided a set of criteria to assess the value and validity of qualitative research, particularly within the area of health psychology. The diversity in methodologies and epistemologies used in qualitative research make it a challenge to create criteria that apply to each unique approach. Despite these challenges, Yardley lists four criteria areas, which she notes are open to flexible interpretation and variance in criterion fulfillment (2000). These areas include sensitivity to context, commitment and rigor, transparency, and coherence, and finally, impact and importance.

Sensitivity to Context. Yardley (2000) wrote that good qualitative research should demonstrate sensitivity to context, which can be established in several different ways. First, there is sensitivity to the context of established theory and to insights gained from previous research in the same area or employing the same methods. In demonstrating sensitivity to this aspect, a thorough examination of research exploring dementia and music was conducted (as demonstrated in chapter 2). Through this examination, I discovered the need for qualitative research that focused on the first-hand perspectives of individuals with dementia, and that enhanced their personhood. These needs served as the rationale for choosing IPA as a methodology and personhood as a research framework, demonstrating a sensitivity to the context of current dementia research. Smith et al. (2009) in his commentary on Yardley's criteria commented that selecting IPA as a research methodology can demonstrate sensitivity when there is a need for "close engagement with the idiographic and the particular" (p.180), which I believe was required for exploring the perspectives of individuals with dementia.

Additionally, Smith et al. wrote that sensitivity to context can be demonstrated through conducting an excellent IPA interview; which requires empathy, ensuring the participant is comfortable, recognizing interactional difficulties, and acknowledging the participant as an experiential expert.

I believe this study did produce interviews that demonstrate the above-mentioned qualities. Being a counsellor, I endeavoured to show the singers the same empathy and unconditional positive regard that I show to my clients. I also searched out quality information on interviewing individuals with dementia, written by experienced researchers (Digby, Lee, & Williams, 2016), written by an individual who themselves has dementia (McKillop & Wilkinson, 2004), as well as articles on accessing the experiences of individuals with dementia (Nygård, 2006). I also met several times with the music therapist who facilitated the sessions and knew the participants well, to learn about the personalities and unique needs of each singer in the group. This helped to ensure that I could put each person at ease throughout the interviews. Sensitivity to the data, that is, the accounts of the participant, is also highlighted by Smith et al. (2009) as a way of fulfilling Yardley's criteria. This sensitivity appeared throughout the written analysis of this study, by using a considerable number of direct quotes from the singers and by presenting my own interpretations cautiously and respectfully.

Commitment and Rigor. Commitment to the research is demonstrated through a prolonged engagement with the topic, development of proficiency in the research methodology, and immersion in the generated data (Yardley, 2000). The current study was developed over the course of two years, spent reviewing relevant literature, meeting with key staff at the research site, observing music therapy sessions, and developing as a skilled and responsive interviewer. I believe this demonstrates a commitment to the research topic and I

personally felt strongly about developing my skills as a researcher and interviewer, so that I could honour the individuals with dementia participating in the research. Throughout the data generation and analysis phase, I endeavoured to follow the guidelines of the chosen method closely and committed to engaging deeply in the analysis process.

Rigor can be thought of as the thoroughness of the study, from how the sample matches the research question to the completeness of the analysis (Smith et al., 2009). In the current study, the research question focused on exploring the experiences of individuals with dementia living in a special care home as they participated in group singing sessions. I believe the sample fit very well with the research question, as demonstrated in the *Singer Recruitment and Selection* section of this text. Yardley (2000) noted that rigor could be demonstrated through triangulation of the data, which can include collecting data from multiple sources. In the current study data was collected through history interviews, observation notes, videotaped observation of sessions, and individual interviews with the singers. Finally, rigor was demonstrated throughout the analysis and write-up by moving beyond a simple description of what was said or observed to sharing my interpretation of the data and supporting that interpretation with direct quotes (Smith et al., 2009). Providing direct quotes ensured that the interpretations are grounded in the narrative of the singers (Stiles, 1993); giving readers the ability to determine how true the interpretations are to the original source.

Transparency and Coherence. Transparency is described by Yardley (2000) as “the degree to which all relevant aspects of the research process are disclosed” (p.222), this includes detailing the data collection process, steps of analysis, and presenting excerpts of the textual data (i.e., direct quotes) for readers; all of which is included in the *Methods* and *Findings* sections of this text. Disclosing assumptions is another important aspect of

transparency, also referred to as trustworthiness by Stiles (1993). To be transparent I also included a discussion of my own background and assumptions in the *Researcher Background* section and a reflection on my own experiences of the research process in the *Discussion* chapter.

Coherency refers to the congruency between the research study and the theoretical assumptions of the selected method (Smith et al., 2009). IPA, the chosen method for this study, requires attention to first hand experiences of the participants. So, rather than seek out perspectives of the singers' caregivers or even the music therapist facilitating the sessions, I interviewed the singers directly. Interviewing the singers also aligned with the chosen research framework of *personhood* (O'Connor et al., 2007), for which a main domain of inquiry should be the subjective experience of individuals with dementia. Finally, in aligning with IPA methodology, I sought in the write-up of the findings to bring awareness to the idea that I was attempting to make sense of the singers making sense of their own experiences and offered my interpretations with caution and sensitivity.

Impact and Importance. The most crucial criterion of Yardley's (2000) characteristics of a quality study is the impact and utility of the research itself. Yardley also commented that the impact and importance of research should be assessed in relation to the research objectives, the functions it was designed for and the target community who could benefit from the research. The focus of the current study was to explore how individuals with dementia experience group singing and well-being; more broadly the study aimed to address the scarcity of qualitative research involving individuals with dementia by engaging them in research that promoted their personhood and provided them with an opportunity to add their mark on the academic landscape. The function of the research was to explore how person-

centered care practices enhance well-being and personhood, specifically music therapy, and to demonstrate that individuals with dementia can directly contribute to research in a valuable and significant manner. I believe that the current study fulfilled both the focus and function described, both in data collection and analysis; the group singing sessions provided the singers with an opportunity to participate and create, the interviews gave them a platform to share their perspectives and feelings, and the analysis generated valuable and novel insights into why group singing promotes well-being. The target community for this research was individuals with dementia, music therapists, care home staff, and dementia researchers, and I believe that the implications and applications discussed in the *Discussion* chapter provide these groups with valuable, applicable insights.

Good qualitative research should also emphasize research-in-context (Yardley, 2000). In the current study, I participated in the group singing sessions prior to conducting each interview; allowing me to be part of the experience that the singers were reflecting on. I believe that adds credibility to my interpretations and allows me to pinpoint the specific elements of the singing group that were particularly beneficial and effective in enhancing well-being.

CHAPTER FOUR: FINDINGS

The goal of this research project was to give a voice to individuals with dementia and hear in their words and from their perspective, how they experience music therapist led group singing in a residential care home. Data were collected through brief history interviews, observation notes, researcher participation, video observation and six semi-structured interviews. The data were then analyzed using an observational checklist (Davidson & Fedele, 2011) and IPA. The analysis process produced six themes and three subthemes that are presented in this chapter. These themes are explored and representative excerpts from the transcripts are included. Select excerpts have been placed inside quotation marks and were edited to ensure comprehensibility and anonymity of the singers. Text unrelated to the topic of this research were omitted, as well as filler words such as “ummm” and “uhhh,” which were instead represented by an ellipsis (...). Added words needed to provide readers with additional context were denoted in square parenthesis. At times the language structure of the singers did not follow typical English language rules or words were repeated; however, to honour the voice of each singer, these structural language differences were not altered in the edited excerpts.

The following section describes and characterizes each of the singers. Following this, the findings are presented thematically and the chapter is concluded with a summary of the findings.

Introduction to the Singers

All the singers were male and residents of the special care home in their late 70's to early 90's who were identified by the music therapist as individuals who enjoyed music and had moderate to severe dementia. Many of the singers had participated in choir growing up or

had previously performed in professional singing groups or bands. The music therapist invited these individuals to participate in the research project due to their familiarity and enjoyment of singing. All the singers have been given pseudonyms to protect their identity. I chose the pseudonyms for each singer based on a famous musician that I felt captured an aspect of their personality or singing style.

Louis. Louis is a 79-year-old man diagnosed with moderate dementia. He was a trumpet player for a regionally well-known dance band that played a wide variety of music genres. He enjoys and appreciates music and reminisced about his trumpet playing days. He brought a wonderful energy to the singing group and would often keep rhythm with his hands and feet, clap after songs, and sing out “oh yeah oh yeah.” Louis also has a natural boyish glee and would often dance and make jokes to other singers. His enjoyment and sense of performance was also clear during his time in the group and I got the sense that he very much enjoyed performing music for others. I named him after Louis Armstrong, the famous trumpet player because they played the same instrument but also because of his incredible “stage” presence, just like Armstrong’s.

Leonard. Leonard is an 86-year-old man diagnosed with moderate vascular dementia. Leonard has a French-Canadian heritage and grew up with music in the home. He enjoys playing both guitar and piano and still plays several songs on both, particularly French guitar songs. The music therapist shared that he and his wife often play and sing together and perform for the community talent shows at the care facility. Leonard was the harmonizer in the group and had a beautiful ability to sing with others. His manner was reserved, serious and straight forward. I got the sense that music was just a normal part of his everyday life, something casual that, in his words, one did on a “sunny afternoon.” I named him after

Canadian musician Leonard Cohen, as he reminded me of the casualness Cohen exuded as he sang his famous song “Closing Time” (Cohen, 1992).

Gord. Gord is a 78-year-old metis man diagnosed with advanced vascular dementia. The music therapist shared that Gord often experienced significant agitation that was reliably alleviated through music listening and music therapy. Gord has enjoyed singing throughout his entire life and especially loved dancing to music. In the group Gord was quiet and reserved, and would sing quietly to the songs. During the interview Gord’s speaking was slow and effortful, but always thoughtful, deep, and insightful. He often had a difficult time finding the right words and as an interviewer I tried to listen closely and aid him when possible. Gord was named after Canadian singer Gord Downie, frontman for the Tragically Hip, as they both have a poetic ability and rock/alternative vibe.

Johnny. Johnny is an 85-year-old man with advanced mixed dementia. He is a retired farmer who had been able to fix anything and everything. Johnny also experiences significant agitation and is often comforted through music listening and music therapy. Johnny grew up with music and especially enjoyed listening. He had a very calm and gentle presence in the group and would often nap during singing sessions. During the interview, Johnny required support in communicating and I endeavored to listen carefully and facilitate his sharing. Johnny was named for American singer-songwriter Johnny Cash. Cash was known for his deep, calm baritone and Johnny’s calming manner and country upbringing reminded me of the country legend.

Jerry. Jerry is an 86-year-old man with moderate unspecified dementia. Jerry grew up singing and had been taught singing and piano from a young age. He also sang in choirs and shared that he enjoyed singing and dancing. Jerry was the “host” of the group and was very

friendly and charismatic. He would often go to stand near the music therapist and the piano and would come over to talk with me during the singing sessions. He also loved to share music with other residents and would often stand near the entrance to the singing room inviting passersby to come and join in the singing. Jerry was named for Jerry Lee Louis, an American singer-songwriter and pianist, known for being rock and roll's first great wild man. Jerry was certainly the life of the party in the singing group and his outgoing energy reminded me of Louis and his famous song "Great Balls of Fire" (Blackwell & Hammer, 1957).

Tony. Tony is a 92-year-old man with moderate vascular dementia. He had served in the Canadian military and this was evident through his manner and bearing; he is proper, conscientious, and well spoken. Tony grew up singing with his mother and had been part of performing choir groups throughout his life. He has a love of and "appreciation for" music and was very attentive during the singing sessions. He attended all the sessions and put a great deal of effort into singing along and being on key. During the interview, he shared how important music had been to his parents and he continued to place a great importance in music as he grew up. He was named for American crooner Tony Bennett. Both Tony and Bennett were refined and gentlemanly, and Bennet also served in the American Military.

How Individuals with Dementia Experience Group Singing

In using IPA as the analytic lens, the experience of the singers needed to be explored in its own terms (Smith et al., 2009). It is recognized in IPA that "access to experience is always dependent on what the participant tells us about the experience, and that the researcher then needs to interpret the account from the participant to understand their experiences" (Smith et al., 2009, p.3). Following that model, I analyzed and interpreted the singers' narratives and several recurrent themes emerged. As additional levels of analysis were completed, these

emergent themes were clustered, merged and subsumed, resulting in six themes and three sub-themes. These themes did not appear in the narrative of all six participants, but each occurred for a minimum of three participants. Figure (4-1) on the following page provides a graphic representation of the themes and sub-themes.

The themes that emerged described three different aspects of the singers’ experiences of group singing; (a) how they experienced themselves, *self as a performer* and *self as part of the group*; (b) how they experienced the music, *live music is special* and *music is a gift*; and (c) how they experienced the impact of dementia and music on themselves, *gaps in time, memory and ability* and *the music is still there*. Within the theme of *the music is still there*, three sub-themes were constructed: *identity*, *memory*, and *ability*. The following section provides an explanation of each theme, illustrations of the themes in the singers’ responses, and my interpretations of their meaning.

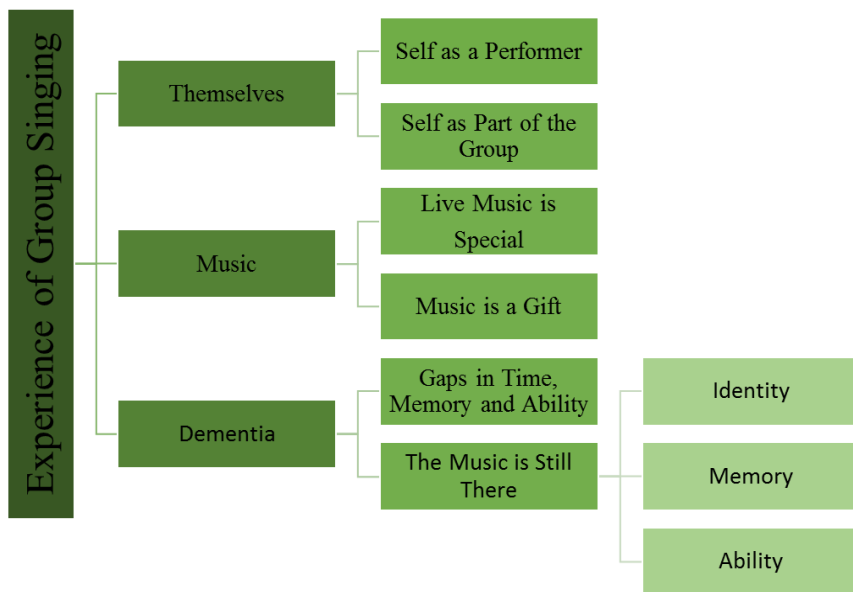


Figure 4-1. Experience of Group Singing: Summary of Themes and Sub-Themes

How They Experience Themselves

Two of the themes that emerged from the interviews centered on how the singers experienced themselves within the singing sessions: *self as a performer* and *self as part of the group*. Within both themes, the singers' experience of themselves was relational in nature, as self-in-relation to others. In the first theme, *self as a performer*, they saw themselves as performers in relation to an audience. In the second theme, *self as part of the group*, they experienced themselves in relation to the other group members.

Self as a Performer. Performance can be thought of as an act of entertainment, usually musical, dramatic, or physical feats, presented for an audience or group of people. The music therapist and I chose to call the singing group a choir, usually described as a group of singers. Many of the singers in our group previously belonged to various bands and choirs, so the choice of the word *choir* may have evoked ideas or thoughts of the group being one that performs. This theme of experiencing *self as a performer* emerged throughout the singing groups and in the conversations after the sessions. This was especially true of the singers that had been part of performance choirs and bands, like Louis, Leonard, and Tony. I had the sense that performing was a source of great enjoyment, joy, and pride for these men.

During the sessions, Louis, would keep time through clapping, tapping and humming. He brought a wonderful energy to the group and would often end the songs by singing out "Oh yeah, oh yeah," reminiscent of a jazz artist singing out his enjoyment of a song as it concluded. As he did this he would look around, smiling at the other singers, taking in and enjoying their reactions to the song. During the interview when asked by the interviewer if he had a favourite song he hummed "Ob-La-Di Ob-La-Da" (Lennon & McCartney, 1968) and as he finished he clapped his hands and exclaimed "There!" He didn't simply share the name or tune of his

favourite song but instead performed it for the music therapist and later in the interview he hummed a medley of “Merrily We Row Along” (Tobias, Mencher, & Cantor, 1935) and “Good Night Ladies” (Christy, 1847) and concluded the song with clapping, laughing and another exclamation of “There!” His musical talent and ability were evident, as was his enjoyment of sharing his ability with others.

When I referenced his role of singing and keeping the beat in the group he responded: “That's what I did and I thought it was good for everybody and that's what I did.” I felt he had a sense of accomplishment in his singing and it resulted in part from performing for others. He shared that when he sings he “did the best I can, I was happy that I did.” Louis went on to say “It gives it other people as well, if they hear, they can listen to the music that you don't get that everyday anymore.” He identified music as something special for someone to hear and saw himself as a performer facilitating that experience for others.

Leonard was another singer who had spent a great deal of time performing music in his life, specifically on guitar. The music therapist shared that he and his wife would often perform together in the care home talent shows, playing guitar, and singing French songs. During sessions, he was very engaged and observant, listening carefully to the music therapist and harmonizing as he sang. As we reflected on the sessions together I commented that many people in the unit had heard our group singing and Leonard suggested that “Well, maybe we can... entertain somebody?” Leonard had a much more reserved approach to performance than Louis and I got the sense that he preferred to perform background music, where people could still enjoy but where he wasn't in the forefront. When the music therapist responded that the choir was “pretty good” and suggested that maybe they would perform, Leonard casually responded “Well something to do on a sunny day.”

Tony also shared parts of his experience in the group that reflected his views of self as performer; when discussing how singing in the group had made him feel Tony shared “That I had paid more attention, I'm not singing at my best.” When asked why, he responded, “I have to get the feel of what's coming in order to come in at the right time and all that.” Singing well as a group was an important part of the experience for Tony and had an impact on how he experienced the group. As we sang together, he watched the music therapist attentively and the effort he put into singing showed in his demeanor and in the quality of his singing.

When asked how he felt after singing with the group he remarked “If it was successful and everybody did their share it's a great feeling.” For him how he felt about the group that day depended on how well he thought the choir sang. He evaluated the group as whole, as a performer would within the singing group they belong to. When asked how he felt after the group finished for the day he shared that “It was a good meeting or whatever you want to call it...yeah and I think it went very smooth.” His enjoyment of the group came from a sense of accomplishment from singing well and sounding pleasing to himself and others. When asked if singing brought him any joy, Tony replied “It's either... pleasing to you and the crowd, which you can tell and... if there's been a goof you know it.”

Self as Part of Group. The concept of “group” was a central focus of this research project and I had expected the group context to be an important piece for the singers. It was interesting to observe the difference between the singers before they joined the group and then as they were singing. When the music therapist and I would walk into the care village, the singers would often be sitting at tables and chairs or in their own rooms and interaction between themselves and other residents would be minimal. As we invited singers to the

singing room and everyone took a seat, they would begin to interact with one another, the music therapist and myself.

One salient interaction occurred between Louis and Tony, where Tony complimented Louis on his singing. On hearing the compliment Louis clapped and exclaimed “You mean I made you wow?” They smiled and laughed together and it was clear that both immensely enjoyed the exchange. Jerry was another singer that enjoyed interacting with others, especially women. He would often walk around the group as we sang and would talk with the music therapist and myself. He would stand at the threshold of the singing room and invite passersby to join the group. I got the sense that Jerry loved to host parties and socialize and his role in the group was certainly that of a host.

For some singers just seeing others appeared to be a therapeutic part of the experience. Louis had shared that the music was helpful to him and when asked how it was helpful he replied “Oh to sit and listen to the playing and seeing the people here.” Later in the conversation Louis expressed his thankfulness to be part of the group “Thank you for doing these things. I was lucky to be able to get to play with them” and again “Oh that just made me really happy, especially playing on the side. I just enjoyed being able to sit in”.

In his own style, Leonard described the group casually, sharing that the group was “Something to do...it’s a good pastime” and “A little gathering... and a chit chat a little bit”. Following this when asked if he felt he belonged to the group Leonard stated the following in a no-nonsense tone “I guess I’d have to say yes. When you go, and join a singing group that’s what it is, you, you belong to a group [laughter].” When asked how he felt when he sang with the group, Leonard responded “Well if you join the group, if you volunteer to join the group and it works out more or less, you know you try again and after a while you figure well maybe

that's a good idea.” As with his other descriptions of his experience, Leonard depicted the setting and group as relaxed and familiar, and I got the sense that he was comfortable as part of the group. When asked if he would like to come join the group again Leonard shared that “It would be nice, a little gathering. You know it's something to do... all you need is people you don't mind talking to.”

When asked if singing in the choir made him feel he was part of the group Gord replied “Oh very much so.” When the music therapist commented that all the voices were important to hear, Gord agreed “Well each person that has to take...each person has a special part.” This was very true of the group, each person had their own function, position, and special place. Gord was often quiet and reserved, but his own account of his experience indicates that he experienced a special place/role within the group. Later in the interview Gord shared that “It was nice to be part of the...choir...and to be all and be part of...” When the music therapist offered the suggestion of “group?” Gord responded “Oh yea!”

How They Experience Music

As I reflected on how the six themes fit together, the theme of *live music is special* and *music is a gift* connected on how the singers experienced the music. For the theme of *live music is special*, the singers spoke about the effect of live, co-created music as well as the symbolic, representative power of the piano. For the themes of *music is a gift*, the singers described music as a treasure for themselves as well as something valuable that they could give to others.

Live Music is Special. There is a special quality to live music and instruments, and those creating the music directly experience this quality. The music seems to have a reciprocal relationship with makers, where it is created and influenced by the maker, but then in turn

influences the maker as they hear the collective sound and continue to sing the song. The music becomes alive and each person singing contributes to the life and movement of the music. This living and influential nature of the music was described by Gord, as he shared about how the music made him feel, “Well there’s...it goes along, makes you move.” Jack also spoke to the special qualities of live music; in response to a question about how live piano was different than recorded piano, he commented that “It’s live. It’s raw.”

Since singing and music making has a reciprocal and continually unfolding and developing quality, it requires makers to listen, process, and create, which requires effort and attention. I believe that the act of creating live music requires engagement, which was reflected in Tony’s transcript when he shared that his favourite part of singing with the group was having “A third ear to hear what we’re singing” and how “the choir helps” this to happen. Although he didn’t share the specifics, Jerry shared that his favourite part of the group was “Just singing with them” and that singing “was the key part” of music. About singing together Louis commented that “Yea, it’s nice, it’s singing, it’s sure. I’m just happy, the more in there the better we had...the more people... I loved it, to listen to it.” These texts show how the singers were engaged in different ways, either through singing, listening or both. Gord also shared his experience of listening to the group harmonize together:

Gord: Well it just felt that all the people were singing were, it was... true... it just felt like it all people were...

Interviewer: It felt that all people were...what did it feel like?

Gord: Well they were true... and then and then everyone just...and that it just came from each coming from each person and it went and...

Interviewer: So, I think what I heard you saying there Gord is that it felt very true coming from every person.

Gord: Oh, very much so.

Interviewer: Yea, is that what you meant?

Gord: [nods]

Gord spoke about how the harmonizing came from each person in the group and his use of the word “true” speaks to a genuineness and authenticity that comes from singing live together. When singing live, one does not have time to pre-meditate a response but instead reacts in the moment to what they hear, creating a space for singers to be more true and real. Perhaps Gord felt that the singers could be their true selves as they sang together because they could access and demonstrate their talents and abilities that normally went unseen and untapped. In the context of dementia, many of the men experience a loss of abilities as the disease progresses, yet singing remained, and in singing they could show a true part of themselves.

Another important element of the live music was the piano. Again, and again the piano emerged as a focal point, an important piece of the singers’ experience. Louis was sharing about his enjoyment of the group and then spoke specifically about the piano “Especially with that [points to piano] thing playing. Boy that that machine, it’s such a nice machine. Just works in there like a real big one” and “Just looking at that piano is something else.” Other singers, such as Jerry, seemed drawn to the piano. He would often walk over to the piano during singing and at times asked to play on it. Jerry also shared that “I liked to play the piano when I was a little kid.” The singers identified and related the piano to music making and past musical experiences. The piano also had a wonderful fullness to it and Gord shared that sitting next to the piano “gave you...that feeling that it was just more than one person.” In this, the piano may

have added fullness or possibly was the connecting factor for all the voices singing together. The piano provided the framework that everyone layered their voices upon.

Music is a Gift. Gifts are something that are given and received to bring joy or happiness to both the giver and the receiver. In that sense, the singing sessions seemed to be experienced as a gift to the singers, as the sessions brought enjoyment and joy to the singers and they expressed their gratitude for the impact of singing on them.

The theme of enjoyment was strong in all the interviews; Louis shared that he felt the singing was “Beautiful, lovely” and when asked if he enjoyed the group he responded “Oh, I loved it! I did appreciate it, it was enjoyable, very much.” Everything that Louis did was big and expressive and his enjoyment of the music shone clearly through the sessions with his clapping and smiles, as well as in his interviews. Other singers were more reserved in their descriptions but Johnny shared that he had “a good feeling” when he finished singing and Gord responded that the singing “was just great.”

The singers also shared the ways that the gift of music impacted them. Louis said that the music “It was something... It helped me” and “Well, it made me feel perfect.” He also shared that the most helpful part of the music was “To sit and listen to the playing.” Not only did he feel the singing had impacted him positively, he also commented on how important the music was to others in the group:

That's really a big thing for those same people that are there as well, being able to listen to the people that are playing, that makes it just that much nicer for the music...It gives it other people as well, if they hear, they can listen to the music that you don't get that everyday anymore.

In the passage above, Louis highlighted that the music is made nicer by having people to listen to it. This comment reminded me of gifts because when a gift is received with joy, the giver also experiences reciprocal joy. Louis seemed to experience himself as both a giver and a receiver of this gift of music.

Gord gave a particularly evocative response when asked how the singing made him feel:

Gord: I had...I felt and I felt a hole in my heart was.

Interviewer: You felt a hole in your heart was.

Gord: Filled...I felt whole hearted then.

Interviewer: Did you say "you felt the hole in your heart was filled and felt whole hearted?"

Gord: Oh yea.

Gord seems to describe the music as something that fills and completes holes that have existed in his heart. In the context of dementia, I wonder if these holes represent gaps in memory or ability and the music represents a filling of those holes by allowing singers to access their ability or meaning that they gain from singing. I also saw this idea of being made whole by music in the words of Louis when he reflected that the music had "made me feel perfect."

Music is a well-known relaxation and calming tool and in response to the singing group Jerry shared "Well I'm more relaxed" and that "not many people realize that [music is good for relaxing us]." While relaxation didn't come up in Johnny's interview, he often had a look of relaxation during sessions and at times would nap during the sessions. The music therapist shared that he was often restless and music was something she would use to help soothe and relax him.

During the sessions, the singers were usually engaged and watched the music therapist the entire time. They never gave the indication of just waiting for the session to be over or that they were focused on other thoughts or tasks. They were engaged and in the moment. There was a sense that this gift was unique and evanescent, that they should pay attention because the moment would not return. Louis characterized this quality of the group with his comment that “I would never ever get another one like that, like that we did today.” I found this comment very poignant in the context of dementia. I wonder if Louis himself has an awareness that he may not remember this experience tomorrow and that reality makes the moment and experience so much more valuable.

How They Experience Dementia

The final category of themes focused on how the singers experienced dementia in the context of the singing group. The first theme was *gaps in time, memory, and ability*, which emerged from the singer’s descriptions of how they were unable to recall certain aspects of the groups or were unsure of their ability to sing. The second theme of the *music is still there* was a redemptive contradiction to the first theme, in that singers spoke with joy of their *identity, memory* and *ability* that remained, despite the loss they experienced from dementia.

Gaps in Time, Memory, and Ability. Some of the themes that have been discussed thus far, such as *music is a gift* and *self as a performer*, are themes that could likely be found in the experiences of singers or singing groups. Elements contained in these themes, such as enjoyment and performance, are more universal for singing and it would be unsurprising for those themes to emerge when exploring the experiences of a singer. For singers with dementia however, there are unique themes that emerge, themes that would not be ubiquitous among

singers. One such theme is that of *gaps in time, memory, and ability*; experiencing time differently, and with difficulty or doubt in accessing musical memory or ability.

Throughout the interview with Leonard it became clear that he had a different experience of time on that day. Leonard experienced himself as coming late to singing and shared this throughout the interview. When asked what, he thought about as he sang he shared “Well I was. I wasn’t, I was late.” Later in the interview he commented that he had missed certain parts of the singing with “No, I missed that part I guess” and “Well I missed most of it I guess hey?” Johnny also had gaps in time and difficulty recalling his experiences of singing. When asked how singing made him feel he responded that “I never heard of it.”

Another common gap in the group was difficulty accessing feelings. All the singers were asked how they felt when they were singing with the group. This is a difficult question because of the abstract, figurative nature of emotion and feeling. In general, accessing and describing feelings and emotions can be a difficult task and with the added dimension of dementia it can be even more difficult. Johnny simply shared “Well I don’t know” when asked about his feelings. Jerry in his usual direct and humorous manner exclaimed that “I didn’t pay any attention to the feelings” and “Damned if I know [how singing made me feel].” In Jerry’s specific case, I don’t believe that dementia was the main factor in his inability to identify or share feelings. I got the sense that he was a more straightforward and literal individual and that he didn’t often attend to feelings. Tony was able to share that he had enjoyed singing but was unable to describe his feelings or why he had enjoyed it “Yes, yep. But I can’t... say why or anything but it was good.”

A response that was common among all the singers was “I can’t remember.” For some it was in response to questions about their favourite songs, how they felt when they sang, or what

they thought about when they sang. For some singers, this response reflected their reality, being unable to access or speak out their favourite moments or songs. For others, I believe it may have been a response they gave when they were unsure of their ability to speak correctly, with the right words or to complete a task properly. During his interview, Louis hummed a tune that the music therapist was unable to identify immediately. When asked to hum it again Louis responded, “I’d do it if I knew I could.” I wondered if this meant that he only wanted to hum the tune if he knew he could do it well or completely. I think this is a reasonable and common response that any person would have if asked to display an ability they were not completely confident in.

When the singers shared about their gaps in time, memory, or ability, it was important that both myself and the music therapist affirmed and agreed with them, instead of correcting or challenging them. This is not only an important aspect of dementia care, but also the Eden Alternative care model. I believe this practice also aligns with the philosophy of phenomenological study, in that each person has unique experiences and experience cannot be invalidated simply because it is different from another person’s experience. Both myself and the music therapist would respond to singers that it was okay that they couldn’t remember and would simply ask about another aspect of their experience. It was important for us to not disagree or discount a singers’ experience of the group, even if it was different from our own.

The Music is Still There. The theme of *gaps in time, memory and ability* speaks of loss and missing pieces, which is part of the reality and experience of individuals who live with dementia. At times in the group, interviews, and analysis it was difficult to acknowledge this theme, because it brought up feelings of sadness and grief for me. It was heartrending at times to engage with these beautiful individuals, knowing that they were dealing with a very

challenging diagnosis, that made it difficult to remember who they were, where they were or how to communicate. I felt grief for the loss they and their families experienced due to dementia.

However, in the face of this sadness and difficult theme of *gaps in time, memory and ability*, a polar theme began to emerge, one that illuminated the music that remained. As I spoke with Louis about the memories that the music had brought forth he spoke out a particularly poignant statement, “Well it’s amazing the music is still there.” As I read and reflected on that statement during analysis I knew that it was the keystone passage for this research project; it characterized my entire hope and supposition for this project, that even with the loss caused by dementia, music remains and is a powerful therapeutic force in the lives of those living with dementia. Louis seemed to recognize that it was remarkable that he was still able to recall musical memory and ability, when so many other areas of himself were difficult to access. This recognition further emphasized the gift that music is to individuals with dementia.

As I participated, observed the group, and spoke with the singers, it became more and more apparent that each had music within them. Not only did they have music within them, but the music itself served as a type of remembrance and was recalling their own abilities, identities, memories. The music was evoked and awakened within them and filled in the gaps left by dementia. As I further explored the theme of *the music is still there*, I found three interconnected subthemes: identity, memory, and ability.

Identity. Identity is defined as “The sense of self, providing sameness and continuity in personality over time” as well as “Condition or character as to who a person or what a thing is; the qualities, beliefs, etc., that distinguish or identify a person or thing” (“Identity”, 2015,

para.5). For individuals with dementia it can be difficult to maintain this sense of self due to the diminishing ability to recall memories, including personal experience, events, and general knowledge of world and self. However, as the singers engaged in singing, they could remember lyrics and past events, and could experience a part of their identity again.

As I spoke with Louis after the singing session he shared with me that “I did a lot of that for years and years and years.” Music had been a significant part of his life and singing again seemed to bring that sense of identity back to the surface. As we spoke more about his experiences I asked if he could remember playing in a band or singing. Louis responded in this way:

Louis: Years ago...I can't remember these things, what I did.

Interviewer: Sure, sure.

Louis: No, I don't remember anything. But I was there, practically everything I was there. But I played the trumpet.

I found myself drawn to his statement that “practically everything I was there” and I wondered if he was referring to being a trumpet player in a band as practically all his identity. Louis’ trumpet player identity seemed to be a *well-worn sweater* that he slipped into each singing session, something recognizable, comfortable, which fit perfectly. He had a place and an identity in the group and he knew instinctively what it was.

Music also seemed to be an important part of Tony’s identity and he shared that he didn’t have specific memories of music because “I have been singing I think, all my life.” It seemed that music had been part of his life for so long that it was a given, an everyday thing. Tony had also shared that he grew up in a musical family, with his mother playing the piano and the children singing around her, “It was our family, mother loved it when she had it.”

Memory. As has been discussed earlier, musical memory will persist in dementia, even when other types of memory are unable to be accessed. The enduring quality of musical memory and memories created in a musical context possibly allowed the singers to recall and share those types of memories, even when they could not remember names of their loved ones or identify what day it was. Music can also have strong ties to feelings, emotions, and impressions. Although you may not remember the specific tune or a song or even the words, you may still remember the way it made you feel when you heard it or the first time you heard it. This experiential aspect of music also seemed to be important for the singers in allowing them to share their experience of singing.

As I talked with Louis about how music was beneficial he shared that “The memories, the tunes going back for years and years.” The “tunes” seem to be a tie to the past, a way to access the memories, which were still there after all those years. In response to a question asking if singing brought up any memories for Louis he responded “I remember being different things, just, years ago. ” The use of the word being was interesting to me, possibly meaning that he remembered the experience of what he did years ago, how it felt to be in that moment, but perhaps not the specific episodic memory of those times.

Leonard was also able to access some wonderful music memories from his past:

Music Therapist: Who did, did somebody teach you to play guitar, did your mom or dad play?

Leonard: Well I bought the books and ...

Music Therapist: Oh, and then you learned?

Leonard: and then I learned on my own.

Music Therapist: Good for you.

Leonard: Cause I learned when I was a kid too. My brother used to sing and play the guitar too. So, we played together once in a while and I guess I like music you know.

Not only guitar but nice music. To me it's an okay thing.

Leonard was able to recall memories from his past, but he also had difficulty remembering exactly how he had participated in the singing group: "Whatever we did it was [hums], it was okay. It was good." His memory of what we did seemed to be fuzzy, but he still remembered how it made him feel. The humming in the middle of the sentence was also interesting, almost as if he could do what we had just done in the group, but was unable to say what we had done. Tony also seemed to have a similar experience, when asked if he enjoyed the songs that were sung that day he replied "Yes, yep. But I can't umm say why or anything but it was good."

Gord was unable to access specific memories, but when asked if he had any memories as we sang he gave a beautiful, evocative response:

Gord: Oh, for sure I did.

Interviewer: For sure?

Gord: Yes, it was in my heart when I was...

Gord did not elaborate on his response, but his use of figurative language and speaking of his heart invoked the belief that Gord felt deeply as we sang. Gord appeared to have difficulty externalizing his internal world, but when he did I felt I was given a glance into his rich inner experiences and feelings. As I read over the above interview excerpt I found myself longing to know what memory or experience Gord was referring to in his heart.

Ability. Each of the singers brought to the group a capacity to participate and sing. In the video observation, each singer engaged independently in singing for much of the session. All the singers, particularly Louis, Leonard, Jerry, and Tony engaged actively in the singing

sessions and watched the music therapist closely as she led the group through the songs. The result was wonderful to hear as the group would often produce beautiful harmonies; they had a clear ability to collaborate and sing together to produce wonderful sounding music.

This ability to sing also came across in the interviews. As I spoke with Leonard about his favourite song he was unable to remember the name, but when the music therapist prompted him with the first few words he sang out the entire first verse of “Waltz Across Texas” (Talmadge, 1965):

Interviewer: Yeah and did you have a favourite song?

Leonard: I can't, I'm not thinking of one at the present time.

Music Therapist: [hums tune of “Waltz Across Texas”]

Music Therapist: I know your favourite song.

Music Therapist & Leonard: [singing] When we dance together my world is in disguise. It's a fairyland tale that's come true. With your hand in my dear I could dance on and on and waltz Texas with you. Waltz across Texas with you in my arms, waltz across Texas with you. Like a storybook ending I'm lost in your charms and I could waltz across Texas with you. And I could waltz across Texas with you.

Despite being unable to recall his favourite song he could sing the words beautifully.

Although the music therapist sang with him, it was clear that he was singing with her and was not only copying her words. The melody, tune and words of the song had remained within Leonard and it seemed to bring him joy to show his ability to myself and the music therapist. He also had a wonderful ability to harmonize and I commented on this he shared “Well, that harmonizing part sometimes it comes automatically you know...so.”

Louis also enjoyed sharing his musical ability with us during the singing group and in the interviews. He hummed his favourite song “Ob-La-Di Ob-La-Da” (Lennon & McCartney, 1968) and ended the song with a flourish “Hey!” Louis also reflected on his ability to sing in the group and commented happily that “I think I did quite a few of them there” and that “I can still get through of some of them.”

Johnny, of all the singers, was typically the quietest during singing practice, preferring to relax and listen to the music. The music therapist shared that music always helped to relax Johnny when he was feeling upset or agitated, and the relaxing effect was clear during practice. So, although Johnny did not usually participate by singing he did sometimes enjoy humming gently to the music. As we spoke after a session Johnny hummed the tune of a song for us, showing his ability to participate and contribute.

Jerry, in his usual direct manner, often proclaimed “I can sing!” during the singing sessions and later during his interview. He was confident in his ability to sing with the group and this showed both in his action and through his words. During the singing sessions, he participated in almost all the songs, even as he walked around the room and invited passersby to come in and listen to the singing. Singing seemed to come naturally to him and he stated it as a fact.

Tony was another singer who had great ability, an eagerness to participate, and a desire to sing well. Tony also had insight into his own abilities and shared that he was a tenor and that he “could do a wider span than usually.” During the interview the music therapist thanked Tony for his good singing and he responded, “Thank you, you know I have to say it doesn't register in my mind for some reason, I just sang. ” I felt the last part of his statement “I just sang” was a poignant commentary on the ability that remained with the singers, even when

memory did not. His use of words reflects the automatic implicit abilities demonstrated by the singers, the music often came out of them, as it so often had throughout their lives, and that ability was not lost over time.

Summary

The experiences of six male singers with dementia singing in a choir group has been interpreted and described in this chapter. The data were collected as observations, video data and interviews using the structure of a personhood framework and analyzed using IPA. Although I cannot completely understand or represent the experiences of the singers, I endeavored to represent my interpretations of their experiences and express their voices to the best of my ability. This is the purpose of IPA, not to completely experience the inside perspective of the participant, but instead to engage in a parallel interpretive process by deciphering how the participants are interpreting their own experiences (Smith & Osborn, 2003).

Through this process of interpretative analysis six themes emerged: *self as performer*, *self as part of group*, *live music is special*, *music is a gift*, *gaps in time*, *memory and ability* and *the music is still there*. The theme, *the music is still there*, contained three subthemes of *identity*, *memory*, and *ability*.

The participants experienced *themselves as performers*, especially those who had previously performed in professional bands or choirs. This role of performer brought joy and meaning to the singers because they could share music with others, take pride in their abilities, and work together to achieve a goal, which gave them “a great feeling.” In singing together they were also able to experience *themselves as part of a group*; the shared task and goal of singing and performing together brought a sense of togetherness. The opportunity to contribute

uniquely to the group brought a sense of “each person [having] a special part.” The singers also expressed that having *live music is special*, that as each of them sang “they were true.” The interactive nature of producing music together engaged the singers and brought gratification.

The singers also experienced *music as a gift*, a gift that they could give as well as receive. The music was a gift to the singers, because it brought them enjoyment and joy and a gift to others because “they can listen to the music that you don't get that everyday anymore.” The singers also experienced *gaps in time, memory, and ability* as they sang and shared during the interviews. At times, they had a different experience of time, or were unable to recall participating in the group. Interestingly some of the singers could recall how they *felt* about the singing group even if they did not recall the exact memory. At times the singers also doubted their ability to sing or recall lyrics or were unable to access their ability. However, despite these gaps *the music was still there*, and each singer could participate and contribute to the group despite the challenges of dementia. *Identity* in singing remained, providing the singers with a sense of self that endured the loss associated with dementia. *Memory* also remained, memories of musical experiences growing up, memories of lyrics and “tunes going back for years and years.” Finally, *ability* remained, the ability to participate, to harmonize, to carry a beat for the group and to recall their experience during interviews. This ability brought a sense of pride and industry to the singers.

Although the singers in the group had significant challenges due to dementia, each could participate and share about how they experienced the singing group. The themes that emerged from the interviews with the singers provide a valuable perspective on how individuals with dementia experience group singing. Their particular words captured in verbatim quotes are

poignant and meaningful. Overall there was a great sense of hope, even with the reality of dementia and this was best represented by Louis' declaration of, "Well it's amazing the music is still there!"

CHAPTER FIVE: DISCUSSION

The purpose of this research was to hear from individuals with dementia about how they experienced group singing and how singing impacts their well-being. There have been calls in the field to include individuals with dementia more directly in research (Alzheimer Society of Canada, 1997) and specifically for qualitative research exploring the subjective experiences of this population (O'Connor et al., 2007). Although there is a dearth of qualitative research that explores the perspectives of individuals with dementia participating in group singing, there has been promising research indicating that group singing can promote well-being and support personhood in individuals with dementia (Ahonen-Eerikainen et al., 2007; Clements-Cortés, 2014; McDermott et al., 2014). Despite quantitative research that has demonstrated the positive effects of group singing on cognition and memory (Oostendorp & Montel, 2014), quality of life (Camic et al., 2013), and negative mood and behaviours (Lesta & Petocz, 2006); there are critiques commenting on the mixed results of group singing with individuals with dementia (Spiro, 2010) and recently a review by Vink et al. (2013) concluded that there was not enough evidence to support the use of music therapy in the behavioural, social, cognitive, and emotional care problems of individuals with dementia. The purpose of this study was to involve individuals with dementia in research and to explore how they perceived group singing to impact their well-being.

Researcher participation, semi-structured interviews, and video observation were used to investigate the impact of group singing, and three separate areas of experience were identified and explored. The first was how the singers *experienced themselves* in the sessions, which included two themes. The first theme, seeing *self as a performer*, represents how the singers viewed themselves as performers during the music group and how they spoke of the singing

group as a type of performance, where joy was derived from doing well and sharing their abilities with one another and various onlookers. The singers also experienced *themselves as part of the group*; in this theme the singers expressed their special places and unique roles within the group and their enjoyment resulting from having shared experiences with others.

The next two themes both focused on how the singers *experienced the music* and how the music impacted them. The singers experienced the *live music as special*; they described the music as being alive, the authenticity of singing together and the symbolic representation of the piano. The second theme, *music is a gift*, explored how the singers received the music as special, beneficial, and transformative and as something they could give, as well as receive.

The last two themes explored how the singers *experienced dementia* in the context of the singing group. The first theme, *gaps in time, memory, and ability*, represented how the singers had alternate experiences of time, difficulty recalling details of the singing group, and at times, doubted their ability to sing and participate. The last theme, *the music is still there*, explored how the singers, through the singing group, could experience *identity, memory*, and a sense of *ability*. This theme and its sub-themes, best represented the impact of music therapy and its ability to transcend the limitations of dementia. In the following portion of this chapter the findings of the current study are reviewed and discussed in relation to current theory and literature. Following this is a discussion of the strengths and limitations of this study and then implications and directions for future research. The chapter is concluded with a reflection of the research process and final thoughts.

Enhancing Well-being and Promoting Personhood Through Group Singing

The ability of music to improve well-being in individuals with dementia has been documented in quantitative research; showing significant reductions of depression, pain,

aggressiveness, anxiety, and activity disturbances, but also significant increases in mood, energy, happiness, lucidity, and social interaction (Clements-Cortés, 2014; Davidson & Fedele, 2011; Myskja & Nord, 2008). Although there is limited qualitative research on this topic, existing studies report that individuals with dementia experience group singing as creating enjoyment, opportunity, and special moments; challenging beliefs and attitudes about self; facilitating relationship building, growth through learning, lucidity, and memory recall; and increasing motivation and feelings of achievement (Camic et al., 2011; Clements-Cortés, 2014; Davidson & Fedele, 2011). While research has detailed the positive impact of group singing on well-being, it can be difficult to determine what qualities of the group contributed to the positive impact. In this study, the semi-structured interviews did not specifically focus on asking questions regarding well-being, but instead focused on how they experienced music.

However, considering the themes alongside the PERMA model of well-being (Seligman, 2011) revealed that all five elements of the model appeared within the narrative of the singers. Furthermore, examining the themes in relation to Kitwood's theories of maintaining personhood presented in *Dementia Reconsidered: The Person Comes First* (1997a) suggested ways in which the singing group helped promote personhood.

Self as a performer. The singers expressed throughout the interview that they saw the singing group as a performance. They spoke of performing for others and the enjoyment they received from knowing they performed well for the audience. During the singing group, the singers would invite staff or residents to come listen and applaud as songs concluded. In relation to PERMA (Seligman, 2011), singers felt a sense of *accomplishment*, that they could produce music, that others could enjoy. Performing also elicited *positive emotion*, as singers felt joy and happiness through being able to sing for each other and onlookers. The singers

seeing themselves as performers also created *meaning* and value, as they acknowledged that their singing was good for others. The acknowledgment that they could create for others was empowering for the singers and empowerment through group singing has also appeared in other studies (Ahonen-Eerikainen et al., 2007; Clements-Cortez, 2014), as well as in studies examining the general impact of music on individuals with dementia (Skingley & Vella-Burrows, 2010; Sixsmith & Gibson, 2007). This empowerment can work as a powerful counteract to *disempowerment*, one of the processes that Kitwood (1997a) identified as undermining personhood.

Performance necessitates being seen or heard, which in the context of dementia is significant as these individuals are so often unseen in society and *being ignored* is another process that undermines personhood (Kitwood, 1997a). As the singers experienced themselves as visible performers, a sense of *inclusion* was created. This sense of *inclusion* has been identified by Kitwood (1997a) as a core psychological need for individuals with dementia. Kitwood noted that by being seen by others “expands” (p.83) the social life and aspects of an individual with dementia. Seeing themselves as performers enhanced well-being in the singers, as they felt positive emotions of pride and happiness, and as they experienced a sense of *accomplishment* from performing for others. The singing group also fostered a sense of visibility and inclusion, meeting core psychological needs and promoting personhood.

Self as part of group. Throughout the interviews the singers expressed their experience of being part of a group. Many of the singers related group belonging to thankfulness or feeling, as Gord did, that they had a “special part” within the group. During the group sessions, they were referred to as a “choir group” and sat in a circle, so that everyone could see one another’s faces. Some of the participants, such as Louis and Tony, would chat

and make jokes together. Jerry would often walk around the group, performing in the role of host, sometimes inviting others to join the group and sing with him. The experience of being part of the group contains three elements from Seligman's (2011) PERMA model. The singers could engage in *relationships* with other members of the group, not only through chatting and joking, but through co-creating together. Many of the singers also expressed *positive emotion* resulting from being included in the group. Louis expressed happiness and thankfulness to be able to "play with them" and both Leonard and Gord thought it was "nice" to be part of the group. Belonging to the group also created *meaning* for some of the singers, because they each had a "special part" within the group.

A similar theme of community building and making friends was found by Clements-Cortés (2014), who commented that singing the same music together enhanced group cohesion. Kitwood (1997a) identified *attachment* as a core psychological need, and that due to the memory loss associated with dementia, people with dementia constantly find themselves in situations they experience as 'strange', which makes the attachment needs even more essential to well-being. Singing groups appear to provide a unique medium for individuals with dementia to build relationships and strengthen attachments.

Kirkland et al. (2014) also identified themes of social inclusion and noted that the singing group provided individuals with dementia an opportunity to be part of a group in a way that was rarely available to them in their daily life. In the current study, Louis expressed his thankfulness and that he "was lucky to be able to get to play with them," and his choice of the word "luck" reflects his knowledge that this type of group interaction is special. Osman, Tischler, and Schneider (2016) also found a similar theme of social inclusion and support, commenting that group singing, "supports social inclusiveness, as it enables all participants to

get involved, regardless of the stage of dementia” (p.1330). This was reflective of the current study, where dementia severity ranged from moderate to severe and the singers each had their own unique way of participating, by singing, humming, listening, or keeping time. *Inclusion* is another core psychological need of individuals with dementia (Kitwood, 1997a), and being able to collaborate and create with others is considered ‘positive person work’, work that enhances personhood.

Live music is special. The elements of live music and live singing, were identified as a special part of the experience for the singers. They had the ability to create with others in the group, to have influence over what was happening in the moment, resulting in a very engaging experience. The experience of live music and singing contributed to three aspects of the PERMA model: *positive emotion*, *engagement*, and *meaning*. Louis described how singing together impacted him, eliciting *positive emotion*, commenting that “Yea, it's nice, it's singing, it's sure. I'm just happy, the more in there, the better we had...the more people... I loved it, to listen to it.” The live music also facilitated *engagement* for the singers, as they listened carefully to the piano, one another to be able respond with their own music. Gord, described the way that the music engaged him, saying that, “Well there’s...it goes along, makes you move”, talking about the music as if it were alive. The singers also found *meaning* in the use of live piano, often focusing on how amazing it was and how the piano often played a special role in their childhood experiences with music.

While the theme of live music being special was a unique finding in this study, other research has identified related themes and outcomes. Participants from a study by Clements-Cortés (2014) commented that singing contributed to their feelings of well-being, in part because of its energizing qualities. Energization through music was evident in the video

observations of the current study; the singers would often be highly engaged, keeping eye contact with the music therapist, tapping their toes, clapping along, smiling, and laughing. Throughout the interviews, they commented on the ability of music to make them move and the emotions the live music elicited. McDermott et al. (2014) found that the families of individuals with dementia noticed the immediacy of their response to musical stimuli. McDermott et al. commented that a beneficial aspect of music is the ability to impact individuals with dementia in the “here and now”, because it is a highly accessible expressive medium that can allow for emotional expression, creation of meaningful experience and is highly stimulating.

The live music and singing also gave the singers an opportunity to engage in meaningful *occupation*, a psychological need identified by Kitwood (1997a). Kitwood noted that “to be occupied means to be involved in the process of life in a way that is personally significant, and which draws on a person’s abilities and powers...if people are deprived of occupation their abilities begin to atrophy, and self-esteem drains away” (p.83). The live music, which is engaging by nature, required the singers to listen and respond, facilitating occupation, which Kitwood noted promotes self-worth and personal satisfaction. Singing together also required *collaboration*, an element of Kitwood’s positive person work.

Music is a gift. The singers experienced music as a gift, something special that was given to them, but also something special they could give to others. The singers experienced *positive emotions*, an element of well-being (Seligman, 2011) through the music itself, as well by creating for others. Louis described the impact the music making him “feel perfect”. The singers also spoke about how *meaningful* the music was for others: “That’s really a big thing for those same people that are there as well, being able to listen to the people that are playing.”

Being able to create something and share it with others is significant for individuals with dementia, because so often they are not provided an opportunity to do so (Kitwood, 1997a).

Camic et al. (2011) also found that group singers identified the opportunity to do something new and to achieve something, providing them with a sense of fulfillment. In their study the singers also commented on the way the music was important to other people. This element of doing something to help others appears to be an important aspect for the singers. Kitwood (1997a) talks about the importance of individuals with dementia being allowed to create and give, especially because it allows them to take a leading role within a relationship, since individuals with dementia are often on the receiving end of care. In being able to give to others, the singers could facilitate attachment and connection, *attachment* being a core psychological need identified by Kitwood.

Gaps in Time, Memory, and Ability. Along with the positive experiences of group singing, came more difficult elements that had resulted from the loss associated with dementia. In the group the singers sometimes were unable to recall the context for the group or when they had arrived, resulting in an alternate experience of time. During the interviews the singers also had difficulty recalling the experience or other autobiographical information about themselves. Although the singers had difficulty expressing why they enjoyed the singing group or their favourite aspects, they seemed to be able to remember *how* they felt. Tony characterized this well with his response to the question of if and why he enjoyed the group, "Yes, yep. But I can't... say why or anything but it was good." This is a strength of music therapy, the ability to impact individuals with dementia on an emotional level, without requiring them to recall exact events or details. This was also an important aspect of the group

facilitation and interviews, to allow the singers to share their experience, without correction or invalidations.

The singers also expressed perceived gaps in their ability to recall experiences or to sing. This would most often happen in the interviews themselves, rather than the actual singing group. It is important to make this distinction, because the gaps in ability did not appear to be present during the actual singing, only when reflecting on the experience in the interviews. This highlights the ability for music to transcend gaps in memory and ability, allowing individuals with dementia to perform in ways they may not have expected or believed they could do. An event that demonstrates this well was with Louis in the interviews, when he hummed his favourite song and was asked to repeat it by the music therapist he replied “I’d do it if I knew I could.” Clearly the ability to hum the tune was there, but Louis experienced gaps in his memory or ability that may have made it difficult to access the tune. However, shortly after this Louis hummed the tune again, which resulted in positive feelings and a sense of accomplishment. A similar process was described by Ahonen-Eerikainen et al. (2007), where they found singers with dementia went through a three-stage therapeutic process beginning with *dealing with difficult feelings within the therapeutic music group process*. The singers could express feelings of frustration, irritation, sadness, and worthlessness in this stage. Following this stage was empowering experiences, where they could experience pride and surprise in their abilities, and eventually feel what they were doing was worthwhile.

The music is still there: Identity. Following a similar therapeutic process to the one described by Ahonen-Eerikainen et al. (2007) the singers found that despite the losses associated with dementia, the music was still there and they could have *empowering experiences* and *joyful moments*. The singers found *identity* in returning to the roles and

activities of their past, which had included performing, singing, and listening to music.

Tomaino (2002) described the power of familiar songs for reconnecting to self: “Familiar songs become a tool for connecting to seemingly lost parts of the personality by providing a necessary link to the *self*” (p. 390). Familiar songs help to evoke associations between the music and memories, allowing a sense of self or identity to emerge.

The singers found *meaning*, an element of well-being (Seligman, 2011), as they could experience those familiar parts of themselves again. Kirkland et al. (2014) identified the promotion of identity as one of the key therapeutic components of their music therapy group for individuals with dementia, noting that a sense of identity is a main psychological need for this population (Kitwood, 1997a). Identity promotion through music therapy was also identified by McDermott et al. (2013) who noted that music therapy interacts with an individual’s personal psychology, or who they are, because music is often part of an individual’s personal or cultural identity and because it facilitates reminiscence, is familiar, is often linked with life events, and song lyrics are often retained. McDermott et al. also noted that the music therapist can further add to an individual’s personal psychology through musical “positive person work”, which is based on Kitwood’s (1997a) activities that promote personhood and meet core needs. This comment calls to attention that, although music is an important factor of music therapy, the music therapist is equally important. Through interactions with individuals with dementia, personhood can be maintained, added to, or diminished. In the current study the music therapist was well versed in the personal history of each singer and was gifted in positive person work. Her knowledge of personal history allowed her to select songs that would be recognizable and meaningful to each of the singers. She also

engaged in positive person work throughout the singing group by recognizing and celebrating each person, as well as collaborating with them to create music.

The music is still there: Memory. All the singers, even those with severe dementia and limited verbal abilities, could sing and participate in the group. Additionally, the ability of the singers to reminisce and share past experiences appeared to increase following participation in the singing group. After singing they could share more easily about the musical experiences they had growing up. Dassa and Amir (2014) also found that singing familiar songs, elicited conversations about past experiences in individuals with Alzheimer's disease. A similar occurrence was also reported by Tomaino (2002), where participants with late stage Alzheimer's, after listening to preferred music, could spontaneously verbalize fragmented information about their past. Tomaino (2002) noted that in dementia, it is not the memories themselves that have been lost; instead it is the retrieval pathways and access processes that are impacted and that music can provide a way to access those memories associated with a song, including melody and lyrics, but also many rich biographical memories. Being able to recall biographical memories and share their past gave *meaning*, an element of well-being (Seligman, 2011), to the singing group and the interviews.

The music is still there: Ability. The singers in the group demonstrated an ability to sing throughout the singing group, as well as an awareness and pride in their talent and ability. The singers expressed both *positive emotions* and experienced a sense of *accomplishment*, both of which are elements of well-being (Seligman, 2011). Experiencing accomplishment is incredibly important for individuals with dementia, considering they often lack the opportunity to achieve this. Themes of empowering individuals with dementia through music therapy have been found in many other qualitative studies (Clements-Cortés, 2014; Dassa & Amir, 2014;

Gibson & Sixsmith, 2007; and Skingley & Vella-Burrows, 2010). Ahonen-Eerikainen (2007) described the *empowering experiences*, as a significant therapeutic factor in group singing, which promoted self-confidence, self-esteem, and feelings of self-worth. In the current study the singers, through displaying their ability, expressed this sense of confidence when sharing about their abilities or exclaiming, as one singer did: “I can sing!”

Music therapy provides a unique opportunity for individuals with dementia to demonstrate ability because of the preservation of musical abilities. It has been found that some individuals with dementia can recognize familiar songs, recall song elements (lyrics or melody) and sing longer than they remember or respond to other types of information (Cuddy & Duffin, 2005). This preservation is thought to occur because the processes related to music are some of the last to deteriorate in the dementia disease process (Brotons, Koger, & Pickett-Cooper, 1997). Cuddy and Duffin (2005) also hypothesized that because musical memory is incredibly complex, requiring integration of various brain regions, it is less likely to be impacted by deterioration of one area.

Enhancing Well-being

All five elements of Seligman’s PERMA model (2011) were present within all the themes described in the current study. The singers experienced *positive emotions* throughout the singing group, evident by the actions of the group (i.e., laughing or smiling) and through their interviews (i.e., describing positive emotions). These positive emotions were related to several factors including; performing for others, engaging in relationships, feeling included, giving, and receiving gifts, and connecting to the past.

The singing group also facilitated *engagement*, demonstrated through the level of singer participation in the group and the interviews. Music, by nature, is engaging, but two

elements added to the engagement: the live music and singing. The singers shared about the special qualities of live music and how they had to listen carefully so they could sing well.

Relationships were also facilitated through the singing group. The singers connected with one another, the music therapist, researcher, and onlookers who would come to watch the group.

Meaning was present in most of the themes, possibly because singing and music had been a significant part of each singer's life. The singers experienced meaning through belonging to a group, feeling connected to others, creating, and giving the gift of music to others, and finding identity in the songs. The singers experience purpose as they sang together.

Finally, the singers experienced a sense of *accomplishment*, as they engaged in singing and creating together. They utilized and shared their abilities with others, an experience that they valued and celebrated, and likely an uncommon experience for individuals living with dementia and in care. Although the singers did not speak directly on the impact the singing group had on their well-being, by applying the PERMA model to the themes, it became evident that all the elements contributing to well-being were enhanced through the group.

Promoting Personhood

The current study used a personhood research framework (O'Connor et al., 2007), designed to focus on two main objectives. The first is to understand personhood and what it looks like within the dementia experience. The second objective of the framework is to support personhood, and identify ways this is accomplished. Within this framework, research on personhood encompasses three domains: (1) *the subjective experience*; (2) *the interactional environment*; and (3) *the socio-cultural context*.

Although all three domains are relevant in the current study, the domain of *subjective experience* was the most extensively explored. This domain is concerned with the subjective experiences of individuals with dementia and the current study explored how this population experienced group singing. The singers' descriptions of their subjective experiences provided valuable information and insight into how and why group singing enhances well-being, explored in the previous sections of this discussion. The ability of individuals with moderate to severe dementia to provide this shows that they can participate and contribute meaningfully to qualitative research.

The second domain, *the interactional environment*, focuses on how an individual's interactions with others, as well as their physical environment can impact personhood. In this domain, Kitwood's (1997a) writing on promoting personhood through *positive person work* was helpful in analyzing how the interactions that occurred in music group promoted personhood. It became evident that many of the interactions occurring throughout the group helped to promote personhood. The personhood of the singers was enhanced through the interactions with the music therapist, the interview, the audience and between one another. Kitwood described interactions that promote personhood as *positive person work* and the interactions found in the current study included recognition, collaboration, celebration, and validation. The group also met many of the main psychological needs of individuals with dementia, including attachment, identity, occupation, and inclusion (Kitwood, 1997a).

The third domain, *the socio-cultural context*, explores how broader society and culture shapes individuals with dementia and personhood. In the context of the current study, factors such as gender and the culture of the care home were relevant. All the singers in the current group were men for whom music had played an important role in their personal histories. The

role of gender in promoting personhood was not widely explored in the current study, but it could be possible that shared gender may have helped to enhance cohesion among the group. The singers grew up in a time with greater gender segregation and participating in all-male clubs or events, such as the Lions Club, Freemasons, Shriners, or men's choirs, was familiar to the group members. The personal history and culture of each singer was also significant, because each had grown up playing instruments or singing, so the singing group was both familiar and meaningful to the singers. Although it was not explicitly explored in the current study, the culture of the care home played a significant role in the promotion of personhood. The music therapist and the staff at the research site were trained in the Eden Alternative care model (*Eden alternative: It can be different*, n.d.), a person-centered care philosophy designed to promote personhood. The site itself was based on the same model, and the overall practices of the site support personhood.

Strengths of the Research

This study had several strengths, resulting in valuable insight into the impact of group singing on well-being. The findings of this study addressed several gaps in the literature, one being the lack of knowledge about how and why individuals with dementia find music beneficial for their well-being (McDermott et al., 2014). As the singers shared about their experience of group singing, it became clear that certain components of the group, such as singing for others or reconnecting to their musical identity, contributed to their well-being.

Another strength of the current study was the triangulation of data through various data collection techniques, including researcher participation, video observation, and semi-structured interviews, as well as the logistics of how the data were collected, including timing and length of the interviews. Participating in the singing group as a researcher aided in

establishing the quality and credibility of the research. By singing with the group, I had a shared experience with each of the singers. I had a ground-level view of the dynamics and atmosphere of the group, adding strength to the interpretations created during the data analysis stage. Participating in the group and sharing experience also aided in establishing rapport with the singers, an element necessary for high-quality interviews (Smith et al., 2009).

The pairing of video recording a singer on the same day as their interview added value and credibility to the research. By pairing the two, I gained insight into the singer's experience in the group. For example, in the video observation, there was an interaction where Louis made Tony laugh. Later, during the interview, when Louis expressed joy over contributing to the group and interacting with others, I could relate directly to the interactions in the video.

The semi-structured interviews also provided the singers an opportunity to share about their experience, in their own words, without the limitations of a strict interview schedule (Smith et al., 2009). The mix of open and closed questions in the interviews was a good fit for this population, as it helped guide the conversation, but also allowed freedom and flexibility.

Successfully interviewing individuals with dementia also requires a specific set of interviewing skills, such as attending behaviours, observation, paraphrasing, summarizing, reflecting feeling, reflecting meaning, and focusing (Ivey, Ivey & Zalaquett, 2013). My experience as a counsellor was a strength in this case, as I engage those same skills everyday in clinical practise and I applied the same skills throughout the interviews. I found my ability to summarize and paraphrase especially valuable with this population as it allowed me to verify the meaning and feelings expressed by the singers.

The logistics of the data collection also added strength to the study. Interviewing the singers immediately following the singing group, in the same room that the group took place,

provided cues and context for the singers. I also believe it mitigated the memory loss associated with dementia, as being in the same context of the singing group facilitated recall of the experience. This reflection stems from interactions between myself and the singers that took place prior to the group singing. I often sat and talked with a few of the singers, when the music therapist was inviting the others to join. I endeavoured to talk with the same singer I would be interviewing after the group to gain a sense of their mood, state of mind, and conversational ability. This allowed me to subjectively observe the effect that the singing group had on those elements. I observed and experienced the improved ability of the singers to engage in conversation and recall past events following the singing group. I believe that improvement was due, in part, to being in the same room that the group took place in immediately after the group sang. The music itself may have also contributed to the improvement, as research has demonstrated the positive impact of music on speech (Dileo & Bradt, 2005), language (Suzuki et al., 2004) and next-morning cognitive functions (Bruer, Spitznagel & Cloninger, 2007).

Another strength of the study was the use of qualitative data analysis, specifically IPA. This data analysis method is valuable in that it allows for in-depth interpretation, but also gives specific guidelines for novice researchers. The philosophical underpinnings of IPA, including idiography and phenomenology, allows for a detailed, interpretative exploration of individual experience (Smith et al., 2009). The analytic structure of IPA requires one case to be interpreted prior to moving to the next, allowing for bracketing and separation of cases. The structure also aids in finding patterns in themes across cases, leading to super-ordinate themes that apply to all cases. In the current study, IPA aided in the exploration of the unique, individual, experiences of the singers while also uncovering broader, universal experiences.

The small sample sizes required for IPA (Smith et al., 2009) was also a good fit for this population, given that larger music group sizes for individuals with dementia has been associated with negative outcomes (Cooke, Moyle, Shum, Harrison, & Murfield, 2010).

A final strength of this research was that the research process itself promoted the personhood of the singers, by giving them an opportunity to be seen and heard. The value of this cannot be underestimated in research with this population, as their voices have historically been silenced in dementia research. Through participation in the current study the singers: were recognized as being able to provide valuable insight into the benefits of group singing; were invited to collaborate and contribute to the creation of new knowledge; and had their experiences validated, all of which Kitwood (1997a) states contribute to promoting personhood.

Delimitations of the Research

This study had several practical and methodological delimitations. One delimitation was convenience sampling, which resulted in a homogenous sample. All the singers were men, identified by the music therapist as individuals who enjoyed music. This limits the generalizability and transferability of findings to other individuals with dementia, especially women and people without a history of music enjoyment. Specifically, the finding that the singing group promoted identity, should be cautiously applied, since all the singers had engaged in meaningful musical experiences in their past, such as choir or performance bands.

Another delimitation is the type of music therapy being explored, in this case small group singing of familiar songs. Generalizations of the findings to other types of music therapy, such as music listening or individual singing, should be made cautiously.

Another delimitation of this study is the use of interviews because it allows only those who speak the same language as the interviewer, in this case English, to participate. The lack of non-English speaking participants is a significant gap in IPA literature because, as a UK based method, most research is conducted in English and published in English (Smith, 2004), limiting the ability to involve populations and participants whose first language is not English.

A final delimitation was that carry-over effects of group singing were not explored. Since the interviews took place immediately following the group singing, there was no opportunity to discuss the long-term benefits that group singing had on well-being. It is unknown if the positive impact on well-being was noticed by the singers in the days and weeks following the singing group. Although quantitative research has found carry-over effects of singing on cognitive abilities (Bruer et al., 2007), disruptive behaviours (Chang et al., 2015), and physical and mental states (Takahashi & Matsushita, 2006), there are no qualitative studies exploring long term impact. This may be due to the limitations of long-term memory associated with dementia.

Implications of the Research

The current study demonstrated the ability of individuals with moderate and even severe dementia to contribute meaningfully to qualitative research through observation and semi-structured interviews. Even with impaired language and cognitive abilities, the singers provided valuable knowledge and insight into the impact of group singing on well-being. This contributes to previous qualitative research that demonstrates that individuals with moderate to severe dementia can contribute to our understanding of complex and abstract experiences including life in residential care (Clare et al., 2008), coping with early onset of dementia

(Clemerson et al., 2013), spirituality (Higgins, 2014), the role of music in spiritual care (Kirkland et al., 2014), and benefits of choral singing (Clements-Cortés, 2014).

The findings provide insight into how and why group singing promotes well-being and personhood in individuals with dementia, which McDermott et al. (2014) identified as a gap in current music and well-being research. This is especially important considering a systematic review by Vink et al. (2013) concluded that the quantitative studies did not provide substantial evidence to support the use of music therapy in the care of individuals with dementia.

Davidson and Fedele (2011) also found that quantitative, standardized measures were ineffective in detecting the impact of group singing on well-being, but that in qualitative interviews, the singers indicated positive gains in lucidity, social interaction, enjoyment, engagement, and carry-over memory recall. The current study provided first-hand accounts that explained how group singing promotes well-being.

Themes relating to the group aspects (*self as part of a group, self as a performer, live music is special, and music is a gift*) shed light on the importance of relationships for well-being in this population. Sixsmith and Gibson (2007) previously called for a deeper examination of the role of music in social worlds for individuals with dementia, as their study demonstrates the ability for music to empower and enable this population to engage socially. Clemerson et al. (2013) identified themes of disconnection and isolation resulting from dementia diagnosis and how reconnection through re-engaging socially was an important part of moving past the initial stages of disconnection. Singing groups may provide a unique way for individuals with dementia to re-engage because they are social in nature and connect people in a way that other group activities cannot. In this group setting the singers felt connection through creating together, having special roles, as well as being able to *gift* one

another through the music. This could be especially meaningful for individuals with limited language abilities, because they can connect through the music by singing, humming, tapping, or listening. Individuals with dementia have noted that familiar music was one of the few accessible mediums they felt they could connect through, because individuals at every stage could participate (McDermott et al., 2014). Themes relating to group and social connection also demonstrate how group singing promotes personhood.

Themes relating to identity (*self as a performer* and *the music is still there*) highlighted how music provides singers with a sense of self and reconnects them to their identity.

Clemerson et al. (2013) found that individuals with dementia felt their diagnosis posed a threat to the way they viewed themselves, and this is linked to the way others responded to them and the way they felt they were viewed. They noted that holding onto their existing self was one way of regaining a stable sense of self. Clare et al. (2008) also found that when individuals with dementia find ways to reaffirm their identity it allows them to cope with the challenges they face. Singing with the group allowed singers to access memories of musical experiences or musical roles they had (choir or band member), reconnecting them to their identity.

Clemerson et al. (2013) also found that individuals with dementia engaged in redefining themselves as a way of reestablishing self-identity. Group singing provided individuals a way to define themselves differently, as performers or creators.

Themes relating to ability (*self as a performer, music is a gift, and the music is still there*) demonstrated how music provides individuals with dementia with opportunities to use and demonstrate their abilities. Dementia diagnoses often result in feelings of powerlessness and loss of agency, and a common coping strategy is regaining control (Clemerson et al.,

2013). Singing groups provide a sense of control, because singers are choosing how and when to participate.

The current study also provides support for previous models exploring the therapeutic factors of music in dementia. Ahonen-Eerikainen (2007) identified three sequential therapeutic factors of music therapy groups: (1) dealing with difficult feelings within the therapeutic music group process; (2) the empowering experiences; and (3) the joyful moments. Themes from the current study identified empowering experiences (being able to demonstrate ability and create) as important to the singers and a contributor to well-being. The singers also highlighted how music made them feel (happy, complete, perfect), which corresponds to the category of joyful moments.

The psychosocial model of music in dementia developed by McDermott et al. (2013) identified three interconnected components: (1) who you are; (2) here and now; (3) connectedness. The first component describes how music impacts an individual's *personal psychology* by connecting them to their personal and cultural identity, and facilitating reminiscence, recall of life events and song lyrics. In the current study, group singing aided in accessing musical memory and experiences, as well as reconnected singers to their musical identities. The second component, here and now, describes how music impacts psychosocial factors because it is an accessible medium, provides emotionally meaningful experiences, is engaging, and provides opportunity for self-expression. The current study also found that singing group was accessible for even those with advanced dementia, was engaging, and was filled with meaning for the singers. The third component, connectedness, describes how music impacts psychosocial factors by providing connection, shared emotional experience, development of new relationships, and positive social interaction. Themes from the current

study also corresponded with this area, as singers shared about being part of a group and connecting through the gift of music.

Future Research

The current study provided new insight into how individuals with dementia experience group singing and its usefulness in enhancing well-being and promoting personhood, and there is a need for more research on this topic. The participants of the current study all had previous interest and enjoyment of music, and it would be beneficial to examine the impact of singing groups on individuals who did not have this same background. Bush and Gick (2012) also called for research examining the effects of singing on both singers and non-singers to broaden the generalizability of the benefits of singing for well-being.

The music therapy group in the current study selected songs that were familiar to the singers, but it would be interesting to see what impact learning new, unfamiliar songs would have on well-being. Ahonen-Eerikainen et al. (2007) reported that participants felt empowered through learning to sing together as a choir, and future research could investigate the impact of learning new songs on self-worth, confidence, and empowerment.

Given the findings of the current study, that the singers seeing themselves as singers contributed to positive feelings and accomplishment, it would be worth examining how formally performing in front of an audience would impact well-being for individuals with dementia. There is also a potential that it could elicit negative feelings or experiences, given that singers in the current study were at times reluctant to demonstrate their singing abilities, or commented that singing in front of audiences made them feel nervous. However, given the model created by Ahonen-Eerikainen et al. (2007), that shows singing groups allow individuals with dementia an opportunity to work through difficult feelings, and then move on

to empowering experiences and joyful moments, a performance group has the potential to be very beneficial for this population.

Findings of the current study highlighted the social impact of singing group and how social connection through group singing contributes to well-being. To further add to this result, comparative studies between group singing and solo singing would be beneficial. Camic et al. (2011) also suggested that research comparing group singing to other social activities (such as art therapy or relaxation training) could further illuminate the unique social impact of group singing.

Both Camic et al. (2011) and Bush and Gick (2011) noted that the positive outcomes of small scale qualitative studies examining singing warrant larger scale studies utilizing control groups, random assignment, and longitudinal designs. These larger scale designs could be applied specifically to group singing for individuals with dementia, and findings could broaden the generalizability and validity of the positive effects of group singing. It would be important in large studies to continue to utilize qualitative measures, as it has been shown that quantitative measures do not always detect the positive benefits reported by the participants themselves (Davidson & Fedele, 2011).

It would also be worthwhile to explore the impact of group singing on individuals who are unable to communicate verbally. Dassa and Amir (2014) suggested that future research could study participant's nonverbal communication, including smiles and gestures. This could be done using the same type of video observation and analysis used in the current study. This would also be a beneficial way to involve individuals with advanced dementia and limited language abilities in qualitative research.

During the data collection of the current study, a few residents with limited language ability would come to watch the group sing every week. As we gathered in the music room and began to sing, they would trickle in and take a seat in the comfy chairs in the corner of the room, or park their wheel chairs around the group. The residents would not participate through singing, but their enjoyment of the music and engagement was evident. In their examination of group singing and dementia, Ahonen-Eerikainen et al. (2007) had participants who expressed their enjoyment of singing group, even though they did not participate. It would be interesting to examine the impact of group singing on receptive music listeners who are also part of the group. If findings of these types of studies demonstrated a positive impact it could impact care practices by informing caregivers of the importance of including all people, even if they cannot participate in a “typical” way.

Finally, it would be interesting to adapt the recently developed PERMA-profiler (Butler & Kern, 2016) to quantitatively measure well-being in individuals with dementia. The PERMA-profiler is a brief quantitative measure of the PERMA model (Seligman, 2011). It has demonstrated acceptable model fit, internal and cross-time consistency, and evidence for content, convergent, and divergent validity. Given that the themes from the current study contained all of the PERMA elements, it would be interesting to apply the PERMA model to group singing in a quantitative measure.

Reflections

Carrying out research with this population felt like an impossible task at the beginning of this research project. I wanted to ensure that I could conduct research that was meaningful, but also ethical and beneficial for the individuals who would participate. Prior to beginning the group, I observed and participated in a therapeutic music group for individuals with dementia,

led by the same music therapist who led the singing group in the current study. It was an incredibly powerful experience, to see individuals who were non-verbal or appeared to have retreated to an inner world, come alive at the sound of the therapist's guitar, pick up sticks and play them in time to a beat, or smile and make eye contact with others in the group. After this, I felt a strong desire to hear first hand from the individuals with dementia, to understand how the music impacted them.

I had the privilege to participate in the singing group and I was thankful for this experience. Through participating, co-creating, and co-experiencing with the singers, I felt more connected to the emotional atmosphere of the group. I found this valuable when I moved to analysis and interpretation, because I had experienced the same phenomena as the singers. I also developed rapport and relationship with the men, because I could talk and sing with them throughout the group sessions. This was incredibly beneficial during the interviews, as I believe both myself and the singers felt more comfortable with one another. I have many memorable moments from the singing group, but the one I treasure most is being sung "Happy Birthday" by the group on my birthday. All the singers expressed happiness and gratitude to be part of the group, but I felt that I received an incredible gift as well.

I began my analysis with a great deal of trepidation. Although I had observed the therapeutic qualities of singing during the group sessions, I was unsure of what factors had contributed to the therapeutic quality from the perspective of the singers. Prior to reading the interviews I questioned if I would be able to identify themes given the short duration of the interviews (on average 15 to 25 minutes) and the relative sparseness of text compared to "typical" semi-structured interviews. This fear rapidly dissipated as I began reading through the interviews. After completing the first read-through, I found myself experiencing a wide

range of emotion in response to the evocative and thoughtful narratives of the singers. Although there was indeed a sparsity of words from the singers they were still able to communicate and share about their experience of singing in the group. Also, as if aware of their own difficulty in speaking at length, the singers appeared to be as precise and concise in their responses as possible. They employed an economy of expression that, while succinct, provided what was needed to be understood. Additionally, being able to connect sparser participant narratives with my field notes and the video observation helped to provide richer data.

I have always had a passion to hear others stories and I know that is a main reason I chose the profession of counselling. There is great value in asking for and listening to people's stories, especially for those whose stories often go untold. As Dassa and Amir (2014) noted, "in a state of language decline, it is important to find ways to prevent people with AD [Alzheimer's Disease] from withdrawing into silence" (p.150). I am so thankful that I could ask for, listen to, and ultimately share the stories of these six singers. They were a joy to sing with and interview, and I treasure the knowledge that they contributed about the impact and importance of music. The impact of these stories on me can be best described by the words of Gord who said, "I felt whole hearted then."

Conclusion

The purpose of the current study was to explore the experience of music therapist-led group singing for individuals with dementia living in a residential care facility. The study provided a way for individuals with dementia to share their perspectives on how group singing impacted their well-being. This study built on previous literature that highlighted the potential

for music interventions to increase social interaction and enhance well-being, even for individuals with severe cognitive impairment (Sherratt, Thornton & Hatton, 2004).

Utilizing IPA to analyze transcribed interviews, six themes and three sub-themes, describing three different aspects of the singers' experience emerged: (1) how they experienced themselves (*Self as Performer, Self as Part of a Group*); (2) how they experienced the music (*Live Music is Special; Music is a Gift*); and (3) How they experienced dementia and music (*Gaps in Time, Memory and Ability; The Music Is Still There*). The themes that emerged from the narratives of the singers provided insight into exactly how and why group singing is beneficial, specifically because it provides social connection, re-connection to identity, and opportunity to demonstrate ability. When the findings were interpreted by the PERMA model (Seligman, 2011), it was found that all five elements of well-being were present because of participating in the group. Additionally, it was found that group singing contributed to many of Kitwood's (1997a) core psychological needs and that elements of positive person work can occur frequently within group singing, all of which promote personhood. The findings provide a fresh perspective and understanding of the impact of group singing for individuals with dementia. My hope is that the findings of this study are helpful and informative for individuals with dementia, their formal and informal caregivers, family members and music therapists.

The theoretical orientation, methodology, and theoretical framework of this study all provided an ideal landscape to explore the lived experiences of individuals with dementia. I believe that the following quote from Tappen, Williams, Fishman, and Touhy (1999) provides an appropriate commentary on the importance of using phenomenological methodologies in dementia research: "through further study of the subjective experience of people with Alzheimer's disease, we can offer care that nurtures and celebrates personhood. With this

perspective, a fuller understanding and appreciation of persons who have the disease can be achieved” (p. 124).

References

- Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research*, 9(3), 407-411.
- Ahonen-Eerikainen, H., Rippin, K., Sibille, N., Koch, R., & Dalby, D. (2007). "Not bad for an old 85-year-old!" -The qualitative analysis of the role of music, therapeutic benefits and group therapeutic factors of the St. Joseph's Alzheimer's adult day program music therapy group. *Canadian Journal of Music Therapy*, 13(2), 37-62. Retrieved from <http://www.musictherapy.ca/en/publications/journal.html>
- Alzheimer Society of Canada. (1997). *Ethical guidelines of the Alzheimer Society of Canada*. Toronto, Canada: Author.
- Alzheimer Society of Canada. (2010). The rising tide: The impact of dementia on Canadian Society. Retrieved from <http://www.alzheimer.ca/en/Get-involved/Raise-your-voice/Rising-Tide/Rising-tide-summary>
- Alzheimer Society of Canada. (2012). A new way of looking at the impact of dementia in Canada. Retrieved from www.alzheimer.ca/en
- American Association of Music Therapy. (2013). *Definition and quotes about music therapy*. Retrieved from <http://musictherapy.org>.
- American Music Therapy Association. (2015). *History of Music Therapy*. Retrieved from <http://www.musictherapy.org/about/history/>
- Blackwell, O., & Hammer, J., (1957). Great balls of fire.
- Bogdan, R. C., & Biklen, S. K. (2003). *Qualitative Research for Education: An introduction to Theories and Methods* (4th ed.). New York, NY: Pearson.

- Bond, J. (1993). The medicalization of dementia. *Journal of Aging Studies*, 6(4), 397-403. doi: 10.1016/0890-4065(92)90020-7
- Bright, R. (1997). *Wholeness later in life*. London: Jessica Kingsley Publishers.
- Brown, S., Götell, E., & Ekman, S. L. (2001). 'Music-therapeutic caregiving': The necessity of active music-making in clinical care. *The Arts in Psychotherapy*, 28(2), 125-135. doi: 10.1016/S0197-4556(00)00085-X
- Brotons, M., Koger, S.M., & Pickett-Cooper, P. (1997). Music and dementias: A review of literature. *Journal of Music Therapy*, 34(4), 204–245. doi: <https://doi.org/10.1093/jmt/34.4.204>
- Bruer, R. A., Spitznagel, E., & Cloninger, C. R. (2007). The temporal limits of cognitive change from music therapy in elderly persons with dementia or dementialike cognitive impairment: A randomized controlled trial. *Journal of Music Therapy*, 44(4), 308–328. doi: <https://doi.org/10.1093/jmt/44.4.308>
- Bunt, L. & Hoskyns, S. (2002). *The handbook of music therapy*. London: Routledge.
- Busch, S. L. & Gick, M. (2012). A quantitative study of choral singing and psychological well-being. *Canadian Journal of Music Therapy*, 18(1), 45-61. Retrieved from <http://cyber.usask.ca/login?url=http://search.proquest.com.cyber.usask.ca/docview/1014190886?accountid=14739>
- Butler, J., & Kern, M. L. (2016). The PERMA-Profiler: A brief multidimensional measure of flourishing. *International Journal of Wellbeing*, 6(3), 1-48. doi:10.5502/ijw.v6i3.1
- Camic, P. M., Williams, C. M., & Meeten, F. (2013). Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*, 12(2), 157-176. doi: 10.1177/1471301211422761

- Canadian Association of Music Therapy. (2014). *Music Therapy*. Retrieved from <http://www.musictherapy.ca/en/information/music-therapy.html>
- Chang, Y. S., Chu, H., Yang, C. Y., Tsai, J. C., Chung, M. H., Liao, Y. M., ... & Chou, K. R. (2015). The efficacy of music therapy for people with dementia: a meta-analysis of randomized controlled trials. *Journal of Clinical Nursing, 24*(23-24), 3425-3440. doi: 10.1111/jocn.12976
- Christy, E. P. (1847). Goodnight, ladies.
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The experience of living with dementia in residential care: An interpretative phenomenological analysis. *The Gerontologist, 48*(6), 711-720. doi: 10.1093/geront/48.6.711
- Clements-Cortés, A. (2014). Buddy's Glee Club Two: Choral Singing Benefits for Older Adults. *Canadian Journal of Music Therapy, 20*(1), 85-109. Retrieved from <http://www.musictherapy.ca/en/publications/journal.html>
- Clemerson, G., Walsh, S., & Isaac, C. (2013). Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed. *Dementia, 13*(4) 451-466. doi: 10.1177/1471301212474149
- Clift, S. (2012). Singing, well-being, and health. In R. MacDonald, G. Kreutz & L. Mitchell (Eds.), *Music, Health, & Well-being* (113-124). New York, NY: Oxford University Press.
- Coffey, J. K., Wray-Lake, L., Mashek, D., & Branand, B. (2014). A Multi-Study Examination of Well-Being Theory in College and Community Samples. *Journal of Happiness Studies, 1*-25. doi: 10.1007/s10902-014-9590-8
- Cohen, L. (1992). Closing time.

- Cooke, M., Moyle, W., Shum, D., Harrison, S., & Murfield, J. (2010). A randomized controlled trial exploring the effect of music on quality of life and depression in older people with dementia. *Journal of Health Psychology, 15*(5), 765-776. doi: 10.1177/1359105310368188
- Corey, G. (2009). *Theory and practice of counseling and psychotherapy* (8th Ed.) Belmont, CA: Brooks/Cole.
- Cuddy, L., & Duffin, J. (2005). Music, memory and Alzheimer's disease: Is music recognition spared in dementia, and how can it be assessed? *Medical Hypotheses, 64*(2), 229–235. doi:10.1016/j.mehy.2004.09.005
- Dassa, A., & Amir, D. (2014). The role of singing familiar songs in encouraging conversation among people with middle to late stage Alzheimer's disease. *Journal of Music Therapy, 51*(2), 131-153. doi: 10.1093/jmt/thu007
- Davidson, J. W., & Fedele, J. (2011). Investigating group singing activity with people with dementia and their caregivers: Problems and positive prospects. *Musicae Scientiae, 15*(3), 402-422. doi: 10.1177/1029864911410954
- Denzin, N. K., & Lincoln, Y. S. (2011). *The SAGE handbook of qualitative research*. Thousand Oaks, CA: Sage.
- Dewing J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia, 6*(1), 11-25. doi: 10.1177/1471301207075625
- Dewing, J. (2008). Personhood and dementia: revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing, 3*(1), 3-13. doi: 10.1111/j.1748-3743.2007.00103.x

- Digby, R., Lee, S., & Williams, A. (2016). Interviewing people with dementia in hospital: Recommendations for researchers. *Journal of Clinical Nursing, 25*(708), 1156-1165. doi: 10.1111/jocn.13141
- Dileo, C., & Bradt, J. (2005). Medical music therapy: A meta-analysis and agenda for future research. Cherry Hill, NJ: Jeffrey Books.
- Eden alternative: It can be different* [Brochure]. (n.d.) Rochester, NY: The Eden Alternative Inc.
- Folstein, M. F., Folstein, S. E., McHugh, P. R. (1975). Mini-mental state. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*(3), 189-198. doi:10.1016/0022-3956(75)90026-6
- Frankl, V. E. (2014). *Man's search for meaning*. Boston, MA: Beacon Press.
- Franssen, E. H., Kluger, A., Torossian, C. L., & Reisberg, B. (1993). The neurologic syndrome of severe Alzheimer's disease: Relationship to functional decline. *Archives of Neurology, 50*(10), 1029-1039. doi: 10.1001/archneur.1993.00540100024010
- Franssen, E. H., & Reisberg, B. (1997). Neurologic markers of the progression of Alzheimer's disease. *International Psychogeriatrics, 9*(S1), 297-306. doi: 10.1017/S1041610297005036
- Frazer, S. M., Oyebode, J. R., & Cleary, A. (2012). How older women who live alone with dementia make sense of their experiences: An interpretative phenomenological analysis. *Dementia, 11*(5), 677-693. doi: 10.1177/1471301211419018
- Goldsmith, M. (1996). *Hearing the voice of people with dementia: Opportunities and obstacles*. London: Jessica Kingsley.
- Harré, R. (1979). *Social being*. Oxford: Blackwell.

- Hays, D.G. & Singh, A.A. (2012). *Qualitative Inquiry in Clinical and Educational Settings*. NY: Guilford Press.
- Heggestad, A. K. T., Nortvedt, P., & Slettebø, Å. (2013). “Like a prison without bars”: Dementia and experiences of dignity. *Nursing Ethics*, 20(8), 881-892. doi: 10.1177/0969733013484484
- Higgins, P. (2014). “It’s a consolation”: The role of Christian religion for people with dementia who are living in care homes. *Journal of Religion, Spirituality & Aging*, 26(4), 320-339. doi: 10.1080/15528030.2014.880773
- Hulme, C., Wright, J., Crocker, T., Oluboyede, Y., & House, A. (2010). Non-pharmacological approaches for dementia that informal carers might try or access: a systematic review. *International Journal of Geriatric Psychiatry*, 25(7), 756-763. doi: 10.1002/gps.2429
- Huppert, F. A., & So, T. T. (2013). Flourishing across Europe: Application of a new conceptual framework for defining well-being. *Social Indicators Research*, 110(3), 837-861. doi: 10.1007/s11205-012-0030-z.
- Identity. (2015). In *dictionary.com*. Retrieved from <http://dictionary.reference.com/browse/identity>
- Idiographic. (2015). In *dictionary.com*. Retrieved from <http://dictionary.reference.com/browse/idiographic>
- Ivey, A., Ivey, M., & Zalaquett, C. (2013). *Intentional interviewing and counseling: Facilitating client development in a multicultural society*. Belmont, CA: Brooks/Cole.
- Innes, A., & Manthorpe, J. (2013). Developing theoretical understandings of dementia and their application to dementia care policy in the UK. *Dementia*, 12(6), 682-696. doi: 10.1177/1471301212442583

- Jayawickreme, E., Forgeard, M. J., & Seligman, M. E. (2012). The engine of well-being. *Review of General Psychology, 16*(4), 327. doi: 10.1037/a0027990
- Kirkland, K., Fortuna, M. C., Kelson, E., & Phinney, A. (2014). Music Therapy and Spiritual Care for Persons with Dementia: A Mixed-Methods Study. *Canadian Journal of Music Therapy, 20*(1), 10-37. Retrieved from <http://www.musictherapy.ca/en/publications/journal.html>
- Kitwood, T. M. (1997a). *Dementia reconsidered: The person comes first*. Open University Press.
- Kitwood, T. M. (1997b). The experience of dementia. *Aging & Mental Health, 1*(1), 13-22. doi: 10.1080/13607869757344
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: personhood and well-being. *Ageing and Society, 12*(03), 269-287. doi: 10.1017/S0144686X0000502X
- Lambert, L., Passmore, H. A., & Holder, M. D. (2015). Foundational frameworks of positive psychology: Mapping well-being orientations. *Canadian Psychology/Psychologie Canadienne, 56*(3), 311–321. doi: 10.1037/cap0000033
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102-120. doi: 10.1191/1478088706qp062oa
- Lennon, J. & McCartney, P. (1968). Ob-La-Di Ob-La-Da.
- Lesta, B., & Petocz, P. (2006). Familiar group singing: Addressing mood and social behaviour of residents with dementia displaying sundowning. *Australian Journal of Music Therapy, 17*, 2-17. Retrieved from <http://www.austmta.org.au/about-us/ajmt>

- MacDonald, R., Kreutz, G. & Mitchell, L. (2012). What is music, health, and well-being and why is it important? In R. MacDonald, G. Kreutz & L. Mitchell (Eds.), *Music, Health, & Well-being* (3-11). New York, NY: Oxford University Press.
- Maguire, L. E., Wanschura, P. B., Battaglia, M. M., Howell, S. N., & Flinn, J. M. (2015). Participation in active singing leads to cognitive improvements in individuals with dementia. *Journal of the American Geriatrics Society*, *63*(4), 815-816. doi: 10.1111/jgs.13366
- Mason, J. (2002). *Qualitative researching*. Thousand Oaks, CA: Sage.
- McDermott, O., Orrell, M., & Ridder, H. M. (2014). The importance of music for people with dementia: The perspectives of people with dementia, family carers, staff and music therapists. *Aging & Mental Health*, *18*(6), 706-716. doi: 10.1080/13607863.2013.875124
- McGilton, K. S. (2004). Relating well to persons with dementia: A variable influencing staffing and quality of care outcomes. *Alzheimer's Care Today*, *5*(1), 71-80. Retrieved from <http://ovidsp.tx.ovid.com.cyber.usask.ca>
- McKillop, J., & Wilkinson, H. (2004). Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed. *Dementia*, *3*(2), 117-125. doi: 10.1177/1471301204042332
- Mitnitski, A. B., Graham, J. E., Mogilner, A. J., & Rockwood, K. (1999). The rate of decline in function in Alzheimer's disease and other dementias. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *54*(2), 65-69. doi: 10.1093/gerona/54.2.M65

- Moore, T. F., & Hollett, J. (2003). Giving voice to persons living with dementia: The researcher's opportunities and challenges. *Nursing Science Quarterly*, *16*(2), 163-167. doi: 10.1177/0894318403251793251793
- Myskja, A., & Nord, P. G. (2008). "The Day the Music Died" A Pilot Study on Music and Depression in a Nursing Home. *Nordic Journal of Music Therapy*, *17*(1), 30-40. doi: 10.1080/08098130809478194
- Nygård, L. (2006). How can we get access to the experiences of people with dementia? Suggestions and reflections. *Scandinavian Journal of Occupational Therapy*, *13*(2), 101-112. doi: 10.1080/11038120600723190
- O'Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., ... & Beattie, L. (2007). Personhood in dementia care developing a research agenda for broadening the vision. *Dementia*, *6*(1), 121-142. doi: 10.1177/1471301207075648
- Oostendorp, J. C., & Montel, S. R. (2014). Singing Can Enhance Episodic Memory Functioning in Elderly People with Alzheimer's Disease. *Journal of the American Geriatrics Society*, *62*(5), 982-983. doi: 10.1111/jgs.12731
- Osman, S. E., Tischler, V., & Schneider, J. (2016). 'Singing for the Brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers. *Dementia*, *15*(6), 1326-1339. doi: 10.1177/1471301214556291
- Phinney, A., & Chesla, C. A. (2003). The lived body in dementia. *Journal of Aging Studies*, *17*(3), 283-299. doi:10.1016/S0890-4065(03)00029-X
- Preston, L., Marshall, A., & Bucks, R. S. (2007). Investigating the ways that older people cope with dementia: A qualitative study. *Aging & Mental Health*, *11*(2), 131-143. doi: 10.1080/13607860600844572

- Saldaña, J. (2011). *Fundamentals of qualitative research*. NY, New York: Oxford university press.
- Seligman, M. E. (2011). *Flourish: A visionary new understanding of happiness and well-being*. New York, NY: Simon and Schuster.
- Sherratt, K., Thornton, A., & Hatton, C. (2004). Music interventions for people with dementia: a review of the literature. *Aging & Mental Health*, 8(1), 3-12. doi: 10.1080/13607860310001613275
- Skingley, A. & Vella-Burrows, T. (2010). Therapeutic effects of music and singing for older people. *Nursing Standard*, 24(19), 35-41. Retrieved from journals.rcni.com/journal/ns.
- Sixsmith, A., & Gibson, G. (2007). Music and the wellbeing of people with dementia. *Ageing and Society*, 27(01), 127-145. doi:10.1017/S0144686X06005228
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11(2), 261-271. doi: 10.1080/08870449608400256
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39-54. doi: 10.1191/1478088704qp004oa
- Smith, J. A. (2007). Hermeneutics, human sciences, and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-being*, 2(1), 3-11. doi: 10.1080/17482620601016120
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis*. Thousand Oaks, CA: SAGE Publications Ltd.

- Smith, J. A & Osborn, M. (2003). Interpretative phenomenological analysis. In J. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 53-80). Thousand Oaks, CA: Sage.
- Spiro, N. (2010). Music and dementia: Observing effects and searching for underlying theories. *Aging & Mental Health, 14*(8), 891-899, doi: 10.1080/13607863.2010.519328
- Stiles, W. B. (1993). Quality control in qualitative research. *Clinical Psychology Review, 13*(6), 593–618. doi: 10.1016/0272-7358(93)90048-Q
- Suzuki, M., Kanamori, M., Watanabe, M., Nagasawa, S., Kojima, E., Ooshiro, H., & Nakahara, D. (2004). Behavioural and endocrinological evaluation of music therapy for elderly patients with dementia. *Nursing and Health Sciences, 6*(1), 11–18. doi: 10.1111/j.1442-2018.2003.00168.x
- Svansdottir, H. B., & Snaedal, J. (2006). Music therapy in moderate and severe dementia of Alzheimer's type: a case–control study. *International Psychogeriatrics, 18*(04), 613-621. doi: 10.1017/S1041610206003206
- Takahashi, T., & Matsushita, H. (2006). Long-term effects of music therapy on elderly with moderate/severe dementia. *Journal of Music Therapy, 43*(4), 317-333. doi: <https://doi.org/10.1093/jmt/43.4.317>
- Talmadge, B. (1965). Waltz Across Texas.
- Tappen, R. M., Williams, C., Fishman, S., & Touhy, T. (1999). Persistence of self in advanced Alzheimer's disease. *Journal of Nursing Scholarship, 31*(2), 121-125. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1958994/>
- Tobias, C., Mencher, M., & Cantor, E. (1935). Merrily we row along.
- Tomaino, C. (2002). The role of music in the rehabilitation of persons with neurologic

diseases. *Music Therapy Today*, 3(3). Retrieved from <http://www.wfmt.info/Musictherapyworld>

van Deurzen, E. (2002). *Existential counselling and psychotherapy in practice* (2nd Ed.). London: Sage.

Vink, A.C., Bruinsma, M.S., & Scholten, R. (2013). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews*, 2013 (9), 1 - 49. doi: 10.1002/14651858.CD003477.pub2.

Whiting, R. A. & Egan, R. B. (1918). Till we meet again.

World Health Organization (2012). *Dementia: A public health priority*. United Kingdom: World Health Organization.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15(2), 215- 228. doi: 10.1080/08870440008400302

Appendix A: Consent Form



UNIVERSITY OF SASKATCHEWAN

College of Education

DEPARTMENT OF EDUCATIONAL
PSYCHOLOGY AND SPECIAL EDUCATION
USASK.CA/EDUCATION

Perspectives of Individuals with Dementia on Group Singing and Well-being

REB #16-134

The individual you have been appointed to make decisions for is invited to participate in a study titled “Perspectives of Individuals with Dementia on Group Singing and Well-being.” Please read this form carefully, and feel free to ask any questions you may have.

Researchers: Stephanie Danger, B. A., Department of Educational Psychology and Special Education, University of Saskatchewan, TEL: (306) 966-7720

Supervisor: Jennifer Nicol, Ph.D., Department of Educational Psychology and Special Education, University of Saskatchewan, TEL: (306) 966-5261

Purpose and Procedure: The purpose of this study is to understand the perspectives and perceived effects of group singing on well-being. Participants will be invited to participate in six group singing sessions that will take place at [REDACTED] and will be lead by resident music therapist, [REDACTED]. They will be asked to sing with a group during these sessions. The six sessions will take place once a week for six weeks and will be approximately an hour long. These sessions will be video recorded. After one of the sessions one individual will be invited to participate in a recorded interview with the researcher. The interview will be approximately 30 to 45 minutes long and will ask questions related to their experiences of the singing group. The interviews will then be transcribed and analyzed for content and themes.

Assent: Assent will be sought for all participants before each group singing session and prior to individual interviews. Seeking assent means asking each individual if they would like to participate in the group singing or interview. Assent will be assessed by the student researcher, Stephanie Danger, along with the staff at [REDACTED].

Potential Risks: There are no known serious health risks that will result from taking part in this study, but participants may find some of the singing activities hard to complete, or feel mildly frustrated and/or tired.

Potential Benefits: By taking part in this study participants will help us to better understand how group singing can affect well-being. We hope that our findings will contribute to the development of new interventions to improve the quality of life for older individuals with memory problems.

Confidentiality and Storage of Data: All information provided for this project is confidential and will only be shared with members of the project team. The data will be stored separately from the consent forms in a secure office assigned to Dr. Jennifer Nicol at the University of Saskatchewan. The information collected in this study will be published as part of Stephanie Danger's master's thesis and may be presented in journal articles and/or professional conference presentations. At all times, a pseudonym will be used to describe any data related to the participants; their real name will never appear with the results.

Participation is Voluntary: You may withdraw your consent from the project for any reason, at any time, without penalty of any sort. The individual participating may also choose to withdraw their assent for any reason at any time without penalty of any sort. If you choose to withdraw from the project, any information that has been contributed will not be used and will be destroyed.

Questions: If you have any questions concerning the project, please feel free to ask at any point; you are also free to contact the researcher (Jennifer Nicol) at the number given below. This project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Office of Research Services (collect at 306-966-2084).

CONSENT FOR _____ TO PARTICIPATE:

I, _____, have read and understood the description provided above; I have been given a chance to ask questions and my questions have been answered satisfactorily. I give my consent for _____ to participate in the study described above, understanding that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.

Substitute Decision Maker Signature: _____ Phone

#: _____

Participant Name: _____

Investigator Signature: _____

Date: _____

Principal Investigator:

Jennifer Nicol, Ph.D., Department of Educational Psychology and Special Education, University of Saskatchewan, TEL: (306) 966-5261

Appendix B: Background Information Form



UNIVERSITY OF SASKATCHEWAN
College of Education
DEPARTMENT OF EDUCATIONAL
PSYCHOLOGY AND SPECIAL EDUCATION
USASK.CA/EDUCATION

Background Information

Participant Name: _____

Age: _____

Gender: _____

Ethnicity: _____

First Language: _____

Dementia Diagnosis (i.e., confirmation, type, severity, MMSE rating)

Relevant Health Information (i.e., any health concerns that may be impacted by participation in singing group)

How does this individual typically give assent to participate in activities?

Appendix C: Assent Log



UNIVERSITY OF SASKATCHEWAN
College of Education
DEPARTMENT OF EDUCATIONAL
PSYCHOLOGY AND SPECIAL EDUCATION
USASK.CA/EDUCATION

Assent Log

Participant Name:
Participant Number:
Unit Manager:

Group Singing Assent

The student researcher will say the following to the potential participants prior to each group singing session: “I would like to invite you to sing in a group with some other residents [REDACTED], the music therapist, will be leading the singing. I will be with the group too and I will take notes on the singers. You can decide to stop singing and go back home at any time. Would you like to sing with the group today?”

Assent Obtained:

Date	Session Number	Student Researcher Initials	Witness Initials
	1		
	2		
	3		
	4		
	5		
	6		

Individual Interview Assent

The student researcher will say the following to the potential participants prior to each group singing session: “I would like to invite you to talk with me about your thoughts on the group singing. I will be recording our conversation and I will type it and read it after. I will then write about the conversation we had. You can choose to stop our conversation or not answer any questions. Would you like to talk with me about the singing group today?”

Assent Obtained:

Date	Following Session Number	Student Researcher Initials	Witness Initials

Appendix D: Song List

Amazing Grace	Oh My Darling, Clementine
Beautiful Brown Eyes	Pack Up Your Troubles in Your Old Kit-Bag
Blessed Assurance	Peggy O'Neil
Catch a Falling Star	Polly Wolly Doodle
Crusin' Down the River	Red River Valley
Dear Hearts and Gentle People	Show Me the Way to Go Home
Good Night Ladies	Side By Side
Happy Birthday	The Old Grey Mare
Has Anybody Seen My Gal	The Old Rugged Cross
Home on the Range	There's a Long Long Trail
I Come to the Garden Alone	This Land is Your Land
I'm Forever Blowing Bubbles	Till We Meet Again
I've Been Working on the Railroad	Waltz Across Texas
In the Good Old Summertime	What A Friend We Have in Jesus
In the Shade of the Old Apple Tree	When I Grow Too Old to Dream
In the Sweet By and By	When Irish Eyes Are Smiling
It's a Long Way to Tipperary	When It's Springtime in the Rockies
Let Me Call You Sweetheart	When the Saints Go Marching In
Let the Rest of the World Go By	When You're Smiling
Margie	Wild Irish Rose
Merrily We Row Along	You Are My sunshine
Mockingbird Hill	

Appendix E: Semi-structured Interview Guide



UNIVERSITY OF SASKATCHEWAN
College of Education
DEPARTMENT OF EDUCATIONAL
PSYCHOLOGY AND SPECIAL EDUCATION
USASK.CA/EDUCATION

1. Did you enjoy singing today?
2. How did the singing make you feel?

Prompt: Ask if they felt specific feelings: Joy and Sadness
3. What did you think about when you were singing?
4. Did you like the songs we sang today? Did you have a favourite song?
5. Do you prefer to sing alone or with a group?
6. What was it like to sing with the group? How does it make you feel to sing with the group?
7. How do you feel now after singing?

Appendix F: Observation Data Checklist

Target behaviour/factor
Attended regularly
Usually sang, danced, moved (active participant)
Usually listened (receptive participant)
Usually participated independently
Usually participated with assistance or when prompted by MT
Usually interacted with others
Usually interacted with other singers
Usually interacted with MT
Usually appeared lucid or confused during singing group
Usually appeared energized or tired during singing group
Usually appeared relaxed or agitated during singing group
Usually appeared focused or unfocused during singing group
Usually demonstrated positive, negative or neutral mood during singing group
Attempted to follow lyrics – never/rarely, sometimes, often/always
Often engaged in spontaneous singing during singing group
Often engaged in reminiscent story telling during singing group

Note: Observation data checklist adapted from Davidson and Fedele (2011)