The Psychosocial Well-being of Caregivers Participating in an Intergenerational Community-based Dementia Choir

by

Matilde Cervantes Navarrete
B.A., Universidad Autónoma de Baja California, 2004
M.E.P., Centro Ericksoniano de México, 2009

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We acknowledge with respect the Lekwungen peoples on whose traditional territory the university stands and the Songhees, Esquimalt and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

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Supervisory Committee
Dr. Debra Sheets, School of Nursing
Supervisor

Dr. Stuart MacDonald, Department of Psychology
Co-Supervisor

Dr. André Smith, Department of Sociology
Member

Abstract

Compared to other kinds of caregivers, caregivers of persons living with dementia (PwD) are at higher risk of experiencing social isolation, emotional distress, and depressive symptoms which can adversely affect their psychosocial well-being. This study uses longitudinal data and multilevel modeling to explore trajectories of change over the course of a choir intervention in affect, social engagement, and caregiver distress. A multilevel coupled model of change was employed to examine two time-varying associations within-person and between-persons: (1) the association between social activities and affect, and (2) the association between caregiver distress and affect. The social activities coupling model (between-persons) found that increasing engagement in social activities was significantly associated with an increase in positive affect. The caregiver distress coupling model (within-person) found that higher levels of caregiver distress were significantly associated with decreases in positive affect. The caregiver distress coupling model (between-persons) found that higher levels of caregiver distress were significantly associated with increases in negative affect. The choir intervention may have a positive impact on caregiver psychosocial well-being but there are many factors to consider (i.e., dementia trajectory) that influence psychosocial well-being. This study advances our understanding of the impact of an arts-based intervention (i.e., community-based choir) as a source of support for caregivers of PwD. Findings can inform efforts to develop community art-based programs to support family caregivers.

Key Words: dementia; caregivers; arts-based intervention; choir intervention; psychosocial well-being; community-based choir

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List of Abbreviations

BP	Between-persons
CG	Caregiver
CGD	Caregiver distress
ICC	Intraclass correlation coefficient
MLM	Multilevel-modeling
NA	Negative affect
PA	Positive affect
PwD	Persons living with dementia
SA	Social activities
SWB	Subjective well-being
ViM	Voices in Motion
WP	Within-person
ZBI	Zarit burden interview

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Dedication

I dedicate this thesis to my loving parents, with respect and honour to my father, Rafael Cervantes Vizcarra, and to my compassionate and exemplary mother, Lucila del Rosario Navarrete, who was my dad's dementia caregiver during his last years.

With infinite love to my whole family and friends in Canada and México.

To my wonderful rocks, Sarai and Shanti, with pure love.

Chapter I. Introduction

Dementia is a growing global concern as population ageing accelerates in the next decade. In Canada, an estimated 564,000 older adults are living with dementia, and this number will rise to 937,000 by 2031 (Alzheimer Society of Canada, 2020). The World Health Organization reports that approximately 50 million people have dementia indicating the global nature of this issue (World Health Organization, 2018a). The Public Health Agency of Canada (2019) reports that nine persons are diagnosed with dementia every hour in Canada. Dementia typically progresses over time and requires increasing amounts of support from family caregivers.

Dementia is a general term that refers to a wide range of disorders characterized by abnormal brain changes that impair memory, language, orientation, calculation, spatial perception, and other cognitive faculties, all of which have a negative impact on people's health, social life, and leisure activities (Villarejo, et al., 2019). There are many causes of dementia (i.e., vascular, Lewy-Body, etc.), but Alzheimer's disease accounts for 60–70% of all dementia cases (Alzheimer's Association, 2020). Alzheimer's Disease refers is a progressive cognitive disorder that slowly damages memory and thinking skills and ultimately causes death (American Psychological Association, 2014, p. 44). It is critical to note that as the number of people diagnosed with dementia rises, so does the need for more caregiver support over time (Alzheimer's Net, 2018).

Compared with family caregivers for other disabling conditions (i.e., stroke, Parkinson's disease), caregivers for persons living with dementia (PwD) are at higher risk of experiencing social isolation, stress, emotional distress, and depressive symptoms and negative affect, which can adversely impact physical and mental health. Caregivers for PwD often report increased distress and negative affect (Mausbach et al., 2013) as the intensity of caregiving increases over time and social supports and activities diminish (Brodaty & Donkin, 2009).

Programs that reduce social isolation among caregivers are critical to preventing caregiver burnout. Typically, caregiver programs focus on education (i.e., legal planning, services) and other practical matters. Until recently, little attention has been given to supporting the psychosocial well-being of caregivers. In particular, they are few community-based programs that offer family caregivers and PwD the opportunity to engage in social activities that are meaningful, joyful, and support social connections.

Arts-based Interventions and the Voices in Motion Program

Arts-based interventions show great promise for improving the well-being and quality of life of PwD and their caregivers. Engagement in the arts evokes memories, stimulates emotions and fosters social connections. Voices in Motion (ViM) is a professionally conducted, intergenerational community-based choir for PwD, their caregivers (CG), and high school students. The choir was founded by a multidisciplinary research team (i.e., Nursing, Psychology, Sociology, Music) at the University of Victoria in Victoria, British Columbia. The choir was not conceptualized as music therapy, but rather as a high quality professionally directed choir that offers a meaningful, socially engaging and joyful activity in which all participants are equal and natural opportunities for social connections occur. Caregivers benefit from opportunities for social connections and an understanding and supportive community.

Hanna, Noelker, and Bienvenu (2015) discuss arts-engagement in gerontology and its positive impact on health outcomes for older adults. The majority of arts-based research involving older adults has not included people with dementia. At present there is no cure for dementia and thus finding low-cost social programs that support the psychosocial well-being of caregivers is of increasing importance (Fraser et al., 2015). The empirical evidence demonstrating the benefits of the arts on health at all ages continues to grow (Kaptein et al., 2018; Fancourt, 2019). Among older adults, findings indicate that group singing improves health and well-being (Pearce et al., 2016) and may slow down cognitive decline (Haslam et al., 2014). For example, singing enhances individual psycho-physiological well-being and induces a socio-biological bonding response (Kreutz, 2014); has a significant neuroendocrine effect (Schladt et al., 2017) and improves breathing and short-term immune response (Gick, 2011). Research suggests that the positive effects of singing are more pronounced in group singing due to the benefits of social engagement (Schladt et al., 2017). Singing in a choir offers opportunities for social connection and friendships and the resulting sense of belonging and acceptance among participants are significant benefits (Southcott & Joseph, 2017).

The World Health Organization (2019) identifies five broad categories of arts: performing arts (i.e., music, dance, singing, theatre, film); visual arts; literature; culture (i.e., going to museums, galleries, concerts, the theatre); and online arts (i.e., animations, digital arts). Arts program differ in whether they invite active (i.e., choir singing) or passive engagement (i.e., listening to a personalized iPod); but generally active engagement shows broader and more persistent health impacts. In particular, arts-based programs can positively affect social and mental health by reducing stress, anxiety, and depression (Davies et al. 2014). Active participation in the arts can reinforce a healthy self-identity and boost self-esteem (Habron et al., 2013). Research on singing and well-being suggests that participants experience increases in life satisfaction, positive mood, and a lowering of distress (Gick, 2011).

Arts initiatives that improve and sustain the psychosocial well-being of CG of PwD have shown promising results. For example, the MoMA Alzheimer's Project which offers an arts activity program at a museum found an increase in wellbeing among caregivers and the PwD (Mittelman & Epstein, 2009). Overall, arts initiatives for family caregivers remain limited and at too early a stage for conclusive findings (Crossick & Kaszynska, 2016).

Interest has risen in music programs for older adults but much of the research has focused on music therapy or on passive entertainment (i.e., performances by local artists) in long-term care settings (Kaptein et al., 2018). The benefits of community-based choral singing have received little attention, perhaps because choirs are ubiquitous and the benefits seemed obvious. However, PwD are often excluded from community choirs once they are unable to memorize songs for public concerts. The stigma of dementia brings cumulative losses over time, the social losses can take a significant toll on health and well-being.

Several studies have recently focused on the participation of older adults in choirs. A large study on community choirs for diverse older adults found that participation significantly reduced loneliness and increased interest in life (Johnson et al., 2020). Similarly, Dingle and colleagues (2013) explored the personal experiences of older adults with health challenges who participated in choirs; they report improvement in emotions and emotional regulation, as well as the creation of a sense of group identity and connectedness within the choir and beyond. To date, the psychosocial benefits of choir participation for CG has not been extensively investigated. This thesis addressees this gap by examining the relationship between psychosocial well-being and CG participation in an intergenerational community-based dementia choir.

Research Questions

This study explores the impact of participation in a community-based dementia choir on the psychosocial well-being (i.e., subjective well-being, social well-being, emotional well-being) of caregivers. This quantitative study investigates the impact of choir participation on trajectories of change for psychosocial well-being. In addition, multi-level models are used to analyze the association between social activities and caregiver distress with affect (i.e., positive, negative).

The research questions guiding this study are:

1. Do caregiver levels of psychosocial well-being (i.e., affect, social engagement, caregiver distress) change over the course of choral seasons as a function of their time participating in the choir?
2. Do caregivers exhibit dynamic time-varying covariation between change in affect and corresponding change in caregiver distress or engagement in social activities (i.e., when scores on the predictor is higher (or lower) is there a corresponding association with higher (or lower) performance on the outcome measure)?

In the next chapter, the theoretical and conceptual elements guiding this study are discussed.

Chapter II. Literature Review

Conceptual Framework

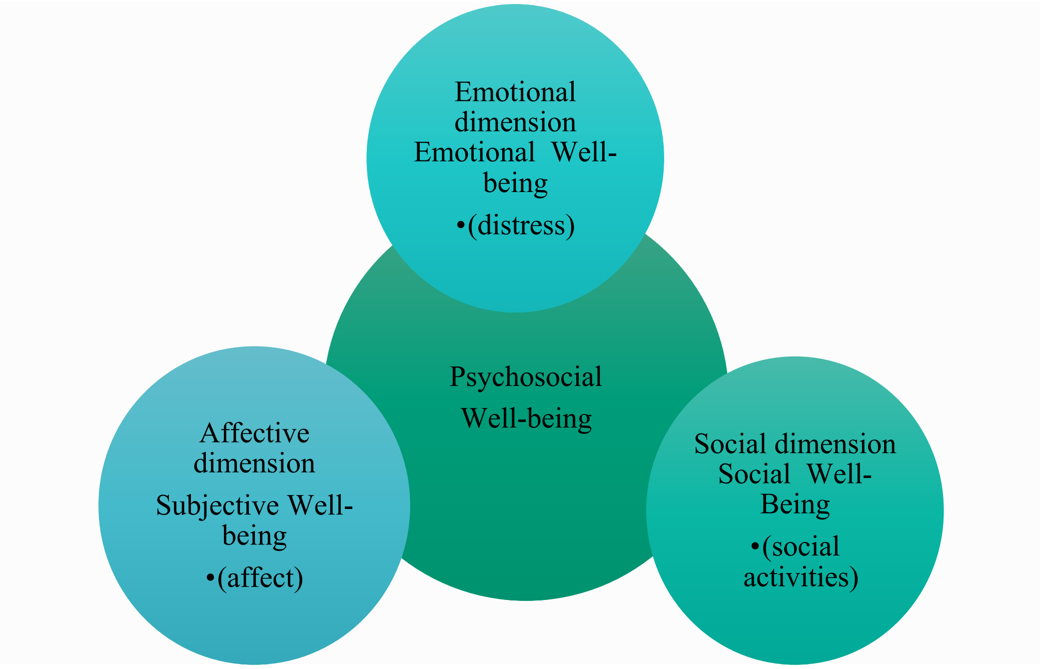
Health is conceptualized broadly as "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity" (World Health Organization, 2018b). The extent to which a CG of a PwD experiences stress, emotions, and is engaged in social activities can impact their health, well-being, and quality of life. This study investigates the psychosocial well-being of dementia caregivers who participated in the Voices in Motion Choir during 2018-2019. This literature review considers the key concepts underlying the construct of psychosocial well-being and how it has been operationalized for this study.

Psychosocial Well-being

Psychosocial well-being is a latent construct affected by many factors (i.e., perceptions of health, social support, financial stability). Assessment of psychosocial well-being in older adults often includes measures for life satisfaction, sense of purpose, feeling of usefulness, and appraisal of legacy (Belgrave, 2011). Other factors that impact psychosocial well-being include presence of depressive symptoms, loneliness, social isolation, distress, and negative affect (Johnson et al., 2020). In this study psychosocial well-being is conceptualized as a multidimensional construct comprised of subjective well-being (i.e., affect), social well-being (i.e., social activities), and emotional well-being (i.e., caregiver distress) (see Figure 1).

Figure 1

Psychosocial Well-being: A Multidimensional construct



(Cervantes, 2020)

Research suggests that arts-based interventions such as a community choir program for older adults may improve the psychosocial well-being in older adults by reducing loneliness (Johnson et al., 2020). Music programs that are intergenerational may amplify these psychosocial well-being benefits. For example, an intergenerational music therapy program brought together older adults in a retirement community and elementary age children. Findings indicated significant increases in mean scores of generativity and self-worth as well as increased feelings of usefulness by the older participants (Belgrave, 2011).

Subjective Well-being (Affect). Subjective well-being (SWB) refers to the appraisal and evaluation of one's life. According to Diener (1984), SWB has three components: life satisfaction (LS), positive affect (PA), and negative affect (NA). SWB has two core dimensions:

the affective dimension of well-being (AWB) and the cognitive dimension of well-being (CWB). AWB refers to one's appraisal of recent events and focuses on feelings and affect. In contrast, CWB refers to global life satisfaction and circumstances (Luhmann et al., 2012). Overall, SWB consists of an evaluation of life satisfaction and positive and negative affective reactions to one's life (Busseri and Sadava, 2010). In this study, SWB is operationalized as *affect* (i.e., positive/negative).

Research indicates that self-reported SWB is associated with participation in the arts and influences health and longevity (Crossick, G., & Kaszynska, P., 2016; Diener & Chan, 2011). Arts engagement can enhance SWB by elevating the mood and enhancing emotional well-being (Fancourt & Finn, 2020). Understanding SWB is complex since positive and negative affect are sometimes correlated and sometimes not (Diener et al., 2009). According to Billings et al. (2000, p. 132), "not only are positive and negative affect empirically separable, but at least some of their neurological and psychological substrates also differ." Certain categories of emotions tend to be correlated both between individuals and within individuals over time. For example, "individuals who experience high levels of sadness are also likely to experience high levels of other negative emotions such as fear or anxiety" (Diener et al., 2009, p. 72). Negative affect measures can provide information about individuals' ways of coping with negative emotions. For example, mild negative affect can enhance motivation, improve memory, reduce judgment errors, and improve communication (Forgas, 2017).

Conversely, positive emotions are a psychological protector for health and well-being and can boost SWB (Davidson et al., 2003). *Positive affect* (PA) refers to the extent to which a person feels enthusiastic, active, alert, and happier (Eid & Larsen, 2008). Higher levels of PA indicate high energy, full concentration, and pleasure. Furthermore, higher levels of PA are strongly associated with human flourishing and contribute to a person's psychological resources, improving coping skills and longevity, as well as social engagement (i.e., number of social activities) (Beiser, 1974; Bradburn, 1969; Clark & Watson, 1986, 1988; Fredrickson & Branigan, 2005, Watson, 1988; Watson & Tellegen, 1988). Importantly, choral singing is known for generating positive emotions (Davies et al., 2014).

Emotional Well-being (Caregiver Distress). Emotional well-being (EWB) is critical for adapting to life's challenges and opportunities and for engaging in a broad range of social behaviours (Chen et al., 2017). Emotional well-being is subjective and reflects one's ability to copes with changes and adverse events in life and includes resilience and adaptability to difficulties (Fredrickson & Joiner, 2002; Ostir et al., 2000). It influences thoughts, behaviours, and physiological responses (Fredrickson & Branigan, 2005; Fredrickson, 2004; Stellar, 2015).

EWB is impacted by the intensity and duration of caregiving. Dementia caregivers report spending on average 26 hours per week on care compared to 17 hours provided by caregivers of persons with physical disabilities (Canadian Academy of Health Sciences, 2019; CIHI, 2019) In this study, EWB is operationalized as caregiver distress which is described in terms that include strain, stress, burden, anger, suffer, sense of uncertainty, and others unpleasant emotions (Chen et al., 2017).

Social Well-being (Engagement in Social Activities). Social well-being is a key component of an individual's overall health (Keyes, 1998). The Public Health Agency of Canada (2012) defines health as a capacity or resource that enables individuals to pursue goals, learn new things, and grow. This definition brings attention to the importance of the social dimensions of health and wellness. This study uses engagement in social activities as an indicator of social well-being.

Theoretical Framework

The proposed framework for psychosocial well-being in this study draws upon three theoretical perspectives: 1) the concept of subjective well-being (Diener, 1984, 2009), 2) the model of successful aging (Rowe & Kahn, 1998), and 3) the process underlying caregiver distress (Pearlin et al., 1990). These theoretical perspectives are operationalized using the proposed framework for psychosocial well-being.

Subjective Well-being Model (Affect)

The concept of subjective well-being (SWB) is strongly influenced by Diener's (1984) seminal article on how people experience and evaluate their quality of life. This process of experience and evaluation includes affect reactions such as positive affect (i.e., pleasant feelings) and negative affect (i.e., unpleasant feelings, distress). Over the last two decades, research on affect and emotions has grown, and gerontologists have shown particular interest in SWB (Diener et al., 2009b). It is important to differentiate between emotion and affect. Emotion is a specific feeling state directed toward a specific target (i.e., caregiver distress) while affect refers to generalized, non-targeted feelings that are unbounded by temporal and contextual factors (Chavez & Méndez, 2008). SWB is often assessed according to subjective evaluations of various aspects of their lives along cognitive and affective dimensions (Burns, 2017). In this study, SWB is operationalized as the affective dimension and its positive or negative valence of affective states.

Assessment of SWB generally includes intensity, duration and frequency of positive and negative affect (Diener et al., 2009a). This study assesses intensity and frequency. Intensity is assessed reflecting over the past week for positive and negative affect at each follow-up. It is essential to accurately assess the effects of various influences of affect on the overall experience of well-being, considering frequency and intensity; this is especially true in longitudinal studies. As Diener (2009b, p. 74) points out, “Research shows that the intensity with which one feels emotions is not the same thing as the frequency with which he or she feels these emotions, and these two aspects of the emotional experience have distinct implications for well-being.” For example, emotions’ intensity may be related to within-person variability and its specific intra-personal traits (Diener, 1999). To get a better appraisal of a high subjective well-being assessment it should be consider intensity, frequency, and duration of people’s positive affect (Diener et al., 2009a).

Interestingly, high positive affect and low negative affect are not necessarily linked; a strong correlation is found on occasions, but not always. SWB is subjective and unique for each person and individuals vary in their capacity to adapt, their temperament and other factors that influence feelings of subjective well-being (Diener, 2000). The affective dimension alone does not suffice to provide an overall evaluation of most people’s lives and their well-being. Therefore, other variables (i.e., quality of life, cognitive appraisal, emotional, distress, social engagement) should be included.

Finally, the concept of SWB extends our understanding of the impact of positive affect on social, psychological, and health outcomes in life, including improved coping skills, a positive and creative lifestyle, and healthier ageing. These positive outcomes can be experienced by individuals and groups of individuals (i.e., human society). Diener offers policy recommendations, suggesting that positive well-being should be a human right and proposing a national subjective well-being index to evaluate and pursue the promotion of the right to well-being at a societal level.

Successful Aging (Engagement in Social Activities)

Rowe and Kahn (1998) shifted the focus from aging as losses related to disease and disability towards the factors that characterize “successful aging”. Although the concept of “successful aging” has been strongly critiqued in subsequent decades, it brought attention to the importance of psychosocial and lifestyle influences on ageing, including attitude, social engagement, nutrition, and physical activity. Social engagement/activity is a key aspect of the ViM choir program. The ViM choir is a socially engaging activity in which the social interaction is viewed as being equal in importance as the music. The ViM program uses an arts-based intervention that supports healthy ageing and may improve health outcomes. Activities that promote social connections can contribute to healthier pathways, especially for dementia CG who are at high risk for distress. Age is not a modifiable risk factor, but there are lifestyle modifiable risk factors (i.e., diet, physical activity, cognitive training and social connections) (Baumgart et al., 2015). There are opportunities to implement interventions that reduce health risks. Preventing loneliness can reduce health risk which are associated with increased caregiver distress. The ViM choir offers multiple health benefits for caregivers that can improve psychosocial well-being. The choir increases social connections, physical activity and also has cognitive component (i.e., remembering songs, reminiscing about your life).

Rowe and Kahn (1998, as cited in DeLiema & Bengtson, 2017) point out that extrinsic factors play a positive role in healthy ageing. For example, being socially active in the context of close interpersonal relationships gives meaning to the older person’s life. Rowe and Kahn (1998) distinguish between the *interpersonal level* of successful ageing, which includes being social engaged in relationships with others, and the *intrapersonal level*, which includes feeling productive by engaging in activities valued by society. Both of these two elements are essential to overall psychosocial well-being and are key benefits of participating in a a professionally directed choir that rehearses weekly to offer a public concert each season.

A Model of Caregivers' Stress (Caregiver Distress)

Pearlin et al. (1990) propose a Caregiver Stress Model for understanding how caring for a cognitively impaired loved one can impact levels of distress experienced by family caregivers. Their model of caregiver distress details a set of interrelated conditions. Primary stressors are the daily dependencies, hardships, and challenges associated directly with the relationship between caregiver and care recipient. Secondary stressors are the strains experienced in roles and activities outside caregiving, including intra-psychic strains such as negative self-concepts. As cognitive impairment progresses, caregivers must adapt to the changing needs of the PwD (Mello et al., 2017). The model has great relevance to caregivers of loved ones suffering from a progressive cognitive impairment associated with sudden changes in mood or behaviours (Alzheimer Society of Canada, 2020) which puts additional stress on caregivers. Social programs such as the dementia choir, can help to mitigate the negative impacts of stress on the caregivers' well-being

Psychosocial Well-being Model

Components of the three theoretical perspectives outlined above are applied in this study to create a multi-dimensional operationalization of the concept of psychosocial well-being. Psychosocial well-being is operationalized as three self-reported measures for: 1) affect (i.e., subjective well-being), 2) social activities (i.e., social-well-being) and caregiver distress (i.e., emotional well-being).

Caregivers and their Psychosocial Well-being; Risks and Challenges

The caregiving role can have positive as well as negative impacts, depending on the context, duration and availability of resources. Caregiving can provide a sense of purpose in life, personal growth, life satisfaction, and confidence that brings a sense of control for the own life, independent of social pressure (Ryff & Singer, 2008, p. 13). However, the negative impacts of caregiving can also be significant and vary considerably depending on the resources and resilience of the individual. Caregivers of PwD face increased risk for distress over time as cognitive impairment progresses and levels of stress rise. Caregiving can take a toll on physical health and exacerbate financial problems. Gender also has an impact since women are more likely to be caregivers which impacts family dynamics and adds to the social role and psychological pressures facing women (Alzheimer's Disease International, 2019).

The well-being of older adults is influenced by their conception of their own health as optimal or not optimal, and people who perceive their health more positively report higher well-being (Mossey and Shapiro, 1982). Two closely related factors that impact the well-being of CG are social isolation and loneliness. *Social isolation* is defined as a lack of meaningful relationships, limited or no contact with family and friends, and limited or no participation in social activities (Holt-Lunstad et al., 2010, p. 9). In contrast, loneliness is a subjective experience that arises in the absence of meaningful interpersonal interactions and can occur even when one is surrounded by people (Coyle & Dugan, 2012). One can be socially isolated and not feel lonely, conversely, one can be lonely and yet have frequent contact with others. Both social isolation and loneliness can have significant negative impacts on health and psychological well-being (Leigh-Hunt et al., 2017). CG often report that they have little time to engage in social activities and thus the experience of social isolation is common.

Social activities reflect lifestyle, social interaction, personal goals, and self-esteem (Kiefer, 2008). Clearly social activities interconnects with other dimensions of well-being, including mental health (Oshio & Kan, 2016) (i.e., well-being, happiness, and life satisfaction). Oshio and Kan (2016) suggest that participation in social activities can alleviate caregivers' psychological distress. A lifestyle that includes social activities is strongly related to multiple psychosocial benefits such as positive affect (i.e., enthusiastic, proud, attentive) (Watson et al., 1988), reduced cognitive risk (Jopp & Hertzog, 2010), improved psychological well-being (Lampinen et al., 2006), and successful ageing (Menec, 2003). In addition, of participation in arts-based activities for PwD suggests the potential for social interaction to improve well-being (Young et al., 2016).

Health, the Arts, and Psychosocial Well-being

Attention to the arts is increasing in gerontology research (Hanna, Noelker, & Bienvenu, 2015), as arts-based programs have shown benefits that include improved quality of life, reduced social isolation and increased social connections (Davies et al., 2014), especially with participation in high quality programs (i.e., Herzog, et al., 1998; Jopp & Hertzog, 2010; Lampinen, et al., 2006; Menec, 2003). Fancourt (2017) proposes an emerging model at the nexus between health and the arts, in which engagement in arts-based activities is recognized as having positive impacts on both individual and societal wellness. In addition, some arts interventions show greater or equivalent cost-effectiveness compared to health interventions (Fancourt and Finn, 2019).

A recent scoping review of 900 publications examining the impact of the arts on health (Fancourt & Finn, 2019) found that exposure to the arts has great potential for supporting health but that further research is needed, particularly since the evidence base is small for many health conditions (i.e., dementia). Although a large number of studies focused on music, none examined dementia choirs. In fact, the contribution of arts-based interventions to the health and well-being of caregivers of PwD has yet to be studied extensively. The role of the caregiver in participation in the arts along with the care recipient need more attention (Fraser et al., 2014). In the UK social prescriptions for the arts programs are being provided to older adults to increase their access to programs that support well-being and reduce anxiety, depression, and stress (All-Party Parliamentary Group on Arts, Health and Wellbeing, 2017a). Demand for arts-based approaches to dementia is growing and there is a need to study their impact and effectiveness (Daykin et al., 2017).

The Voices in Motion study builds on existing research on engagement in the arts by assessing the impact of participation in a choir for older adults (Unadkat et al., 2016). Older adults who participate in choirs report positive emotions about the pleasure and enjoyment they derive from group singing (Mittelman & Papayannopoulou, 2018). Moreover, group singing significantly decreases negative affect and anxiety levels in participants (Sanal & Gorsev, 2014). Importantly, the ViM program is novel in integrating: 1) an intergenerational approach; 2) a professionally directed community-based choir program, and 3) focuses on PwD and their caregivers.

Participation in a community-based choir may provide significant support for CG and the PwD. Research suggests that participating in a choir can improve communication and social interactions for PwD and their caregivers, bringing participants a sense of well-being, social connectedness, and relational support. Music is a social activity thus participation in group singing fosters opportunities for playful interaction and the development of social relationships and feelings of social connection (Moran, 2014). Engagement in the arts can reduce social isolation, which is an essential component of well-being for older adults with dementia and their caregivers (Camic et al., 2016; Cherry et al., 2013).

Choir singing requires physical movement, intensive breathing, motor coordination, memory recall, and a sense of rhythm, thus activating many regions of the brain. According to the Alliance for Aging Research (2012), cognitive training is more effective when combined with exercise. Cognitive stimulation has beneficial effects on cognitive function and on some aspects of well-being for both PwD and their CG (Gaugler et al., 2019). Choirs that are intergenerational may offer additional benefits to both CG and the PwD Intergenerational programs offer benefits that include additional social connections, reducing ageism, diminishing the stigma of dementia, and increasing empathy (Kuehne & Melville, 2014).

Benefits of participation in a community choir for CG and PwD include reduced depression, increased social engagement, and improved well-being. Of course, there remain gaps in evidence-based knowledge regarding engagement in arts-based programs for CG and PwD. Little is known about the effects of participation in a community-based dementia choir on CG well-being, or whether CG affect is associated with changes in distress and engagement in social activities. Findings from this study will extend our understanding of the impact of CG participation in a dementia choir on psychosocial well-being and distress.

Chapter III. Methodology

To address the research questions, this study employed longitudinal data from the Voices in Motion (ViM) study. In this chapter, information will be provided to better understand the methodological components such as the program/intervention, design/sample, measures, data collection, ethical considerations, and methods and analyses. The final section (statistical procedures) will overview the specific analyses employed for addressing each research question.

Program/Intervention

The intergenerational ViM choirs are community-based, professionally-directed choirs. ViM partnered with local high schools, with select high school students partnered with specific PwD each week. The choir met for weekly rehearsals for a 12-week season, spanning 3 seasons, starting in Jan 2018 and ending in Spring 2019 (approximately 18 months in total). The 90-minute rehearsals included social activities at the start, middle and end of each choral session, concluding with refreshments and time to talk. The culminating event of each choral season were public concerts that attracted audiences of up to 300 family and friends per concert.

Design/Sample

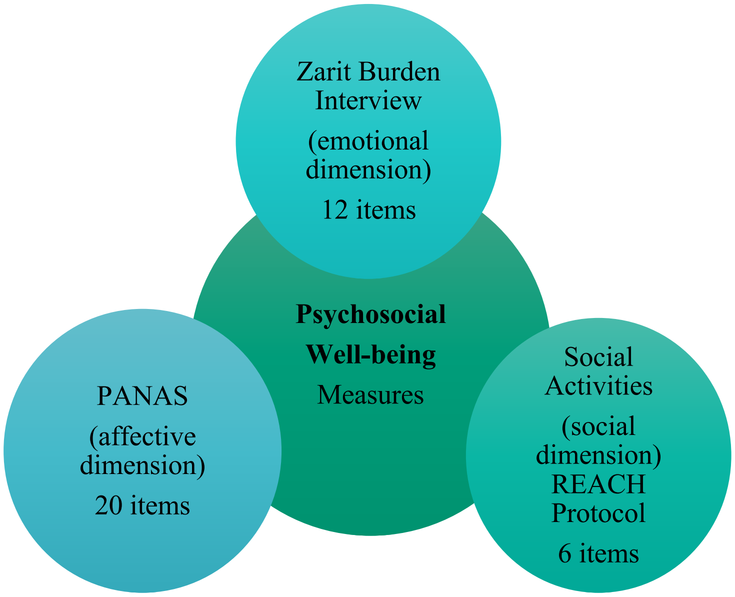
Data for this study comes from the ViM project, funded by the Alzheimer's Society Research Program and the Pacific Alzheimer's Research Foundation. The study employed a snowball sampling procedure for recruitment (see Tamburri et al., 2019, for sampling details). The present thesis focuses on a subsample, family caregivers (n=34) who were participating in the choir for up to three seasons. Caregivers (CG) ranged in age from 48 to 89 years. Eligibility criteria for the choir included: 1) being a caregiver of a community-dwelling older adult with mild to moderate dementia; 2) English-speaking; and 3) able to attend weekly 90-minute choir rehearsals.

Measures

Caregivers completed questionnaires that included standardized measures for: 1) demographics (i.e., gender, birth date, current marital/partner status, ethnic background, academic diplomas or degrees obtained, and current employment status), 2) health, 3) well-being and quality of life (see Table 1 and Appendix A for more details). Psychosocial well-being is conceptualized as a multidimensional construct (including affective, social, and emotional dimensions) that reflects perceived wellness of each CG participant (see Figure 2).

Figure 2

Psychosocial Well-being: A Multidimensional measure approach



(Cervantes, 2020)

Subjective Well-being

The terms “affect,” “mood,” “feelings,” and “subjective well-being,” are used interchangeably, but the operational term used in the analyses for this study is subjective well-being (affective dimension). To measure subjective well-being, this study utilizes the positive and negative affect scale (PANAS), a 20-item instrument (see Appendix B) in which each item is an adjective describing feelings. Ten items are indicators of positive affect (i.e., “*interested*”, “*excited*”, “proud”, “inspired” “active”), and 10 items are indicators of negative affect (i.e., “*irritable*”, “*nervous*”, “guilty”, “afraid”). Participants were asked to what extent they felt each emotion over the past week. Each item was measured on a 5-point Likert-type scale ranging from 1 (“Very slightly” or “Not at all”) to 5 (“Extremely”). The PANAS has excellent psychometric properties, and is one of the most widely used measures of positive and negative affect (Watson et al., 1988).

Social Well-Being

To measure social well-being (social dimension), data were gathered using a social activities instrument from the REACH II protocol (Schulz et al, 2006). The construct of self-reported social activities (SA) is used as an index of social engagement, a component of social well-being. SA was assessed using 6 items (see Appendix C) measured on a 3-point Likert-type scale ranging from 0 (“Not at all”) to 2 (“A lot”). These items were adopted from the REACH II–Baseline Battery from the social activities domain/SA 62-63.

Emotional Well-being

Emotional well-being (emotional dimension) was operationalized as a pleasant feeling directed toward a specific target and context (i.e., caregiver role). The emotional dimension includes assessment on the caregiver's emotional distress, indexed using the Zarit Burden Interview (ZBI). This instrument is one of the most effective for assessing caregivers' burden (Zarit & Zarit, 1987). The ZBI-12 is a commonly-used short version (Bedard et al., 2001; Hébert et al., 2000). The ZBI assesses caregiver burden (distress) in areas such as health and personal relationships (Springate & Tremont, 2013). A meta-analysis of the short version of the ZBI found it to be reliable across the many and diverse contexts in which it has been used (Yu et al., 2019). The ZBI-12 is comprised of 12 items (see appendix D), each beginning with the phrase ("Do you feel...): (1): "That because of the time you spend with your relative that you don't have enough time for yourself?" (2) "Stressed between caring for your relative and trying to meet other responsibilities (work/family)?" (3) "Angry when you are around your relative?" (4) "That your relative currently affects your relationship with family members or friends in a negative way?" (5) "Strained when you are around your relative?" (6) "That your health has suffered because of your involvement with your relative?" (7) "That you don't have as much privacy as you would like because of your relative?" (8) "That your social life has suffered because you are caring for your relative?" (9) "That you have lost control of your life since your relative's illness?" (10) "Uncertain about what to do about your relative?" (11) "You should be doing more for your relative?" and (12) "You could do a better job in caring for your relative?" Response options are "never (0), rarely (1), sometimes (2), quite frequently (3), or nearly always (4)," yielding a score of 0 to 4 points per item, with the total score ranging from 0 to 48. Suggested guidelines for scoring indicate that 0-9 represents no to mild burden; 10-19, mild to moderate burden; and 20 or higher, high burden.

Data collection

Data were collected using a longitudinal, intensive, repeated-measures design (Stawski et al., 2015). Participants were assessed and completed surveys at the Institute on Aging and Lifelong Health at the University of Victoria. During the 12-week choir season, data was collected up to four times (i.e. ~ monthly) during the 3-season choir program implemented in 2018 and 2019. To facilitate statistical analysis, time was coded as time in study (TIS), reflecting number of months elapsed between each follow-up assessment and baseline testing (with baseline assessment coded as 0). Follow-up assessments ranged from two to seven per participant.

Ethical Considerations

This ViM study received ethics approval from the University of Victoria (see Appendix E). This research meets the appropriateness standards of ethics involving human participants. Data are de-identified, and analyses are reported only in the aggregate to maintain the anonymity of participants. All data are stored on a secure University of Victoria network drive with encryption and password protection.

Statistical Procedure

Data were cleaned and checked to ensure the range/scale of all variables fell within expected ranges prior to running analyses. For data entries where no answer (-88) or missing values (-99) were identified, the data were re-coded as system missing (".") before running descriptive statistics or other analyses. Maximum likelihood estimation (also known as full information maximum likelihood or FIML) was employed to derive estimates based upon all available data.

Descriptive statistics and multilevel-modeling (MLM) analyses (also known as linear mixed effect analyses, hierarchical linear models, or mixed-effect models) were used to analyze the longitudinal data (Mumper, 2017). The MLM or linear-mixed models facilitate appropriate assessment of change for nested data (multiple times of assessment nested within individual caregivers). An alpha of ≤ .05 was considered statistically significant, and 95% confidence intervals (CI) are provided. Reliability tests using Cronbach's alpha were derived with values above .70 considered acceptable for all indexes (Tavakol & Dennick, 2011).

This study employs multilevel models, deriving effects at both the within-person (level 1) and between-person (level 2) levels of assessment to explore the stated research questions: 1) Do caregiver levels of psychosocial well-being (i.e., affect, social engagement, caregiver distress) change over the course of choral seasons as a function of their time participating in the choir?, and 2) Do caregivers exhibit dynamic time-varying covariation between change in affect and corresponding change in caregiver distress or engagement in social activities (i.e., when scores on the predictor is higher (or lower) is there a corresponding association with higher (lower) performance on the outcome measure)? An initial unconditional growth model explores time in the study as the sole predictor to characterize change over time, with a subsequent model including age as a covariate (centered at 68 years – the average CG age; see Equation 1). For all MLM equations, the intercept will provide a modeled estimate of the mean of the responders when all predictors are zero (i.e., the level-1 TIS predictor = 0 for baseline assessment) and will be used as the start point for the graphs. Change was modelled for all variables for all participants as a function of their time participating in the choir. The slope provides an estimate of the rate of change over time among CG who participated in the choir. For both intercept and slope, random effects (variances) are also estimates that explore the magnitude of between-persons differences in intercepts (i.e., variance in performance at baseline assessment) and slopes (i.e., variance in rates of change across months participating in the choir). The intraclass correlation coefficient (ICC) is derived for a fully unconditioned (no predictors) model, with the ICC indicating the proportion of total variation in the outcome variable that is attributed to between-person differences.

Research Question 1

The first research question explores whether the CG's levels of psychosocial well-being (affect, social activities, and caregiver distress) change over the course of choral seasons as a function of their time participating in the ViM choir.

To answer research question 1, time was modelled as TIS reflecting months elapsed between baseline and each subsequent assessment. This study explores patterns of caregiver change spanning several choir seasons for three outcomes: 1) positive/negative affect, 2) social activities, and 3) caregiver distress.

<u>Equation 1. MLM Equation for Change</u>:

$$\begin{aligned} Affect_{ij}/CGD_{ij}/SA_{ij} &= \beta_{0j} + \beta_{1j}Time + e_{ij} && \text{Level 1} \\ \beta_0 &= \gamma_{00} + \gamma_{01}(Age_{Centered} at\, 68) + \mu_{0i} && \text{Level 2} \\ \beta_1 &= \gamma_{10} + \mu_{11} && \end{aligned}$$

Research Question 2

The second research question explores whether CGs exhibit dynamic time-varying covariation between change in affect and corresponding change in caregiver distress or social engagement. Such within-person MLM models of coupled change explore whether, on occasions when scores on the predictor is higher (or lower), there is a corresponding association with higher (or lower) performance on the outcome measure.

To answer research question 2, a multilevel coupled model of change was employed to examine two time-varying associations: 1) the association between affect and social activities and 2) the association between affect and caregiver distress. The dependent variables in these analyses are positive and negative affect and the independent variables are social activity/social engagement and caregiver distress. As person-mean centering was employed, the Level-1 effect of the time-varying predictor becomes a pure estimate of the *within-person* effect, with the level-2 effect reflecting a constant *between-persons* effect (Hoffman & Stawski, 2009). The coupled model of change is useful for dissociating the proportion of variation of an effect that is systematically within-persons vs. between-persons. Moreover, the coupled change model parameterization allows caregivers to serve as their own controls; thus, changes in the variables (PA/NA) are interpreted relative to each individual CGs own average levels for each of the predictor variables (CGD/SA). In addition to the fixed effects, the coupling model (see equation 2) also includes the estimate of random effects for intercept (estimate of variance for between-persons differences in starting points), slope (estimate of variance for between-persons differences in rates of change), and coupling (estimate of variance for between-persons differences in the magnitude of within-person coupling effects).

After deriving the intra-class correlation coefficient to inform the percentage of variation that is systematically between-persons, the next step was to add a within-person (level-1) predictor in the coupling equation (see equation 2). In contrast to equation 1, TIS was included in equation 2 as a covariate to minimize the impact that individual differences in change over time may have on the coupling parameter estimates. The following equation was used for the analyses.

Equation 2. MLM Equation for Coupled Change:

$$Affect_{ij} = \beta_{0i} + \beta_{1i}(Time\_Month) + B_{2j}(CGD\_WP/\ SA\_WP/) + e_{ij}$$ Level 1

$$\beta_{0i} = \gamma_{00} + \gamma_{01}(Age_{Centered}at\ 68) + \gamma_{02}(CGD\_BP/SA\_BP) + \mu_{0i}$$ Level 2
$$\beta_{1i} = \gamma_{10} + \mu_{1i}$$
$$\beta_{2i} = \gamma_{20} + \mu_{2i}$$

Chapter IV. Findings

In this chapter, the results of the analyses are presented. First, sociodemographic information and descriptive statistics are discussed. Next, information regarding the within-person and between-persons sources of variation (Fully Unconditioned Model). Third, findings for the two research questions are presented (trajectories of change models and coupled models). The chapter concludes with a summary of the results of analyses on the impact of participating in the choir upon CG psychosocial well-being.

Sociodemographic Information

Demographic data is presented on 32 caregivers (see Table 1), data was missing on 2 caregivers. The mean age of CG was 68 years (range 49–89 years). Not surprisingly, the majority (81.3%, n=26) of CG were female. This finding is consistent with the literature, which shows that women are more likely than men to assume the burden of serving as family caregivers. With regard to family relationships, 62.5% of CG were spouses of the PwD in their care, 25.0% were sons or daughters, and 12.5% had other relationships to their care recipients. The CG sample was well-educated with nearly one-half (43.8%) having completed community college or other training and one-fourth having completed a baccalaureate or higher degree.

Table 1

Summary of Sample Demographics

	Caregivers (n=32)
Age	M=68 years (range 49-89)
Sex	Male: 6 (18.8%) Female: 26 (81.3%)
Educational Level	12.5% no degree 18.8% high school diploma 43.8% technical/trade school or community college 15.6% Bachelor's degree 9.4% other
CG Relationship to PwD	62.5% spouse 25.0% son or daughter 12.5% other relationship

Descriptive Statistics

Table 2 summarizes the descriptive findings for the psychosocial measures. Higher scores for affect (range: 10-50) represent higher levels of affect with a score of thirty being considered high. Positive affect was high (M=37.51) and negative affect (M=17.47) was low among caregivers. Scores for positive affect were larger in magnitude (range: 17-50) versus negative affect (range: 10-42). Social activities (M=7.74) fell in the middle of the score which ranged from 0 to 18. Caregivers differed in the level of distress they felt, 25% reported none to mild distress, 32% reported mild to moderate distress, and 43% report high levels of distress. The mean for caregiver distress (M=17.32) indicated mild to moderate distress.

Cronbach's alpha was run to test the internal consistency (i.e., scale reliability) for the selected measures (e.g. affect, social activities, caregiver distress). The internal consistency was high for all indices (i.e., alpha coefficient above .70), as shown in Table 2.

Table 2

Summary of Descriptive Statistics for Psychosocial Measures

Variable	Number of items	Cronbach Alpha	Standard deviation	Mean	Minimum	Maximum
Positive Affect	10	.917	7.46	37.51	17.00	50.00
Negative Affect	10	.918	6.72	17.47	10.00	42.00
Social Activities	6	.882	2.72	7.74	1.00	12.00
Caregiver distress	12	.942	10.23	17.32	0	41.00

Within-person and Between-person Sources of Variation (Fully Unconditioned Model)

The intraclass correlation coefficient (ICC) was calculated to find the within-person and between-persons percentages of variation. The intraclass correlation is commonly used to quantify the degree to which individuals with a fixed degree. It helps to get measures with percentages to differentiate the variance within-person versus between-persons. The ICC for the unconditional model indicates that the covariance parameter estimates for each one of the variables at baseline were as follows, 0.73 (73% of the variance in positive affect is between-persons, 27% within-person); 0.30 (30% of the variance in negative affect is between-persons, 70% within-person); 0.72 (72% of the variance in social activities is between-persons, 28% within-person); and 0.92 (92% of the variance in caregiver distress is between-persons, 8% within-person). The majority of the variability in the dependent variables in this study were attributable to between-person variation with the exception of negative affect that has more variability in the within-person.

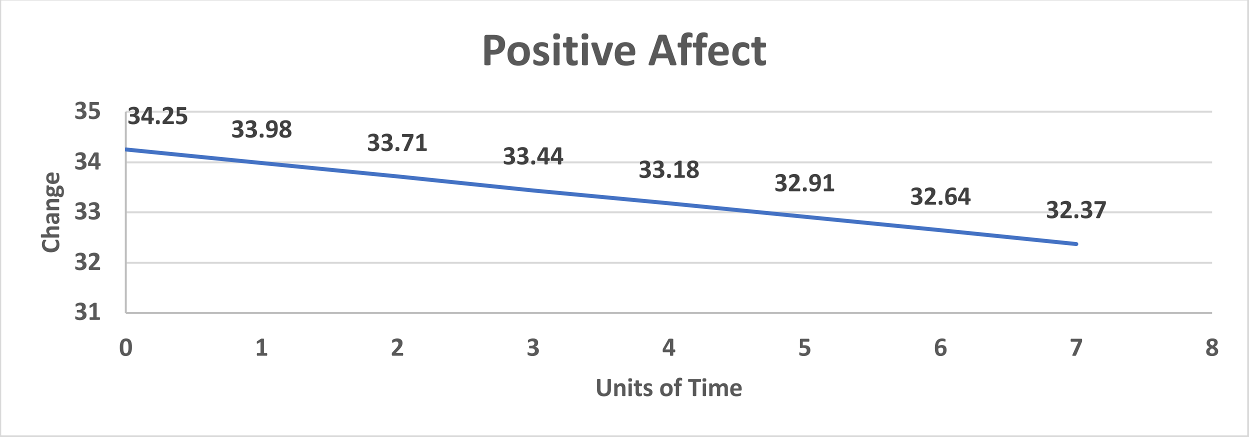
The MLM equation for change model explores patterns of change over several choir seasons for psychosocial well-being including: positive/negative affect (subjective well-being), social activities (social well-being), and caregiver distress (emotional well-being). Overall, there were no significant changes in any of the psychosocial measures over time.

Change in Affect (subjective well-being)

Although positive affect decreased over time (see Figure 3), this change was not significant.

Figure 3

Trajectory of Change for Positive Affect



Note: p=ns

Table 3

Fixed Effect Estimates for Positive Affect

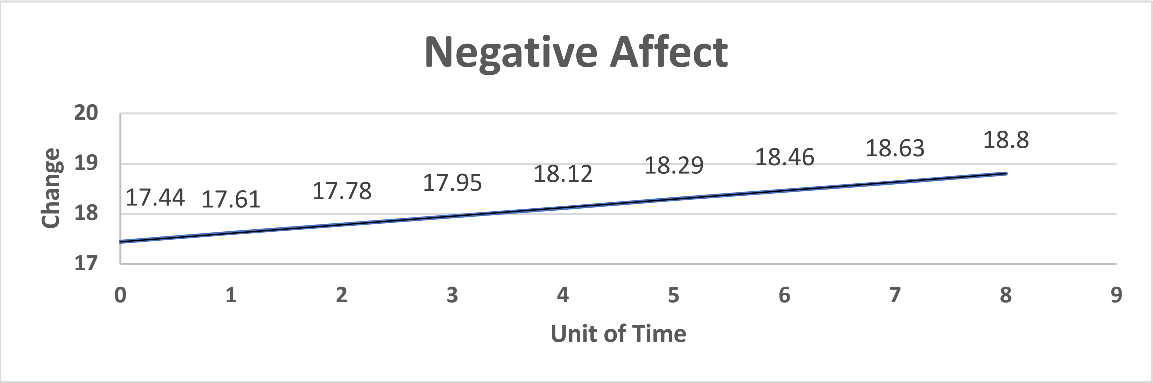
				CI 95%	
Parameter	**Estimate**	**S. E.**	**p-value.**	**Lower Bound**	**Upper Bound**
Intercept	34.25	1.37	.001***	31.43	37.07
Slope	-0.27	.10	.118	-0.72	0.17

Note: *p ≤ .05. **p ≤ .01. ***p ≤ .001, S.E.=standard error, CI=confidence interval.

The change in negative affect over time (see Figure 4) was not significant.

Figure 4

Trajectory of Change for Negative Affect



Note: p=ns

Table 4

Fixed Effect Estimates for Negative Affect

				CI 95%	
Parameter	**Estimate**	**S.E.**	**p-value**	**Lower Bound**	**Upper Bound**
Intercept	17.44	1.15	.001***	15.07	20.00
Slope	0.17	0.13	.176	-0.23	0.57

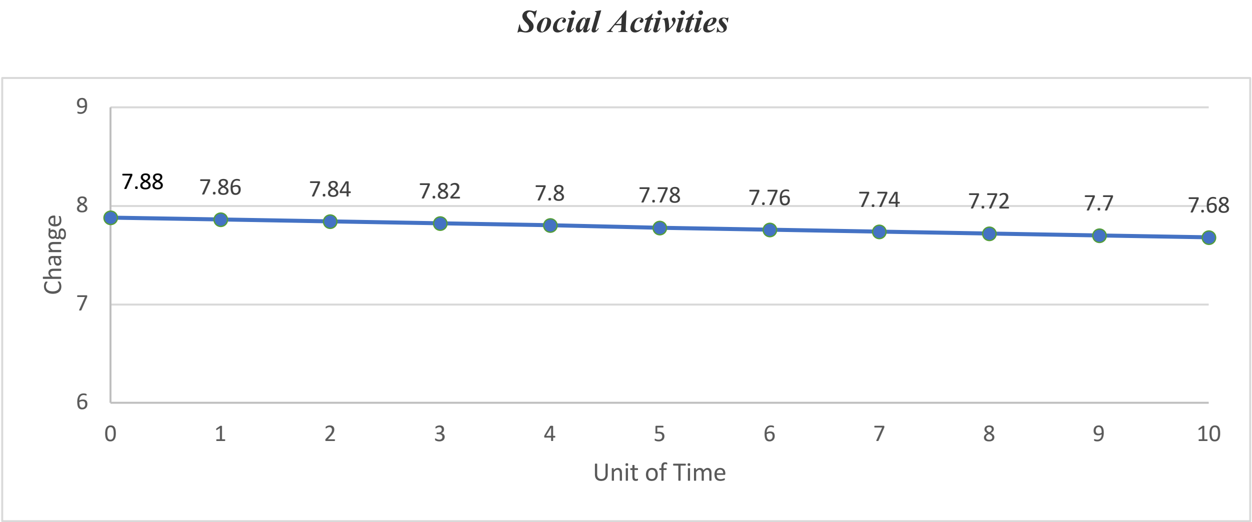
Note: *p ≤ .05. **p ≤ .01. ***p ≤ .001, S.E.=standard error, CI=confidence interval.

Change in Social Activities (social well-being)

Social activities decreased over time but this change was not significant. (see Figure 5).

Figure 5

Trajectory of Change for Social Activities



Note: p=ns

Table 5

Fixed Effect Estimates for Social Activities

				CI 95%	
Parameter	**Estimate**	**S.E.**	**p-value**	**Lower Bound**	**Upper Bound**
Intercept	7.88	.44	.001***	7.01	8.75
Slope	-0.02	.04	.522	-0.10	0.05

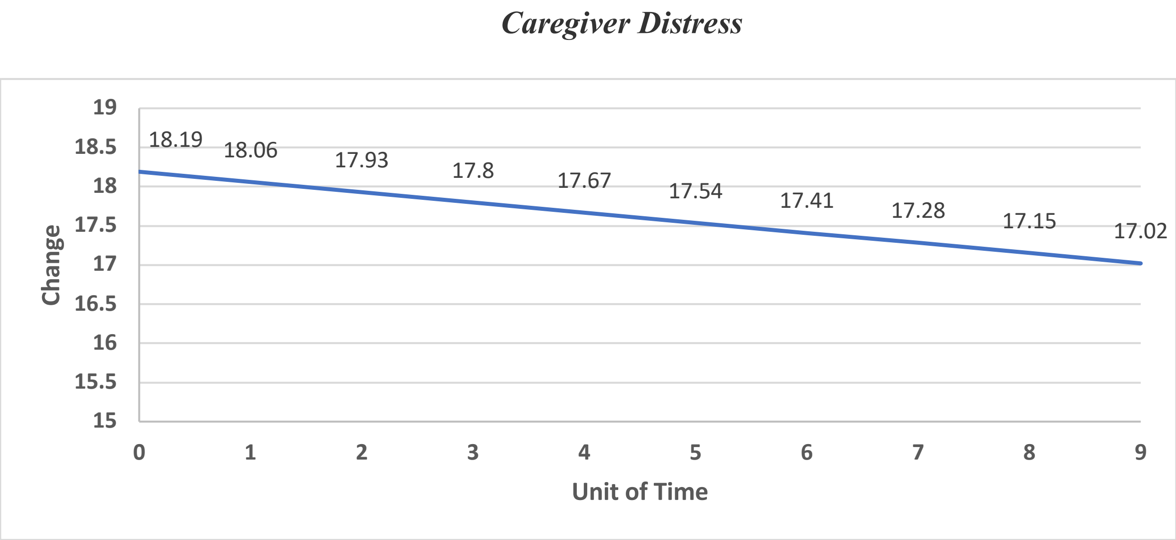
Note: *p ≤ .05. **p ≤ .01. ***p ≤ .001, S.E.=standard error, CI=confidence interval.

Change in Caregiver Distress (emotional well-being)

Caregiver distress decreased over time (see Figure 6) but this change was not significant.

Figure 6

Trajectory of Change for Caregiver Distress



Note: p=ns

Table 6

Fixed Effect Estimates for Caregiver Distress

				CI 95%	
Parameter	**Estimate**	**S.E.**	**p-value**	**Lower Bound**	**Upper bound**
Intercept	18.19	1.81	.001**	14.49	21.89
Slope	-0.13	.12	.319	-0.41	0.14

Note: *p ≤ .05. **p ≤ .01. ***p ≤ .001, S.E. = standard error, CI=confidence interval.

Summary of Equations for Change

Overall, none of the equations for change achieved significance. Rates of change were similar and variances was limited.

Table 7

Summary of results of trajectories of change of Affect, Social Activities and Caregiver Distress

Variable	Intercept	Slope
Positive Affect	34.25	-0.27 (ns)
Negative Affect	17.44	0.17 (ns)
Social Activities	7.88	-0.02 (ns)
Caregiver distress	18.19	-0.13 (ns)

Exploring the Time-Varying Associations Among Affect, Caregiver Distress, and Social Engagement

This section explores potential time-varying associations among key combinations of the study variables (i.e., affect and social activities and affect and caregiver distress). Specifically, the coupled models of change explore whether time-varying fluctuations in social activities or caregiver distress (the level-1 predictors) have a corresponding impact on positive and negative affect (the level-1 outcomes). All models control for individual differences in caregiver age. The unique strengths of the intensive repeated measures design and employment of person-mean centered predictors in the MLM analyses facilitates reporting of the findings at both the between-persons and the within-person level of analysis.

Time-Varying Association Between Caregiver Distress and Positive Affect

At the between-persons level of analysis, a non-significant trend was observed whereby every unit increase in CGD was associated with a -0.20 unit decrease in PA (see Table 8 and Figure 7a, between-persons (BP) effect). This finding suggests that, on average, individuals with greater levels of CGD had lower levels of PA.

In contrast, results examining the pure within-person coupling effect between CGD and PA (see Figure 7b and Table 8, within-person (WP) effect) suggest that for every unit increase in CGD relative to an individual's usual level, that a corresponding significant decrease (WP coupling slope = -0.41, $p \leq .05$) in PA was observed. This significant within-person finding supports the interpretation that levels of caregiver distress and positive affect share a dynamic within-person association, and that the VIM intervention can modulate this time-varying relationship.

Table 8

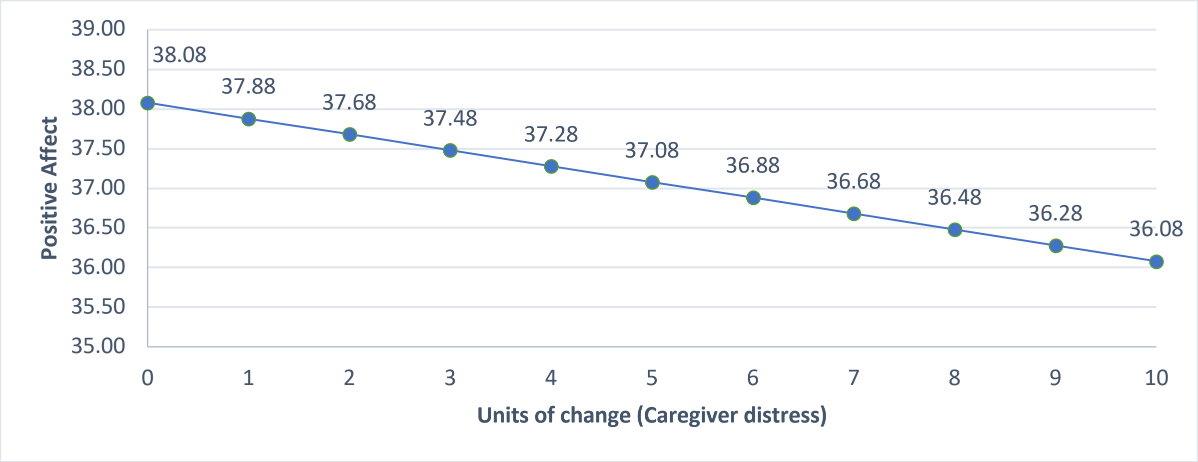
Fixed Effect Estimates for Caregiver Distress (CGD) and Positive Affect (PA)

				CI 95%	
Parameter	**Estimate**	**S.E.**	**p-value**	**Lower Bound**	**Upper Bound**
Intercept	38.08	2.61	.001***	32.74	43.42
CGD_BP/slope	-0.20	.13	.130	-0.47	0.07
CGD_WP/slope	-0.41	.16	.018**	-0.75	-0.08

Note: $*p \leq .05$. $**p \leq .01$. $***p \leq .001$. CGD = caregiver distress; PA = positive affect; S.E. = standard error, CI = confidence interval; BP = between-persons; WP = within-person.

Figure 7a

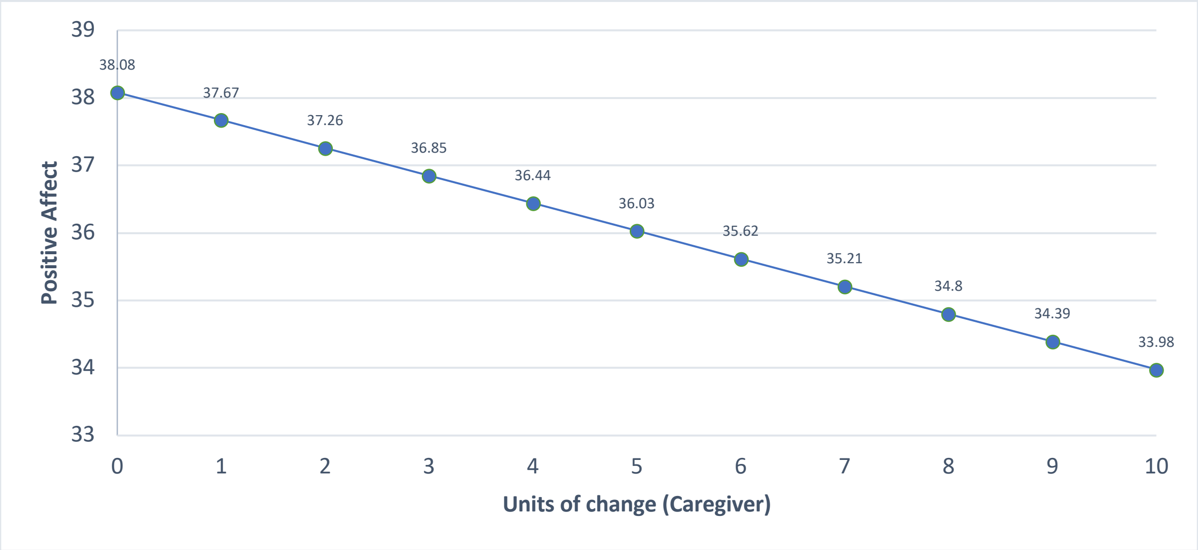
Between-Person association between caregiver distress (CGD) and positive affect (PA)



Note: p=ns

Figure 7b

Within-Person association between caregiver distress (CGD) and positive affect (PA)



Note: **p ≤ .01. This figure indicates that when caregiver distress (predictor) increased by 1 unit, there was a corresponding -0.41** unit decrease for positive affect at the within-person level.

Time-Varying Association between Caregiver Distress and Negative Affect

As expected, at the between-person level, every unit increase in CGD was associated with a significant 0.53 unit increase in NA ($p \leq .01$, see Table 9 and Figure 8a, BP effect). This finding suggests that, on average, individuals with greater levels of CGD also have higher levels of NA. In comparison, the within-person coupling effect between CGD and NA (see Figure 8b and Table 9, (WP effect) was not significant (WP coupling slope = 0.12, ns).

Table 9

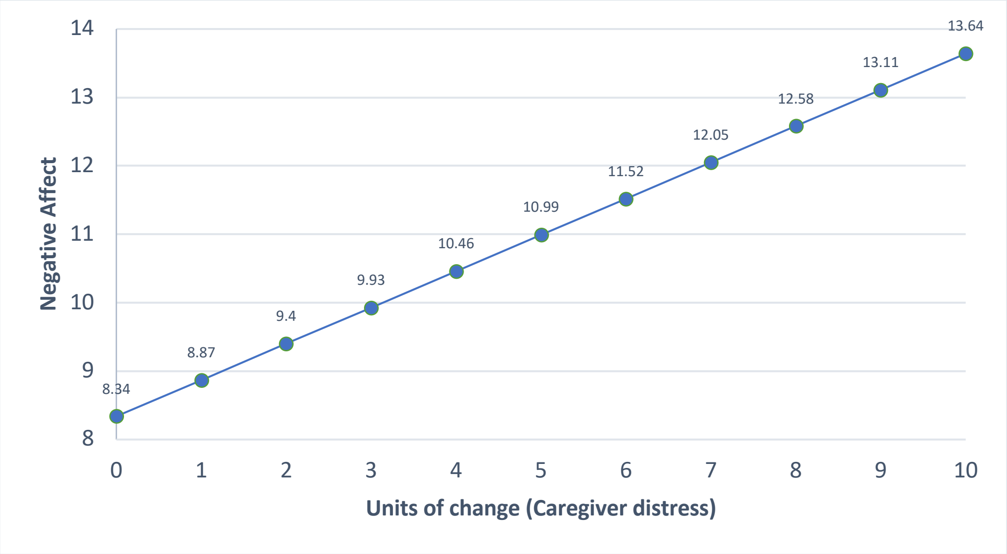
Fixed Effect Estimates for Caregiver Distress (CGD) and Negative Affect (NA)

				CI 95%	
Parameter	**Estimate**	**S.E.**	**p-value**	**Lower Bound**	**Upper Bound**
Intercept	8.34	1.51	.001***	5.17	11.52
CGD_BP	0.53	.07	.001***	0.37	0.68
CGD_WP	0.12	.24	.629	-0.46	0.71

Note: *$p \leq .05$. **$p \leq .01$. ***$p \leq .001$. CGD = caregiver distress; NA = negative affect; S.E. = standard error, CI = confidence interval; BP = between-person; WP = within-person.

Figure 8a

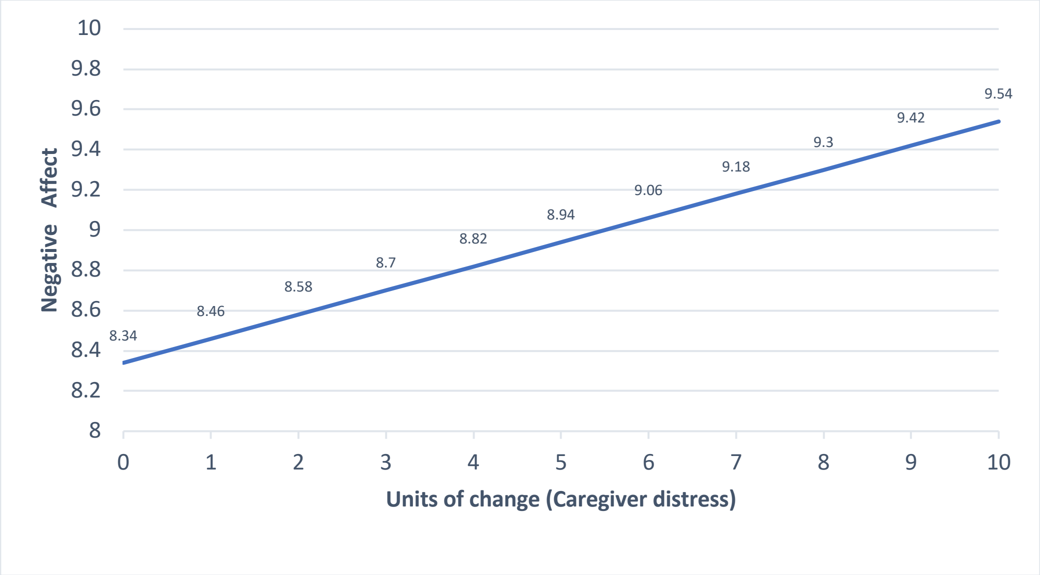
Between-Persons association between caregiver distress (CGD) and negative affect (NA)



Note: This graph shows that when caregiver distress increased by 1 unit, there was a corresponding 0.53** unit increase for the negative affect at the between-person level. **p ≤ .01

Figure 8b

Within-Person association between caregiver distress (CGD) and negative affect (NA)



Note: p=ns

Time-Varying Association between Social Activities and Positive Affect

As expected, the between-persons effect in the coupling model of SA and PA suggests that PA increases with every unit increase of SA. Specifically, between-persons, every unit increase in SA was associated with a 1.27 unit increase in PA (see Table 10 and Figure 9a, between-person (BP) effect). This finding suggests that, on average, individuals with greater levels of social engagement had higher levels of PA.

At the within-person level, the coupled association between PA and SA was not significant (see figure 9b and Table 10, within-person (WP) effect). The non-significant finding indicates that, relative to an individual's usual level of SA, on occasions when SA was 1 unit higher, there was a corresponding 0.61 unit increase in PA. Overall, these findings suggest that an arts-based intervention, such as group singing programs, can increase PA in caregivers at both, individual level and group level.

Table 10

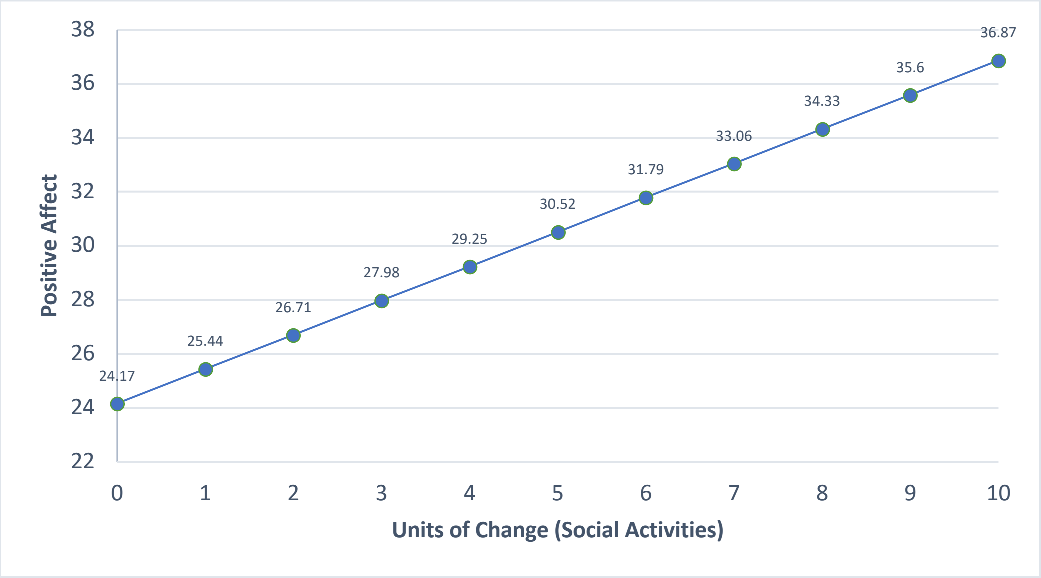
Fixed-effect Estimates for Social Activity (SA) and Positive Affect (PA)

				CI 95%	
Parameter	**Estimate**	**S.E.**	**p-value**	**Lower Bound**	**Upper Bound**
Intercept	24.17	4.25	.001***	15.48	32.85
SA_BP	1.27	.52	.020*	0.21	2.33
SA_WP	0.61	.47	.255	-0.64	1.86

Note: *p ≤ .05. **p ≤ .01. ***p ≤ .001. SA = social activities PA = positive affect; CI = confidence interval; BP = between-persons; WP = within-person.

Figure 9a

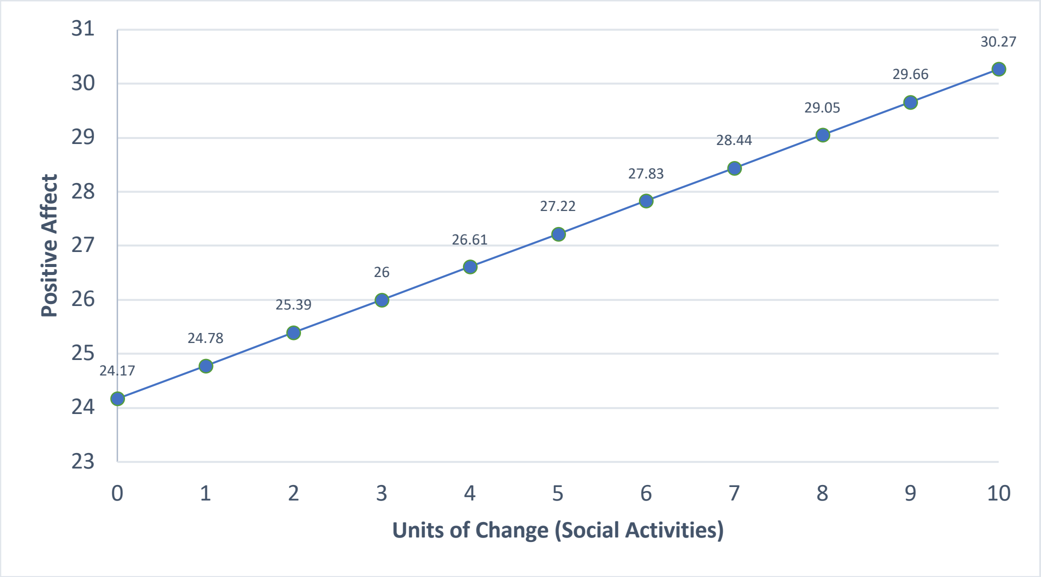
Between-Person association for social activities (SA) and positive affect (PA)



Note: *p ≤ .05. This figure indicates that when social activities increased by 1 unit, there was a corresponding 1.27* unit increase in positive affect at the between-person level.

Figure 9b

Within-Person association between social activities (SA) and positive affect (PA)



Note: p=ns

Time-Varying Association between Social Activities and Negative Affect

The between-persons effect in the coupling model of SA and NA suggests that NA decreases with every unit increase of SA. Specifically, between-persons, every unit increase in SA was associated with a -1.66 unit increase in NA (see Table 11 and Figure 10a, between-persons (BP) effect). This finding suggests that, on average, individuals with greater levels of social engagement exhibit lower levels of NA.

At the within-person level, the non-significant coupled association between SA and NA (see figure 10b and Table 11, within-person (WP) effect) indicated that, relative to an individual's usual level of SA, on occasions when SA was 1 unit higher, there was a corresponding 0.29 unit increase in NA.

Table 11

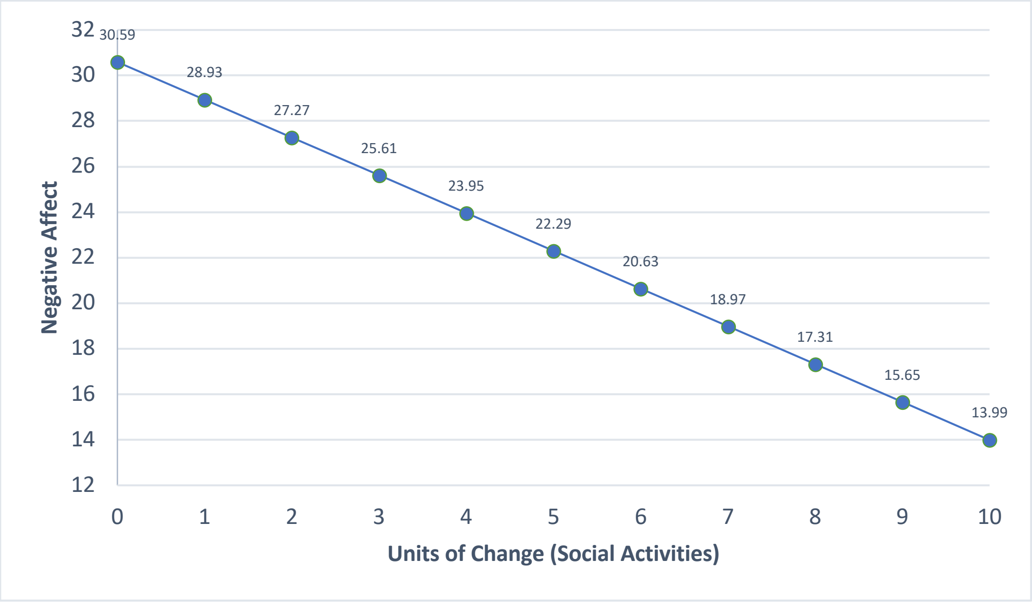
Fixed-effect Estimates for Social Activities (SA) and Negative Affect (NA)

Parameter	Estimate	Standard error	p-value	CI 95% Lower Bound	CI 95% Upper Bound
Intercept	30.59	2.82	.100	- 45.8	107.04
SA_BP	-1.66	.32	.261	-36.9	33.65
SA_WP	0.29	.45	.522	-0.60	1.18

Note: *p ≤ .05. **p ≤ .01. ***p ≤ .001, SA = social activities NA = negative affect; 95% CI = confidence interval; BP = between-person; WP = within-person.

Figure 10a

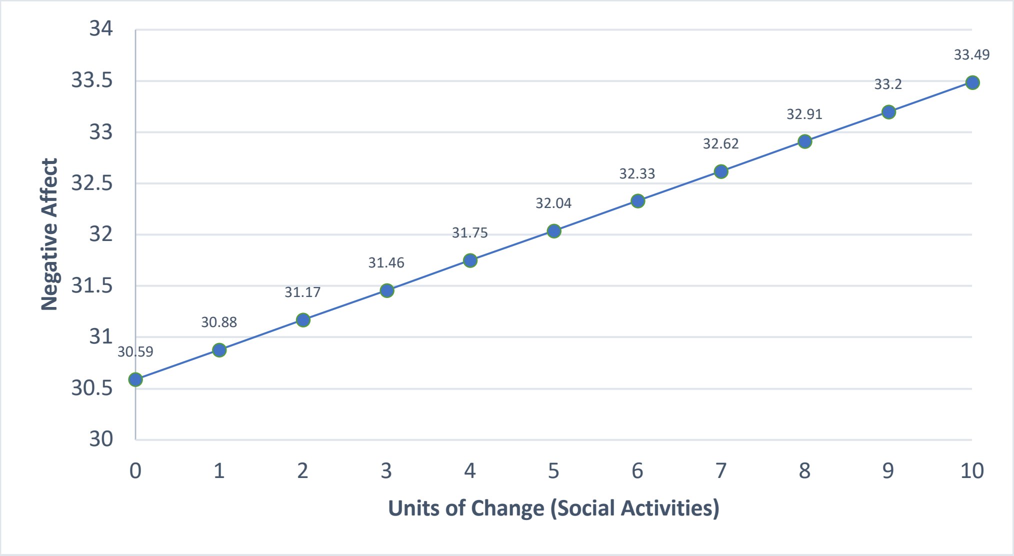
Between-Persons association for social activities (SA) and negative affect (NA)



Note: p=ns

Figure 10b

Within-Person association between social activities (SA) and negative affect (NA)



Note: p=ns

Summary of Findings for the Coupled Models of Change

Table 12 provides a summary of results for all models of coupled change. Overall, the findings can be briefly summarized as follows:

- **Caregiver Distress and Positive Affect (Within-person):** Findings for the within person model indicates that increased caregiver distress significantly corresponded with decreased positive affect. On average, when an individuals' level of caregiver distress was higher than usual, the corresponding level of positive affect was diminished (p-value $\leq .01$).
- **Caregiver Distress and Negative Affect (Between-persons):** Furthermore, negative affect was positively associated with caregiver distress in the between-persons model ($p \leq .001$). Relative to individuals with lower levels of CGD, those with higher levels than others exhibited significantly higher levels of negative affect.

- **Social Activities and Positive Affect (Between-persons):** The between-persons model showed a significant association between increasing social activities and increasing positive affect ($p \leq .05$). Relative to individuals with lower levels of social activities, those with higher levels of social engagement than others exhibited significantly higher levels of PA.
- **Social Activities and Negative Affect**. None of these models were significant.

Table 12

Summary of Results for all Models of Coupled Change

Variables (Association)	Intercept	Slope	p-value
Positive affect & Caregiver distress (BP)	38.08	-0.20	0.130
Positive affect & Caregiver distress (WP)	38.08	-0.41	.018**
Negative affect & Caregiver distress (BP)	8.34	0.53	.001***
Negative affect & Caregiver distress (WP)	8.34	0.12	0.629
Positive affect & Social activities (BP)	24.17	1.27	0.020*
Positive affect & Social activities (WP)	24.17	0.61	0.255
Negative affect & Social activities (BP)	30.59	-1.66	0.100
Negative affect & Social activities (WP)	30.59	0.29	0.522

Note: *$p \leq .05$. **$p \leq .01$. ***$p \leq .001$, BP = between-persons; WP = within-person.

Chapter V. Discussion

This chapter is organized in 3 sections to discuss findings and consider them in the context of the broader research: 1) findings for research question 1, 2) findings for research question 2, and 3) a general discussion.

Research Question 1: Do caregiver levels of psychosocial well-being (i.e., affect, social activities, caregiver distress) change over the course of choral seasons as a function of their time participating in the choir?

None of the MLM equations for change were significant. This may reflect the fact that this was a well-educated sample with nearly 70% reporting some college or more. Despite this, caregivers had mild to moderate levels of distress on average. It seems likely that distress will increase over time as the dementia progresses. In addition, the average age of the caregivers was 68 (range 49-89 years), 81% were female and 63% were spouses. These characteristics reflect the literature on caregiving and are likely to result in increased distress as age and duration compound strains of caregiving.

Why didn’t this study find significant changes in affect, social activities or caregiver distress over the course of the choir? There are several possibilities that are likely to influence the analyses. First, key factors (i.e., duration of caregiving, support network, attendance at weekly rehearsals) that impact psychosocial well-being were not included in the model. Second, perhaps the small sample lacks the necessary power to for models to detect a change. Third, this well-educated and homogeneous sample has resources (i.e., economic, educational) that buffer the impact of caregiving so that distress, social activities, and affect lack the variability that might be seen in a more heterogenous sample.

Research Question 2: Do caregivers exhibit dynamic time-varying covariation between change in affect and corresponding change in caregiver distress or engagement in social activities (i.e., when scores on the predictor is higher (or lower) is there a corresponding association with higher (or lower) performance on the outcome measure)?

Findings from the coupled change models indicate that the relationship between caregiver distress and affect is not fully captured in this model. Only one *within-person* coupled change model (i.e., caregiver distress (CGD) and positive affect (PA) showed significance ($p \leq .01$). As caregiver distress increased, then positive affect decreased. The finding is supported in the literature which suggests that positive emotions are linked to increases in personal psychological resources, which improve coping skills and outcomes (Fredrickson & Branigan, 2005).

Two coupled change models showed a significant *between-person association*. First, as CGD increased there was a corresponding and significant ($p \leq .001$) increase in negative affect (NA). This coupled change (BT) finding make sense—as the expectation is that increasing CGD would be associated with a parallel increase in negative affect. Relative to individuals with lower levels of caregiver distress, those with higher levels of caregiver distress than others exhibited significantly higher levels of positive affect. Second, as social activities increase, the coupled change model (BT) showed a significant increase ($p \leq .05$) in positive affect. This finding is consistent with the literature suggesting that PA is highly associated with social activities (i.e., frequency of social events) (Beiser, 1974; Bradburn, 1969; Clark & Watson, 1986, 1988; Watson, 1988; Watson & Tellegen, 1988). It is also consistent with existing research showing that engagement in arts-based activities stimulates higher positive emotions (Davies et al., 2014), which increases the likelihood of positive impacts on health.

For the association between social activities and negative affect, non-significant findings were observed. But, intriguingly the directions were different at the BP versus WP, and the variable of NA showed more variability in the within-person for the intraclass correlation coefficient calculation (see page 29). It is interesting to ponder that sometimes there can be significant results at the BP effect but not at the WP effect, or the other way around. If this happens, it reflects the differences in levels given to individuals performing higher or lower relative to their own personal levels (i.e., with-in person effect). It is critical to recognize the individual differences that may influence the experience of negative affect among caregivers.

Findings from the coupled change models deepen our appreciation of the subjective nature of the caregiving experience and the unique ways of coping among individuals with negative affect. Caring for a loved one with dementia can bring satisfaction and meaning but can also have negative impacts on affect that reflect the complexity of how CG cope with stress.

According to the literature individuals with higher neuroticism may have a higher likelihood of an increased magnitude of emotional reactivity to negative life events partly because of how they cope with stress (Lahey, 2009). For example, differences in the between-persons ($p \leq .05$) and within-person (ns) coupling model between positive affect and social activities, may reflect the complexity, challenges and uniqueness of each individual versus at group level. The findings are consistent with the literature on regard to distinguish the individual differences and how they may impact differently in each person's well-being experience self-assessment (Diener et al., 2009). Indeed, it is important to identify and understand the differences between within-person and between-person effects in longitudinal analyses to reduce the potential for bias and incorrect interpretation (Kowalski et al., 2018).

General Discussion

With regard to the psychosocial well-being of CG participating in the ViM choir, the results are promising. This study revealed the dynamic association over time (i.e., in the study), in tandem between several dimensions of the psychosocial well-being construct and how they systematically change as a function of time in the choir. This is an initial effort to begin to examine the specific areas in which the choir intervention (i.e., choir participation) can have an impact on the psychosocial well-being of caregivers.

Overall, these findings are consistent with the literature on arts engagement (Fancourt & Finn, 2019) as well as the positive association between social activity and affect (subjective wellbeing) (Crossick & Kaszynska, 2016). Findings add to the evidence on the impact of the engaging in social activities, such as a choir, to increase positive affect ($p \leq .05$). The literature on social activities or a socially engaged lifestyle clearly points to its importance in "successful aging" (Lampinen et al., 2006; Menec, 2003; Rowe & Kahn, 1998).

In particular the impact of the choir on caregiver distress was significant and as expected. Increased caregiver distress was associated with a decrease in positive affect ($p \leq .01$) and an increase in negative affect ($p \leq .001$). Arts-based interventions (i.e., participating in a choir) can have positive health impacts (i.e., a reduction in stress, distress, social isolation, and loneliness), thereby potentially reducing healthcare costs and positively affecting public health policies. Previous research indicates that engagement in social activities contributes to a positive self-perception of the psychosocial well-being (Belgrave, 2011; Burns, 2017).

Notably, when caregivers engage in more social activities relative to their average levels, levels of positive affect increased at the group level. This significant association suggests that increasing participation in social activities (such as singing in a choir) may be an effective social intervention for addressing CG depressive feelings, loneliness, social isolation, and improve their psychosocial well-being (Belgrave, 2011), and perhaps also for addressing their psychological needs (Oshio & Kan, 2016), and improving their overall well-being (Paggi et al., 2016).

Findings indicate an important association between decreasing caregiver distress and increasing positive affect. For example, if there is more distress than usual, then negative affect will increase and positive affect will decrease. This connection is relevant to elucidate the potential benefits of the choir intervention in multiple domains and to identify covariation in changes.

In sum, the between-person results show that positive affect increases as social activities increase. This is consistent with the literature, which indicates that social interventions that offer support and respite to caregivers can reduce their distress, boost their positive affect, and reduce their negative affect, all of these effects contributing to their overall psychosocial well-being (Sanal & Gorsev, 2014). The findings also highlight the positive influences of choir participation, including its potential to decrease caregiver distress. Perlin et al. (1990) suggest that social interventions can help develop skills for coping in challenging contexts such as dementia caregiving. Participation in the choir required engagement in a social activity that appears to have significant impacts on affect and caregiver distress.

Research Limitations, and Strengths

This study uses self-reported data (i.e., affect, caregiver distress, and social activities) to capture the multi-dimensional construct of psychosocial well-being. The focus of the original study was not on psychosocial well-being so efforts to operationalize the constructs were limited by the available data. In particular, social activity did not focus on choir participation (i.e., attendance, engagement), but rather more generally on a range of social activities that were fairly vague (i.e., do fun things with people, able to visit family and friends). So, this measure may not have adequately capture the social domain for psychosocial well-being.

Other limitations of this research include the homogeneity of the sample (i.e., ethnic/racial, socioeconomic status/class diversity) and the convenience sample (non-randomized, no control group). However, it was already known that choirs have beneficial impacts on older adults and this thesis wanted to test the choir intervention with the specific population of dementia caregivers. A control group was not necessary given what is already known about the benefits of choirs on the health of older adults. Thus, the repeated measures research design allowed individuals served as their own controls (up to 8 assessments completed) with change examined relative to personal baseline. Limited power due to small sample size. Finally, current data set, went through several data set error checking, but it may have further refinements.

Chapter VI. Conclusion

In this conclusion, I consider the impact of participation in a community-based choir on the psychosocial well-being of caregivers. The findings are considered in the context of the social dimensions of health and arts-in-healthcare perspectives. It is important to note that the psychosocial well-being framework focuses attention on only one facet of caregiving. Caregiver perceptions of health and well-being are affected by many things that are beyond the scope of this analysis (i.e., economic resources, physical health, age, living situation). Future analyses should consider assessing a broader range of measures that capture the elements unique to individual context and that contributes to differences between-persons and within-person findings. At times, the between-person or within-person effects differed in the results. These differences highlight the importance of the changes over time relative to their own personal levels (i.e., within-person) versus examining differences between individuals (i.e., between-persons). These findings can guide further analyses to better understand individual challenges and create strategies for person-centered care versus contextual issues that contribute to differences between persons. Despite the complexity of caregiving and the limitations inherent in research to capture a context, my argument is simple. It is critical to care for the carers. I hope findings from this research will advance recognition of the importance of ensuring access to arts-based programs that provide psychosocial support for caregivers.

Family caregivers provide 80% of the long-term care that is needed by older adults. The psychosocial well-being of caregivers is at risk as they provide care for those they love. In particular, this study brings attention to negative affect among caregivers and the need to support resilience, effective coping, and mitigate depressive feelings (Diener, 2009). The importance of psychosocial well-being to overall health was discussed in the theoretical framework presented earlier. Programs need to be responsive to caregiver preferences and needs.

The findings advance knowledge about the positive impacts of participating in a community-based choir on the psychosocial well-being of CG. This study suggests the potential of dementia choirs to improve affect, increase social connections, and mitigate caregiver distress. Results can inform the development of dementia-related policies, programs, and services. The approach taken with the choir intervention to support caregivers is crucial and adds to the body of research on the impact of arts-based programs in promoting healthy ageing, supporting caregivers, and creating age-and dementia-friendly communities.

More generally, findings also contribute to our knowledge about ageing well. It adds to the research on the positive impact of engagement in group music on psychological and social well-being. It provides evidence useful to advocates of arts-based interventions as community measures to promote healthy ageing (Fisher & Specht, 1999; Fong et al., 2020; Humphrey et al., 2019; Menec, 2003; Robertson & McCall, 2020).

As the demographic transition continues, it is crucial to find ways in which people with dementia can be integrated into society. ViM can be considered not only an arts-based intervention or a social intervention, but also an “anti-stigma intervention” (Mukadam & Livingston, 2012) that offers social connectedness to people with dementia and their families and friends. ViM is an exemplary case of a community-based choir that fosters a safe, affordable social activity in a supportive, and intergenerational environment. People who engage in social activities experience a sense of purpose and a feeling of belonging. Social activities with family members and friends can strengthen personal relationships and help consolidate a person’s social support network.

Social engagement is a key element of healthy (i.e., “successful”) ageing and this study offers a perspective on how social engagement can be conceptualized as a domain of psychosocial well-being. The proposed multidimension psychosocial construct suggests how subjective, emotional, and social well-being are essential to psychosocial well-being. This may stimulate insights into how programs can affect multiple dimensions. For example, the choir program offers opportunities for social connections/social activities but can also boost positive affect and decrease distress.

Caregivers are at great risk for social isolation and a range of adverse health effects. Arts-based programs that offer opportunities for joyful, meaningful activity, and social connections are needed to support caregiver well-being. Findings suggest that choir participation can increase positive affect and diminish negative affect. It is critical to recognize the biopsychosocial model of health which has shifted from attention away from the biomedical model towards a preventive and health promotion focus to improve health outcomes. This is particularly relevant because it integrates the multiple dimensions of health-- the psychological and sociological aspects of wellbeing (i.e., affective, emotional, and social well-being).

Not surprisingly most of the ViM participants were women which is consistent with the literature that shows that women assume the role of family caregivers, or as caregivers in general, more often than men. In Canada, about 90 percent of the dementia caregivers are women (Canadian Academy of Health Sciences, 2019). Caring can bring emotional rewards, but it can also be psychologically and physically demanding and can thus have an overall negative impact on caregiver well-being.

On another note, it was interestingly to find the association between negative affect and social activities showed different outcomes for the within-person and the between-persons. These outcomes are consistent with the literature that suggest that every individual has its unique ways of coping that are part of other underlying psychological and neuroticism processes and personality traits. As (Diener et al., 2009, p. 70) notes “there are times when people are willing to sacrifice fun and enjoyment for other values” which suggest that every CG possesses individual differences that may influence their ways of coping with stress (Billings et al., 2000). This finding also offers a deeper understanding and reflections on what the experience of negative affect can bring with it; for example, negative affect may enhance coping skills (Forgas, 2017) at the individual level (i.e., improve motivation, memory, and communication).

Importantly, choir participation may offer a respite to caregivers and mitigate the negative impacts of caregiving on their psychosocial well-being. Participation in group singing thus appears to be a promising social intervention that boosts positive affect and that offer protective opportunities, respite, and mitigates negative affect.

The within-person and between-persons coupled analysis linking positive affect and social activities was consistent for both levels (intra-individual and group level), indicating that, overall pattern of change over time, positive affect was increased on occasions when social activities were increased. This showcases the relevant potential of art-based activities as a social intervention that boost the psychosocial well-being and it may offer protective effects of positive affect (Watson, 1988), and fosters positive affect for individuals and groups.

Furthermore, since positive and negative affect are not necessarily linked, it is critical to understand how SWB operates and how to take the opportunities of arts-based programs to increase levels of SWB and gain the benefits of it. Benefits range from protective factors to strengthening health and coping skills to maintain and fostering psychosocial well-being. Ultimately, these findings showcase the potential of an intergenerational, community-based dementia choir to offer a socially engaged lifestyle that can mitigate caregiver distress and strengthen psychosocial well-being at both the interpersonal level (social dimension) and the intrapersonal level (affective and emotional dimensions). In sum, this arts-based intervention promotes a social engagement lifestyle, that influences the boost of positive affect, and mitigates negative effects (i.e., distress and depression). Additionally, it may offer protective factors, sense of belonging and pathways to successful ageing. Its overall effect may support thrive the psychosocial well-being of CG.

Reports in this study on the social activities remind us of the importance to differentiate loneliness from social isolation and to better understand the intra-personal component from the inter-personal component. Hence the choir intervention is already offering a social engagement lifestyle, participants seem not to perceived the intra-personal component as fulfill in their self-reports. These variations of the social dimension may need further exploration while the current data does not include an index for social isolation or loneliness but, it can be analyzed through each of the questions of the SA (6 items) in future analyses.

Also, it would be interesting to gather data on the intrinsic motivation to move towards social connection. It appears that the social dimension has been historically overlooked in its multiple benefits and impacts on other dimensions of well-being, including the physical impacts. For example, a socially engaged lifestyle may create changes in the brain, and positively impact sleep patterns, cognitive health, vascular health and others. Indeed, there are health authorities in the UK, that are already utilizing social prescription to tackle social isolation, loneliness and health concerns related to this vital dimension of the integral health and well-being. Certainly, social prescription can bring potential benefits to the health strategies to work with the psychosocial well-being and health of CG of PwD, by exploring patterns of social engagement lifestyle as part of their daily life activities.

Recommendations: Community-based Arts-Programs for Dementia

The literature offers several models of arts-based interventions and the broad benefits of group-music. This study proposes that a community-based dementia choir program with an intergenerational component can offer potential benefits to mitigate negative effects of the dementia caregiver experience of participants and strengthen their psychosocial well-being. Although a professionally directed dementia choir intervention is relatively novel, this study contributes to knowledge in regard to better understand how participating in a choir is associated with a reduction on the caregiver distress and negative emotions, and boost positive affect. Overall, this choir intervention can support and engage CG of PwD regardless of the challenging context of caregiving a loved one with dementia. The choir offers an inclusive and dementia-friendly activity to enjoy with family and friends. Mindful of the challenges on how to make sustainable programming in the communities that includes arts-based interventions. I offer the following recommendations on where to start.

Recommendations for Public Policies and Community Program Development

We live in complex times, and innovative strategies are needed; the current challenges require multi-dimensional solutions and work to strengthen individuals' psychological resilience. This study's findings suggest that choir participation may represent a promising, non-pharmacological and low-cost lifestyle intervention that reduces caregiver distress and boosts positive feelings by facilitating a social engagement lifestyle. Arts-based interventions are among the non-pharmacological alternatives to reduce the risk of depression, loneliness, and social isolation. The public-health system needs policies, programs, and strategies to address the current social and mental challenges. Group singing can have positive health impacts (including a reduction in depression, negative affect, social isolation, and loneliness); hence it has the potential to reduce healthcare costs.

Public-health actions are needed to encourage social connectedness and a socially engaged lifestyle; therefore, it is essential to offer community resources to increase social activity in the context of dementia care. Healthcare systems should employ a social model of health that fosters community connection, providing services and activities such as community-based choirs. It is critical to increasing financial support for intergenerational community programs that can be sustained in the long term. Policies based on a social model of health and a community-based approach promote social connectedness and active citizenship. In this social model, there is an essential role for multi-agency partnerships in which local authorities, the public, and charitable agencies all participate to engage people in improving their health (Crossick & Kaszynska, 2016).

Policymakers should consult scientific evidence in drafting innovative legislation and policies to support intergenerational community members in the context of dementia. Developing and implementing community programs with an intergenerational focus will strengthen social cohesion and build active and senior-friendly communities (Kaplan & Sanchez, 2014). Indeed, if more focus is placed on non-pharmacological alternatives and best practices, it will lead to more possibilities for implementing social and arts-based interventions that benefit multiple generations in the community. The way to achieve successful results is with substantial efforts and actions from the state, including funding, evaluation, and new programs and policies. Paying attention to the workforce is a crucial component of both public-health and health-economics policy. In this case, the workforce refers to family caregivers, and it is vital to offer support and resources to them. As the United Kingdom's National Alliance for Arts, Health and Well-being (2012) states, "In our current political and economic climate, which is forcing a reassessment of human priorities, and where well-being is a declared government priority, arts in health offer a professional, value-for-money contribution to mainstream health care." Since dementia caregivers are valuable citizens, they should be given due consideration in information-based public-health policies.

Particular attention should be paid to high-burden caregivers, who are vulnerable to the negative effects of caregiving and should hence be targeted by social interventions that can help them cope while fostering and protecting their psychosocial well-being. The present study can inform and encourage the development of interventions for preventing and treating the many adverse outcomes associated with dementia caregiving.

Evidence-based information is useful in shedding light on the potential of the arts to provide health benefits. As Davies et al. (2016) state, there is a need to tackle misunderstanding and ignorance of the emerging field of arts and health and how it can contribute to public health. In the international arena, the U.K. and Australia are leaders in using the arts to promote health and well-being through the public-health system. The Australian Centre for Arts and Health (ACAH) is a not-for-profit organization that advocates for the arts-and-health nexus. Their mission is "to promote and develop the application of creativity and the arts for health" (ACAH, n.d.).

Furthermore, since 2013 Australia has had two organizations, the Standing Council on Health and the Meeting of Cultural Ministers, which have developed that country's National Arts and Health Framework to enhance the profile and the implementation of arts-and-health approaches to health-promotion services and facilities (Australian Government, n.d.). In the U.K. in 2014, the All-Party Parliamentary Group on Arts, Health and Wellbeing was formed to improve awareness of the benefits that the arts can bring to health and well-being (All-Party Parliamentary Group on Arts, Health and Well-being, July 2017b); between 2015 and 2017, this group conducted an inquiry into practice and created a report with recommendations to improve policy and practice (Howarth, 2018).

Finally, Diener and colleagues (2018) point out the promising avenue to enhance well-being with proper interventions considering SWB for societal and individual benefits. In general, Diener's model proposes that individuals with a high SWB often achieve healthy ageing, are more sociable and creative, and have stronger immune systems. High SWB is suitable for individuals and groups; therefore, governments should develop and evaluate social policy with an eye toward SWB outcomes (Eid & Larsen, 2008).

Community Organization Recommendations

1) Integrate arts-based approaches in existing recreational and community programming.
2) Develop strong partnerships with stakeholders that shared arts-based approaches, including researchers, community members, organizations, and policymakers, to maximize stakeholder' engagement and create sustainable programming.
3) Develop collaborations and informational resources to be up-to-date about funding agencies and volunteer organizations to promote sustainable programming in communities
4) Make the social component a priority to amplify the benefits of the linkages of art-social-health.

5) Extend the length of arts-based interventions throughout programs across months to sustain the benefits of the intervention. Offer alternatives to keep engaged when holidays are present, and interruption of the program is inevitable.
6) Solidify community-based initiatives throughout the development of programming, evaluation, and better practices in communities.
7) Ensure accessibility to community programs by using social justice lens, equity and aligning with indigenous reconciliation work.

Public Health Recommendation

1) Enhance potential networking and affiliations with organizations working with nexus Arts and Health, such as the *Arts Health Network in Canada and the Arts* and *Health: Healthy Aging through the Arts.*
2) Develop interdisciplinary projects with Arts-based methods along with Universities, artists, and community.
3) Create evaluations and reports to inform the potential benefits of the Arts on Health.
4) Continue the momentum of the Arts in Health beyond the biomedical model, embrace the psychosocial model as an integrative model to achieve health outcomes with effective interventions.
5) Reduce the health care strains by promoting ageing in place and the value of communities in the life span in a dementia context.
6) Acknowledge the value of arts-based interventions (i.e., choir intervention) as low-cost social approach to support CG and PwD in the community.

Research recommendations

1) Develop strategic interdisciplinary research collaborations.

2) Gather quantitative data but also qualitative data from Arts-based interventions to identify and inform further research.
3) Design and implement meta-analyses studies to address the statistical power concern and better understand how well a choir intervention works across patterns and studies.
4) Develop neuropsychology and neuroimaging studies to track changes of Arts-based and psychosocial interventions on the brain over time.
5) Develop and maintain community collaborations with everyday purposes between the health authorities and health workers and artists, older adults, universities, funding agencies and volunteer organizations to promote sustainable Arts-based practices and research.
6) Develop interdisciplinary evaluation methods to inform future project development.
7) Develop psycho-sociological studies to explore the intersectional and diversity components along CG of PwD to understand their challenges across time and contexts better and identify social resources with equity and gender-based lens.
8) Offer training across research teams on regard to Indigenous themes and align research with the work on reconciliation, for example, the Indigenous Cultural Acumen Training (ICAT) at the University of Victoria.
9) Ensure the inclusion of equity and diversity considerations, for example into the demographic criteria that can contemplates sex, gender, and other intersecting identity factors to contribute to the development of effective policies and programs, services, and other initiatives on diverse groups of people.
10) More broadly, future project concerned with arts-based interventions may be extended beyond research per se into knowledge mobilization, since the health sciences aim not only

to acquire knowledge but to disseminate in to the community, where it can be employed in the design and implementation of evidence-based public-health initiatives.

11) Develop interdisciplinary projects with Arts-based methods in socially engaged research practice (Wang et al., 2017) along with Universities, artists, and community.

Future Research

Future studies using ViM data may employ dyadic analyses to elucidate the choir's impact on both caregivers and care recipients. Models may be further refined by adding additional predictors to explore the differences in variation within-person and between-persons. Future research can also explore the influence of personality traits such as extraversion and neuroticism on dementia caregiver burden. The inclusion of additional psychosocial constructs such as intrinsic motivation, spirituality, and resilience may expand research to explore alternative mechanisms towards developing and maintaining practical coping skills for CG of PwD.

Finally, rigorous research on arts-based programs is needed to develop strategies and programs to support caregivers and PwD. Findings are key to inform and assist policymakers in developing community-based programs to support caregivers and PwD.

References

All-Party Parliamentary Group on Arts, Health and Wellbeing. (July, 2017a) *Creative health: the arts for health and wellbeing, Inquiry Report, 2nd edition*. Retrieved June 24, 2020 from http://www.artshealthandwellbeing.org.uk/appg-inquiry/

All-Party Parliamentary Group on Arts, Health and Wellbeing. (July, 2017b). *Arts Engagement and Well-being*; *policy briefing.* Retrieved June 4th, 2020 from https://www.culturehealthandwellbeing.org.uk/appg-inquiry/Briefings/WWCW.pdf

Alliance for Aging Research (2012, November). *Translating Innovation to Impact: Evidence-based interventions to support people with Alzheimer's disease and their caregivers at home and in the community.* Retrieved November 4, 2019, from https://www.agingresearch.org/document/translating-innovation-to-impact-evidence-based-interventions-to-support-people-with-alzheimers-disease-and-their-caregivers-at-home-and-in-the-community/

Alzheimer's Association (2020). *What is dementia?* Retrieved January 29, 2020, from https://www.alz.org/alzheimers-dementia/what-is-dementia

Alzheimer's disease International (2019). World Alzheimer Report 2019: Attitudes to dementia. London: *Alzheimer's Disease International*.

Alzheimer's net. (2019, February) *Internet-Based resources and support for dementia caregivers.* Retrieved February 11, 2019, from https://www.alzheimers.net/internet-based-resources-and-support-for-dementia-caregivers/

Alzheimer Society of Canada. (2020, May) *Latest information and Statistics*. Retrieved May 12th, 2020, from https://alzheimer.ca/en/Home/Get-involved/Advocacy/Latest-info-stats#:~:text=The%20number%20of%20Canadians%20with,increase%20of%2066%20per%20cent.

American Psychological Association. (2014). Guidelines for Psychological Practice with Older Adults. *American Psychologist*, *69*(1), 34–65.

Australian Government. Meeting of Cultural Ministers. (2020, September) *National Arts and Health Framework.* Retrieved September 8th, 2020 from https://www.arts.gov.au/national-arts-and-health-framework

Australian Centre for Arts and Health. (n.d.). *Our Mission.* Retrieved September, 8th, 2020 from https://www.artsandhealth.org.au/

Baumgart, M., Snyder, H. M., Carrillo, M. C., Fazio, S., Kim, H., & Johns, H. (2015). Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. *Alzheimer's & Dementia*, *11*(6), 718–726.

Bedard, M., Molloy, W., Squire, L., Dubois, S., Lever, J., O'Donnell, M. (2001). The Zarit Burden Interview: A New Short Version and Screening Version. *The Gerontologist* 41 (5): 652-657

Belgrave, M. (2011). The effect of a music therapy intergenerational program on children and older adults' intergenerational interactions, cross-age attitudes, and older adults' psychosocial well-being. *Journal of music therapy*, *48*(4), 486-508.

Billings, D. W., Folkman, S., Acree, M., & Moskowitz, J. T. (2000). Coping and physical health during caregiving: The roles of positive and negative affect. *Journal of personality and social psychology*, *79*(1), 131.

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in clinical neuroscience*, *11*(2), 217.

Burns R.A. (2017) Psychosocial Well-Being. In: Pachana N.A. (eds) Encyclopedia of Geropsychology. Springer, Singapore. https://doi.org/10.1007/978-981-287-082-7_251

Busseri, M. A., & Sadava, S. W. (2010). A Review of the Tripartite Structure of Subjective Well-Being: Implications for Conceptualization, Operationalization, Analysis, and Synthesis. *Personality and Social Psychology Review*, *15*(3), 290–314.

Camic, P. M., Baker, E. L., & Tischler, V. (2016). Theorizing How Art Gallery Interventions Impact People with Dementia and Their Caregivers. *The Gerontologist*, *56*(6), 1033–1041.

Canadian Academy of Health Sciences. (2019). Improving the quality of life and care of persons living with dementia and their caregivers. Ottawa (ON): The Expert Panel on Dementia Care in Canada, CAHS.

Chavez, C. I., & Méndez, M. J. (2008). Mood, emotion, and affect in group performance: An experiential exercise. *Organization Management Journal*, *5*(3), 153-166.

Chen, K.-H., Wells, J. L., Otero, M. C., Lwi, S. J., Haase, C. M., & Levenson, R. W. (2017). Greater Experience of Negative Non-Target Emotions by Patients with Neurodegenerative Diseases Is Related to Lower Emotional Well-Being in Caregivers. *Dementia and Geriatric Cognitive Disorders*, *44*(5–6), 245–255.

Cherry, M. G., Salmon, P., Dickson, J. M., Powell, D., Sikdar, S., & Ablett, J. (2013). Factors influencing the resilience of carers of individuals with dementia. *Reviews in Clinical Gerontology*, *23*(4), 251.

Coyle, C. E., & Dugan, E. (2012). Social Isolation, Loneliness and Health Among Older Adults. *Journal of Aging and Health*, *24*(8), 1346–1363.

Crossick, G., & Kaszynska, P. (2016). Understanding the value of arts & culture. *The AHRC cultural value project*.

Daykin, N., Gray, K., McCree, M., & Willis, J. (2017). Creative and credible evaluation for arts, health and well-being: opportunities and challenges of co-production. *Arts & Health*, *9*(2), 123–138.

Davidson, R.J., Scherer, K.R., & Goldsmith, H.H. (2003). *Handbook of affective sciences.* New York: Oxford University Press.

Davies, C., Pescud, M., Anwar-McHenry, J., & Wright, P. (2016). Arts, public health and the National Arts and Health Framework: a lexicon for health professionals. *Australian and New Zealand Journal of Public Health*, *40*(4), 304-306.

Davies, C. R., Knuiman, M., Wright, P., & Rosenberg, M. (2014). The art of being healthy: a qualitative study to develop a thematic framework for understanding the relationship between health and the arts. *BMJ Open*, *4*(4), e004790.

DeLiema, M., & Bengtson, V. L. (2017). Activity theory, disengagement theory, and successful aging. *Encyclopedia of geropsychology. Springer Singapore*, 15-20.

Diener, E. (1984). Subjective well-being. *Psychological Bulletin, 95*(3), 542–575.

Diener, E. (2000). Subjective well-being: The science of happiness and a proposal for a national index. *American psychologist*, *55*(1), 34.

Diener, E. (2009). Subjective well-being. In *The science of well-being* (pp. 11-58). Springer, Dordrecht.

Diener, E., & Chan, M. Y. (2011). Happy people live longer: Subjective well-being contributes to health and longevity. *Applied Psychology: Health and Well-Being*, *3*, 1–43.

Diener, E., & Emmons, R. A. (1984). The independence of positive and negative affect. *Journal of personality and social psychology*, *47*(5), 1105.

Diener, E., Sandvik, E., & Pavot, W. (2009a). Happiness is the frequency, not the intensity, of positive versus negative affect. In *Assessing well-being* (pp. 213-231). Springer, Dordrecht.

Diener, E., Scollon, C. N., & Lucas, R. E. (2009b). The evolving concept of subjective well-being: the multifaceted nature of happiness.

Diener, E., Lucas, R. E., & Oishi, S. (2018). Advances and Open Questions in the Science of Subjective Well-Being. *Collabra: Psychology*, *4*(1).

Dingle, G. A., Brander, C., Ballantyne, J., & Baker, F. A. (2013). 'To be heard': The social and mental health benefits of choir singing for disadvantaged adults. *Psychology of Music*, *41*(4), 405–421.

Eid, M., & Larsen, R. J. (2008). *The science of subjective well-being*. New York: Guilford Press.

Fancourt, D. (2017). *Arts in Health: Designing and researching interventions*. Oxford University Press.

Fancourt, D., & Finn, S. (2019). What is the evidence on the role of the arts in improving health and well-being? A scoping review. World Health Organization. *Health Evidence Network synthesis report 67*. 133 pp. Retrieved from: https://www.euro.who.int/en/data-and-evidence/evidence-informed-policy-making/publications/2019/what-is-the-evidence-on-the-role-of-the-arts-in-improving-health-and-well-being-summary-2019

Fisher, B. J., & Specht, D. K. (1999). Successful Aging and Creativity in Later Life. *Journal of Aging Studies*, *13*(4), 457–472.

Fong, Z. H., Tan, S. H., Mahendran, R., Kua, E. H., & Chee, T. T. (2020). Arts-based interventions to improve cognition in older persons with mild cognitive impairment: A systematic review of randomized controlled trials. *Aging & Mental Health*, *0*(0), 1–13.

Forgas, J. P. (2017). Can sadness be good for you? On the cognitive, motivational, and interpersonal benefits of mild negative affect. *Australian Psychologist*, *52*(1), 3-13.

Fraser, K., Archibald, M., & Nissen, C. (2014). Uncovering the Meaning of Home Care Using an Arts-Based and Qualitative Approach. *Canadian Journal on Aging; Toronto*, *33*(3), 246–258.

Fredrickson B. L. (2004). The broaden-and-build theory of positive emotions. *Philosophical transactions of the Royal Society of London. Series B, Biological sciences*, *359*(1449), 1367–1378.

Fredrickson, B. L., & Branigan, C. (2005). Positive emotions broaden the scope of attention and thought-action repertoires. *Cognition and Emotion*, *19*(3), 313–332.

Fredrickson, B. L., & Joiner, T. (2002). Positive Emotions Trigger Upward Spirals Toward Emotional Well-Being. *Psychological Science*, *13*(2), 172–175.

Gaugler, J., James, B., Johnson, T., Marin, A., Weuve, J. (2019). Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 15*(3), 321-387.

Gick, M. L. (2011). Singing, health and well-being: A health psychologist's review. *Psychomusicology: Music, Mind and Brain*, *21*(1-2), 176.

Habron, J., Butterly, F., Gordon, I., & Roebuck, A. (2013). Being Well, Being Musical: Music Composition as a Resource and Occupation for Older People. *British Journal of Occupational Therapy*, *76*(7), 308–316.

Hanna, G. P., Noelker, L. S., & Bienvenu, B. (2015). The Arts, Health, and Aging in America: 2005–2015. *The Gerontologist*, *55*(2), 271–277.

Haslam, C., Cruwys, T., & Haslam, S. A. (2014). “The we's have it”: Evidence for the distinctive benefits of group engagement in enhancing cognitive health in aging. *Social Science & Medicine*, *120*, 57-66.

Hébert, R., Bravo, G., & Préville, M. (2000). Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging*, *19*, 494–507.

Hoffman, L., & Stawski, R. S. (2009). Persons as contexts: Evaluating between-person and within-person effects in longitudinal analysis. *Research in Human Development*, *6*(2-3), 97-120.

Holt-Lunstad, J., Smith, T. B., & Layton, J. B. (2010). Social Relationships and mortality risk: a meta-analytic review. *PLoS Medicine*, 7(7).

Howarth, L. (2018). Creative health: The arts for health and wellbeing. *Perspectives in Public Health*, *138*(1), 26–27.

Humphrey, J., Montemuro, M., Coker, E., Kilgour-Walsh, L., Moros, K., Murray, C., & Stanners, S. (2019). Artful Moments: A framework for successful engagement in an arts-based programme for persons in the middle to late stages of dementia. *Dementia*, *18*(6), 2340–2360.

Johnson, J. K., Stewart, A. L., Acree, M., Nápoles, A. M., Flatt, J. D., Max, W. B., & Gregorich, S. E. (2020). A Community Choir Intervention to Promote Well-Being Among Diverse Older Adults: Results from the Community of Voices Trial. *The Journals of Gerontology: Series B*, *75*(3), 549–559.

Jopp, D. S., & Hertzog, C. (2010). Assessing adult leisure activities: An extension of a self-report activity questionnaire. *Psychological Assessment*, 22, 108-120.

Southcott, J., & Joseph, D. (2017). Changing the world one voice at a time: philanthropy and community choirs in Australia. *Creative Industries Journal*, *10*(2), 155-167.

Kaptein, A. A., Hughes, B. M., Murray, M., & Smyth, J. M. (2018). Start making sense: Art informing health psychology. *Health Psychology Open*, *5*(1), 205510291876004.

Kaplan, M., & Sánchez, M. (2014). Intergenerational programs and policies in aging societies. (pp. 367-383) Edward Elgar Publishing.

Keyes, C. L. M. (1998). Social well-being. *Social Psychology Quarterly, 61*(2), 121-140.

Kiefer R.A. (2008) An integrative review of the concept of well-being. Holist Nurs Pract.; 22(5):244–252.

Kowalski, K. A., MacDonald, S. W., Yeates, K. O., Tuokko, H. A., & Rhodes, R. E. (2018). Decomposing the within-person and between-person sources of variation in physical activity-cognition associations for low-active older adults. *Psychology & health*, *33*(12), 1431-1455.

Kreutz, G. (2014). Does singing facilitate social bonding. *Music Med*, *6*(2), 51-60.

Kuehne S. V. & Melville J. (2014) The State of Our Art: A Review of Theories Used in Intergenerational Program Research (2003–2014) and Ways Forward, *Journal of Intergenerational Relationships*, 12:4, 317-346.

Lampinen, P., Heikkinen, R. L., Kauppinen, M., & Heikkinen, E. (2006). Activity as a predictor of mental well-being among older adults. *Aging and mental health*, *10*(5), 454-466.

Leigh-Hunt, N., Bagguley, D., Bash, K., Turner, V., Turnbull, S., Valtorta, N., & Caan, W. (2017). An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health*, *152*, 157–171.

Luhmann, M., Hawkley, L. C., Eid, M., & Cacioppo, J. T. (2012). Time frames and the distinction between affective and cognitive well-being. *Journal of Research in Personality*, *46*(4), 431–441.

Mausbach, B. T., Chattillion, E. A., Roepke, S. K., Patterson, T. L., & Grant, I. (2013). A comparison of psychosocial outcomes in elderly Alzheimer caregivers and noncaregivers. *The American Journal of Geriatric Psychiatry*, *21*(1), 5-13.

Mello, J. D. A., Macq, J., Van Durme, T., Cès, S., Spruytte, N., Van Audenhove, C., & Declercq, A. (2017). The determinants of informal caregivers' burden in the care of frail older persons: a dynamic and role-related perspective. *Aging & mental health*, *21*(8), 838-843.

Menec, V. H. (2003). The relation between everyday activities and successful aging: A 6-year longitudinal study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *58*(2), S74-S82.

Mittelman, M., & Epstein, C. (2009). Research results. *The MoMA Alzheimer's project: Making art accesible to people with dementia. New York, NY: The Museum of Modern Art*.

Mittelman, M. S., & Papayannopoulou, P. M. (2018). The Unforgettables: a chorus for people with dementia with their family members and friends. *International Psychogeriatrics*, *30*(6), 779–789.

Moran, N. (2014). Social implications arise in embodied music cognition research, which can counter musicological "individualism" *Frontiers in Psychology*, *5*.

Mossey J.M., & Shapiro E. (1982) "Self-rated health: a predictor of mortality among the elderly," *American Journal of Public Health* 72, no. 8, pp. 800-808.

Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia: approaches and goals. *Aging Health*, *8*(4), 377-386.

Mumper M. (2017, January). *Multilevel modeling a quick introduction*. Psychological Science Agenda. American Psychological Association. Retrieved, January 11, 2020 from https://www.apa.org/science/about/psa/2017/01/multilevel-modeling

Oshio, T., & Kan, M. (2016). How do social activities mitigate informal caregivers' psychological distress? Evidence from a nine-year panel survey in Japan. *Health and Quality of Life Outcomes*, *14*(1), 117–117.

Ostir, G. V., Markides, K. S., Black, S. A., & Goodwin, J. S. (2000). Emotional Well-Being Predicts Subsequent Functional Independence and Survival. *Journal of the American Geriatrics Society*, *48*(5), 473–478.

Paggi, M. E., Jopp, D., & Hertzog, C. (2016). The importance of leisure activities in the relationship between physical health and well-being in a life span sample. *Gerontology*, *62*(4), 450-458.

Pearce, E., Launay, J., Machin, A., & Dunbar, R. I. (2016). Is group singing special? health, well-being and social bonds in community-based adult education classes. *Journal of Community & Applied Social Psychology*, *26*(6), 518-533.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583-594.

Public Health Agency of Canada. Government of Canada (2018). *Dementia in Canada.* Retrieved June, 2nd, 2020 from https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia.html

Public Health Agency of Canada (2012). *What is the population health approach?* Retrieved February 26, 2019, from https://www.canada.ca/en/public-health/services/health-promotion/population-health/population-health-approach.html#def_health

Ryff, C. D., & Singer, B. H. (2008). Know Thyself and Become What You Are: A Eudaimonic Approach to Psychological Well-Being. *Journal of Happiness Studies*, *9*(1), 13–39

Roberts, S., Camic, P. M., & Springham, N. (2011). New roles for art galleries: Art-viewing as a community intervention for family carers of people with mental health problems. *Arts & Health*, *3*(2), 146-159.

Robertson, J. M., & McCall, V. (2020). Facilitating creativity in dementia care: The co-construction of arts-based engagement. *Ageing & Society*, *40*(6), 1155–1174.

Rowe J. W., Kahn R. L., (1998). *Successful aging* Pantheon/Random House, New York.

Sanal, A. M., & Gorsev, S. (2014). Psychological and physiological effects of singing in a choir. *Psychology of Music*, *42*(3), 420–429.

Schladt, T. M., Nordmann, G. C., Emilius, R., Kudielka, B. M., de Jong, T. R., & Neumann, I. D. (2017). Choir versus solo singing: effects on mood, and salivary oxytocin and cortisol concentrations. *Frontiers in human neuroscience*, *11*, 430.

Schulz, Richard, Burgio, Louis, Stevens, Alan B., Burns, Robert, Czaja, Sara, Gallagher Thompson, Dolores, Nichols, Linda. (2006) Resources for Enhancing Alzheimer's Caregiver Health (REACH II), 2001-2004. Ann Arbor, *MI: Inter-university Consortium for Political and Social Research*. 2006-10-27.

Springate, B. A., & Tremont, G. (2013). Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables. *The American journal of geriatric psychiatry: official journal of the American Association for Geriatric Psychiatry*, *22*(3), 294-300.

Stawski, R. S., MacDonald, S. W., & Sliwinski, M. J. (2015). Measurement burst design. *The encyclopedia of adulthood and aging*, 1-5.

Stellar, J. E., John-Henderson, N., Anderson, C. L., Gordon, A. M., McNeil, G. D., & Keltner, D. (2015). Positive affect and markers of inflammation: Discrete positive emotions predict lower levels of inflammatory cytokines. *Emotion*, *15*(2), 129–133.

Sutin, A. R., Stephan, Y., Luchetti, M., & Terracciano, A. (2020). Loneliness and Risk of Dementia. *The Journals of Gerontology: Series B*, *75*(7), 1414–1422.

Tamburri, N., Trites, M., Sheets, D., Smith, A., & MacDonald, S. (2019). The Promise of Intergenerational Choir for Improving Psychosocial and Cognitive Health for Those with Dementia: The Voices in Motion Project. *The Arbutus Review*, *10*(1), 66-82.

Tavakol, M. and Dennick, R. 2011 Making sense of Cronbach's alpha. International. *Journal of Medical Education*, 2, 53-5

The Canadian Institute for Health Information (CIHI). *Unpaid caregiver challenges and supports.* Retrieved November 4, 2019. https://www.cihi.ca/en/dementia-in-canada/unpaid-caregiver-challenges-and-supports

The National Alliance for Arts, Health and Wellbeing (2012). *A Charter for arts, health and wellbeing.* Retrieved, December 5th, 2019 from http://www.artshealthandwellbeing.org.uk/sites/default/files/A%20Charter%20for%20Arts,%20Health%20and%20Wellbeing.pdf

Unadkat, S., Camic, P. M., & Vella-Burrows, T. (2016). Understanding the Experience of Group Singing for Couples Where One Partner Has a Diagnosis of Dementia. *The Gerontologist*, *57*(3), 469–478.

Young, R., Camic, P. M., & Tischler, V. (2016). The impact of community-based arts and health interventions on cognition in people with dementia: a systematic literature review. *Aging & Mental Health*, *20* (4), 337–351.

Yu, J., Yap, P., & Liew, T. M. (2019). The optimal short version of the Zarit Burden Interview for dementia caregivers: diagnostic utility and externally validated cutoffs. *Aging & mental health*, *23*(6), 706-710.

Voices in Motion | *Voices in Motion: an intergenerational community choir for persons with alzheimer's disease and their caregivers*. (n.d.). The University of Victoria. Retrieved March 3, 2019, from https://onlineacademiccommunity.uvic.ca/voicesinmotion/

Villarejo Galende, A., Eimil Ortiz, M., Llamas Velasco, S., Llanero Luque, M., López de Silanes de Miguel, C., & Prieto Jurczynska, C. (2019). Report by the Spanish Foundation of the Brain on the social impact of Alzheimer disease and other types of dementia. *Neurología*

Wang, Q., Coemans, S., Siegesmund, R., & Hannes, K. (2017). Arts-based Methods in Socially Engaged Research Practice: A Classification Framework. *Art/Research International*, *2*(2), 5–39.

Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. *Journal of Personality and Social Psychology*, *54*(6), 1063–1070.

World Health Organization. *Ageing and health*. (2018a) Retrieved October 15, 2018a, from http://www.who.int/news-room/fact-sheets/detail/ageing-and-health

World Health Organization. *Constitution.* (2018b) Retrieved September 21, 2020 from https://www.who.int/about/who-we-are/constitution

World Health Organization. (2019, November) *Can you dance your way to better health and well-being?* World Health Organization. Retrieved November 18, 2019, from http://www.euro.who.int/en/media-centre/sections/press-releases/2019/can-you-dance-your-way-to-better-health-and-well-being-for-the-first-time,-who-studies-the-link-between-arts-and-health

Yu, J., Yap, P., & Liew, T. M. (2018). The optimal short version of the Zarit Burden Interview for dementia caregivers: diagnostic utility and externally validated cutoffs. *Aging & Mental Health*, *0*(0), 1–5.

Zarit, S. H., & Zarit, J. M. (1987). *Instructions for the burden interview*. University Park: Pennsylvania State University.

Appendices

Appendix A. Family Caregiver questionnaire/survey

Date: _______________ Participant #: _______________

FAMILY CAREGIVER SURVEY

INTRODUCTION

Thank you for participating in research on the **Voices in Motion (ViM)** choir. The purpose of this study is to identify the effects of participation in a community choir designed for persons with dementia (PwD) and their family care partners on social inclusion, health, and well-being. Attached is a survey with questions about your health and background information that will take about 45 minutes to complete.

All of the information you provide will be kept strictly confidential. At any time, if you are uncomfortable answering any questions in the survey, you can refuse to answer the questions. You are also free to take a break at any time. However, you should know that your answers are very important to us.

For most of the questions, there are no right or wrong answers. If you do not understand any of the questions, you should feel free to ask us to clarify them.

HEALTH STATUS

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. For each of the following questions, please circle the number that best describes your answer.

1. **In general, would you say your health is:**

Excellent 1	Very Good 2	Good 3	Fair 4	Poor 5

2. **Compared to <u>one year ago,</u> my health is?**

Much better now than one year ago 1	Somewhat better now than one year ago 2	About the same 3	Somewhat worse now than one year ago 4	Much worse now than one year ago 5

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? **(Circle One Number on Each Line)**

	Yes, Limited a Lot (1)	**Yes, Limited a Little (2)**	**No, Not Limited at All (3)**
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. Bending, kneeling, or stopping	1	2	3
g. Walking **more than a mile**	1	2	3
h. Walking **several blocks**	1	2	3
i. Walking **one block**	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a **result of your physical health**? **(Circle One Number on Each Line)**

	Yes	**No**
a. Cut down the amount of time you spent on work or other activities	**1**	**2**
b. Accomplished less than you would like	**1**	**2**
c. Were limited in the kind of work or activities	**1**	**2**
d. Had difficulty performing the work or other activities (for example, it took extra effort)	**1**	**2**

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a **result of any emotional problems** (such as feeling depressed or anxious)? **(Circle One Number on Each Line)**

	Yes	**No**
a. Cut down the amount of time you spent on work or other activities	**1**	**2**
b. **Accomplished less** than you would like	**1**	**2**
c. Didn't do work or other activities as **carefully** as usual	**1**	**2**

6. **During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?**

Not at all	Slightly	Moderately	Quite a bit	Extremely
1	2	3	4	5

7. **How much bodily pain have you had during the past 4 weeks?**

None	Very Mild	Mild	Moderate	Severe	Very Severe
1	2	3	4	5	6

8. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework?**

Not at all	A little bit	Moderately	Quite a bit	Extremely
1	2	3	4	5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. (**Circle One Number on Each Line)**

9. How much of the time during the **past 4 weeks….**

	All of the Time	**Most of the Time**	**A Good Bit of the Time**	**Some of the Time**	**A Little of the Time**	**None of the Time**
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot	**1**	**2**	**3**	**4**	**5**	**6**

of energy?						
f. Have you felt downhearted and blue?	**1**	**2**	**3**	**4**	**5**	**6**
g. Did you feel worn out?	**1**	**2**	**3**	**4**	**5**	**6**
h. Have you been a happy person?	**1**	**2**	**3**	**4**	**5**	**6**
i. Did you feel tired?	**1**	**2**	**3**	**4**	**5**	**6**

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the Time 1	Most of the Time 2	Some of the Time 3	A little of the Time 4	None of the Time 5

11. How TRUE or FALSE is each of the following statements for you. (Circle One Number on Each Line)

	Definitely True	**Mostly true**	**Don't know**	**Mostly false**	**Definitely false**
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

12. Have you EVER been <u>diagnosed</u> with any of the conditions listed below <u>by a medical practitioner only</u>?

	No	**Yes, not serio**	**Yes, moderatel**	**Yes, ver**
a. Arthritis or rheumatism?	**0**	**1**	**2**	**3**
b. High blood pressure?	**0**	**1**	**2**	**3**
c. Acute bronchitis or emphysema?	**0**	**1**	**2**	**3**
d. Diabetes?	**0**	**1**	**2**	**3**
e. Cancer?	**0**	**1**	**2**	**3**
f. Stomach or intestine ulcers?	**0**	**1**	**2**	**3**
g. Effects of Stroke?	**0**	**1**	**2**	**3**
h. Vision problems? Specify:____________	**0**	**1**	**2**	**3**
i. Hearing problems? Specify:___________	**0**	**1**	**2**	**3**
j. Any other medical conditions? k. Specify:_____________________ ____	**0**	**1**	**2**	**3**

13. Please list all the current medications YOU are taking routinely, including vitamins or over the counter medications (*e.g. antihistamines).*

(Participant will bring in a bag of meds or this can be completed over the phone by the interviewer. Please do not rely on memory.)

Medication	**DIN #**	**Dose (mg)**	**How often?** (e.g. times per day)

14. Since the beginning of the choir have you had ANY CHANGES in prescribed medications (*e.g, dosage*)?

- ○ Yes
- ○ No

IF YES, please explain: ____

15. Since the beginning of the choir have you STOPPED taking any medications (*e.g. anti-depressants*)?

- ○ Yes
- ○ No

IF YES, please explain: ____

16. Since the beginning of the choir have you STARTED ANY NEW medications?

- ○ Yes
- ○ No

IF YES, please explain: ____

QUALITY OF LIFE

In this section we will ask you about your quality of life. If you have difficulty rating any item, just give it your best guess. **(Circle One Number on Each Line)**

17. How would you rate your quality of life?

Very	**Poor**	**Neither poor nor**	**Good**	**Very**
1	2	3	4	5

18. How satisfied are you with your health?

Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very Satisfied**
1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the **last two weeks**.

	Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
19. To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5

	Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
20. How much do you need any medical treatment to function in your daily	1	2	3	4	5
21. How much do you enjoy life?	1	2	3	4	5
22. To what extent do you feel your life to be meaningful?	1	2	3	4	5

	Not at all	**A little**	**A moderate amount**	**Very much**	**Extremely**
23. How well are you able to concentrate?	1	2	3	4	5
24. How safe do you feel in your daily life?	1	2	3	4	5
25. How healthy is your physical environment?	1	2	3	4	5

The following questions ask **how completely** you experience or were able to do certain things in the **last two weeks**.

	Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
26. Do you have enough energy for everyday life?	1	2	3	4	5
27. Are you able to accept your bodily appearance?	1	2	3	4	5
28. Have you enough money to meet your needs?	1	2	3	4	5

	Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
29. How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
30. To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

	Very poor	**Poor**	**Neither poor nor good**	**Good**	**Very good**
31. How well are you able to get around?	1	2	3	4	5

The following questions ask you to say **how satisfied** you have felt about various aspects of your life over the **last two weeks**.

	Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very Satisfied**
32. How satisfied are you with your sleep?	1	2	3	4	5
33. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
34. How satisfied are you with your capacity for work?	1	2	3	4	5
35. How satisfied are you with yourself?	1	2	3	4	5

	Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very Satisfied**
36. How satisfied are you with your personal relationships?	1	2	3	4	5
37. How satisfied are you with your sex life?	1	2	3	4	5
38. How satisfied are you with the support you get from your friends?	1	2	3	4	5
39. How satisfied are you with the conditions of your living place?	1	2	3	4	5

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
40. How satisfied are you with your access to health services?	1	2	3	4	5
41. How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the **last two weeks**.

	Never	**Seldom**	**Quite often**	**Very often**	**Always**
42. How often do you have	1	2	3	4	5

ACTIVITIES OF FAMILY MEMBER WITH DEMENTIA

This next section focuses on the specific kinds of problems your family member with Dementia might have been having this **past week**. For each area, please indicate whether he/she has needed any kind of help. “Help” means supervision, direction, or personal assistance. **(Circle One Number on Each Line)**

43. During the past week, has your family member with dementia needed any kind of help.

	No	**Yes**
Using the telephone?	0	1
Shopping (going to a store for light groceries)?	0	1
Food preparation (making lunch or light) meals?	0	1
Housekeeping (making bed, vacuuming, dusting)?	0	1
Doing laundry?	0	1
Traveling by car, bus, etc.?	0	1
Taking his/her medications in the correct dosages or at the correct time?	0	1
Handling his/her finances?	0	1

44. In the past six months, how would you describe the change in the areas just discussed? *(e.g. using the telephone, shopping, handling finances, taking medications, traveling*).

○ Substantial decline
○ Minimal decline
○ No change
○ Minimal improvement
○ Substantial improvement

45. During the past week, has your care recipient needed any kind of help?

a. getting into or out of a bed, chair or wheelchair?		
b. eating meals?		
c. bathing, either in the tub, shower, or a sponge bath, such as rinsing or drying the body, excluding the back?		
d. dressing?		
e. toileting, such as adjusting clothing before and after toilet use or cleansing?		
f. grooming, such as brushing teeth, combing or brushing hair, washing hands, washing face, and either shaving or applying makeup?		

46. In the past six months, how would you describe the change in the areas just discussed? (*e.g., bathing, grooming, dressing, eating, toileting).*

○ Substantial decline
○ Minimal decline
○ No change
○ Minimal improvement
○ Substantial improvement

47. How many days in the past week have other family members or friends (*who are not being paid*) **provided help?** *("Help" means supervision, direction or personal assistance*).

○ No others have provided help
○ One day in the past week
○ Two days in the past week
○ Three days in the past week
○ More than four days in the past week

48. On average, how many HOURS PER DAY do you care for your family member? (*"care" means anything you need to do for your family member because he/she is not able to do this on their own anymore*)

○ Less than 3 hours
○ 3 to 6 hours
○ 6 to 12 hours
○ More than 12 hours

49. On average, how many DAYS PER WEEK do you care for your family member?
- ○ 1 day
- ○ 2 to 3 days
- ○ 4 to 5 days
- ○ 6 to 7 days

I would now like to ask you questions that will cover all the areas we've discussed today as a general overview. We realize that many of these questions may seem repetitive, and we appreciate your patience and participation.

50. Do you ever leave the care recipient home alone or unsupervised in the home?
- ○ Never
- ○ Sometimes
- ○ Often
- ○ Refused

51. **In the past six months, what kind of cognitive changes have you seen overall in your family member with dementia?**
- ○ Substantial decline
- ○ Minimal decline
- ○ No change
- ○ Minimal improvement
- ○ Substantial improvement

52. In the past six months, what kind of behavioral changes (*e.g. agitation, anger, wandering*) **have you seen overall in your family member with dementia?**
- ○ Substantial decline
- ○ Minimal decline
- ○ No change
- ○ Minimal improvement
- ○ Substantial improvement

53. In the past six months, how would you describe the changes in the mood (e.g. irritable, arguing, depressed) **overall of your family member with dementia?**
- ○ Substantial decline
- ○ Minimal decline
- ○ No change
- ○ Minimal improvement
- ○ Substantial improvement

Below are some questions regarding your feelings about caring for your family member with dementia. “CR” means care recipient. **(Circle One Number on Each Line)**

54. Do you feel:

	Never	**Rarely**	**Sometimes**	**Quite Frequently**	**Nearly Always**
a. that because of the time you spend with (CR) that you don’t have enough time for yourself?	0	1	2	3	4
b. stressed between caring for (CR) and trying to meet other responsibilities (work/family)?	0	1	2	3	4
c. angry when you are around (CR)?	0	1	2	3	4
d. that (CR) currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
e. strained when you are around (CR)?	0	1	2	3	4

	Never	**Rarely**	**Sometimes**	**Quite Frequently**	**Nearly Always**
f. that your health has suffered because of your involvement with (CR)?	0	1	2	3	4
g. that you don't have as much privacy as you would like because of (CR)?	0	1	2	3	4
h. that your social life has suffered because you are caring for (CR)?	0	1	2	3	4
i. that you have lost control of your life since (CR)'s illness?	0	1	2	3	4
j. uncertain about what to do about (CR)?	0	1	2	3	4
k. you should be doing more for (CR)?	0	1	2	3	4

	Never	**Rarely**	**Sometimes**	**Quite Frequently**	**Nearly Always**
l. you could do a better job in caring for (CR)?	0	1	2	3	4

SOCIAL ACTIVITIES

We are interested in **how satisfied** you are with the amount of time you have been able to spend in various activities that you might enjoy. **(Circle One Number on Each Line)**

55. Over the past month, how often have you been able to:

	Not at all	**A little**	**A lot**
a. Engage in activities that you enjoy?	0	1	2
b. Spend quiet time by yourself?	0	1	2
c. Take part in hobbies or other interests?	0	1	2
d. Able to go out for meals or other social activities?	0	1	2
e. Do fun things with other people?	0	1	2
f. Able to visit with family and friends?	0	1	2

SOCIAL SUPPORT

	Never	**Sometimes**	**Often**
56. Do you have someone (other than your care recipient) that you can talk to about important decisions or difficult caregiving situations?	0	1	2
57. Do you have someone, (other than your care recipient), like a family member, friend, or neighbor who can take your care recipient places if you needed help?	0	1	2
58. Is it hard for you to find services like adult day care, sitters, or respite care?	0	1	2

	Never	Sometimes	Often
59. Is it hard for you to find a friend or family member who can stay with your care recipient to give you a break from caregiving?	0	1	2
60. Do you have someone to comfort you, listen to your feelings, or express concern for you?	0	1	2
61. Do you feel isolated from your family/friends?	0	1	2
62. Is it hard for you to have quiet time for yourself or time to do the things you enjoy?	0	1	2
63. In the **past month or so**, has caregiving made you feel overwhelmed or extremely tired?	0	1	2
64. In the **past month**, have you felt depressed, sad, had crying spells or felt like you often needed to cry?	0	1	2
65. In the **past month**, have you been angry or frustrated as a result of your caregiving?	0	1	2
66. In the **past month**, have you had trouble falling asleep, staying asleep, or waking up too early in the	0	1	2
67. In the **past month**, has it been hard to eat healthy or well-balanced meals on a regular basis?	0	1	2

MOOD

Over the last two weeks, how often have you been bothered by any of the following problems? (Circle One Number on Each Line)

	Not at all	Several days	More than half the days	Nearly every day
68. Little interest or pleasure in doing things.	0	1	2	3
69. Feeling down, depressed, or hopeless.	0	1	2	3
70. Trouble falling/staying asleep, sleeping too much.	0	1	2	3
71. Feeling tired or having little energy.	0	1	2	3

	Not at all	Several days	More than half the days	Nearly every day
72. Poor appetite or overeating.	0	1	2	3
73. Feeling bad about yourself, or that you are a failure, or have let	0	1	2	3
74. Trouble concentrating on things, such as reading the newspaper or watching	0	1	2	3
75. Moving or speaking so slowly that other people could have noticed. <u>Or the opposite</u>: being so fidgety or restless that you have	0	1	2	3
76. Thoughts that you would be better off dead or of hurting yourself in some way.	0	1	2	3

77. If you checked off any problem on Q.68 to Q.76, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

No	Somewha	Ver	Extremel

<u>WELL-BEING</u>

This scale consists of a number of words that describe different feelings and emotions. **(Circle One Number on Each Line)**

78. Indicate to what extent you have felt this way over the <u>past week</u>.

	Very slightly or Not at all	A little	Moderately	Quite a bit	Extremely
a. Interested	1	2	3	4	5
b. Distressed	1	2	3	4	5
c. Excited	1	2	3	4	5
d. Upset	1	2	3	4	5
e. Strong	1	2	3	4	5

	Very slightly or Not at all	A little	Moderately	Quite a bit	Extremely
f. Guilty	1	2	3	4	5
g. Scared	1	2	3	4	5
h. Hostile	1	2	3	4	5
i. Enthusiastic	1	2	3	4	5
j. Proud	1	2	3	4	5
k. Irritable	1	2	3	4	5
l. Alert	1	2	3	4	5
m. Ashamed	1	2	3	4	5
n. Inspired	1	2	3	4	5
o. Nervous	1	2	3	4	5
p. Determined	1	2	3	4	5
q. Attentive	1	2	3	4	5
r. Jittery	1	2	3	4	5
s. Active	1	2	3	4	5
t. Afraid	1	2	3	4	5

PERSONAL INFORMATION

This next section asks about your personal characteristics. This information will be kept strictly confidential. Please respond to the following items completely.

79. What is your sex? (Please select ONE response)

Male
Female

80. My birth date is?

____/_____/________
Day/Month/Year

81. What is your current marital/partner status? (*Please select* ***ONE response)***

○ Single, never married or never lived with a partner
○ Married/living with a partner in a common-law relationship
○ Widowed
○ Divorced

- ○ Separated

82. What is the language that you first learned at home in childhood and can still understand? (Please select **ONE response)**

- ○ English
- ○ French
- ○ Other: *(please specify)* ____________________________

83. What is your ethnic background? (*Please check the appropriate alternative.)*

- ○ **First Nations** origin (This includes any of the original peoples of North America, and who maintains a cultural identification through tribal or band affiliation)
- ○ **Asian or Pacific Islander** (This includes China, India, Pakistan, Japan, Korea, the Philippine Islands, and Samoa.)
- ○ **Black**, not of Hispanic origin (This includes any of the black racial groups of Africa)
- ○ **Hispanic** (This includes persons who are Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race)
- ○ **White**, not of Hispanic origin (This includes anyone having origins in any of the original peoples of Europe, North Africa, or the Middle East)
- ○ **Other** *(please explain)* _______________________________________

84. Which academic diplomas or degrees or certificates have you obtained? (*Please circle **ALL that apply***).

- ○ No degree/diploma/certificate
- ○ High school diploma
- ○ Technical/trade school or community college
- ○ Bachelor's (e.g., BA, BSc, BComm., LLB)
- ○ Master's (e.g., MA, MSc, MEd, LLM, MD)
- ○ PhD or other doctoral degree
- ○ Other or additional degrees/diplomas/certificates: (*Please specify*) ________________

85. For EACH of the following levels of education, PLEASE CIRCLE the highest grade or years of full-time attendance you have COMPLETED. (*Do not include part-time or extension courses taken for interest*).

a) Grade/Intermediate School

Grade 1   Grade 2   Grade 3   Grade 4

Grade 5   Grade 6   Grade 7   Grade 8

b) Secondary/High School

none   Grade 9   Grade 10   Grade 11

Grade 12   Grade 13

c) Technical, Trade or Community College

none   1 year   2 years   3 years   4 years

5+ years

d) University (Bachelor's Level)

none   1st year   2nd year   3rd year   4th year   5+ years

e) Post-Graduate School (e.g., LLB, Master's, MD, PhD)

none   1 year   2 years   3 years   4 years   5+ years

86. What is your current employment status? (*Please check ALL that apply)*

○ Employed at a job for pay, full-time
○ Employed at a job for pay, part-time
○ Homemaker, not currently working for pay
○ Not currently employed, retired
○ Not currently employed, not retired

87. What kind of work have you/did you do for most of your life? (*Please select* ***ONE response*****)**

○ Never employed
○ Homemaker
○ Other (State the specific occupation in detail): ___________________________

88. How much of a financial strain do you feel as a caregiver at this point in your life? (*Please select* ***ONE response*****)**

○ Not a financial strain at all
○ Slight financial strain
○ Somewhat of a financial strain
○ Moderate financial strain
○ Significant financial strain

89. What is your relationship with the family member you care for? (*Please select* ***ONE response*****)**

○ Spouse
○ Son or daughter
Other: specify___________________

90. Approximately how long have you been caring for your family member? (*Please select* ***ONE response*****)**

○ Less than 1 year
○ 1 to 3 years
○ 4 to 6 years
○ 7 to 10 years
○ More than 10 years

91. Do you and your family member with dementia live together?

○ Yes
○ No

92. Other than problems with memory or confusion, how would you rate the physical health of your family member with dementia?

Excellent 1	Very Good 2	Good 3	Fair 4	Poor 5

Appendix B. Items to measure subjective well-being (PANAS)

Indicate to what extent you have felt this way over the <u>past week</u>.

	Very slightly or Not at all	A little	Moderately	Quite a bit	Extremely
a. Interested	☐	☐	☐	☐	☐
b. Distressed	☐	☐	☐	☐	☐
c. Excited	☐	☐	☐	☐	☐
d. Upset	☐	☐	☐	☐	☐
e. Strong	☐	☐	☐	☐	☐
f. Guilty	☐	☐	☐	☐	☐
g. Scared	☐	☐	☐	☐	☐
h. Hostile	☐	☐	☐	☐	☐
i. Enthusiastic	☐	☐	☐	☐	☐
j. Proud	☐	☐	☐	☐	☐
k. Irritable	☐	☐	☐	☐	☐
l. Alert	☐	☐	☐	☐	☐
m. Ashamed	☐	☐	☐	☐	☐
n. Inspired	☐	☐	☐	☐	☐
o. Nervous	☐	☐	☐	☐	☐
p. Determined	☐	☐	☐	☐	☐
q. Attentive	☐	☐	☐	☐	☐
r. Jittery	☐	☐	☐	☐	☐
s. Active	☐	☐	☐	☐	☐
t. Afraid	☐	☐	☐	☐	☐

Appendix C. Items to measure Social Activities

We are interested in **how satisfied** you are with the amount of time you have been able to spend in various activities that you might enjoy. **(Circle One Number on Each Line)**

Over the past month, how often have you been able to:

	Not at all	**A little**	**A lot**
g. Engage in activities that you enjoy?	0	1	2
h. Spend quiet time by yourself?	0	1	2
i. Take part in hobbies or other interests?	0	1	2
j. Able to go out for meals or other social activities?	0	1	2
k. Do fun things with other people?	0	1	2
l. Able to visit with family and friends?	0	1	2

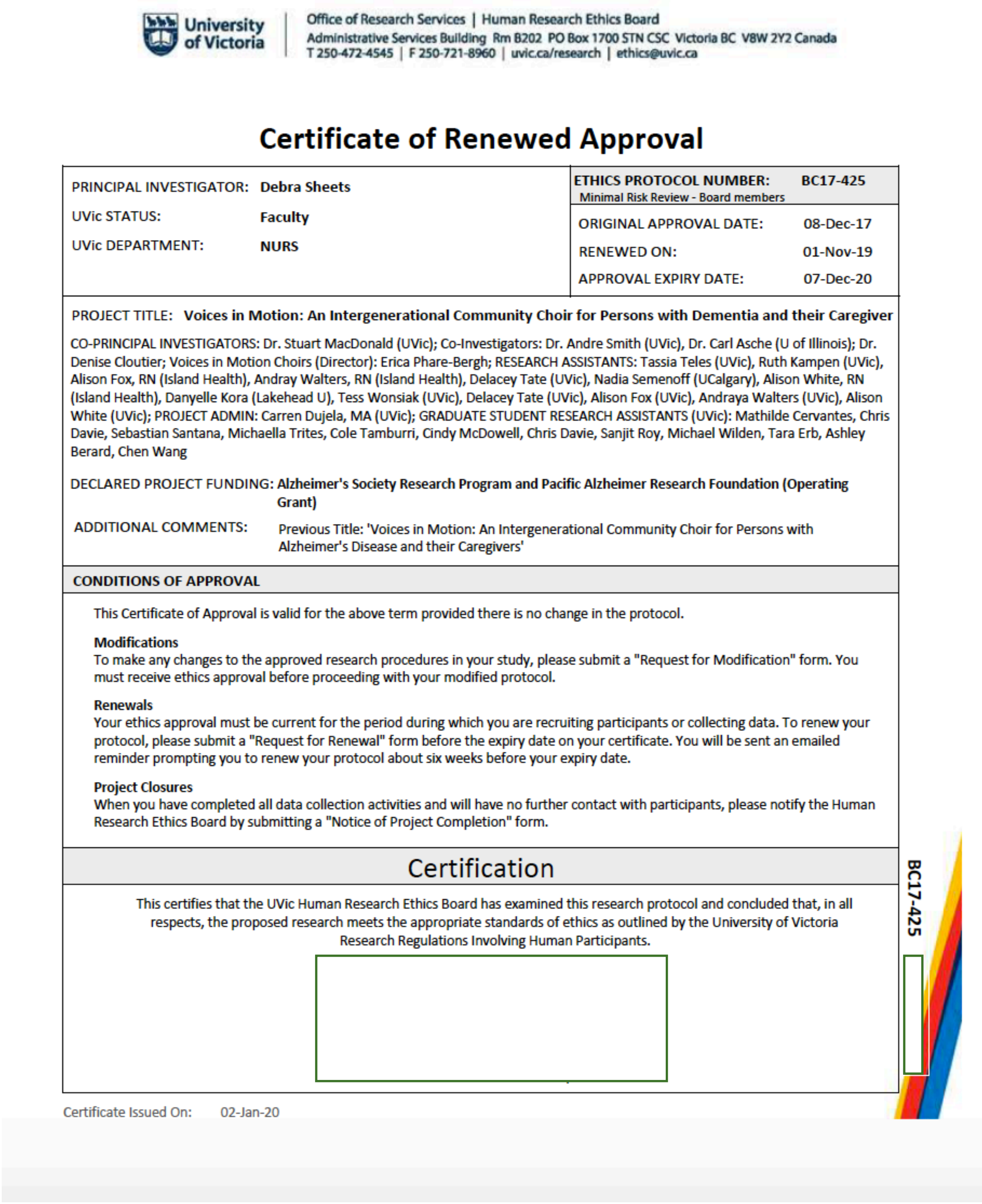
Appendix D. Items to measure caregiver distress. Short Form Zarit Burden Interview (ZBI-12)

Do you feel:

	Never	**Rarely**	**Sometimes**	**Quite Frequently**	**Nearly Always**
1. that because of the time you spend with (CR) that you don't have enough time for yourself?	0	1	2	3	4
2. stressed between caring for (CR) and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3. angry when you are around (CR)?	0	1	2	3	4
4. that (CR) currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
5. strained when you are around (CR)?	0	1	2	3	4

	Never	**Rarely**	**Sometimes**	**Quite Frequently**	**Nearly Always**
6. that your health has suffered because of your involvement with (CR)?	0	1	2	3	4
7. that you don't have as much privacy as you would like because of (CR)?	0	1	2	3	4
8. that your social life has suffered because you are caring for (CR)?	0	1	2	3	4
9. that you have lost control of your life since (CR)'s illness?	0	1	2	3	4
10. uncertain about what to do about (CR)?	0	1	2	3	4
11. you should be doing more for (CR)?	0	1	2	3	4
12. you could do a better job in caring for (CR)?	0	1	2	3	4

Appendix E. Certificate of Ethical Approval



University of Victoria

Office of Research Services | Human Research Ethics Board
Administrative Services Building Rm B202 PO Box 1700 STN CSC Victoria BC V8W 2Y2 Canada
T 250-472-4545 | F 250-721-8960 | uvic.ca/research | ethics@uvic.ca

Certificate of Renewed Approval

PRINCIPAL INVESTIGATOR:	**Debra Sheets**	**ETHICS PROTOCOL NUMBER:** Minimal Risk Review - Board members	**BC17-425**
UVic STATUS:	**Faculty**	ORIGINAL APPROVAL DATE:	08-Dec-17
UVic DEPARTMENT:	**NURS**	RENEWED ON:	01-Nov-19
		APPROVAL EXPIRY DATE:	07-Dec-20

PROJECT TITLE: **Voices in Motion: An Intergenerational Community Choir for Persons with Dementia and their Caregiver**

CO-PRINCIPAL INVESTIGATORS: Dr. Stuart MacDonald (UVic); Co-Investigators: Dr. Andre Smith (UVic), Dr. Carl Asche (U of Illinois); Dr. Denise Cloutier; Voices in Motion Choirs (Director): Erica Phare-Bergh; RESEARCH ASSISTANTS: Tassia Teles (UVic), Ruth Kampen (UVic), Alison Fox, RN (Island Health), Andray Walters, RN (Island Health), Delacey Tate (UVic), Nadia Semenoff (UCalgary), Alison White, RN (Island Health), Danyelle Kora (Lakehead U), Tess Wonsiak (UVic), Delacey Tate (UVic), Alison Fox (UVic), Andraya Walters (UVic), Alison White (UVic); PROJECT ADMIN: Carren Dujela, MA (UVic); GRADUATE STUDENT RESEARCH ASSISTANTS (UVic): Mathilde Cervantes, Chris Davie, Sebastian Santana, Michaella Trites, Cole Tamburri, Cindy McDowell, Chris Davie, Sanjit Roy, Michael Wilden, Tara Erb, Ashley Berard, Chen Wang

DECLARED PROJECT FUNDING: **Alzheimer's Society Research Program and Pacific Alzheimer Research Foundation (Operating Grant)**

ADDITIONAL COMMENTS: Previous Title: 'Voices in Motion: An Intergenerational Community Choir for Persons with Alzheimer's Disease and their Caregivers'

CONDITIONS OF APPROVAL

This Certificate of Approval is valid for the above term provided there is no change in the protocol.

Modifications
To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.

Renewals
Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.

Project Closures
When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.

BC17-425

Certificate Issued On: 02-Jan-20