The Impact of Group Singing on Health-Related Quality of Life in Parkinson’s Disease: A Qualitative Study

Romane Victoria Abell

BA (Hons) (Psych), Dip. Bus., MAPS

This thesis is submitted in partial fulfilment of the requirements for the degree of

Professional Doctorate in Clinical Psychology,

School of Psychology,

The University of Newcastle

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Preamble

Declarations

1. This thesis contains no material which has been accepted for award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis being made available worldwide when deposited in the University’s Digital Repository (unless an embargo has been approved for a determined period) subject to the provisions of the Copyright Act 1968.

2. I hereby certify that the work embodied in this thesis has been done in collaboration with Dr Kerry Chalmers\(^a\) and Dr Amee Baird\(^b,c\):
\(^a\) School of Psychology, Faculty of Science and Information Technology, University of Newcastle, Callaghan, NSW, Australia
\(^b\) ARC Centre of Excellence in Cognition and its Disorders, Sydney, Australia
\(^c\) Department of Psychology, Faculty of Human Sciences, Macquarie University.

3. I hereby certify that the work embodied in this thesis contains a co-authored scholarly work, of which I am a joint author. I confirm that I contributed to each phase of the joint scholarly work including the research design, recruitment, data collection, data analysis and interpretation and the writing of the manuscript.

Supervisor Endorsement Date 13/4/2016

\textit{Dr Kerry Chalmers}

4. The work in this thesis was carried out under the supervision of Dr Kerry Chalmers, University of Newcastle.

5. The conduct of this research was approved by the University of Newcastle Human Research Ethics Committee (approval number H-2014-0284, Appendix A) and Macquarie University Human Ethics Committee (approval number 5201400414, Appendix B).

Signed Date 13/4/2016

\textit{Romane Abell}
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Publication and Conference Presentation

Journal Manuscript Submission

A component of this thesis is a research manuscript that has been submitted to, and peer reviewed by, the American Psychological Association Journal Health Psychology (No. HEA-2015-3592). Please refer to Appendix C for confirmation of the peer review, Appendix D for the Journal’s scope, and Appendix E for the Journal’s Guidelines for Authors.


Presentation

The qualitative findings of this research were presented by the author at the Parkinson’s Australia National Conference, Adelaide Convention Centre, 27 – 29 May, 2015. Refer to Appendix F for the submitted abstract and, Appendix G for the confirmation of the speaker acceptance.

Structured Abstract

Scope

Idiopathic Parkinson’s disease (PD) is a chronic, progressively disabling neurological disorder, comprising both motor symptoms (MS) and non-motor symptoms (NMS). People with PD have reduced health-related quality of life (HRQoL; Karlsen, Tandberg, Årsland, & Larsen, 2000; Simpson, Lekwuwa, & Crawford, 2014). To date there is no cure for PD. The primary goal of treatment is to restore or maintain HRQoL through assessment and intervention, while simultaneously managing MS (Fung, 2015).

PD predominately affects older adults. Deloitte Access Economics (2015) confirms that in Australia PD is the most common major movement disorder and the second highest prevalence neurodegenerative condition (after Alzheimer’s disease). The estimated prevalence is approximately 70,000 (one in every 340 people) with an economic cost to the country of over $9.9 billion. In 2014, there were 11,900 new cases of PD diagnosed; this rate is expected to grow by 4% per annum over the next 20 years, compared to the general population growth rate of 1%, due to the aging population.

Purpose

Group singing is a non-pharmacological, low cost, community-based activity that has been found to improve HRQoL (Clift & Hancox, 2010; Judd & Pooley, 2013) across a variety of populations: mental health (Tavormina, Tavormina, & Nemoianni, 2014), cancer (Gale, Enright, Reagon, Lewis & Deursen, 2012) and neurological conditions including Alzheimer’s disease (Simons-Stern, Budson & Ally, 2010), dementia (Osman, Tischler & Schneider, 2014) and stroke (Tamplin, Baker, Jones, Way, & Lee, 2013; Tomaino, 2012). The aim of this study was to explore the effects of group singing on HRQoL for people diagnosed with PD.
Methodology

Eleven participants (mean age 70.6 years) with a formal diagnosis of PD were recruited from an existing community singing group specifically created for people with PD, their carers and family members. Participants presented with mild to moderate severity of MS and disability (Hoehn and Yahr stage (frequency): level I (6), level II (3) and level III (2)) and moderate to very severe NMS burden (NMSB; (frequency): moderate (4), severe (5) and very severe (2)) and low to significantly impacted HRQoL (Parkinson Disease Questionnaire-39 scores ranged from 6.93 to 43.59).

Interpretive Phenomenological Analysis (IPA; Smith, 1996), a qualitative methodology well established in the field of health psychology (Brocki & Wearden, 2006), informed the data collection and analysis. To ensure research rigour, the recommendations of the Consolidated Criteria for Reporting Qualitative Studies (COREQ; Tong, Sainsbury & Craig, 2007) were incorporated into the research design. Participants’ perceptions of the effect of group singing on their HRQoL were captured in a semi-structured interview designed for this research.

Results

All participants reported improved wellbeing since attending the choir and a desire to recommend the singing group to others with PD. The results of the IPA analysis revealed six themes that characterised the effects of group singing: physical, mood, cognitive functioning, social connectedness, ‘flow-on’ effects, and sense-of-self. All participants reported positive effects across at least four of these themes. Three participants reported a negative effect in at least one theme (physical, mood or sense-of-self). The most common sub-themes reported by participants were related to social connectedness, with all participants reporting camaraderie and new friendships as important aspects of attending the choir. Other sub-themes, identified by the majority of participants, included improved voice quality, raised energy levels, PD-
specific choir, enhanced mood, increased self-confidence and greater control over day-to-day activities. Three factors were identified as important in the success of the choir: the Choir Maestro, PD-carer support group, and a PD-specific choir.

**General conclusions and implications**

This study is unique for the following reasons. It is the only study to use a qualitative methodology to examine group singing and HRQoL in participants regularly attending a choir specifically established for people with PD, their carers and family members. It is the only study to report on the cognitive benefits of group singing in a PD specific choir, and the only study to report the duration of the effects across the domains of physical (body and voice), mood and cognitive functioning. Furthermore, this research has revealed both positive and negative effects of group singing, whereas previous studies have not reported on the latter in a PD specific choir. Participants reported multiple benefits from engagement in group singing that counteracted many of the negative effects of PD, suggesting that group singing has the ability to ‘give back’ some of what PD ‘takes away’.
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Critical Literature Review

“Acceptance doesn’t mean resignation.
It means understanding that something is what it is &
there’s got to be a way through it” (M. J. Fox quoted in Marikar, 2012)

Michael J. Fox

Overview

The aim of this thesis was to investigate the effects of participating in group singing for people with Parkinson’s disease, especially with respect to quality of life. There is no cure for this neurodegenerative disorder and it has been shown that people with this disease have reduced health-related quality of life (HRQoL; Karlsen, Tandberg, Årsland, & Larsen, 2000; Simpson, Lekwuwa, & Crawford, 2014). Group singing is a non-pharmacological, low cost, community-based activity that has been found to improve HRQoL (Clift & Hancox, 2010; Judd & Pooley, 2013)

The following review provides an overview of the history and prevalence of Parkinson’s disease, as well as the pathology and symptomatology of this disorder. A definition of health-related quality of life is provided, along with background information to explain the relevance of music, singing, and singing in unison (group singing) for improving quality of life in other populations. A review of the current literature examining the effects of group singing in Parkinson’s disease is presented. The current study, a qualitative exploration of the phenomenon of group singing for people with Parkinson’s disease (PD), is then introduced. Finally, an outline of the remainder of the thesis is provided.
Parkinson’s disease: presentation and prevalence

PD is a progressive neurodegenerative disorder of the central nervous system where the main neuropathological hallmark is dopaminergic neuronal loss. This chronic heterogeneous multisystem condition is associated with both motor and non-motor manifestations. Days are dictated by medication regimes. Nights often bring no sleep. Movements become stiff and slow, restless and rolling. Emotional wellbeing can be undermined by apathy, fatigue, anxiety, depression, and cognitive impairment. Uncertainty, fear of the future and self-isolation are common experiences.

This disease continues to be shrouded by stigma regardless of increased community awareness, or the celebrity status of sufferers. Well known people diagnosed with PD include: Michael J Fox, Billy Connolly, Linda Ronstadt, Muhammad Ali, Adolf Hitler (1889 -1945), Pope John Paul II (1920 - 2005), the past Australian Senator Don Chipp (1925 – 2006) and the late Robin Williams (1951 – 1914). Each person’s experience with PD is unique; disease onset, symptom severity and disease progression is highly individualistic. There are changes in quality of life for everyone who shares the infliction - patient, carer and family members alike.

PD is universal with a global incidence estimated at 6.3 million people (European Parkinson’s Disease Association, 2015). This figure is expected to increase to 9.3 million (for people with PD over 50 years of age) by 2030 based on published prevalence studies of people with PD in Western Europe’s five, and the world’s ten, most populous nations (Dorsey, 2007). Incidence rates also vary across race, with the highest PD incidence rate in the Hispanic population, followed by Non-Hispanic white, Asian, and finally black populations (Van den Eeden et al., 2003).

Typically, PD presents in adults aged 60 years and older (Shafique, Blagrove, Chung & Logendrarajah, 2011) and is more prevalent in males than females, with a male to female
ratio of 1.9:1 (Van Den Eeden et al., 2003). There is an increased incidence of PD with advancing age (Van Den Eeden et al., 2003). The reference ‘early onset PD’ refers to the small proportion of cases that are diagnosed prior to 40 years of age: ‘young onset PD’ if age at diagnosis is between 21 and 40 years, and ‘juvenile Parkinsonism’ when age at diagnosis is less than 20 years of age.

Deloitte Access Economics (2015) analysis for Australia, 2014, found that PD was the most common major movement disorder and the second highest prevalence neurodegenerative condition (after Alzheimer’s disease) with an estimated prevalence of 69,208, or approximately one in every 340 people. The demographics of diagnosed cases included: 82% over the age of 65 years, 18% of working age and 53% male (a male to female ratio of 1.13:1 - smaller compared to Van Den Eeden et al., 2003, cited above). The economic cost to Australia, in the same year, was over $9.9 billion.

In 2014, 11,900 new cases of PD were diagnosed in Australia. This number is expected to grow by 4% per annum over the next 20 years, compared to the general population growth rate of 1%. This is due to the aging population; people aged 60 years and over is an expanding demographic and expected to represent 25% of the population within 10 years (Deloitte Access Economics, 2015). This demographic currently represents 19.89% of the population (Australian Bureau of Statistics, 2015).

Disease history, diagnosis and development

Parkinsonism is a clinical syndrome characterized by lesions in the basal ganglia within the brain, predominantly in the substantia nigra. While PD is the most common neurodegenerative cause of Parkinsonism, comprising 80% of cases, other causes include the ‘atypical parkinsonism’ or ‘Parkinson-plus syndromes’ including atrophy, progressive supranuclear palsy and corticobasal degeneration.
Medically described in 1817 by Dr James Parkinson as a clinical syndrome (for an in-depth review of the history of PD see Goetz, 2011; Parkinson, 1817), the cause of PD, and its cure, are still unknown 200 years later. There is no definitive test to confirm the presence of PD. The ‘gold standard’ for an implied clinical diagnosis relies heavily on the emergence of motor complications that increase in severity over time. Importantly, these symptoms need to be responsive to L-Dihydroxyphenylalanine (levodopa, L-DOPA), an amino acid which upon ingestion can be metabolized to dopamine, the neurotransmitter that is deficient in the brains of people with PD. By the time a clinical diagnosis is made it is estimated that between 60% – 80% of the dopamine-producing neurons have died. Only upon autopsy, with the pathological findings of intraneuronal inclusions containing aggregated alpha-synuclein deposition (Lewy bodies) and dopamine neuronal loss in the substantia nigra pars compacta, a section of the basal ganglia, is a diagnosis of PD confirmed (Berg, et al., 2014).

Dopamine neuronal loss and the presence of Lewy bodies pathology may be the result of exposure to a chemical or environmental toxin, combined with a genetic vulnerability. The widely accepted Braak model of PD staging (Braak, Del Tredici et al., 2003) includes a ‘dual-hit’ hypothesis. They propose that PD is the result of pathogenic access to the brain through two access points: the nose and the stomach. The nasal route accounts for olfactory dysfunction common in early PD and is often cited by patients as a prodromal symptom (Braak, Rub et al., 2003; Hawkes et al., 2007). Similarly, the gastric route accounts for the gastrointestinal dysfunction common in early PD and is also cited as a prodromal symptom (Abbott et al., 2001; Pfeiffer, 2003).
The Braak model assumes a non-random, progressive process with specific nuclei and neuronal types giving rise to the development of Lewy bodies pathology in a stereotypic pattern with a pre-symptomatic period of several years, eventually resulting in a cascade of neurodegenerative events (Braak et al., 2003). Schematically summarised by Visanji,

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Brooks, Hazrati and Lang (2013), and reproduced in Figure 1, PD commences in the lower brainstem and advances rostrally; travels through susceptible regions of the midbrain and forebrain, then into the cerebral cortex. As PD progresses the severity of lesions in the susceptible regions increases.

An alternate staging system has been proposed by Beach et al. (2009), to account for the 42% of PD cases that are not classifiable by the Braak model due to their olfactory bulb-only presentation or due to limbic system involvement in the absence of brainstem pathology. This ‘Unified Staging System’ (Beach et al., 2009) has a regional progression pathway and allows for the classification of all major Lewy body disorders (PD, dementia with Lewy bodies, incidental Lewy body disease and Alzheimer’s disease with sparse, predominately limbic Lewy bodies). The model comprises four stages: Stage I (cases with pathology only in the olfactory bulb), Stage IIa (brainstem-predominant involvement), Stage IIb (limbic system-predominant involvement), Stage III (brainstem and limbic regions equally involved), and Stage IV (neocortex involvement) as shown in Figure 2. All disorders can be assigned to a defined stage and progress through these stages can be non-sequential.

The suggestion of a pre-morbid personality to predict people at risk of developing PD is both controversial and inconclusive. The body of research is limited and has produced mixed findings. In their controlled study, using Cloninger’s Tridimensional Personality Questionnaire, Menza, Golbe, Cody and Forman (1993) describe a “low novelty seeking” pre-morbid PD presentation comprising several characteristics: reflective, rigid, stoic, slow-tempered, frugal, orderly and persistent. They suggest that novelty-seeking behaviour is dopamine dependent and that damage to the mesolimbic dopaminergic system causes the described personality of PD patients. Arabia et al. (2010) administered the Minnesota Multiphasic Personality Inventory (MMPI) and found no relationship between the personality traits related to introversion (MMPI scales of sensation seeking, hypomania and positive
emotionality) and extroversion (MMPI scales for social introversion and constraint) and the prediction of risk of PD. Instead their large (n = 6,822) historical cohort study with long follow-up (four decades) did find an association between higher scores for constraint and an increased risk of all types or Parkinsonism pooled together.

Figure 2. Schematic depiction of hypothetical progression pathways and stages for Lewy body disorders. From “Unified staging system for Lewy body disorders: correlation with nigrostriatal degeneration, cognitive impairment and motor dysfunction” by Beach et al, Acta Neuropathologica, 117(6), p 28. Copyright 2009 Springer. Reproduced with permission under licence2.

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**Motor symptoms**

The loss of the dopamine producing neurons causes alteration to vital ‘motor’ circuits in the brain that leads to a slowing of intentional movements and reduced muscle control. The motor symptoms (MS) of PD include bradykinesia (slow execution of movement and impaired ability to adjust the body's position), hypokinesia (decreased range of movement), akinesia (absence of movement), rigidity, a resting tremor and postural disturbances. Late-onset MS include postural instability and falls, freezing of gait.

Assessment of MS severity is guided by the Hoehn and Yahr clinical staging scale (HY; Hoehn & Yahr, 1967), still the international standard after nearly 50 years (Chaudhuri, Tolosa, & Schapira, 2009). Rated by a trained clinician, usually a neurologist, a severity level ranging from I to V is assigned based on the presenting motor symptoms and the resultant level of disability. This measure captures typical patterns of progressive motor impairment that correlate with motor decline, deterioration in quality of life (QoL), and neuro-imaging studies of dopaminergic loss (Bhidayasiri & Tarsy, 2012). A rating of III denotes mild to moderate disability with impaired postural reflexes while remaining physically independent. In contrast, a rating of V describes severe motor disability with confinement to bed or a wheelchair unless aided.

Management of MS requires medication; frontline intervention is dopaminergic therapy (Hayes, Fung, Kimber & O'Sullivan, 2010). Initial oral therapy includes monoamine oxidase B (MAO-B) inhibitors, dopamine agonists (DAs) and levodopa. Each of these medications has advantages and disadvantages (see Ferreira et al., 2013, for an overview) and no current medication has the ability to slow the progression of the disease. The primary goal of therapy, according to Fung (2015), is therefore to manage motor symptoms and restore, or maintain, health-related quality of life (HRQoL).
As PD progresses, medication regimes become less effective, resulting in a reduced ability to control movement; initially only occurring upon waking, and as the disease progresses, during the day. Therefore, ongoing medication reviews are essential throughout the disease course. A satisfactory motor response with medication is referred to as the ‘on’ period. Conversely, in the ‘off’ period there is insufficient dopamine stimulation from medication and a ‘wearing off’ period is experienced towards the end of a dose of medication. In contrast to bradykinesia, which is present in all cases, dyskinesia (unintended, involuntary and uncontrollable movements including twitches, jerking, twisting or simple restlessness) affects 50% of cases. Dyskinesia is due to increased sensitivity to dopamine in the brain as a result of levodopa, combined with the natural progression of PD. Advanced therapies for severe MS symptoms that are unresponsive to adjustments in medication regimes include surgery - deep brain stimulation (DBS) (of the subthalamic nucleus), and levodopa-cardbidopa intestinal gel delivered as a continuous infusion via a permanent percutaneous endoscopic gastrostomy tube.

**Non motor symptoms**

PD extends beyond the boundaries of the central nervous system, affecting both the peripheral nervous system and the enteric nervous system. The symptoms that are not related to movement are known as non-motor symptoms (NMS). NMS were identified as early as 1817, with Dr James Parkinson documenting a variety of non-motor experiences reported by patients. These included sleep disturbance, constipation, dysarthria, dysphagia, dysphonia, sialorrhoea, urinary incontinence, and in the later stages of PD, constant sleepiness with slight delirium (Goetz, 2011).

NMS involve multiple systems, comprise a vast array of symptoms and have a significant impact on QoL. Empirical research shows that PD patients frequently experience a wide range of NMS relating to the dysfunction of the peripheral nervous system (Visanji et
al., 2013), however NMS are still not well recognised or effectively managed in the clinical setting (International PD Non Motor Group, 2015). The majority of NMS are a result of the involvement of non-dopaminergic nervous system structures by the pathological process underlying PD. Prefrontal atrophy, in addition to neurotransmitter imbalances, has recently been implicated as contributing to neuropsychiatric symptoms (O’Callaghan, Shine, Lewis & Hornberger, 2014). Medication prescribed in early PD can also induce or aggravate some NMS, especially orthostatic hypotension, hallucinations, excessive daytime sleepiness, leg oedema, insomnia and memory problems requiring alterations to medication regimes.

Chaudhuri, Healy and Schapira (2006) have classified NMS into seven categories. They include: neuropsychiatric symptoms, sleep disorders, autonomic symptoms, gastrointestinal symptoms, sensory symptoms (including olfactory disturbance), other symptoms (including fatigue, vision problems and weight loss) and symptoms that fluctuate in frequency and duration such as pain, screaming, panic attacks, altered blood pressure and ‘restless legs’ (see Appendix J for the complete list of NMS).

NMS usually predate the emergence of MS (and the formal PD diagnosis) often up to several years earlier (Berg et al, 2014). The most common NMS during this pre-motor phase include olfactory loss, autonomic dysfunction, affective disorders, fatigue and REM sleep behavioural disorder (Gallagher & Schapira, 2009). These NMS symptoms correspond to areas affected by Lewy body deposition, consistent with the temporal sequence predicted by the Braak hypothesis (Braak et al., 2003) discussed earlier, suggesting that these NMS may be markers of the pre-clinical stage of PD (International PD Non Motor Group, 2015).

NMS prevalence and severity increase throughout the disease course, especially in the later stages of PD (Martinez-Martin, Marinus, & van Hilten, 2008). It is the worsening of NMS symptoms that ultimately determines nursing home placement and the progression of
overall disability (Healy et al., 2005). NMS contribute significantly to morbidity and are estimated to more than quadruple the cost of care (International PD Non Motor Group, 2015).

Assessment of NMS requires completion of a self-report screening and assessment tool, interpreted by a clinician. Over the past decade, several NMS measures have been developed and validated, including, the PD NMS Questionnaire (NMS Quest; Chaudhuri et al., 2006), the NMS Symptom Scale for PD (NMSS; Chaudhuri & Martinez-Martin, 2008; Chaudhuri et al., 2007) and the Movement Disorder Society – Unified Parkinson’s Disease Rating Scale (MDS-UPDRS; Goetz et al., 2008).

Until the early 2000s the focus of PD treatment was to manage MS (Chaudhuri, Healy, & Schapira, 2006) with NMS going unrecognised (Gallagher & Schapira, 2010; Shulman, Taback, Rabinstein, & Weiner, 2002) or receiving little attention (Chaudhuri & Schapira, 2006; Chaudhuri et al. 2009). For example, in one American study, neurologists failed to identify the existence of depression, anxiety and fatigue in 50% of consultations, while sleep disturbance was overlooked in 40% (Shulman et al. 2002).

Over the past 15 years there has been a shift in clinical practice due to profound changes in the understanding of PD. The formalisation of a non-motor prodrome of PD (Berg et al., 2014) has aided early diagnosis and intervention. The awareness of NMS and their significant role in patient wellbeing has helped to make NMS a management priority. Recognition of the importance of NMS to patient wellbeing has been aided by the establishment of the International PD Non Motor Group, a multidisciplinary not-for-profit educational society with the aim to increase the recognition, awareness and assessment tools for NMS.

There is no cure for PD. Current best practice management of PD is holistic and involves a well-coordinated multidisciplinary team approach that includes a neurologist, a general practitioner (GP), a PD nurse specialist (where funding permits) as well as allied
health professionals (speech therapist, occupational therapist, physiotherapist, psychologist) (Lee, Shine & Lewis, 2015). The primary goal of treatment is to restore, or maintain, HRQoL through assessment and intervention while simultaneously managing MS (Fung, 2015).

**Health-related quality of life**

People with PD have reduced HRQoL (Karlsen et al., 2000; Simpson et al., 2014). The PD literature defines HRQoL as ‘the patient’s own perception and self-evaluation regarding the effects of an illness and its consequences on her or his life’ (Martinez-Martin, 1998, p. S2). It is important to note that HRQoL and QoL, while often used interchangeably in the literature, are different, yet related subjective concepts. QoL has a broad scope and encompasses all aspects of life (Calman, 1984) and has been defined as “an individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns” (World Health Organization, 1997, p.1). HRQoL is narrower in scope with a focus on the effects of illness and treatment on QoL. Not all studies expressly report HRQoL with some studies referring to QoL or wellbeing, while other studies report specific benefits that fall under the HRQoL umbrella, but are not referred to as such.

People at a similar PD stage can often have different levels of perceived HRQoL (Gotham, Brown, & Marsden, 1986) and as symptom severity increases with PD progression, there is a concomitant decline in HRQoL (Karlsen, Tandberg, Årsland & Larsen, 2000; Simpson, Lekwuwa, & Crawford, 2014). A number of factors comprise HRQoL including physical, emotional, cognitive, sexual, social and role functioning (Fayers & Machin, 2013). Several PD-specific HRQoL measures have been developed over the past 15 years including the Parkinson’s Disease Questionnaire (PDQ-39), the Parkinson’s Disease Quality of Life Questionnaire (PDQL), the Parkinson’s Impact Scale (PIMS), the Parkinson’s Disease
Quality of Life Instrument (PDQUALIF) and Scales for Outcomes in PD-Psychosocial (SCOPA-PS).

Strong predictors of HRQoL in PD include sleep problems (Duncan et al., 2013; Martinez-Martin, Rodriguez-Blazquez, Kurtis, & Chaudhuri, 2011; Walton et al., 2014), fatigue (Martinez-Martin et al., 2011), mood disturbance (Chaudhuri et al., 2009; Martinez-Martin et al., 2011; Soh, Morris & McGinley, 2011; Soundy, Stubbs & Roskell, 2014; Walton et al., 2014), cognitive impairment (Martinez-Martin et al., 2011; Soh et al., 2011), anxiety (Duncan et al., 2013; Walton et al., 2014), incomplete bowel emptying (Duncan et al., 2013), freezing of gait (Perez-Lloret et al., 2014; Walton et al., 2014), apathy, lack of motivation, loss of purpose and diminished self-worth (Chaudhuri et al., 2009; Soundy et al., 2014) as well as reduced social functioning (Schrag, Jahanshahi, & Quinn, 2000).

The combined NMS of PD has been shown to be the most significant predictor of HRQoL when compared to MS (Duncan et al., 2013; Martinez-Martin et al., 2011). More recently, freezing of gait has been identified as the strongest predictor of HRQoL in the early stages of disease progression (HY levels I to III) after accounting for MS and the NMS of cognition, sleep problems and mood disturbance (Walton et al., 2014).

**Communication difficulties and social isolation.** Communication challenges develop with disease progression. Speech deficits occur in 60% - 80% of cases (Adams, Till & Yorkston, 1994) and can include a variety of issues: decrease in volume and quality (dysarthria), an increase in rate of speech, slurred words, ‘breathy’ and hoarse quality, a loss of voice inflection and monotone speech. Emotional communication is impacted with changes to the perception and production of emotional prosody (Schroder, Nikolova, & Dengler, 2010). Facial masking (amimia) caused by a reduction in facial muscle activity creating a fixed and vacant expression severely impacts the ability to convey emotions and to be understood. Small and cramped handwriting (micrographia), due to hypokinesia, can
make written communications difficult to read and deter written communication. Once communication abilities become reduced, isolating behaviours develop and HRQoL is reduced (Rinn, 1984).

Social networks may be lost through medical retirement from paid work, the inability to physically participate in social activities, or disengagement from loss of independence and fear of falling due to freezing of gait (Walton et al. 2014). The physical symptoms can diminish a person’s world through shortened gait, reduced movements, stooped posture, freezing, and fatigue (Larsen, Dupont, & Tandberg, 1994). There are also ‘knock-on’ effects from mood and sleep disorders, apathy, impaired emotional processing and cognitive decline on the motivation and ability to communicate. When others have little appreciation of these difficulties that people with PD experience, feelings of self-worth are reduced and the desire to socialise, or communicate one-to-one, diminishes (Miller, Noble, Jones & Burn, 2006).

**Music listening as an intervention to improve HRQoL**

It is well known that music can evoke psychological and emotional reactions, and can positively change our lives (Schafer, Smulakka, & Oelker, 2014). Listening to music activates emotion and reward-related brain networks, including the mesolimbic dopaminergic reward processing (Koelsch, 2010). As an intervention, music listening has been shown to reduce depression symptoms in older adults (Chan, Chan, Mok, & Tse, 2009) and enhance emotional and cognitive functioning in neurological conditions for stroke patients (Forsblom, Laitinen, Särkämö, & Tervaniemi, 2009). Emotional responses to music can also be accompanied by physiological changes (Salimpoor, Benovoy, Larcher, Dagher & Zatorre, 2011) impacting heart rate, respiratory rate and blood pressure (Standley, 1986).

Music can facilitate memory rehabilitation in people with acquired brain injury (ABI). Baird and Samson (2013) found that listening to music evokes autobiographical memories in patients with impaired verbal, visual memory or autobiographical memory impairment.
Specifically, they found that the type of music that evoked memories were familiar and 'liked' songs. The memories recalled were positive and vivid, and pertained to people or a period in the patient’s life. Similarly, for patients with Alzheimer's disease, listening to familiar music has been shown to increase autobiographical memory (El Haj, Postal & Allain, 2012). Exposure to a patient’s preferred music can reduce aggressive behaviours in patients with advanced dementia and limited communication abilities. Gerdner (1997) suggested that familiar music stimulates remote memories associated with positive feelings (love, happiness, hope, etc.) to soothe the listener, changing the focus of attention and overriding confusing or threatening stimuli in the environment (for an in-depth review of the Evidence-Based Guideline: Individualised Music for Elders with Dementia, see Gerdner, 2010).

**Active music making as an intervention to improve HRQoL**

In contrast to listening to music, ‘active music making’ (using sound-producing objects, musical instruments or the voice, Raglio & Gianelli, 2009) places additional demands on the nervous system, leading to a strong coupling of perception and action; processes that are mediated by sensory, motor, and multimodal integrative regions distributed throughout the brain (Wan, Rüber, Hohmann & Schlaug, 2010). Combining music with rhythmic interventions has been shown to improve gait parameters in PD (McIntosh, Brown, Rice, & Thaut, 1997; Thaut et al., 1996). Singing creates measurable physiological and psychological effects (Sanal & Gorsev, 2013). Singing requires a slower than normal respiration, and when coupled with a slower heart rate results in a biologically soothing effect that is beneficial for cardiovascular function and promotes relaxation and wellbeing (Vickhoff, 2013). Singing also improves lung function (Gale, Enright, Reagon, Lewis, & Deursen, 2012) and strengthens voice quality and volume, especially in neurological patients (Di Benedetto et al., 2009; Elefant, Baker, Lotan, Lagesen & Skeie, 2012; Evans, Canavan, Foy, Langford & Proctor, 2012; Fogg-Rogers et al., 2015; Tomaino, 2012), due to a shared
network in the brain that underlies both singing and speaking (Kleber et al., 2009; Ozdemir, Norton, & Schlaug, 2006). Furthermore, long-term singing has been found to be associated with brain plasticity in opera singers (Kleber, Veit, Birbaumer, Gruzelier, & Lotze, 2010) and in musicians (Gaser & Schlaug, 2003; Schlaug, 2001).

There are additional benefits derived from singing in unison (singing in a choir, or ‘group singing’). The regularity of song structures synchronises respiration and heart rates between singers (Müller & Lindenberger, 2011; Vickhoff, 2013). Choir singing has also been shown to improve immune functioning through the increased levels of secretory immunoglobulin A, and to reduce emotional stress as measured by a decrease in cortisol (Beck, Cesario, Yousefi, & Enamoto, 2000; Kreutz, Bongard, Rohrmann, Hodapp, & Grebe, 2004).

The therapeutic benefits of music and active music making have been formalised into the discipline of music therapy. Music therapy has been defined as the ‘research-based practice and profession in which music (both active and passive) is used to actively support people as they strive to improve their health, functioning and wellbeing’ (Australian Music Therapy Association, 2015). In music therapy, qualified music therapists use music to address the physical, emotional, cognitive, and social needs of individuals.

Music therapy has been found to improve motor symptoms and wellbeing in PD (Hanesi, 2001, 2006; Pacchetti et al. 2000). Nombela, Hughes, Owen and Grahn (2013) suggest that automatic engagement of motor areas of the brain (premotor, supplementary motor areas, basal ganglia and cerebellum - areas compromised to varying degrees in PD) during rhythm perception may be the mechanism underlying motor improvements related to music engagement in PD. Patients become entrained with the beat and rhythm, which helps to organise movement.
**Group singing as an intervention to improve HRQoL**

Group singing has evolved to provide an alternative intervention to the more formalised music therapy. Group singing is defined here as singing in a choir led by a choir maestro or music therapist (Vella-Burrows & Hancox, 2012; Talmage, Ludlam, Leao, Fogg-Rogers & Purdy, 2013). Group singing is a community-based activity that has been found to improve HRQoL (Judd & Pooley, 2013), elevate positive affect and create a sense of community (Dunbar, Kaskatis, MacDonald, & Barra, 2012). It can provide the opportunity for social connection and contribution through public performance (Bailey & Davidson, 2005). Social groups can be an important psychological resource, with the capacity to protect health and well-being (Jetten, Haslam, Haslam, & Dingle, 2014). Choirs specifically formed for health-related benefits are now becoming a reality in some populations (Clift & Hancox, 2010).

The effect of group singing on HRQoL has been examined in healthy, disadvantaged and patient populations, including chronic mental health, physical and intellectual disabilities, cancer, and neurological conditions. In healthy populations, group singing (often referred to as choral singing) has been shown to relate to sustained psychological wellbeing (Clift & Hancox, 2010). In their qualitative study, Davidson et al. (2014) found that community-based singing programs impacted positively on the wellbeing of older Australian adults. Using interpretative phenomenological analysis (IPA) they identified three criteria for the success and viability of the singing program: recruitment, transport and funding.

The group singing experience has been found to exert a counteractive influence on factors that are potentially detrimental to wellbeing (Clift et al., 2010). Clift et al. conducted a large cross-national mixed-methods study (principal components analysis and thematic analysis) of older adult choral singers (N = 633, mean age 61 years). They identified six themes to explain the generative mechanisms linking choral singing with wellbeing and
health: (1) engenders happiness and raises spirits to counteract feelings of sadness and depression; (2) involves focused concentration, which blocks preoccupation with sources of worry; (3) involves deep controlled breathing which counteracts anxiety; (4) offers a sense of social support and friendship, which ameliorates feelings of isolation and loneliness; (5) involves education and learning, which keeps the mind active and counteracts decline of cognitive functions; and (6) involves a regular commitment to attend rehearsal, which motivates people to avoid being physically inactive.

Von Lob, Camic and Clift (2010) found that group singing can strengthen coping responses to adverse life events. In their qualitative study (n = 16) using grounded theory, they divided the multiple psychosocial benefits of group singing into two intrapersonal mechanisms (collective experience and building relationships) and four interpersonal mechanisms (competence, purposefulness, managing emotions and wellbeing, and creating a meaningful life). Von Lob et al. (2010) conclude that participants draw on these various mechanisms (environmental, social, cognitive and emotional processes) during stressful times.

Group singing has been used with disadvantaged sectors of society to build resilience and improve mental health outcomes. Dingle, Brander, Ballantyne and Baker (2013) investigated the experience of participation in group singing for adults with mental illness and social disadvantage. Using a longitudinal design and a qualitative analysis (IPA), Dingle et al. (2013) concluded that participants form a new and valued group identity (as a choir member) that is associated with three major benefits: personal impact, social impact and broader functional outcomes occurring over time. At the initial interview, conducted during the early days of the choir, participants experienced emotional and psychological benefits. At six months, social connections and networks had developed, leading to functional outcomes
of employment, improved health, routine and structure when assessed at the 12 month follow-up.

Sun and Buys (2015) conducted a longitudinal study involving a group singing intervention for Australian Aboriginal and Torres Strait Islander participants. Their results showed a reduction in depression (at the 18 month follow-up) that was mediated by increased resilience, social connectedness and social support. The authors also reported a significant increase in the frequency of visits to preventative health services and a significant decrease in frequency of presentation to acute health services during this timeframe.

People with chronic physical, intellectual or mental health conditions can benefit from group singing, due to this activity providing a form of psychosocial rehabilitation (Tavormina, Tavormina, & Nemoianni, 2014). The Italian singing group “Sing the You Go”, established in 2008 (described in Tavormina et al., 2014), is now an ongoing, long-term intervention for patients suffering from chronic mental illness (mood disorders with depression, bipolar disorders, neurotic depression, paranoid schizophrenia, and premenstrual dysphoric disorder), their family and their carers. Positive outcomes included enhanced mood, improved self-care and self-esteem, stronger emotion regulation, increased interests, reintegration into their family and social context, and socialisation overcoming the isolation of their mental illness.

Patients with cancer, and their carers, have both experienced positive outcomes after attending the ‘Sing for Life Choir’ for three months (Gale et al., 2012). This mixed-methods pilot study, incorporating IPA, found participants experienced improved vitality, social functioning, mental health and bodily pain. They also found a trend of reduced anxiety and depression, but no change in fatigue. Six themes were identified as contributing to participants’ improved QoL: friendship and support (for cancer sufferers); a common goal and focus for the future; improved mood, increased confidence and self-esteem; an
extraordinary choir (amateurs allowed, choir purpose is support focused not just singing); physical changes (improved breathing, posture and encourages physical activity); and challenges and future directions.

There is accumulating evidence that group singing can also provide cognitive, mood and social benefits for people with neurological conditions. Qualitative studies have described improved memory, mood, and social functioning such as enhanced relationships and feelings of social inclusiveness in dementia (e.g., Osman, Tischler & Schneider, 2014) and enhanced mood and cognition, especially memory, in Alzheimer’s disease (Simons-Stern, Budson & Ally, 2010).

Similarly, group singing for people who have suffered a stroke have been found to increase confidence and motivation, enhance mood, facilitate communication and social functions (Tamplin, Baker, Jones, Way, & Lee, 2013), mood functions (Särkämö et al., 2008; Tamplin et al. 2013) and cognition, especially memory (Särkämö et al., 2008). Language and speech benefits have been found for patients with stroke and non-fluent aphasia. Group singing has been shown to provide multiple physical and communication benefits: strengthened breathing and vocal ability, improved articulation and prosody of speech, and increased verbal and nonverbal communicative behaviours (Tomaino, 2012).

**Group singing and HRQoL for people with Parkinson’s disease**

Over the past 15 years seven studies have examined the effects of group singing in PD populations. A summary of the main design features and results of these studies is presented in Table 1. The main research focus for the majority (six) of these studies is physical symptomatology. Three studies reported physical benefits including improvements in bradykinesia (Pacchetti, Mancini, Aglieri, Martignoni & Nappi. 2000), facial masking (Elefant, Lotan, Baker & Skeie, 2012) and breathing (Fogg-Rogers et al., 2015). Four studies reported improvements in aspects of voice, including voice and speech parameters (Di
Benedetto et al. 2009), singing quality and voice range (Elefant, Baker, et al., 2012), laryngeal elements (Evans et al., 2012) and loudness, tone, prosody and voice confidence (Fogg-Rogers et al., 2015), while one study reported no changes in vocal or maximum loudness, pitch range or phonation (Shih et al., 2012).

There has been limited research into the psychological effects experienced by PD participants involved in group singing. Three studies reported improvement in aspects of HRQoL: emotional wellbeing (Pacchetti et al., 2000), communication abilities (Evans et al. 2012; Fogg-Rogers et al., 2015) and social engagement (Fogg-Rogers et al., 2015). Improved mood was found by Fogg-Rogers et al. (2015), however Elefant, Baker et al. (2012) found no changes in depressive symptoms during their intervention or at follow-up two months later. Fogg-Rogers et al. (2015) found higher HRQoL for their PD and stroke participants when compared to disability norms. The impact of group singing on cognitive functioning in a PD population has not yet been explored.

As shown in Table 1, there are a number of methodological differences between the studies with respect to the intervention employed, including frequency and duration of sessions and length of the intervention. The type of intervention also differed across studies. While the majority of studies employed group singing only, one study combined both group singing and playing musical instruments during each session, plus a music therapy control group (Pacchetti et al., 2000). Another study combined group singing with a non-musical intervention (Di Benedetto et al., 2009) by including speech therapy before the commencement of the group singing intervention. The difference in type of intervention across these studies makes interpretation and comparison of outcomes difficult. It is not always clear which activity underpinned the positive outcomes.
### Table 1.

**Summary of Previous Studies Reporting on the Benefits of Group Singing for Persons with Parkinson’s Disease.**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Participants</th>
<th>Design</th>
<th>Symptom</th>
<th>Choir sessions - Frequency</th>
<th>Intervention(s)</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pacchetti et al. (2000)</td>
<td>16 PD</td>
<td>Quantitative</td>
<td>Motor Symptoms</td>
<td>- Weekly 2 hours 12 weeks</td>
<td>Group singing Playing musical instruments (combined)</td>
<td>Improved bradykinesia Improved activities of daily living Improved QoL</td>
</tr>
<tr>
<td>Di Benedetto et al. (2009)</td>
<td>20 PD</td>
<td>Quantitative</td>
<td>Voice</td>
<td>- Weekly 2x1 hour 10 weeks</td>
<td>Speech therapy (propedeutic)</td>
<td>Improved speech and voice parameters: functional residual capacity, maximum inspiratory and expiratory pressures, maximum duration of sustained vowel phonation; and prosodia reading a passage</td>
</tr>
<tr>
<td>Evans et al. (2012)</td>
<td>8 PD</td>
<td>Quantitative</td>
<td>Voice QoL</td>
<td>- Fortnightly 2 hours 2 years</td>
<td>Group singing (lessons)</td>
<td>Improved speech Improved communication abilities Small improvement in QoL</td>
</tr>
<tr>
<td>Elefant, Baker, et al. (2012)</td>
<td>10 PD</td>
<td>Quantitative</td>
<td>Voice Mood</td>
<td>- Weekly 1 hour 20 weeks</td>
<td>Group singing</td>
<td>Improved singing quality Improved voice range No change in depression symptoms</td>
</tr>
<tr>
<td>Elefant, Lotan et al. (2012)</td>
<td>10 PD a</td>
<td>Quantitative</td>
<td>Facial masking</td>
<td>- Weekly 1 hour 20 weeks</td>
<td>Music therapy</td>
<td>Improved facial expression</td>
</tr>
<tr>
<td>Shih et al. (2012)</td>
<td>13 PD</td>
<td>Quantitative</td>
<td>Voice Voice related QoL</td>
<td>- Weekly 1.5 hours 12 weeks</td>
<td>Choral singing</td>
<td>No changes in vocal loudness, pitch range, phonation time or maximum loudness No change in voice related QoL</td>
</tr>
<tr>
<td>Fogg-Rogers et al. (2015)</td>
<td>8 PD 8 stroke 7 significant others n=23</td>
<td>Qualitative evaluation (detailed interview)</td>
<td>Mood Psychosocial Factors QoL</td>
<td>- Weekly 1.5 hours An established, and ongoing choir</td>
<td>Choral Singing Therapy b</td>
<td>Improved mood Improved language (stroke participants) Improved breathing &amp; voice parameters Improved social communication QoL scores were higher than published normative data for people with disabilities.</td>
</tr>
</tbody>
</table>

Note. PD = Parkinson's disease. QoL = Quality of Life

a Research conducted as two separate groups (n=5) to limit the physical size for effective videotaping purposes.

b See Talmage, Ludlam, Leao, Fogg-Rogers and Purdy (2013).
In their recent qualitative study, Fogg-Rogers et al. (2015) examined the factors influencing participation, and the experience of taking part, in a Choral Singing Therapy (see Talmage et al., 2011, for a detailed description of their intervention). The participants were a mixed neurological population (eight stroke and eight PD patients) as well as their ‘significant others’. Fogg-Rogers et al. (2015) found that participation in group singing provided social benefits, improved mood (especially for the PD participants), improved voice qualities (loudness, tone, prosody and confidence) and improved breathing. Whilst the authors separate their results by neurological condition, the themes generated were derived from a mixed neurological sample, making it difficult to form conclusions about the outcomes for PD patients.

In summary, the majority of studies examining the beneficial effects of group singing and PD have predominantly focused on speech and motor symptoms, using a quantitative methodology. This may reflect the model of care at the time of this research; management of MS and physical symptoms. Current rehabilitation programs in PD aim to elicit sustained functional changes to movement, reduced reliance on medication as well as improved HRQoL (Rochester, et al, 2010). The recent study by Fogg-Rogers et al. (2015), exploring aspects of HRQoL, is a reflection of the current best practice for PD management.

The current study

HRQoL is significantly impaired for those with PD (Karlsen et al., 2000; Simpson et al., 2014). There is no cure for PD, therefore the primary goal of treatment is to restore, or maintain HRQoL, while simultaneously managing both MS and NMS symptoms. This relatively new treatment focus has created a demand for accessible, cost effective interventions to improve life quality in PD.

There is evidence that other neurological populations have responded well to a group singing intervention (Osman et al., 2014; Simons-Stern et al., 2010). There is limited
research with respect to the PD population. There are six quantitative studies investigating the benefits of group singing on specific PD symptoms (Di Benedetto et al., 2009; Elefant, Baker, et al., 2012; Elefant, Lotan et al., 2012; Evans et al., 2012; Pacchetti et al., 2000; Shih et al., 2012) and one qualitative study examining the factors influencing group singing participation in a mixed neurological sample (Fogg-Rogers et al., 2015). There is anecdotal evidence suggesting group singing has physical and emotional benefits for people with PD (e.g. Magee, Temple, Grimes & Benson, n.d.) however these personal observations and case study reports lack systematic scientific evaluation and rigour.

**Research aim.** The aim of this study was to explore the effects of group singing for PD. IPA (Smith, 1996) was used to capture PD patients’ perceptions of HRQoL across a range of domains. Given the previous research findings in PD and other patient populations reviewed above, it was predicted that participants would report positive benefits of group singing in at least physical, mood, and cognitive functioning.

**Qualitative methodology.** The focus of this thesis is the qualitative exploration of the phenomenon of choir participation and the effect of group singing on HRQoL. “There are times we wish to know not how many or how well, but simply how” Shulman (1981, p.7). Smith and Osborn (2003) describe the participants as the “primary experts” and the researcher’s role, using minimal probes, is to identify meaning behind participants’ experiences in an attempt to answer broad research questions as opposed to specific generated hypotheses. Qualitative research is more exploratory than quantitative research. This methodology creates the opportunity to hear from participants; to capture the subjective experience of participating in an activity. Qualitative research allows for analytic inductive interpretation to identify common themes that can in turn direct future research.

Interpretive phenomenological analysis (IPA; Smith, 1996) is well established in the field of health psychology (Brocki & Wearden, 2006) and informed the design and data
collection for this study. IPA makes it possible to understand at the detailed level how participants make sense of their personal lived experience (Smith, 2004). IPA is a distinctive approach for conducting qualitative research; exploring participant’s experiences, understandings, perceptions and views. Through in-depth analysis of small sample sizes (ideally between 5 – 10 participants), the results can be discussed in relation to the broader extent of the current literature.

In accordance with IPA the interpretive aspect of this research will include a series of semi-structured interview questions exploring the immediate impact for participants after attending a single choir session, as well as the longer-term impact on both MS and NMS since joining the choir. The phenomenological aspect of this research will comprise the participants’ descriptions of their group singing experience.

A semi-structured interview, the Choir Participant Interview, comprising open ended questions designed to capture the group singing experience on physical, emotional and cognitive domains, as well as psychosocial functioning, was developed for this study (refer Appendix K). The semi-structured interview incorporates the principle of IPA; open-ended questions and minimal probes allowing the interviewees to be the ‘primary experts’. Interviews will be transcribed and interpreted according to IPA protocol to identify emerging themes and concepts.

Recommendations from the Consolidated Criteria for Reporting Qualitative Studies (COREQ; Tong, Sainsbury, & Craig, 2007) were incorporated to guide the research design, analysis, interpretation and presentation of findings. The COREQ is a 32-item checklist for interviews and focus groups comprising three domains: (1) research team and reflexivity, (2) study design and (3) data analysis and reporting. A copy of the self-completed COREQ for this study is included in Appendix L (see Booth et al., 2014, for a thorough explanation and application guidelines). As directed in the COREQ, a reflexive approach to data collection
was followed; the author, who conducted the participant interviews, acknowledged her family experience with PD and used self-reflective practice and supervision as required.

Incorporating the COREQ into research design is a relatively new concept to strengthen rhetorical power (Brocki & Wearden, 2006; Shaw, 2010) and provide additional methodological rigor. To date the COREQ has mainly been used by peer reviewers and editors to evaluate qualitative research submissions, and also by researchers preparing systematic reviews of the literature (Booth et al., 2014).

**Outline of thesis**

The remainder of this thesis comprises four main sections: Journal Article, Extended Discussion, Extended Methodology and Extended Results.

- The Journal Article contains a manuscript titled: *Group Singing and Health-Related Quality of Life in Parkinson’s Disease*, has been peer reviewed by the American Psychological Association Journal Health Psychology (No. HEA-2015-3592). The manuscript contains the background and aims of the methodology for this study, a summarised version of a section of the results, and a discussion of the benefits of group singing for people with PD. The recommendations from the peer review are reflected in this version of the manuscript.

- The Extended Discussion expands on the submitted manuscript and also includes detail relating to factors identified as impacting on the success of the choir that have not been included in the manuscript. The implications of all findings and the direction of future research are discussed.

- The Extended Methodology contains a more detailed version of the Methods section contained in the submitted manuscript (see Appendix M).
The Extended Results contains a more detailed version of the Results section contained in the submitted manuscript relating to sub-theme and theme generation, as well as two additional themes not presented in the submitted manuscript (refer Appendix N).
Group Singing and Health-Related Quality of Life in Parkinson’s Disease

Romane V Abell
University of Newcastle

Amee D Baird
Macquarie University

Kerry A Chalmers
University of Newcastle

Romane V Abell, School of Psychology, Faculty of Science & IT, University of Newcastle, Newcastle, Australia; Dr Amee D Baird, ARC Centre for Excellence in Cognition and its Disorders, Macquarie University, Sydney Australia; Dr Kerry A Chalmers, School of Psychology, Faculty of Science & IT, University of Newcastle, Newcastle, Australia.

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Correspondence concerning this article should be addressed to Dr Kerry Chalmers, School of Psychology, Faculty of Science & IT, University of Newcastle, University Drive, Callaghan, NSW, 2308, Australia.

Email: kerry.chalmers@newcastle.edu.au
Abstract

**Objective:** Parkinson’s disease (PD) has a negative impact on health-related quality of life (HRQoL). Previous studies have shown that participating in group singing activities can improve quality of life in some patient populations (e.g., people with chronic mental health or neurological conditions). The aim of this study was to investigate the effects of group singing on HRQoL for people diagnosed with PD.

**Methods:** Eleven participants (mean age 70.6 years) with a formal diagnosis of PD between Hoehn and Yahr Stages I – III were recruited from a community singing group for people with PD, their family and their carers. Participants’ perceptions of the effect of group singing on their quality of life were captured in a semi-structured interview. Interpretive Phenomenological Analysis (IPA), a qualitative methodology, informed data collection and analysis.

**Results:** The IPA analysis revealed six categories that characterised the effects of group singing: physical, mood, cognitive functioning, social connectedness, ‘flow-on’ effects, and sense-of-self. All participants reported positive effects across at least four of these categories. Three participants reported a negative effect in one category (physical, mood or sense-of-self).

**Conclusions:** Group singing improved HRQoL for all participants, regardless of PD stage or symptom severity. Weekly engagement in group singing resulted in multiple benefits for the participants and counteracted many of the negative effects of PD. These findings suggest that group singing ‘gives back’ some of what PD ‘takes away’.

**Keywords:** Parkinson’s disease, group singing, choir, health-related quality of life, quality of life
Group Singing and Health-Related Quality of Life in Parkinson’s Disease

People with Parkinson’s disease (PD) have reduced health-related quality of life (HRQoL; Karlsen, Tandberg, Årsland, & Larsen, 2000; Simpson, Lekwuwa, & Crawford, 2014). HRQoL is defined as ‘the patient’s own perception and self-evaluation regarding the effects of an illness and its consequences on her or his life’ (Martinez-Martin, 1998, p. S2) and is determined by a number of factors including physical, emotional, cognitive, sexual, social and role functioning (Fayers & Machin, 2013). Symptom severity increases with PD progression, with a concomitant decline in HRQoL (Karlsen et al., 2000; Simpson et al., 2014). People at a similar PD stage can often have different levels of perceived HRQoL (Gotham, Brown, & Marsden, 1986).

The non-motor symptoms of PD have been shown to have a greater impact on HRQoL than motor symptoms (Duncan et al., 2013; Matinez-Martin, Rodriguez-Blazquez, Kurtis, & Chaudhuri, 2011). Strong predictors of HRQoL include depressed mood and cognitive impairment (Martinez-Martin et al., 2011; Soh, Morris, & McGinley, 2011), anxiety, incomplete bowel emptying and insomnia (Duncan et al., 2013), fatigue (Larsen, Dupont, & Tandberg, 1994), freezing of gait (Perez-Lloret et al., 2014; Walton et al., 2014), apathy, lack of motivation, loss of purpose and diminished self worth (Martinez-Martin, Marinus, & van Hilten, 2009; Soundy, Stubbs, & Roskell, 2014) as well as reduced social functioning (Schrag, Jahanshahi, & Quinn, 2000).

Communication challenges develop with the progression of PD. Speech deficits occur in 60% - 80% of cases (Adams, Till, & Yorkston, 1994). These include a decrease in volume and quality (dysarthria) and an increase in speech rate. Slurring of words, mumbling, ‘breathy’ and hoarse quality, and monotone speech are also observed. Emotional communication is impacted, with changes in the perception and production of emotional prosody (Schroder, Nikolova, & Dengler, 2010). Facial masking (amimia) caused by a
reduction in facial muscle activity severely impacts the ability to convey emotions. Small and cramped handwriting (micrographia) can make written communication difficult to read. A decline in communication abilities may reduce the desire to socialise or to communicate one-to-one (Miller, Noble, Jones, & Burn, 2006), resulting to an overall decline in HRQoL (Rinn, 1984).

PD is idiopathic, with no known cure. Current best practice for the management of PD involves a multidisciplinary team (Lee, Shine, & Lewis, 2015) with the primary goals of assessment and interventions designed to manage motor symptoms and simultaneously restore, or maintain, quality of life (QoL, Fung, 2015).

**Group Singing as an Intervention to Improve HRQoL**

The effect of group singing on quality of life has been examined in both healthy and patient populations, including persons with chronic mental health, physical and intellectual disabilities, and neurological conditions. Group singing is defined here as singing in a choir led by a choir maestro or music therapist (Talmage, Ludlam, Leao, Fogg-Rogers, & Purdy, 2013; Vella-Burrows & Hancox, 2012). In healthy populations, group singing has been shown to impact positively on the wellbeing of older adults (Davidson et al., 2014). Clift et al. (2010) conducted a cross-national mixed-methods study of choral singers (633 older adults) and concluded that the group singing experience exerts a counteractive influence on factors potentially detrimental to health and wellbeing. In patient populations, group singing has been found to provide a form of psychosocial rehabilitation (Tavormina, Tavormina, & Nemoianni, 2014), allowing participants to form a new and valued group identity (as a choir member) that is associated with emotional and health benefits including improved self-perception, mood, emotional regulation, social functioning and employment capacity (Dingle, Brander, Ballantyne, & Baker, 2013).
There is accumulating evidence that group singing can provide cognitive, mood and social benefits for people with neurological conditions. Qualitative studies of persons with dementia have described improved memory, mood, and social functioning such as feelings of social inclusiveness (e.g., Osman, Tischler, & Schneider, 2014). Similarly, group singing for people who have sustained a stroke has been found to facilitate communication, social and mood functions (e.g., Tamplin, Baker, Jones, Way, & Lee, 2013). Specific benefits for stroke patients with non-fluent aphasia include strengthened breathing and vocal ability, improved articulation and prosody of speech, and increased verbal and nonverbal communicative behaviours (Tomaino, 2012).

**Group Singing and HRQoL for People with Parkinson’s Disease**

Over the past 15 years, seven studies have examined the effects of group singing in PD populations. A summary of the main design features and results of these studies is presented in Table 1. The main research focus for the majority (six) of these studies is physical symptomatology. Three studies reported physical benefits including improvements in bradykinesia (Pacchetti, Mancini, Aglieri, Martignoni, & Nappi, 2000), facial masking (Elefant, Lotan, Baker, & Skeie, 2012) and breathing (Fogg-Rogers et al., 2015). Four studies reported improvements in aspects of voice, including voice and speech parameters (Di Benedetto et al., 2009), singing quality and voice range (Elefant, Baker, Lotan, Lagesen, & Skeie, 2012), laryngeal elements (Evans, Canavan, Foy, Langford, & Proctor, 2012) and loudness, tone, prosody and voice confidence (Fogg-Rogers et al., 2015), while one reported no change in vocal loudness, maximum loudness, pitch range or phonation (Shih et al., 2012).
Table 1

Summary of Previous Studies Reporting on the Benefits of Group Singing for Persons with Parkinson’s Disease

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<td>Motor Symptoms</td>
<td>Weekly 2 hours 12 weeks</td>
<td>Group singing, Playing musical instruments (combined)</td>
<td>Improved bradykinesia, Improved activities of daily living, Improved QoL</td>
</tr>
<tr>
<td>Di Benedetto et al., (2009)</td>
<td>20 PD</td>
<td>Quantitative</td>
<td>Voice</td>
<td>Weekly 2x1 hour 10 weeks</td>
<td>Speech therapy (propedeutic)</td>
<td>Improved speech and voice parameters: functional residual capacity, maximum inspiratory and expiratory pressures, maximum duration of sustained vowel phonation; and prosodia reading a passage</td>
</tr>
<tr>
<td>Evans et al. (2012)</td>
<td>8 PD</td>
<td>Quantitative</td>
<td>Voice QoL</td>
<td>Fortnightly 2 hours 2 years</td>
<td>Group singing (lessons)</td>
<td>Improved speech, Improved communication abilities, Small improvement in QoL</td>
</tr>
<tr>
<td>Elefant, Baker, et al. (2012)</td>
<td>10 PD</td>
<td>Quantitative</td>
<td>Voice Mood</td>
<td>Weekly 1 hour 20 weeks</td>
<td>Group singing</td>
<td>Improved singing quality, Improved voice range, No change in depression symptoms</td>
</tr>
<tr>
<td>Elefant, Lotan et al. (2012)</td>
<td>10 PD</td>
<td>Quantitative</td>
<td>Facial masking</td>
<td>Weekly 1 hour 20 weeks</td>
<td>Music therapy</td>
<td>Improved facial expression</td>
</tr>
<tr>
<td>Shih et al. (2012)</td>
<td>13 PD</td>
<td>Quantitative</td>
<td>Voice Voice related QoL</td>
<td>Weekly 1.5 hours 12 weeks</td>
<td>Choral singing</td>
<td>No changes in vocal loudness, pitch range, phonation time or maximum loudness, No change in voice related QoL</td>
</tr>
<tr>
<td>Fogg-Rogers et al. (2015)</td>
<td>8 PD 8 stroke 7 significant others n=23</td>
<td>Qualitative evaluation (detailed interview)</td>
<td>Mood Psychosocial Factors QoL</td>
<td>Weekly 1.5 hours An established, and ongoing choir</td>
<td>Choral Singing Therapy</td>
<td>Improved mood, Improved language (stroke participants), Improved breathing &amp; voice parameters, Improved social communication, QoL scores were higher than published normative data for people with disabilities.</td>
</tr>
</tbody>
</table>

Note. PD: Parkinson’s disease; QoL: quality of life

* Research conducted as two separate groups (n=5) to limit the physical size for effective videotaping purposes.

* See Talmage, Ludlam, Leao, Fogg-Rogers and Purdy (2013).
There has been limited research into the psychological effects experienced by PD participants involved in group singing. Three studies reported improvements in aspects of HRQoL: emotional wellbeing (Pacchetti et al., 2000), communication abilities (Evans et al., 2012; Fogg-Rogers et al., 2015) and social engagement (Fogg-Rogers et al., 2015). Improved mood was found by Fogg-Rogers et al., however Elefant, Baker et al. (2012) found no changes in depressive symptoms during their intervention or at follow-up two months later. Fogg-Rogers et al. also found higher HRQoL for their PD and stroke participants when compared to quality of life disability norms. The impact of group singing on cognitive functioning in a PD population has not yet been explored.

As shown in Table 1, there are a number of methodological differences between the studies with respect to the intervention employed, including frequency and duration of sessions and length of the intervention. The type of intervention also differed across studies, with most employing group singing only, whereas others combined both group singing and playing musical instruments during each session (Pacchetti et al., 2000) or combined group singing with a non-musical intervention (e.g., Di Benedetto et al., 2009, applied a speech therapy intervention before the commencement of the group singing intervention). The difference in type of intervention across these studies makes interpretation and comparison of outcomes difficult. It is not always clear which activity underpinned the positive outcomes.

Fogg-Rogers et al. (2015) explored the experiences of, and factors influencing, participation in choral singing by people with PD or stroke. Although they separate their qualitative results by neurological condition, the themes generated in their analysis were derived from the combined PD and stroke sample, making it difficult to form conclusions about the outcomes for PD patients specifically.
Present Research

The aim of the present study was to explore the effects of group singing for PD. Interpretive Phenomenological Analysis (IPA; Smith, 1996) was used to better understand PD patients’ perceptions of HRQoL across a range of domains. Given the previous research findings in PD and other patient populations reviewed above, it was predicted that participants would report positive benefits of group singing in physical, mood, and cognitive functioning.

Method

Participants and Recruitment

Eleven participants (mean age 70.6 years) with a formal diagnosis of PD were recruited from a community singing group (the ‘Shake, Rattle and Roll Choir’). All 12 choir members with PD initially volunteered to participate in the study, but one member withdrew due to illness. There were three inclusion criteria: a formal diagnosis of PD made by a neurologist; a score of 26 or above on the Standardised Mini-Mental State Examination (SMMSE); and nil to mild symptoms of depression and/or anxiety as measured by the Hospital Anxiety and Depression Scale (HADS). All participants had been choir members for a minimum of six months prior to participating in the study (average length 12 months). Written informed consent was obtained from all participants. Approval for the research was granted by both the University of Newcastle Human Research Ethics Committee and the Macquarie University Human Research Ethics Committee.

The Choir

The ‘Shake, Rattle and Roll Choir’ was established in 2013 in Newcastle, Australia as a dedicated choir for people with PD, their family and their carers. The choir is an á cappella group led by a qualified choir maestro who holds an Advanced Diploma in Theatre and Music. The position of choir maestro is funded by the Arts Health Institute Ltd., a not-for-
profit, social enterprise organisation whose purpose is to integrate the arts into health care. The choir meets weekly at a local community centre. The choir regularly participates in public performances, which may require up to two additional rehearsals per week. Solo parts, role playing and costumes are incorporated in these performances.

Choir members meet for afternoon tea prior to the choir session proper. Choir sessions commence with a warm-up (approximately 20 minutes) which consists of deep breathing, stretching, and vocal exercises led by the choir maestro. Singing takes place for the following 90 minutes. The choir maestro selects the musical repertoire in consultation with the choir members. Printed lyric sheets are distributed to members but participants are strongly encouraged to commit the song lyrics to memory, particularly for performances.

Measures

**Psychological screening.** The Standardised Mini-Mental State Examination (SMMSE, Molloy & Clarnette, 1999) was used to screen for cognitive impairment. Depression and anxiety symptoms were assessed using the Hospital Anxiety and Depression Scale (HADS), a self-report questionnaire (Zigmond & Snaith, 1983).

**PD symptom severity.** The HY staging scale was used to assess the severity of motor symptoms (Hoehn & Yahr, 1967). The HY comprises five Stages (level I through level V), ranging from mild to severe, and captures typical patterns of progressive motor impairment in PD based on the presenting motor symptoms and level of disability observed. Non-motor symptom burden was assessed by the Non-Motor Symptom Scale (NMSS), a PD specific validated self-report questionnaire (Chaudhuri & Martinez-Martin, 2008; Chaudhuri et al., 2007) comprising 30 items across nine domains. Each item is scored by multiplying the severity (on a scale of 0 to 3) by the frequency over the previous 30 days (on a scale of 1 to 4), and summing the scores. A measure of total burden, ranging from mild to very severe, is derived from the summed item scores (Chaudhuri et al., 2013).
Health-related quality of life. The Parkinson’s Disease Questionnaire-39 (PDQ-39; Jenkinson et al., 2012) was used to quantitatively assess HRQoL. The PDQ-39 is a validated self-report questionnaire consisting of 39 items covering eight dimensions: mobility; activities of daily living; emotional well-being; stigma; social support; cognition; communication; and bodily discomfort. Responses are made on a 5-point scale (0 = never; 1 = occasionally; 2 = sometimes; 3 = often; 4 = always). Scores on each dimension are converted to a percentage score (0 = no problem at all; 100 = maximum level of problem).

Choir participation interview. The semi-structured ‘Choir Participation Interview’ (see Table 2) was specifically designed for the present research. The interview consists of open-ended questions addressing the perceived effects of group singing on both the motor and non-motor symptoms of PD. During the interview, participants are referred to a rating scale (ranging from 1 = much worse, through to 20 = much better) to assist them in describing the magnitude of any perceived changes in body, voice, mood and thinking skills from attending a choir session. The semi-structured interview incorporates the principle of IPA; open-ended questions and minimal probes allowing the interviewees to be the ‘primary experts’. The phenomenological aspect of this study comprised the participants’ descriptions of their singing experience.
Table 2

Questions from the Semi-structured Choir Participation Interview

<table>
<thead>
<tr>
<th>Section</th>
<th>Question</th>
</tr>
</thead>
</table>
| Immediate impact of participating in a choir session | How does your [body, voice, mood, thinking skills] feel immediately after a choir practice session?  
  Can you indicate on the rating scale?  
  How long does this feeling last for? |
| Choir involvement                      | How did you find out about the choir?  
  What were your initial reasons for joining the choir?  
  What do you enjoy most about attending the choir?  
  How long have you been attending the choir?  
  How frequently do you attend the choir?  
  What brings you back to choir practice each week?  
  Has attending the choir been helpful in any ways?  If yes, in what ways?  
  Has participating in the choir had an impact on your overall wellbeing? |
| Ongoing impact of participating in choir sessions | Since joining the choir have you noticed any changes in your Parkinson’s Disease symptoms?  
  Since joining the choir have you noticed any changes to the following:  
  • mood  
  • self confidence  
  • sense of independence  
  • sense-of-control  
  • voice  
  • cognitive skills  
  • ability to concentrate |
| General                                | Would you recommend attending the choir to others?  
  How do you suggest others could find out about the choir?  
  Is there anything else that you would like to share about attending the choir? |

Procedure

Informed written consent and demographic information were obtained at an initial meeting at the participant’s home. The SMMSE, HADS and NMSS were administered in this session. The Choir Participation Interview took place approximately 4 months later, also in the participant’s home. Interview duration was typically 1.5 hours. All Choir Participation Interviews were conducted within a 10 day period, to minimise the potential for interviewees to share their experiences with fellow participants. For three participants, their spouse was
present during the interview and contributed comments regarding their own experience of choir participation as well as their perspective of the impact of the choir on their partner. The initial meeting (including administration of assessments) and the semi-structured interview were conducted by the same researcher (RA).

Responses to the Choir Participation Interview were audio-recorded (Sony digital voice recorder, ICD-UX533F) and hand transcribed verbatim into a Microsoft Word document. Participants were invited to comment on their transcript prior to analysis, as per the IPA protocol. Only minor changes were requested and transcripts were edited accordingly. Transcripts were read a minimum of five times to gain a thorough understanding of the data and hand coding commenced at this time. Transcripts were transferred into QSR International’s NVivo10 qualitative data analysis software (Richards, 2005) for electronic assistance in the following: language selection and frequency, further coding and the identification and collation of key themes. Themes were transformed into sub-categories and then merged into categories.

Post-analysis, an independent and confidential review of the transcripts (all identifiers removed) was conducted by another member of the research team (AB). No additional themes or categories were identified by this process. The rhetorical power of this study (Brocki & Wearden, 2006; Shaw, 2010) was enhanced through incorporating the recommendations of the Consolidated Criteria for Reporting Qualitative Studies (COREQ) into the research design (Booth et al., 2014; Tong, Sainsbury, & Craig, 2007).

Results

Demographic Information

All participants (n=11, three females) were retired (three medically retired due to PD) and six regularly engaged in volunteer work. Five participants held university degrees: PhD (2), Masters (1), undergraduate (2). The majority (8) had held professional positions.
Eight participants joined the choir at its inception, 18 months prior to the conduct of this study. The remainder joined the choir between 6 and 12 months prior to this study. Excluding the participant who was instrumental in forming the choir, participants learned of the choir through a PD support group (7), word of mouth (2) or from an advertising poster (1). Six participants had joined the choir of their own volition; the other five had joined on the recommendation of their spouse or children. Three spouses disclosed their self-interest in joining the choir, seeking social contact and support.

All participants were living at home: seven with their spouse and four alone (two were divorced and two were widowers). Seven of the participants managed daily living independently while the remainder relied on their spouse for assistance with transportation, household organisation, medication regimes and personal management. Six participants had voluntarily surrendered their drivers’ licence after their PD diagnosis.

**Parkinson’s Disease Symptom Duration and Severity**

The average age at PD diagnosis was 64.3 years, slightly higher than the Australian average of 60 years (Deloitte Access Economics, 2011). The average time since diagnosis was 6.3 years. All but one participant reported a prodromal phase; the presence of non-motor symptoms prior to the emergence of motor symptoms and a formal diagnosis (Berg et al., 2014), which ranged from 2 to 28 years across this sample.

Participants presented with mild to moderate severity and disability of motor symptoms (HY levels I to III), moderate to very severe levels of non-motor symptom burden (as assessed by the NMSS) and low to significantly impacted HRQoL (PDQ-39 scores ranged from 6.93 to 43.59). A summary of each participant’s symptom severity matched with responses from the Choir Participation Interview is presented in Table 3.
Impact of Participating in Group Singing

Participants’ perceived changes in their body, voice, mood and thinking skills from attending a choir session were assessed using the semi-structured ‘Choir Participation Interview’ and associated rating scale.

**Ratings scale.** The reported intensity of change in each domain ranged from ‘much better’ to ‘worse’ across participants. The duration of positive change lasted from the length of the choir session up to 2-3 days. These results are presented in Table 3.
Table 3


<table>
<thead>
<tr>
<th>Participant</th>
<th>HY</th>
<th>PDQ-39</th>
<th>NMSS</th>
<th>Change</th>
<th>Duration</th>
<th>Change</th>
<th>Duration</th>
<th>Change</th>
<th>Duration</th>
<th>Change</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>1</td>
<td>7.55</td>
<td>Very Severe</td>
<td>Same</td>
<td>N/A</td>
<td>Better</td>
<td>Half Day</td>
<td>Better</td>
<td>Half Day</td>
<td>Same</td>
<td>N/A</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>22.08</td>
<td>Severe</td>
<td>Much Better</td>
<td>2-3 days</td>
<td>Much Better</td>
<td>Half Day</td>
<td>Much Better</td>
<td>1 Day</td>
<td>Much Better</td>
<td>2-3 Days</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>22.66</td>
<td>Severe</td>
<td>2-3 Days</td>
<td>Better</td>
<td>Half Day</td>
<td>Same</td>
<td>N/A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>22.97</td>
<td>Severe</td>
<td>Much Better</td>
<td>Half Day</td>
<td>Much Better</td>
<td>Half Day</td>
<td>Same</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>9.64</td>
<td>Moderate</td>
<td>Better</td>
<td>0</td>
<td>Better</td>
<td>Half Day</td>
<td>Worse</td>
<td>Half Day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>28.65</td>
<td>Severe</td>
<td>Same</td>
<td>N/A</td>
<td>Same</td>
<td>N/A</td>
<td>Worse</td>
<td>0</td>
<td>Same</td>
<td>N/A</td>
</tr>
<tr>
<td>10</td>
<td>1</td>
<td>12.40</td>
<td>Moderate</td>
<td>Worse</td>
<td>Half Day</td>
<td>Worse</td>
<td>Half Day</td>
<td>Better</td>
<td>1 Day</td>
<td>Same</td>
<td>N/A</td>
</tr>
<tr>
<td>11</td>
<td>3</td>
<td>6.93</td>
<td>Moderate</td>
<td>Same</td>
<td>N/A</td>
<td>Same</td>
<td>N/A</td>
<td>Much Better</td>
<td>Half Day</td>
<td>Much Better</td>
<td>Half Day</td>
</tr>
</tbody>
</table>

*Participant 4 appeared to not understand the question. No rating obtained.*

Note: N/A = Not Applicable; HY = Hoehn & Yahr Scale; PDQ-39 = Parkinson’s Disease Questionnaire -39; NMSS = Non Motor Skills Scale
**Interpretive Phenomenological Analysis.** A combined deductive and inductive approach to coding and theme generation was applied. A literature review directed the initial areas for exploration with additional themes emerging over successive interviews. Data saturation occurred after the ninth interview. All participants reported an improvement in overall wellbeing since commencing group singing and further, all participants stated that they would recommend group singing to others with PD. Participants’ reported experiences of the benefits of group singing were coded into six categories: physical, mood, cognitive functioning, social connectedness, flow-on effects and sense-of-self. A description of each category, along with an example provided from participants’ transcripts, is presented below.

**Category 1: physical.** Engagement in group singing has a strong physical component. Improvement in voice quality was reported by the majority (nine) of participants. Participant descriptions included: “sharper”, “you can speak clearly”, “better clarity”, and “I feel I’m doing my vocal chords good and potential to have volume” (P3). One participant who lived alone rated their voice quality as worse due to ‘overuse’ at choir practice compared to seldom speaking at home.

The majority of participants (nine) did not report any changes in their motor symptoms as a result of ongoing choir participation, however, two participants reported significant improvements in their motor symptoms, including balance, gait and reduced falls. “The only thing I notice is that I’m less likely to fall over; I’m controlling my balance while I’m with the choir. I don’t know [why]. That’s more psychological I think . . . . I have had stumbles, but very few” (P11).

Group singing is an energising experience. Eight participants reported increased energy and motivation to engage in physical activities: “They get a buzz out of it. As I do. We get a buzz out of watching other people get a buzz. The buzz is we are doing something pleasurable, something that is constructive in the context of Parkinson’s” (P6).
**Category 2: mood.** Group singing is mood enhancing and helps to foster optimism. Ten participants reported enhanced mood: "Complete change of mood. Not that I had a bad mood before. Before I joined the choir I would sometimes think ‘why me?’ and since I have been in the choir those types of thoughts have completely vanished. Acceptance.” (P9). One participant reported a decline in mood after a singing session due to frustration with the session length lasting too long and becoming tired.

**Category 3: cognitive functioning.** Ongoing participation in group singing was identified by six participants as beneficial for their ‘thinking skills’ including memory and concentration: “They all go together – thinking, memory, and concentration. Because you are doing something where you have to make an effort. It is not just singing. . . . trying to remember the notes, or the ups and downs. . . . A mental workout” (P8). One participant reported feeling frustrated when choir attendance highlighted the deterioration in their cognitive functioning due to PD.

**Category 4: social connectedness.** All participants reported social benefits. The initiative to join the singing group was often socially motivated; to reduce loneliness and isolation. All participants described a sense of camaraderie that is highly valued and contributes to group cohesion. The acquisition of new friends and the role of friendship are both important and motivate attendance. The exclusive nature of the group, for people with PD, provides additional group cohesion and access to a rich and valued source of information about PD: “There is a big social aspect to it [the singing group]. . . . And more importantly good friends who are walking the same path with Parkinson’s” (P6).

**Category 5: flow-on effects.** This category is eclectic and includes external activities participants engage in as a consequence of choir membership. Participants engage in social activities including weekly bike rides, group dinners, film nights and an annual Christmas party. There is also a semi-regular social gathering that is exclusively for the spouses of the
PD choir members. The performance aspect of group singing (at PD support meetings, conferences and public events) provides goal-setting opportunities, additional challenges to master, as well as a sense of achievement upon completion: “I was all for the concept of a choir, of performance. I wasn’t sure of what it would produce necessarily, but I was pretty confident that it would be good, and it has proved to be” (P6). Three participants and their spouses reported increased activity in creative arts, including writing poetry, drawing and painting, and creating greetings cards.

**Category 6: sense-of-self.** All participants reported at least one psychological benefit that had significantly improved their sense-of-self since joining the choir. These benefits included increased self-confidence, independence, a sense of control over day-to-day activities, and a sense of control over PD. “I think if you do something you are taking control. You are accepting. It takes a while to accept that you have Parkinson’s” (P3). One participant reported a negative impact on their self-confidence as the experience highlighted a decline in their abilities.

**Discussion**

This study employed an IPA methodology to investigate the effect of group singing on HRQoL for people with PD. Six categories emerged to capture the positive effects experienced by participants: physical, mood, cognitive functioning, social connectedness, flow-on effects and enhanced ‘sense-of-self’.

The most common sub-categories reported by participants were related to social connectedness, with all participants reporting camaraderie and new friendships as important aspects of attending the choir. Other sub-categories identified by participants included improved voice quality, raised energy levels, enhanced mood, increased self-confidence and greater control over day-to-day activities.
The Benefits of Group Singing for Parkinson’s Disease

All participants in this study reported benefits across at least four of the six categories (physical, mood, cognitive functioning, social connection, flow-on effects and sense-of-self) from their participation in group singing. This finding is consistent with previous research showing that the presence of multiple non-motor symptoms of PD is a better predictor of low HRQoL when compared to motor symptoms (Duncan et al., 2013; Martinez-Martin et al., 2011). This finding is also consistent with previous research of positive impacts of group singing on the wellbeing of healthy older adults (e.g., Clift et al., 2010; Davidson et al., 2014) and quality of life in PD (Pacchetti et al., 2000; Evans et al., 2012). These findings were observed irrespective of motor symptom severity, level of non-motor symptom burden, and HRQoL as assessed by the PDQ-39, supporting the notion that improvement in HRQoL from participation choir singing is not necessarily dependent on PD stage (Gotham et al., 1986).

The physical benefits of group singing reported by participants in this study are consistent with previous findings in the PD literature. Two participants reported significant improvements in motor symptoms (walking, standing, balance, gait and reduced falls), which is similar to Pacchetti et al.’s (2000) finding of a reduction in bradykinesia. Improvements in voice quality were reported by the majority of participants, supporting previous findings reported by Di Benedetto et al. (2009), Elefant, Baker et al. (2012), and Fogg-Rogers et al. (2015). ‘Freer’ facial muscles was reported by only one participant, which differs from Elefant, Lotan et al.’s (2012) findings of reduced facial masking in all 10 of their participants over a 17 week period of weekly choir singing. These contrasting results warrant further exploration, especially given Rinn’s observation (1984) that facial masking impacts severely on communication abilities and heightens isolating behaviours.

Enhanced mood, sustained for up to three days, was reported by all but one participant. This outcome is similar to Fogg-Rogers et al.’s (2015) finding of improved mood
that was maintained post singing, although they did not specify the duration of this sustained effect. A sense-of-control over day-to-day activities was reported by most participants, which may be similar to Pacchetti et al. (2000)’s finding of improvement in the activities of daily living. With mood disturbance (Chaudhuri et al., 2009; Martinez-Martin et al., 2011; Soh et al., 2011; Soundy et al., 2014; Walton et al., 2014), apathy, lack of motivation, loss of purpose and diminished self-worth (Chaudhuri et al., 2009; Soundy et al., 2014) all strong predictors of HRQoL, it appears that group singing may hold significant benefits for people with PD.

Significant social benefits were reported by all participants, including new friendships, camaraderie, and a sense of community and companionship. This result is similar to Fogg-Rogers et al.’s (2015) finding of improved social engagement in their PD participants. This is an important finding given the reduced desire to socialise and communicate one-on-one (Miller et al., 2006) and the high incidence of isolating behaviours (Rinn, 1984) in this population. Together, these findings show the potential of group singing to increase social functioning, which is a strong predictor of HRQoL in PD patients (Schrag et al., 2000).

In the cognitive domain, five of the eleven participants reported improvements in ‘thinking skills’, especially memory and concentration. The duration of this improvement in cognitive function was reported to continue for up to two days. While previous research in other neurological populations (e.g., dementia) has found cognitive benefits for people who engage in group singing (Osman et al., 2014), the present study extends this finding to people with PD. With cognitive impairment a strong predictor of HRQoL in PD (Martinez-Martin et al 2011; Soh et al., 2011) more investigation is required.

The ‘Shake, Rattle and Roll’ choir is exclusively for people with PD, their family and carers. Participants reported finding acceptance, validation and emotional support within this
community, and rated highly the opportunity to share experiences and information relevant to fellow PD sufferers. This finding could be contrasted with Fogg-Rogers et al. (2015) who reported that their PD participants found a mixed-community group-setting helpful in enabling people with stroke or PD to help others with a condition different from themselves.

**A framework for exploring the effect of group singing on HRQoL.** The present findings suggest group singing enables participants to engage in a variety of experiences that may enhance HRQoL. These experiences include physical, emotional and cognitive activities as well as social interactions and external activities that flow from the established core of the choir. A framework for exploring the effect of group singing on HRQoL for people with PD is presented in Figure 1. The positive impact of group singing on HRQoL is represented by the solid arrows leading from group singing to each of the six categories emerging from the qualitative analysis (IPA). Improvements in any or all of these categories are assumed to enhance HRQoL, as depicted by the ‘dotted’ arrows pointing towards HRQoL.

![Figure 1. A framework for exploring the effect of group singing on health-related quality of life for people with Parkinson's disease.](image)

**Figure 1.** A framework for exploring the effect of group singing on health-related quality of life for people with Parkinson's disease.
Implications of Findings

**Group singing: a social intervention for PD.** People with PD are vulnerable to apathy, fatigue, mood disorders, stigma, and in turn, social isolation. Group singing enables people with PD to be ‘heard’ again. They are heard by their fellow choir members and the audiences to whom they perform, but most importantly they are heard because they are re-engaging in life. Our results suggest that the positive effects of group singing can counteract some of the negative effects of PD symptoms.

**Group singing: a complementary intervention.** Current best practice for treatment of PD includes both the assessment of, and interventions for improving HRQoL, to complement the traditional approach of motor symptoms management with medications (Chaudhuri & Martinez-Martin, 2008; Chaudhuri et al., 2007; Fung, 2015) and the more recent surgical procedures (Fung, 2015). The results of this study suggest that group singing could become an effective complementary intervention for improving factors that contribute to HRQoL (Fayers & Machin, 2013) in people with PD. Our study shows that group singing enables people with PD to experience reprieve from some disease symptoms, for up to 3 days. The framework conceived in this study could be further developed to create education material for General Practitioners and Allied Health Professionals managing people with PD.

**Negative effects of group singing.** Three participants reported negative experiences in one of three categories: (1) physical, an irritated throat due to overuse; (2) sense-of-self, reduced self-confidence due to a decline in singing ability; and (3) mood, due to frustration with the song type, fatigue from session duration, or the reminder of memory decline when unable to recall lyrics. These negative reactions appear to mirror the functional limitations of PD that prevent participants from engaging to their full desire based on past abilities and expectations.
Negative effects related to group singing have not been reported in previous PD studies. However, in a study of participants with mental health and social disadvantage attending group singing, Dingle et al. (2013) found negative emotional effects related to difficulties remembering song lyrics. The authors also found the organisation required to attend rehearsals, while managing symptoms, was stressful for participants. Together, these findings suggest that provision of information about possible negative effects and strategies for dealing with them could be provided to new choir members.

**Limitations of this Study**

It must be acknowledged that the participants in this study were self-selected. They had independently chosen to attend the PD choir, presumably in the expectation that they would benefit from the experience. Further, whilst the sample-size was ideal for qualitative analysis (between 5-10 participants), the small number of participants limits the ability for triangulation of methods.

This study was not designed to evaluate the effect of singing, independent of the group setting. Future research could compare and contrast the benefits of participation in PD group activities, for example ‘Dance PD’ (Jeffery, 2014) and ‘PD Warrior’ (McConaghy, 2014), with participation in a dedicated Parkinson’s singing group. Future research could also compare the benefits for people with PD attending a dedicated Parkinson’s singing group versus attending a singing group that is independent of disease focus.

**Conclusion**

This study examined group singing and HRQoL in a choir specifically established for people with PD, their family and their carers. All participants reported improved functioning in at least four of the six categories that emerged from the IPA of our Choir Participation Interview: physical, mood, cognitive functioning, social connectedness, flow-on effects and sense-of-self, suggesting group singing may help to enhance HRQoL for people with PD.
References


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Extended Discussion

This study employed an IPA methodology to investigate the effect of group singing on HRQoL for people with PD in an established choir. Six themes emerged to describe the domains of effect experienced by participants when they engage in group singing, namely, physical, mood, cognitive functioning, social connectedness, flow-on effects and sense-of-self. The duration of positive effects across the domains of physical (body and voice), mood and cognition after attending a choir session was also captured. Each domain will be discussed separately in relation to the literature for group singing in PD, and in other populations. A framework is proposed to explore the effect of group singing on HRQoL in PD. Negative effects of group singing were also reported and the impact on participation is considered.

Three factors important to the success of the choir also emerged from the analysis of participant interviews and through additional feedback from the participants’ spouses. The role of the choir maestro and the dual function of the choir to perform as a support group for carers, were additional themes to surface before data saturation was achieved. The PD-specific nature of the choir was a strong subtheme emerging for both participants and spouses. Suggestions for the ongoing development of the choir are considered.

The opportunity for group singing to be formally recognised, and promoted, as a complementary intervention for improving HRQoL in PD is explored within the implications of findings. Finally, a critique of this qualitative study, with respect to strengths and limitations, is provided along with recommendations for the direction of future research.

The Benefits of Group Singing for People with Parkinson's Disease

All participants in this study reported benefits across at least four of the six themes (physical, mood, cognitive functioning, social connection, flow-on effects and sense-of-self) from their participation in group singing. This finding is consistent with previous research of
positive impacts of group singing on the wellbeing of healthy older adults (e.g. Clift et al., 2010; Davidson et al., 2014) and aspects of HRQoL in PD (Pacchetti et al., 2000; Evans et al., 2012).

The most common sub-themes reported by participants were related to social connectedness, with all participants reporting camaraderie and new friendships as important aspects of attending the choir. Other sub-themes, identified by the majority of participants, included improved voice quality, raised energy levels, enhanced mood, increased self confidence, greater control over day-to-day activities and PD exclusivity (see Appendix N, Table N1. for a summary of themes and subthemes).

**Physical benefits.** The current study is the first study to report the duration of physical benefits from group singing in PD. The majority of participants reported feeling ‘better’ (including positive feelings such as energised or uplifted) in their body after attending a choir session, with five participants enjoying this benefit for the remainder of the day and up to three days for one participant. Two participants reported improvements in their MS (walking, standing, balance, gait and reduced falls), which is similar to Pacchetti et al.’s (2000) finding of a reduction in bradykinesia for their PD participants. Improvements in voice quality were reported by the majority of participants, supporting previous findings in a PD population reported by Di Benedetto et al. (2009), Elefant, Baker et al. (2012), and Fogg-Rogers et al. (2015). Participants reported the duration of improvements to their voice to last for the remainder of the day (three participants) up until three days (two participants). ‘Freer’ facial muscles was reported by only one participant, which differs from Elefant, Lotan et al.’s (2012) findings of reduced facial masking in all 10 of their participants over a 17 week period of weekly choir singing.

Other qualitative studies, in non PD populations, to identify the existence of physical benefits include: Judd and Pooley (2013) who reported elevated physical sensations, and
Tavormina et al. (2014) who reported stimulated energetic resources of the individual from group singing.

**Cognitive functioning.** Participants reported improvements in their ‘thinking skills’, especially memory and concentration. This enhancement to cognitive function was experienced for the remainder of the day (three participants), and up to two days for two participants. Improved cognitive functioning has been reported in other qualitative studies: Clift et al. (2010) who found that ‘choral singing involves education and learning, which keeps the mind active and counteracts decline of cognitive functions’ in their study with older adult choral singers (p.31), and Tavormina et al. (2014) who report improved concentration, memory and performance in mental activities in their study with participants suffering chronic mental health conditions. While previous research in neurological populations (e.g., dementia) has found cognitive benefits for people who engage in group singing (Osman et al., 2014), the present study extends this finding to people with PD.

**Mood.** Enhanced mood was reported by all but one participant. This experience lasted from the remainder of the day (six participants), for one day (two participants) and up to three days for two participants. This outcome is similar to Fogg-Rogers et al.’s (2015) finding of improved mood, in a mixed neurological sample that was maintained post singing, although they did not specify the duration of this sustained effect. Singing together elevates positive affect (Dunbar, Kaskatis, MacDonald & Barra, 2012) as was captured in participant reports of feeling optimistic and positive. One participant attributed their positive outlook to achieving acceptance of their PD diagnosis.

**Social connection.** The social benefits of camaraderie and new friendships were reported by all participants. The decision to join the choir was socially motivated to reduce loneliness and social isolation. Once engaged, the social aspect of the choir is highly valued and motivates attendance; a cohesive ingredient keeping the group in existence. One
participant referred to the act of singing as ‘secondary’ compared to the camaraderie they derived from attending the choir. New friendships were referred to as “caring”, “selfless”, “team mates”, and “walking the same path with Parkinson’s”.

When people sing together a sense of community is created (Dunbar et al. 2012). The theme of social connection identified in this current study is consistent with other qualitative studies across different populations: Fogg-Rogers et al. (2015) whose participants (PD and stroke) reported improved social engagement; Dingle et al (2014) who reported both connectedness within the choir, and improved social functioning, in their study with disadvantaged adults (mental health, and physical and cognitive disabilities); and within the general population Judd and Pooley (2013) identified ‘group dynamic’ to capture the strong bonds that connect choir members, and Brisola and Cury (2015) who reported a ‘promotion of integration’. Sun and Buys (2015), using quantitative measures, also found increases in sense of connectedness and social support among Australian Aboriginal and Torres Strait Islander people after engagement in a community choir for 18 months.

**Flow-on effects.** This is an eclectic theme and included social activities, performing and creativity. These are activities occurring as a consequence of participation. Social activities, both formalised and spontaneous, included bike riding group, tai chi attendance, movie nights, social meals together, annual Christmas celebration and a coffee group for spouses. The performance component of group singing has been linked to positive benefits (Bailey & Davidson, 2015). Participants rated highly the experience of performing citing goal setting, structure, additional challenges and a sense-of-achievement upon completion. Increased creativity, or trialling a new creative art (poetry, writing of song lyrics, drawing and painting), was reported by four participants. Increased artistic and expressive capacity was also reported by Tavormina et al. (2014).
The ‘flow-on effects’ reported here may be a reflection of the duration of attendance for participants and the strengthening of interpersonal relationships during that time. Dingle et al. (2013) in their longitudinal study reported themes of social impact and functional outcomes, identified at 6 and 12 months respectively. An additional theme, time, was also identified by Dingle et al. (2013) as the benefits they measured occurred once relationships developed and self-confidence increased. In the current study, participants had been attending the ‘Shake, Rattle and Roll’ choir for between 6 to 18 months.

**Sense-of-self.** Group singing provides many psychological benefits (Judd & Pooley, 2003) that help to re-establish a sense-of-self, often eroded by the symptoms of PD. The majority of participants reported improved self-esteem. A finding also reported by Tavormina et al. (2014) and von Lob et al. (2010). Increased sense-of-control over day-to-day activities was also reported, which is similar to the finding of improvement in the activities of-daily-living (Pacchetti et al. 2000). Participants in the present study reported an increased acceptance of their diagnosis; an experience similar for cancer patients (Gale et al., 2012). Finally, for the participants who acknowledged low levels of independence prior to joining the choir, they attributed the support network provided by the choir members, and the challenge of coordinating transport to attend choir, to their increased sense-of-control.

**A Framework for Exploring the Effect of Group Singing on HRQoL in Parkinson’s Disease**

**The impact of Parkinson’s disease on HRQoL.** Physically, PD can diminish a person’s world through reduced movements, stooped posture, shortened gait, freezing, micrographica, dysarthria and fatigue (Larsen, Dupont & Tandberg, 1994). Emotional communication is restricted through loss of facial expression (masking) and impaired emotional processing (Gray & Tickle-Degnen, 2010). Cognitive processing may slow, with many experiencing memory and concentration problems (Chiaravalloti et al., 2014; Lewis &
HRQoL is negatively impacted by mood disorders, apathy, lack of motivation, loss of purpose and diminished of self-worth (Soundy, Stubbs & Roskell, 2014). Social networks may shrink, through medical retirement, loss of friends who are discouraged by the presence of PD, and a reduction in the physical inability to participate in social activities. Physically, and metaphorically, Parkinson’s can take away a person’s voice so they are no longer heard.

**The impact of group singing on HRQoL.** This study has shown that engaging in group singing provides access to multiple positive experiences in several factors that contribute to HRQoL (Fayers & Machin, 2013). Physically, group singing can expand a person’s world through increased energy levels (the “buzz” as described by one participant), deeper breathing, improved posture, better balance, strengthen voice quality and volume, and enhanced facial expression (“free-er” facial muscles as described by one participant). The group singing experience is mood enhancing and can stimulate cognitive processing to improve memory and concentration. Emotional wellbeing is improved, motivation heightened, and a sense-of-purpose returns. Social connections are formed and a sense of community develops. Further opportunities for engagement flow from the choir. The challenge of performing in public provides further motivation and a sense of achievement (Bailey & Davidson, 2015). Participants become ‘heard’ again, not only by the audiences to whom they perform, but because these participants have a renewed purpose in life and they regain their sense-of-self.

A framework for exploring the effect of group singing on HRQoL for people with PD is presented in Figure 3. Group singing is a vehicle for participants to engage in a variety of experiences that can enhance HRQoL. These experiences include physical, emotional and cognitive activities as well as social interactions and external activities that flow from the established core of the choir.
The positive impact of group singing on HRQoL is represented by the solid arrows leading from group singing to each of the six themes emerging from the qualitative analysis (IPA). These themes reflect the range of outcomes, from physical through to psychological; factors comprising HRQoL (Fayers & Machin, 2013). Improvements in any or all of these themes are assumed to enhance HRQoL, as depicted by the ‘dotted’ arrows pointing towards HRQoL.

**Health-Related Quality of Life**

- Physical
- Mood
- Cognitive Functioning
- Social Connection
- Flow-on Effects
- Sense of Self

**Group Singing**

*Figure 3.* A framework for exploring the effect of group singing on health-related quality of life for people with Parkinson's disease.

**Group singing gives back what Parkinson’s disease takes away.** When our framework is compared with what we currently know about PD symptoms from the literature, it is evident that the positive effects of group singing on HRQoL can counteract some of the negative effects of PD on HRQoL. It could be proposed that group singing can help to give back some of what Parkinson’s takes away in terms of HRQoL. This concept of group singing’s ability to return what has been removed, to counteract what has become, or to replace what has been lost, is reported by studies in non-PD populations.
Clift et al. (2010) report the existence of six ‘generative’ mechanisms linking group singing with wellbeing. They interpreted the benefits of group singing as providing a “counteractive influence to factors detrimental to mental health” (p.29). For example, the happiness and raised spirits experienced from participating in group singing counteracted feelings of sadness and depression. Similarly, the focused concentration required from singing became a distraction from the preoccupation with sources of worry. Tavormina et al. (2014) report “the recovery of lost or compromised ability of patients with mental illness and they facilitate the reintegration of the user in his family and into his social context” (p.173) through the engagement in group singing. Their participants overcame social problems, recovered lost skills, enhanced their strengths, and overcame the social stigma of their disease.

**Additional benefits not measured in this study.** People with PD are vulnerable to apathy, fatigue, mood disorders, stigma and social isolation. It is important, therefore, not to overlook the physical, cognitive and psychological capacity that is needed in order to attend choir. These are simple activities for many, but critically important for people with PD. To arrive at a choir session all participants undergo necessary physical activities: movements to get ready (rise, shower, dress and personal grooming), depart home, and coordinate public transport or drive in traffic. Once arrived, each participant helps in setting out chairs, partakes in warm-up exercises, negotiates sitting and standing, and take turns in washing-up. Similarly, cognitive functioning is activated in numerous ways: in the planning and self-organisation, contributing to afternoon tea through baking, scheduling other activities to accommodate singing, practicing homework between sessions, learning new lyrics and musical themes. Psychologically, there is the requirement to manage and balance mood disorders, apathy and fatigue with the motivation and self-confidence required to attend singing, then engage and socialise with others.
Negative Effects of Group Singing in Parkinson’s Disease

Three participants reported negative experiences in one of three domains: (1) physical (an irritated throat due to overuse); (2) sense-of-self (reduced self-confidence due to a decline in singing ability) and (3) mood (due to frustration with the song type, fatigue from session duration, or the reminder of memory decline when unable to recall lyrics). These negative effects did not continue into the afternoon after the choir session. In addition, another participant reported that the stress of performing exacerbated her tremor. However, this experience was not identified by the participant as negative.

Negative effects related to group singing have not been reported in previous PD studies. However, in a study of participants with mental health and social disadvantage attending group singing, Dingle et al. (2013) found negative emotional effects related to difficulties remembering song lyrics. Dingle et al. (2013) also found the organisation required to attend rehearsals, while managing symptoms, was stressful for participants. This latter finding did not emerge in the current study. In contrast, one participant attributed the challenge of negotiating public transport as contributing to strengthened sense-of-control.

Since this research was conducted, two participants have left the choir. It is perhaps significant that they were two of the three participants who reported experiencing a negative effect from group singing, voice and mood, respectively. These collective findings suggest that provision of information about possible negative effects, and strategies for dealing with them, could be provided to participants and new members. Similarly, ongoing and follow-up communication to better understand the frequency and severity of negative effects, as well as reasons for leaving the choir, would assist in developing appropriate participant support.

Success Factors for a Parkinson’s Choir

Three factors were identified as contributing to the success of the choir. Two factors emerged as themes from the IPA: the choir maestro and a PD-carer support group. The third
factor, a PD-specific choir, emerged as a subtheme of two themes ‘social connectedness’ and ‘PD-carer support group’. These factors are presented in Figure 4, and a discussion of each factor follows.

As illustrated in Figure 4 concentric circles represent the interactive influence each factor has on the other factors, culminating in a successful choir. An example of this influence is the ability of the PD focus of the choir to bring together previously isolated spouses. Another example is the choir maestro’s expertise to cultivate a PD inclusive environment. Through her knowledge of PD, specific needs of participants can be addressed, for example, allowing sufficient breaks to counteract fatigue, or providing lyric sheets to avoid embarrassment from impaired memory.

![Figure 4. Success factors of a choir for people with Parkinson's disease](image)

**The choir maestro.** All participants credited the choir maestro for the energy, group cohesion and success of the choir. One participant stated ‘The choir is as good as it is because of her’. Specifically, personality, interpersonal skills, professionalism and technical competence were cited as important components of the choir maestro role. This is similar to Judd and Pooley (2013) who found that the Musical Director in their study affected the
overall tone of the choir via their personality, musical ability, teaching style and vision for the
group. The importance of the choir maestro (or similar singing leader role), along with the
competency, expertise and qualities of the incumbent, for the success of a PD choir has been
previously identified in guidelines for setting up a PD choir (Vella-Burrows & Hancox,
2012). A constraint in the establishment and continuation of a PD singing group is the
availability and remuneration of a choir maestro (Parkinson’s SA, personal communication,
March, 2015; Parkinson’s Queensland, personal communication, December, 2015).

PD-carer support group. An unanticipated benefit of the choir was the pseudo
support group for carers. The spouses who attend the choir are all involved, to various
degrees, in providing support and care for their partner with PD. The singing group provides
validation, companionship and social connection for these carers. Attending group singing
provides respite as well as the opportunity to enjoy a shared activity with their partner. It is
noted that at the time this research was conducted there was no support group for spouses,
carers or family members operating in the surrounding geographical area and this may have
contributed to this outcome. Some group singing studies have been conducted in choirs
whose membership includes the spouse, carer or significant other (e.g., Fogg-Rogers et al.,
2015; Gale et al., 2012, & Tavormina et al., 2014) however the effects of group singing for
this subset of participants are not reported separately.

PD-specific choir. The ‘Shake, Rattle and Roll’ choir was specifically established for
people with PD, carers and family members. Participants reported finding acceptance,
validation and the ability to normalise their circumstance within this exclusive PD
community. The choir provides a rich and valued source of information relevant to PD and
the sharing of personal experiences with fellow PD sufferers. Spouses rated the PD focus as
important; bringing together other spouses in the same circumstances to provide validation
and support.
This finding is similar to Gale et al. (2012) who found that the choral group in their study became a support mechanism for cancer patients, carers and supporters. In contrast however, Fogg-Rogers et al. (2015) whose study comprised a mixed neurological sample, reported that their PD participants found “the mixed community setting helpful” as it enabled people with stroke or PD to help others in the group with a condition different from themselves.

**Strengths and Limitations**

This study has a number of strengths. First, and most importantly, it is the only study to use a qualitative methodology to examine group singing and HRQoL in participants regularly attending a choir that was specifically established for people with PD, their carer and family members.

Second, this study is also the first to report on the cognitive benefits of group singing in a PD-specific choir. These results invite further investigation of the potential benefits of group singing on cognitive functioning in PD, a condition severely impacted by cognitive decline, especially executive dysfunction. Mild cognitive delay is present in approximately 25% of all PD cases and is difficult to diagnose (Aarsland et al., 2013). Group singing may provide a possible intervention.

Third, this is the only study to report the duration of the effects across the domains of physical (body and voice), mood and cognition. The results showed that positive effects in each domain can last for hours, and up until three days, for some participants. This finding highlights the ongoing benefits of group singing in this population.

Fourth, the COREQ was used to strengthen the rigour of data collection and analysis. The exercise of self-evaluating the research design proved beneficial. Minor changes were made to the methodology to achieve a full score on the COREQ, resulting in a more robust
study. The COREQ is a helpful resource in the comparison of study design and assessing credibility and its use is further encouraged.

Fifth, this study presented both positive and negative effects of group singing. Acknowledgement of possible negative effects can help to better prepare, and support choir members through psychoeducation and follow-up activities. The group singing literature is silent with respect to negative experiences for PD participants, and has rarely been mentioned in studies in other populations (see Dingle et al., 2013, for an exception).

The study also has limitations. Participants were interviewed twice for this research; first to capture demographic and clinical information, and again for IPA. On each occasion participants were asked to nominate their best ‘functioning’ time of day. In addition, participants were interviewed in the comfort of their own home to minimise inconvenience and better manage fatigue. However, the possible effects of medication on participants’ performance were not formally documented. For example, the ‘wearing off’ period, when symptoms return or worsen due to the timing of medication regimes, can significantly impact on motivation and clarity of thought, and could impact on participant’s responses to interview questions and self-assessment questionnaires.

It is noted that few studies in the PD group singing literature make reference to medication effects (Gale et al., 2012, an exception). In the current study, two participants qualified their responses with references to medication interfering with interpreting the impact of choir sessions, namely, “Varies to the cycle of medication” and “It’s difficult in terms of medication”. A ‘motor diary’ is a management tool used for patients to record their medication administration concurrently with their symptom severity and frequency to assist accurate timing, dosage and overall medication management. A similar tool would help to better co-ordinate baseline assessments, plan intervention timing, and allow participants to alter medication regimes in advance for research interventions.
Another limitation included the choice of assessment tool to measure cognitive functioning. The Standardised Mini-Mental State Examination (SMMSE) was relied upon for the exclusion criteria of cognitive impairment. Although regularly cited in research studies, the MMSE has recently been deemed unsuitable for use in PD because it does not capture mild cognitive decline and fails to access executive function (Whitehead & Brown, 2015, cited in Chaudhuri, Tolosa, Schapira & Poewe, 2015). These authors recommend the use of a measure specifically designed for PD, inter alia, the PD-Cognitive Rating Scale (PD-CRS, Pagonabarraga et al., 2008).

**Implications of Findings**

**Benefits of group singing and symptom severity for Parkinson’s disease.** As discussed earlier, people at a similar PD stage can often have different levels of perceived HRQoL (Gotham et al., 1986). The benefits experienced from engaging in group singing were observed across all participants irrespective of MS severity and disability (HY levels I to III, mild to moderate), self-reported NMS burden (NMSB, moderate to very severe) and self-reported HRQoL (PDQ-39, zero to 34.2). When the results for the immediate impact of group singing, and the duration of positive effects are matched against HY level, PDQ-39 & NMSB scores for participants, it is clear that there is no distinct trend for outcomes (refer Appendix N, Table N2.

In particular, one participant described several positive benefits from group singing even though he presented with moderate MS severity and disability (HY level III) and moderate frequency and severity of NMS (NMSS = 51). Despite his many symptoms, this participant reported significant physical, psychological, emotional, cognitive and social benefits from group singing:

I can use the singing to make me feel better, and get rid of nausea. If I can get myself to sing, I can get myself launched for the day. Usually I feel a lot better, there is a
definite ‘up’ which lasts for the rest of the day, and we can go shopping. Sometimes flows to the next day. My memory actually gets better, and, “What the choir did was to reconnect me with the community, the society. I got very isolated”. These findings of beneficial effects of group singing, regardless of symptom severity or disability, indicate that this activity may also be effective for patients with more severe symptoms.

The current PD group singing literature reports findings for participants with mild to moderate symptom severity only (HY levels 1 to III); no studies have explored the benefits of group singing for people with severely disabling symptoms (HY levels IV and V). In addition, as symptom severity increases with PD progression, there is a concomitant decline in HRQoL (Karlsen et al., 2000; Simpson et al., 2014). There is an opportunity for a longitudinal mixed-methods investigation exploring the effects of group singing on HRQoL for people with severe and extremely severe MS symptoms.

**Promoting the benefits of group singing for Parkinson’s disease.** There is growing awareness of the physical and psychosocial advantages of attending group singing. Parkinson’s Australia, through its State and Territory affiliations, advocate for group singing as a complementary intervention to help manage NMS. The Parkinson’s NSW website (Parkinson’s NSW, 2015) cites the benefits of singing with others:

- Exercising your voice helps to minimise the common loss of power, breathing to sing improves your fitness and strengthens your lungs, socialising with your peers in a choir helps to ward off depression and getting out and about is good for you generally.

At present there are very few dedicated PD singing groups in Australia, compared to the approximate 70,000 people currently diagnosed with PD (Deloitte Access Economics, 2015).
Created with the assistance of Parkinson’s Australia, there are up to 15 singing groups specifically for people with PD, their carers and family members, across Australia. In 2013, Parkinson’s SA was forced to close its two singing groups due to funding issues and now it refers people with PD to attend one of four ‘Sing for Joy’ community choirs. These choirs target participants over 65 years; and a range of conditions, predominately geriatric and neurological disorders, including dementia and PD, are welcome. People residing outside capital cities are often referred to Sing Australia, a private company with 150 established singing groups around Australia (Parkinson’s SA, personal communication, 15 March 2015). Whilst not providing the benefits that a PD-specific provides as detailed in the current study, participants would still enjoy the other benefits of group singing.

In the general community, and in many parts of the health services community “there remains a lack of awareness…of the challenges and needs of people with Parkinson’s, their families and carers” (Deloitte Access Economics, 2011, p. iv). Australian GPs were identified as lacking in confidence in their ability to treat early PD (60.2%) and to manage the late stages of the disease (68.4%) (Peters et al., 2006). Knowledge deficits across GPs regarding the diagnosis and management of both MS and NMS have also been identified (Abbott, Naismith & Lewis, 2011). None of the participants in the current study were advised to engage in group singing by their health care professional. Instead, participants, their spouse or a family member, learnt about the choir’s existence through word of mouth from attending their local monthly ‘Parkinson’s Support Group’ (an educational group with guest speakers, organised by the state branch of Parkinson’s NSW) or from reading a poster advertisement.

The level of PD knowledge held by health care professionals was important to the participants in the current study. One participant recounted his experience:
Yes I would [recommend the choir] because I know that the Neurologist won’t. I had to explain to my GP what it [the Parkinson’s Support Group] was. He had never heard of it. He is only half a km away from the hall we meet in and he had never heard of it apparently. The Neurologists are the same. My Neurologist has never mentioned anything to me about a support group. He is in [the same suburb] as well. It’s a bit of a lost cause. It’s almost as if it is second rate information that they don’t want to be involved in.

This is in contrast to Lee, Shine and Lewis’s (2014) survey into patient preferences for interventions in PD where patients ranked *better General Practitioner education* as least important from a selection of five options including increased research funding and more PD nurse resources.

Further promotion of the benefits of group singing is required. Psycho-education regarding group singing as a social intervention for PD could be made available to medical and allied health professionals and subsequently be incorporated in to a holistic treatment program. Parkinson’s Australia could take a national position on disseminating information and use their nation-wide networks to share empirical evidence detailing the benefits of group singing. An example is their program titled Caring for people with Parkinson’s, designed to educate and inform staff working in residential aged care facilities to improve the quality of care for people with PD (Parkinson’s SA, 2015).

Professional development, for health care professionals, is another channel for promoting the benefits of group singing. The Australian College of Rural & Remote Medicine (2015) offers an online module titled General Practitioners Guide to Parkinson's Disease, in its Rural Remote Medicine Education Online program. This is available to all health care professionals and is sponsored by Parkinson's Australia and the Australian College of Rural Remote Medicine. This module could be updated with current empirical
evidence for group singing and PD. Similarly, the professional associations such as Speech Therapy Australia, Occupational Therapy Australia, Australian Physiotherapy Association and the Australian Psychological Association, all provide professional development training for both their members and non-members. An e-learning PD awareness and intervention program could be developed and tailored for each profession. Finally, with the aging population and predicted increase in the prevalence of PD (Deloitte Access Economics, 2015), holistic management of PD, including complementary interventions, could now be included in undergraduate curriculums (not currently taught).

**Future Directions**

**Formalising group singing for Parkinson’s disease.** Group singing as an intervention for improving HRQoL in PD is still in its infancy. Direction for future development can be gleaned from other complementary social interventions for PD that have now been trialled, implemented and standardised over the past 10 years. Two of the more creative approaches are dancing (Dance for PD, Jeffery, 2014) and exercising at a gymnasium (PD Warrior, McConaghy, 2014). These interventions have been standardised, formalised into registered programs for quality assurance, and distributed internationally. Both interventions require the certification of trainers and teachers to administer the program, by registered providers.

Until such time that group singing is formalised, there is an immediate need for the consolidation and easy dissemination of information. An international consolidated repository of all group singing for PD activity would facilitate knowledge sharing and the development of future programs. The service could support multiple customers: researchers, consumers and health care professionals; a creative and informative space for all interested parties.
**Future Research**

The current study is the first to report on the cognitive benefits of group singing in a PD specific choir, and the duration of effects experienced across the domains of physical (body and voice), mood and cognitive functioning. These findings need to be further investigated with a longitudinal mixed-methods study. This would provide the opportunity to replicate these qualitative findings, as well as quantify the specific components of each domain that contribute to the benefits reported here.

Overall, more studies that are controlled, and with larger samples, are required to build the research base of the benefits (or otherwise) of group singing for PD. Sample size in the existing literature (including the current study) ranges from eight to 20 participants. Only one study to date has included a control group; a physical therapy intervention with minimal contact with other participants (Pacchetti et al. 2000). The important challenge for future research is to identify an appropriate control group; people with PD engaged in a group activity that is not singing-related, or no engagement in any group activity. To acquire sufficient participants within Australia, a multicentre strategy would be required. There are up to 15 specific PD choirs across Australia, with none in some states (Parkinson’s SA, personal communication, March 13, 2015). Where singing groups are operational, the take-up rate is relatively low, approximately 10 to 15 people with PD (excluding carers, family and friends). Alternatively, new choirs could be created however this would require addressing the resource issue of suitable choir maestros as discussed earlier. An advantage of new choirs would be the opportunity to measure outcomes from inception. Finally, another option for building participant numbers would be to link with overseas research.

There are no longitudinal studies in the qualitative group singing literature for PD. This disease is progressive and degenerative. As such, knowledge of the effects of group singing over time, for all ranges of symptom severity (HY levels I to V), could identify
important variables for treatment planning. Using a mixed-methods longitudinal design could highlight optimum duration of attendance and expected changes in HRQoL available for patients at different stages of disease progression.

The importance of group singing providing a pseudo support-group for carers of people with PD was also reported in the current study. There is limited research into the impact of PD on informal carers (Jenkinson, Fitzpatrick et al., 2012). An informal carer is usually a family member, a partner or a close friend, and sometimes a combination of these people provides support. Only one instrument exists to measure the QoL in the carers of people with PD, the PD Carer Questionnaire (PDQ-Carer, Jenkinson, Dummett et al., 2012). Incorporating this measure for carers in future research would be an effective way to build a research base on the effects of group singing on carers for people with PD.

Finally, it is acknowledged that other factors may be contributing to the success of the choir in addition to those reported here. Future research investigating the attributes of successful choirs, comparing and contrasting different populations would help to provide standardisation of procedures and the creation of best practice guidelines.

**Conclusion**

Current best practice for treatment of PD involves improving HRQoL to complement symptom management with medication (Chaudhuri & Martinez-Martin, 2008; Chaudhuri et al., 2007; Fung, 2015) and advanced therapies (Fung, 2015). Creative social group interventions are emerging to help address many of the negative effects of this disease. Singing groups for PD have evolved in the last 15 years (Vella-Burrows & Clift, 2012) however empirical evidence of their benefits is limited.

The results of this study provide support for group singing as effective in improving HRQoL for people with PD, regardless of symptom severity. Group singing is a social intervention offering potential ongoing benefits across physical, emotional, cognitive and
psychosocial domains. A sense of community fosters camaraderie and additional ‘flow-on’ effects become available to participants. The cumulative benefit from engaging in a choir of similarly diagnosed people is a re-engagement in life; a sense-of-self returns.

This study has significantly contributed to the limited research base of group singing for PD. It is the only study to use a qualitative methodology to examine group singing and HRQoL in participants regularly attending a choir specifically established for people with PD, their carers and family members. It is the only study to report on the cognitive benefits of group singing in a PD-specific choir, and the only study to report the duration of the effects across the domains of physical (body and voice), mood and cognitive functioning. Furthermore, this research has revealed both positive and negative effects of group singing, whereas previous studies have not reported on the latter in a PD specific choir.

In Australia there are up to 15 specialist PD singing groups to cater for approximately 70,000 people diagnosed with PD. Financial support is limited and awareness of the benefits for PD across the healthcare field, and within the general community, is low. Promotion is required to build the profile of group singing as a complementary intervention to improve HRQoL.

There is still no cure for PD. However, the results from this study suggest that the positive effects of group singing may counteract many of the negative effects of PD, suggesting that group singing has the ability to ‘give back’ what PD ‘takes away’.

*For everything that this disease has taken,*
*something with greater value has been given*
* - sometimes just a marker that points me in a new direction*
*that I might not otherwise have travelled (Fox, 2009)*

Michael J. Fox
Reference List (full)


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Appendices
Appendix A

University of Newcastle Human Research Ethics Committee Approval

HUMAN RESEARCH ETHICS COMMITTEE

Notification of Expedited Approval

To Chief Investigator or Project Supervisor: Doctor Kerry Chalmers
Co-investigators / Research Students: Dr Nicolas Bultot
Dr Aimee Baird
Professor Bill Thompson
Ms Maggie Hurnisch
Ms Romane Aheill

Re Protocol: Group singing in Parkinson’s Disease: immediate cognitive and emotional effects.

Date: 09-Sep-2014
Reference No: H-2014.0284
Date of Initial Approval: 06-Sep-2014

Thank you for your Initial Application submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under L2 Low Risk Research Expedited review by the HREC Panel.

I am pleased to advise that the decision on your submission is Approved effective 08 Sep. 2014.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. If the approval of an External HREC has been “noted” the approval period is as determined by the HREC.

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal Certificate of Approval will be available upon request. Your approval number is H-2014.0284.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants. You may then proceed with the research.

Conditions of Approval

This approval has been granted subject to you complying with the requirements for Monitoring of Progress, Reporting of Adverse Events, and Variations to the Approved Protocol as detailed below.

PLEASE NOTE:
In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University’s HREC.

- Monitoring of Progress
Appendix B

Macquarie University Human Research Ethics Committee Approval

23 July 2014

Dr Amee Baird
Centre for Cognition and its Disorders
Department of Cognitive Science
Faculty of Human Sciences
MACQUARIE UNIVERSITY NSW 2109

Dear Dr Baird

RE: Group singing in Parkinson's Disease: immediate cognitive and emotional effects

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Medical Sciences)) at its meeting on 24 April 2014 at which further information was requested to be reviewed by the HREC (Medical Sciences) Executive.

The requested information was received with correspondence on 4 July 2014.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted at:

- Macquarie University

This research meets the requirements set out in the National Statement on Ethical Conduct in Human Research (2007 – Updated March 2014) (the National Statement).

Details of this approval are as follows:

Reference No: 5201400414

Approval Date: 23 July 2014

The following documentation has been reviewed and approved by the HREC (Medical Sciences):

<table>
<thead>
<tr>
<th>Documents reviewed</th>
<th>Version no.</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Macquarie University Ethics Application Form</td>
<td>2.3</td>
<td>July 2013</td>
</tr>
<tr>
<td>Correspondence from Dr Amee Baird responding to</td>
<td>Received</td>
<td></td>
</tr>
<tr>
<td>the issues raised by the HREC (Medical Sciences)</td>
<td>4/07/2014</td>
<td></td>
</tr>
<tr>
<td>MQ Participant Information and Consent Form (PICF)</td>
<td>2</td>
<td>4/07/2014</td>
</tr>
<tr>
<td>entitled Group singing in Parkinson's Disease: Immediate</td>
<td></td>
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<tr>
<td>cognitive and emotional effects</td>
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<tr>
<td>Initial Interview</td>
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<tr>
<td>Choir Participant Interview</td>
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</tbody>
</table>
Song Questionnaire

**BMRQ** (Barcelona Music Reward Questionnaire)

Non-Motor Symptom assessment scale for Parkinson’s Disease

**PANAS** (Positive Affect Negative Affect Scale)

Summary of Protocol: 4 assessments including type of measures, duration and location

This letter constitutes ethical and scientific approval only.

**Standard Conditions of Approval:**

1. Continuing compliance with the requirements of the *National Statement*, which is available at the following website:


2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol must be submitted to the Committee for approval before implementation.

   It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

   Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Medical Sciences) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

The HREC (Medical Sciences) wishes you every success in your research.

Yours sincerely

Professor Tony Eyers  
Chair, Macquarie University Human Research Ethics Committee (Medical Sciences)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)* and the CPMP/ICH Note for Guidance on Good Clinical Practice.
Appendix C

Confirmation of manuscript peer review

From: Health Psychology <em@editorialmanager.com>
Date: 13 February 2016 at 10:30:12 AM AEST
To: Kerry Ann Chalmers <kerry.chalmers@newcastle.edu.au>
Subject: Your Submission
Reply-To: Health Psychology <health.psy.apa@gmail.com>

Ref.: Ms. No. HEA-2015-3592
Group Singing Gives Back What Parkinson's Disease Takes Away: A Qualitative Study
Health Psychology

Dear Dr Chalmers,

Thank you for submitting your manuscript for consideration for publication in Health Psychology. I have asked three experts in the area of your research to provide a critique of the paper. I have also read your paper myself. As you will see, there was considerable enthusiasm for your paper and appreciation for the importance, methodological rigor and presentation of the data. In sum, although the paper is not acceptable for publication in its present form, I hope that you will be willing to revise and resubmit the paper to us for further consideration.

The reviewers made many suggestions. I will not review each one of them but want to emphasize a few of them. First, they are recommending a title change. This theme quoted in your title did not seem to be substantiated in the manuscript. In addition, I advise against putting an explanatory element in a title at the beginning of a title as that may inhibit cataloging of your work. Second, in the body of manuscript, your results section actually seems very choppy to me. That is, you run through the rating made by the individual and then give a quote or two. I would remove the ratings from the body of the Results and put them in a table. They are distracting in the text. Then take the space in the manuscript to explain the theme or category (yours are really categories as themes are really statements). Please only use one quote per theme/category because quotes are only for illustration and are really raw data not technically findings. Conceptually you are not telling a coherent story - you said you are studying quality of life and your findings are arranged in categories reminiscent to quality of life, e.g. physical, but you do not draw it call it back to a component of quality of life in the findings. Then Figure 1 doesn't even mention quality of life nor the theme mentioned in your title. This is not an exhaustive list of suggestions - please see the critiques offered below!

Please be aware that a revise and resubmit decision does not imply eventual acceptance of the paper. I will again send the paper out for peer review. The new paper will be evaluated based on your responsiveness to the prior round of reviews, and also with respect to the extent to which the new paper makes a cohesive contribution to Health Psychology.

Your revision should also be accompanied by a detailed cover letter outlining the changes made in response to the reviews and those additionally in this letter. I look forward to seeing your revised paper.
For your guidance, reviewers' comments are appended below.

Your revision is due by 04/12/2016.

To submit a revision, go to http://hea.edmgr.com/ and log in as an Author. You will see a menu item call Submission Needing Revision. You will find your submission record there.

Sincerely,
Janet Alma Deatrick, Ph.D.
Associate Editor
Health Psychology
Appendix D

Health Psychology Journal - Scope

The following text is copied directly from the American Psychological Association (2015) website.

*Health Psychology* is a scholarly journal devoted to understanding the scientific relations among psychological factors, behavior and physical health and illness. The readership is broad with respect to discipline, background, interests, and specializations.

*Health Psychology* is the official scientific publication of APA's Division 38 (Society for Health Psychology).

The main emphasis of the journal is on original research, including integrative theoretical review papers, meta-analyses, treatment outcome trials, and brief scientific reports. Scholarly case studies, commentaries, and letters to the editor will also be considered.

Papers should have significant theoretical or practical importance for understanding relations among behaviour, psychosocial factors, and physical health, as well as their application. All papers should emphasize, whenever possible, the translation of scientific findings for practice and policy.

*Health Psychology* publishes original scholarly articles on topics such as:
- Contextual factors that may contribute to disease or its prevention
- Prevention
- Interfaces among biological, psychosocial, social and behavioral factors in health
- Assessment approaches in health
- Health risk and resilience behavior
- Health promotion
- Child and adolescent health
- Couple and family relationships in health
- Lifespan approaches to health, including those related to older adults
- Evaluation and dissemination of treatment approaches that target the individual, family, group, multicenter, or community level
- Ethnicity, social class, gender and sexual orientation in health
- Health disparities
- Research methodology, measurement, and statistics in health psychology
- Implications of research findings for health-related policy
- Advances in health-related theory
- Innovations in technology
- Professional issues in health psychology, including training and supervision
Appendix E

Health Psychology Journal – Guidelines for Authors

The following text is copied directly from the American Psychological Association (2015) website.

Manuscript Submission

Prior to submission, please carefully read and follow the submission guidelines detailed below. Manuscripts that do not conform to the submission guidelines may be returned without review.

Submission

The main emphasis of Health Psychology® is on original research in health psychology. Analytical reviews of research and brief scientific reports are also considered for publication. Submissions are welcomed from authors in psychology and other health-related disciplines.

Submit manuscripts electronically (.rtf, PDF, or .doc) to

Anne E. Kazak
Center for Healthcare Delivery Science
A.I. du Pont Hospital for Children
Administration and Research Building, Room 281
1600 Rockland Road
Wilmington, DE 19803

Keep a copy of the manuscript to guard against loss. Do not submit manuscripts via mail or email.

In recognition of the reality that institutional spam filters may capture files from the APA and the Journals Back Office, please take the following steps to facilitate communication with our editorial office:

• Provide an alternative email address which we can use to contact you in the event of technical difficulties with email communication using your primary address;

• Add "apa.org" to your list of "safe" addresses and consider asking your IT administrators to add it to their "white list;" and

• Contact Lindsay MacMurray if you do not receive confirmation of your submission within three business days or an editorial decision letter within three months.

General correspondence may be directed to the Editor's Office.
Information About Submissions

The page limit for research manuscripts is 25–30 pages. The page limit is inclusive of all parts of the manuscript, including the cover page, abstract, text, references, tables and figures.

Authors may request consideration of longer papers, in advance of submission, when there is clear justification for additional length (e.g., the paper reports on two or more studies or has an unusual or complex methodology).

Scholarly reviews and meta-analyses should not exceed 25 pages, but tables and references may be outside this page limit.

Brief reports are encouraged for innovative work that may be premature for publication as a full research report because of small sample size, novel methodologies, etc. Brief reports should be designated as such and should not exceed a total of 12 pages, inclusive of all parts of the manuscript, including the cover page, abstract, text, references, tables and figures.

All manuscripts should be double-spaced, with margins of at least 1 inch on all sides and a standard font (e.g., Times New Roman) of 12 points (no smaller).

On the submission portal you will be asked to provide contact information for three individuals who are qualified to serve as unbiased reviewers for your paper. These people must have published peer reviewed work in a relevant field. They must be without any real or perceived conflict of interest with you and your co-authors. They cannot be at the same institution as any author, cannot be a co-author on any publications, and must not be a former or current trainee, advisor or mentor, etc.

Health Psychology considers letters concerning previously published articles. Letters should be no more than 500 words and have a maximum of five references.

Authors also have the option of placing supplemental materials online.

Submissions that exceed the page limits will be returned to the author for shortening prior to the initiation of peer review.

Submission Letter

The cover letter should indicate that the authors have read and followed the Health Psychology Instructions for Authors. It should also include a statement indicating that the paper has been seen and approved by all authors. The cover letter should describe how the paper advances research in health psychology, referring to the journal mission to assure that the submission fits with the types of papers published in Health Psychology.

The full mailing address, telephone, fax, and email address for the corresponding author should be included in the cover letter and title page, along with the names and affiliations of all co-authors.

The cover letter must confirm that the manuscript has not been published, is not currently submitted elsewhere, and that it does not contain data that is currently submitted or published elsewhere.
When a manuscript contains data that is part of a larger study, authors should describe the larger study and provide references for other study papers. Authors must be prepared to provide copies of related manuscripts when requested as part of the editorial review process. Authors should clarify the relationship between their paper, including detailed specification of the overlap in participants, measures, and analysis, and others from the study. The value-added scientific contribution of their study must be clearly stated in the cover letter.

Authors of brief reports should indicate in the cover letter that the full report is not under consideration for publication elsewhere and similarly address potential overlap with other papers.

**Manuscripts**

The manuscript title should be accurate, fully explanatory, and no longer than 12 words. The title should reflect the content and population studied. If the paper reports a randomized clinical trial, this should be indicated in the title. The title of brief reports should start with the words "Brief Report".

The title page should include the names of all authors and their affiliations at the time the research was done. This information will be masked to ensure a blind peer review process by the editorial office. Authors should make sure that all other identifying information in the text of the paper is masked/removed prior to submission.

All manuscripts must include a structured abstract containing a maximum of 250 words with the following sections:
- Objective (brief statement of the purpose of the study);
- Methods (summary of the participants, design, measures, procedure);
- Results (primary findings); and
- Conclusions (specific statement of the implications of the data).

Please supply up to five keywords or brief phrases after the abstract. The Introduction should not exceed 3–4 pages in length. The paper should be referenced appropriately but excessive citations should be avoided.

All research involving human participants must describe oversight of the research process by the relevant Institutional Review Boards and should describe consent and assent procedures briefly in the Methods section.

All statistical tests should include effect size whenever possible.

First person language ("I", "we") should be avoided. Terminology should be sensitive to the individual who has a disease or disability. The journal endorses the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of people with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

It is important to highlight the significance and novel contribution of the work. The translation of research into practice must be evidenced in all manuscripts. Authors should incorporate a meaningful discussion of the clinical and/or policy implications of their work throughout the manuscript, rather than simply providing a separate section for this material.
Health Psychology publishes a broad array of types of papers. Authors of qualitative and measure development papers should read the guidelines for these types of papers, noted below.

Qualitative Research

Research papers that utilize qualitative methods should follow the general instructions to authors for style and format. We ask that authors of qualitative papers review the additional guidance below to assure that papers meet the following criteria utilized by Health Psychology.

The introduction should make a compelling case for the significance of the study and clearly identify if the study is a stand-alone study or if it fits into a larger study. For example, qualitative manuscripts may inform the development of a survey, use small-incident samples, or establish feasibility. The specific qualitative paradigm should be specified (e.g., grounded theory, qualitative descriptive approach, interpretive phenomenology) with a rationale as to why it was selected to address the research question.

At the same time, authors are encouraged to avoid methodological tutorials and cite appropriate references for the methodology. Describe your sampling frame clearly and how the sample was selected, justifying the type and size of your sample using appropriate language for qualitative studies.

While many qualitative studies may not use a conceptual model, if you have done so, explain how the model may have shaped the design, data collection, analysis and interpretation. Explain carefully how you strengthened and insured rigor in your study e.g., data analysis protocols (including how coders were trained), audit procedures, and demonstration of data saturation. Describe the data analysis and how it relates to your overall approach or paradigm. Present rich and compelling results with data that have been analyzed and interpreted appropriately for your method (e.g., discourse analytic results would be presented differently than those of a grounded theory).

The paper should convey how this research fills an important gap in the science and promises to change the way we approach future studies.

Scale Development

Empirical papers related to the development of new instruments related to health psychology should follow the general guidelines for style and format of this journal. Authors should make a convincing case for the need and rationale for the new instrument, particularly with respect to new and innovative constructs. Included in this rationale should be the theoretical foundation on which their new instrument rests along with presentation of other, related scales currently in use.

It is important that the research have a degree of generalizability across populations and settings. Instruments that are more narrow in scope or of limited clinical utility may be better suited for subspeciality journals.

Authors should clearly articulate the specifics of the study design and of the analytical techniques used. There should be strong consistency among the purpose statements, methods, and the manner in which findings are presented.
An increasing number of studies are incorporating mixed-methods designs in their research. The specifics of these designs should be equally well-detailed without being excessive. Attention should be given to the nature of the items, the basis for their creation, and the rationale for the response options.

The underlying theoretical structure of the approach should be evident, for example, whether one is premising their study on classical or modern theory (IRT, Rasch) techniques. The characteristics of the research will be in part dictated by the nature of the scale. For instance, large, nationally-normed tests may have a much different make-up than that of small, more narrowly-defined measures. Research involving both types of instruments will be considered.

Finally, all instrument development papers should convey how the literature base will be strengthened with the addition of the particular instrument along with a clear and convincing case for the clinical relevance of the information that it provides.

**Letters to the Editor**

*Health Psychology* will, at the discretion of the Editor-in-Chief, publish Letters to the Editor on the journal website.

Letters should be prepared in direct response to articles published in the journal, should include reference to the published paper in the letter, and should be sent to the Editorial Manuscript Coordinator, Lindsay MacMurray within 60 days of the date when the relevant article is published in hard copy.

The text of the letter, excluding the title, references and author(s) name, title, affiliation and email, may not exceed 400 words.

In a separate cover letter, the author should indicate that the submission is a Letter to the Editor for consideration of posting on the *Health Psychology* website and provide the full citation of the original article to which the letter refers. The cover letter should also indicate if the letter writer(s) have any conflicts of interest related to the article or correspondence.

Note: Letters will not be a forum for ongoing dialogue.

**Masked Review Policy**

Masked review is used. Do not include author information (addresses, phone numbers, electronic mail addresses, and fax numbers) in the manuscript.

Please ensure that the final version for production includes a byline and full author note for typesetting.

**Use of CONSORT Reporting Standards**

All randomized controlled trials must include a diagram indicating participant flow into the study and a completed CONSORT checklist. CONSORT diagrams (and adaptations) should be included whenever possible to clarify the flow of participants through a study.
Manuscript Preparation

Prepare manuscripts according to the Publication Manual of the American Psychological Association (6th edition). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the Publication Manual).

Review APA's Checklist for Manuscript Submission before submitting your article.

Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the Manual.

Below are additional instructions regarding the preparation of display equations, computer code, and tables.

Display Equations

We strongly encourage you to use MathType (third-party software) or Equation Editor 3.0 (built into pre-2007 versions of Word) to construct your equations, rather than the equation support that is built into Word 2007 and Word 2010. Equations composed with the built-in Word 2007/Word 2010 equation support are converted to low-resolution graphics when they enter the production process and must be rekeyed by the typesetter, which may introduce errors.

To construct your equations with MathType or Equation Editor 3.0:
- Go to the Text section of the Insert tab and select Object.
- Select MathType or Equation Editor 3.0 in the drop-down menu.

If you have an equation that has already been produced using Microsoft Word 2007 or 2010 and you have access to the full version of MathType 6.5 or later, you can convert this equation to MathType by clicking on MathType Insert Equation. Copy the equation from Microsoft Word and paste it into the MathType box. Verify that your equation is correct, click File, and then click Update. Your equation has now been inserted into your Word file as a MathType Equation.

Use Equation Editor 3.0 or MathType only for equations or for formulas that cannot be produced as Word text using the Times or Symbol font.

Computer Code

Because altering computer code in any way (e.g., indents, line spacing, line breaks, page breaks) during the typesetting process could alter its meaning, we treat computer code differently from the rest of your article in our production process. To that end, we request separate files for computer code.

In Online Supplemental Material

We request that runnable source code be included as supplemental material to the article. For more information, visit Supplementing Your Article With Online Material.

In the Text of the Article

If you would like to include code in the text of your published manuscript, please submit a separate file with your code exactly as you want it to appear, using Courier New font with a
type size of 8 points. We will make an image of each segment of code in your article that exceeds 40 characters in length. (Shorter snippets of code that appear in text will be typeset in Courier New and run in with the rest of the text.) If an appendix contains a mix of code and explanatory text, please submit a file that contains the entire appendix, with the code keyed in 8-point Courier New.

Tables

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

Submitting Supplemental Materials

APA can place supplemental materials online, available via the published article in the PsycARTICLES® database. Please see Supplementing Your Article With Online Material for more details.

References

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.

Examples of basic reference formats:

- **Journal Article:**

- **Authored Book:**

- **Chapter in an Edited Book:**

Figures

Graphics files are welcome if supplied as Tiff or EPS files. Multipanel figures (i.e., figures with parts labeled a, b, c, d, etc.) should be assembled into one file.

The minimum line weight for line art is 0.5 point for optimal printing.

For more information about acceptable resolutions, fonts, sizing, and other figure issues, please see the general guidelines.

When possible, please place symbol legends below the figure instead of to the side.
APA offers authors the option to publish their figures online in color without the costs associated with print publication of color figures.

The same caption will appear on both the online (color) and print (black and white) versions. To ensure that the figure can be understood in both formats, authors should add alternative wording (e.g., "the red (dark gray) bars represent") as needed.

For authors who prefer their figures to be published in color both in print and online, original color figures can be printed in color at the editor's and publisher's discretion provided the author agrees to pay:
- $900 for one figure
- An additional $600 for the second figure
- An additional $450 for each subsequent figure

Permissions

Authors of accepted papers must obtain and provide to the editor on final acceptance all necessary permissions to reproduce in print and electronic form any copyrighted work, including test materials (or portions thereof), photographs, and other graphic images (including those used as stimuli in experiments).

On advice of counsel, APA may decline to publish any image whose copyright status is unknown.

- Download Permissions Alert Form (PDF, 13KB)

Publication Policies

APA policy prohibits an author from submitting the same manuscript for concurrent consideration by two or more publications.

See also APA Journals® Internet Posting Guidelines.

APA requires authors to reveal any possible conflict of interest in the conduct and reporting of research (e.g., financial interests in a test or procedure, funding by pharmaceutical companies for drug research).

- Download Disclosure of Interests Form (PDF, 38KB)
  Authors of accepted manuscripts are required to transfer the copyright to APA.

- For manuscripts not funded by the Wellcome Trust or the Research Councils UK Publication Rights (Copyright Transfer) Form (PDF, 83KB)

- For manuscripts funded by the Wellcome Trust or the Research Councils UK Wellcome Trust or Research Councils UK Publication Rights Form (PDF, 34KB)

Ethical Principles

It is a violation of APA Ethical Principles to publish "as original data, data that have been previously published" (Standard 8.13).
In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 8.14).

APA expects authors to adhere to these standards. Specifically, APA expects authors to have their data available throughout the editorial review process and for at least 5 years after the date of publication.

Authors are required to state in writing that they have complied with APA ethical standards in the treatment of their sample, human or animal, or to describe the details of treatment.

- Download Certification of Compliance With APA Ethical Principles Form (PDF, 26KB)

Other Information

- Appeals Process for Manuscript Submissions
- Preparing Auxiliary Files for Production
- Document Deposit Procedures for APA Journals
Appendix F

Submitted Abstract: Parkinson’s Australia National Conference

IN THIS TOGETHER
NATIONAL CONFERENCE
ADELAIDE CONVENTION CENTRE
27 - 29th May 2015

ABSTRACT TITLE

The role of group singing in Parkinson’s Disease: a qualitative study of quality of life

Abell, Romane (Author – 1)
Chalmers, Dr Kenny (Author – 2)
Baird, Dr Amee (Author – 3)

Affiliations (1+2)
The University of Newcastle, University Drive, Callaghan NSW 2308

Key Contact Name: Ms Romane Abell
Full Mailing Address: 77 Whyte Street, Somerton Park, SA, 5044
Phone Number: 0402 165697
Key Contact Email Address: rvachcclc@gmail.com

Please indicate if your submission is relating to the following:
☐ Parkinson’s Research
☐ The Parkinson’s Nurse Role
☐ Multidisciplinary Care
☐ Genetics and Predisposition in Parkinson’s
☐ Advocacy
☒ Living Well with Parkinson’s
☒ Keeping Active
☐ Young Onset Parkinson’s
☐ The Caring Role (family or paid carer)
☒ The Non Motor Symptoms of Parkinson’s
☐ Other – provide detail

Please nominate your submission format:
☒ Presentation (25 minutes including 5 minutes for questions)
☐ Poster

Please indicate the Instructional Level of your presentation:
☐ Introductory: assumes audience has little or no knowledge on this topic
☒ Intermediate: assumes audience has general knowledge on this topic
☐ Advanced: assumes audience has significant knowledge on this topic
Abstract (250 words only):

**Aim**
This study investigated the role of group singing in perceived quality of life for people with Parkinson’s Disease, and to explore the impact that this activity may have on non-motor symptoms: physical, emotional and cognitive.

**Method**
Participants were 11 members of an established community singing group for people with Parkinson’s Disease, their family and carers, NSW, Australia. Semi-structured interviews were audio taped, hand transcribed verbatim and analysed using an interpretive phenomenological approach (IPA). Codes were merged into main themes and subsequently mapped onto the study’s aims.

**Results**
All participants reported improvements in emotional wellbeing. After attending a choir session 91% of participants reported feeling instantly better across at least one domain: body, voice, mood or cognitive functioning. These benefits were sustained for up to 7 days for some participants. Key emerging themes from participation in group singing include therapeutic benefits, attendance motivation, the meeting of unmet needs and key elements required for a successful PD singing group.

**Conclusion**
Multiple benefits are derived through weekly engagement in group singing with other PD participants. This experience appears to ‘give back’ what the disease of Parkinson’s ‘takes away’. The collective exchange occurring at each session fulfils unmet needs. This social intervention offers significant therapeutic benefits under the guise of a choir. Ongoing attendance motivation differs to initial motivation for joining the group. Implications for group singing as an ongoing, low cost, intervention to improve quality of life for people with Parkinson’s, their family and carers are discussed.
Appendix G

Confirmation of speaker: Parkinson’s Australia National Conference

Gmail - Parkinson’s Australia National Conference 2015 - New Speaker

Romane Abell <rvacbcdc@gmail.com>

Parkinson’s Australia National Conference 2015 - New Speaker

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Adelaide Convention Centre

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8 October 2014

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Psychologist
University of Newcastle
SOMERTON PARK, SOUTH AUSTRALIA, 5044, AUSTRALIA

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Appendix H

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Appendix J

Non-motor Symptoms of Parkinson’s disease

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<th>Neuropsychiatric symptoms:</th>
<th>Gastrointestinal symptoms (also overlap with autonomic)</th>
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<tr>
<td>Depression, Apathy, Anxiety, Panic attacks</td>
<td>Delayed gastric emptying, Aguesia</td>
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<tr>
<td>Anhedonia, Attention deficit</td>
<td>Dysphagia Choking, Reflux</td>
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<tr>
<td>Hallucinations, Illusions, Delusions (disease and/or drug-induced)</td>
<td>Vomiting/Nausea (usually drug-related)</td>
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<td>Dementia, Confusion or Delirium (disease and/or drug-induced)</td>
<td>Constipation / Anismus / Volvulus s/ Megacolon /</td>
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<td>Obsessional and Impulsive behavior (usually drug-induced)</td>
<td>Incomplete voiding of bowel/Faecal incontinence</td>
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<td>Repetitive behaviour (punding)</td>
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<th>Sensory symptoms</th>
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<td>'Restless legs', Periodic limb movements</td>
<td>Pain, Paraesthesia</td>
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<td>REM behaviour disorder</td>
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<td>Vivid dreaming</td>
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<td>Orthostatic hypotension: Coathanger pam</td>
<td>Blurred vision</td>
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<td>Sexual dysfunction: Hypersexuality, Erectile dysfunction, Lack of libido</td>
<td>Seborrhoea</td>
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<td>Dry eyes (xerophthalmia) or wet eyes (lachrymation)</td>
<td>Weight loss</td>
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<td>Dry mouth (xerostomia)</td>
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<td>Dribbling of saliva (sialorrhoea)</td>
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Appendix K

Choir Participant Interview

Participant number ____________________ Date: __________________

Instructions:

- You will be asked a series of questions about participating in the choir group.
- Your answers will be written down as well as recorded, are you comfortable with this?

Immediate impact of participating in the choir

How does your **body** feel IMMEDIATELY after a choir practice session?

(Heiberger et al, 2011)

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*If you answered ‘much better’ or ‘better’, how long does this improvement last for?.......minutes.....hours....days*

How does your **voice** feel IMMEDIATELY after a choir practice session?

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*If you answered ‘much better’ or ‘better’, how long does this improvement last for?.......minutes.....hours....days*

How does your **mood** feel IMMEDIATELY after a choir practice session?

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</tbody>
</table>

*If you answered ‘much better’ or ‘better’, how long does this improvement last for?.......minutes.....hours....days*

What are your **thinking skills** -(memory, concentration, etc) feel like IMMEDIATELY after a choir practice session?

<table>
<thead>
<tr>
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<th>16</th>
<th>17</th>
<th>18</th>
<th>19</th>
<th>20</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Much worse</td>
<td>worse</td>
<td>same</td>
<td>better</td>
<td>much better</td>
<td></td>
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</tbody>
</table>

*If you answered ‘much better’ or ‘better’, how long does this improvement last for?.......minutes.....hours....days*
Choir involvement
How did you find out about the choir?

.................................................................................................................................................................................................
.................................................................................................................................................................................................
What were your initial reasons for joining the choir?

.................................................................................................................................................................................................
.................................................................................................................................................................................................
What do you enjoy most about attending the choir?

.................................................................................................................................................................................................
.................................................................................................................................................................................................
How long have you been attending the choir?

.................................................................................................................................................................................................
.................................................................................................................................................................................................
How frequently do you attend the choir group?   weekly / fortnightly / monthly / other
What brings you back to choir practice each week? (Heiberger et al, 2011)

.................................................................................................................................................................................................
.................................................................................................................................................................................................
Has attending the choir been helpful in any ways?    Yes   No
How has the choir been helpful?

.................................................................................................................................................................................................
.................................................................................................................................................................................................
How helpful is participating in the choir to your overall wellbeing?

.................................................................................................................................................................................................
.................................................................................................................................................................................................
**Impact of choir on PD symptoms**

Since joining the choir have you noticed any change in your PD symptoms?

........................................................................................................................................................................

........................................................................................................................................................................

Since joining the choir have you noticed any changes to the following:

Mood / how you feel

........................................................................................................................................................................

........................................................................................................................................................................

Self confidence

........................................................................................................................................................................

........................................................................................................................................................................

Your sense of independence

........................................................................................................................................................................

........................................................................................................................................................................

Your sense of control

........................................................................................................................................................................

........................................................................................................................................................................

Voice  how loud you can speak (strength/quality)

........................................................................................................................................................................

........................................................................................................................................................................

Voice  the sound of your voice (volume)

........................................................................................................................................................................

........................................................................................................................................................................

Thinking skills
Your memory

Your ability to concentrate

General

Would you recommend attending the choir to others with PD..............Yes / No

Why? ...

How do you suggest other could be encouraged, helped to find out about the choir?

Is there anything else that you would like to share about attending the choir?

Do you have any recommendations or suggestions for the organisers of the choir?

Reference List
Appendix L

COREQ

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist for interviews and focus groups

<table>
<thead>
<tr>
<th>No.</th>
<th>Item</th>
<th>Guide Questions / Description</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Domain 1: Research Team and Reflexivity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Interviewer / facilitator</td>
<td>Which author/s conducted the interview or focus group?</td>
<td>Ms Romane Abell</td>
</tr>
<tr>
<td>2.</td>
<td>Credentials</td>
<td>What were the researcher’s credentials? e.g.</td>
<td>BA (Hons)</td>
</tr>
<tr>
<td>3.</td>
<td>Occupation</td>
<td>What was their occupation at the time of the study?</td>
<td>Psychologist</td>
</tr>
<tr>
<td>4.</td>
<td>Gender</td>
<td>Was the researcher male or female?</td>
<td>Female</td>
</tr>
<tr>
<td>5.</td>
<td>Experience and training</td>
<td>What experience or training did the researcher have?</td>
<td>Previous qualitative data collection (n-120) for Honours thesis supervised by a qualitative researcher, Dr Rhonda Brown. Completed postgraduate coursework in qualitative methods.</td>
</tr>
<tr>
<td><strong>Relationship with participants</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Relationship established</td>
<td>Was a relationship established prior to study commencement?</td>
<td>No. The participants were not acquainted to the researcher prior the commencement of this study.</td>
</tr>
<tr>
<td>7.</td>
<td>Participant knowledge of the interviewer</td>
<td>What did the participants know about the researcher? e.g. <em>personal goals, reasons for doing the research</em></td>
<td>The participants were informed that the aim of the research was to better understand the impact of group singing on the quality of life of people with Parkinson’s Disease. They were also aware that this research was part of the researcher’s professional Doctorate in Clinical Psychology, University of Newcastle, NSW, Australia.</td>
</tr>
<tr>
<td>8.</td>
<td>Interviewer characteristics</td>
<td>What characteristics were reported about the interviewer/facilitator? e.g. <em>Bias, assumptions, reasons and interests in the research topic</em></td>
<td>The participants were aware that the researcher had a personal interest in this area as her mother was diagnosed with Parkinson’s Disease 15 years prior.</td>
</tr>
<tr>
<td><strong>Domain 2: study design</strong></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Theoretical framework</td>
<td></td>
<td></td>
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<tr>
<td>No.</td>
<td>Item</td>
<td>Guide Questions / Description</td>
<td>Response</td>
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<tr>
<td>9.</td>
<td>Methodological orientation and Theory</td>
<td>What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</td>
<td>Interpretive Phenomenological Analysis (IPA), Smith, J.A. (1996). Beyond the divide between cognition and discourse; using interpretive phenomenological analysis in health psychology. Psychology and Health 11:261-271.</td>
</tr>
<tr>
<td>10</td>
<td>Sampling</td>
<td>How were participants selected? e.g. purposive, convenience, consecutive, snowball</td>
<td>Participants were recruited through a convenience sample.</td>
</tr>
<tr>
<td>11</td>
<td>Method of approach</td>
<td>How were participants approached? e.g. face-to-face, telephone, mail, email</td>
<td>Participants were invited face-to-face at a choir session.</td>
</tr>
<tr>
<td>12</td>
<td>Sample size</td>
<td>How many participants were in the study?</td>
<td>11</td>
</tr>
<tr>
<td>13</td>
<td>Non-participation</td>
<td>How many people refused to participate or dropped out? Reasons?</td>
<td>Nobody refused to participate in the research.</td>
</tr>
<tr>
<td>14</td>
<td>Setting of data collection</td>
<td>Where was the data collected? e.g. home, clinic, workplace</td>
<td>Each Participant was interviewed in his/her own home.</td>
</tr>
<tr>
<td>15</td>
<td>Presence of non-participants</td>
<td>Was anyone else present besides the participants &amp; researchers?</td>
<td>3 participants had their Spouse/Carer present</td>
</tr>
<tr>
<td>16</td>
<td>Description of Sample</td>
<td>What are the important characteristics of the sample? e.g. demographic data, date</td>
<td>Age, gender, level of education, duration of disease, symptom severity, time since diagnosis and self reported quality of life are all reported in the manuscript.</td>
</tr>
<tr>
<td>17</td>
<td>Interview guide</td>
<td>Were questions, prompts, guides provided by the authors?</td>
<td>Yes. The Choir Participation Interview, a semi-structured interview consisting of open-ended questions was designed for this study.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Was it pilot tested?</td>
<td>Yes. A pilot test of the questionnaire was conducted on a person with Parkinson’s Disease who was not associated with the choir or involved in the research.</td>
</tr>
<tr>
<td>No. Item</td>
<td>Guide Questions / Description</td>
<td>Response</td>
<td></td>
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<tr>
<td>----------</td>
<td>-------------------------------</td>
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</tr>
<tr>
<td>18.</td>
<td>Repeat interviews</td>
<td>Repeat interviews were not carried out, however, for the 3 participants who chose to make changes to their transcript a telephone call was made to acknowledge the changes and clarify any ambiguity.</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Audio/visual recording</td>
<td>An audio recorder was used for data collection and interviews were hand transcribed into MS Word files by the researcher before analysis.</td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>Field notes</td>
<td>Yes. Field notes were made during participant interviews.</td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>Duration</td>
<td>Interviews lasted between 38 minutes and 196 minutes.</td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>Data saturation</td>
<td>Yes. Data collection from participants ended when saturation was achieved.</td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>Transcripts returned</td>
<td>Yes. Each participant had the opportunity to comment upon their transcript as to its accuracy and tone.</td>
<td></td>
</tr>
</tbody>
</table>

**Domain 3: Analysis and Findings**

**Data Analysis**

<table>
<thead>
<tr>
<th>No. Item</th>
<th>Guide Questions / Description</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>24.</td>
<td>Number of data coders</td>
<td>One researcher coded the interviews. A second researcher blind reviewed the interviews, however no new themes emerged.</td>
</tr>
<tr>
<td>25.</td>
<td>Description of the coding tree</td>
<td>The coding tree was not shared with the reviewer (as per criteria 24).</td>
</tr>
<tr>
<td>26.</td>
<td>Derivation of themes</td>
<td>Both. Various themes were noted during the transcription, but also derived from the data.</td>
</tr>
<tr>
<td>27.</td>
<td>Software</td>
<td>QSR International’s NVivo 10 qualitative data analysis software was used to store and manage the data.</td>
</tr>
<tr>
<td>No. Item</td>
<td>Guide Questions / Description</td>
<td>Response</td>
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<tr>
<td>----------</td>
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</tr>
<tr>
<td>28. Participant checking</td>
<td>Did participants provide feedback on the findings?</td>
<td>Yes. When transcripts were collected, after participants had a chance to review/make corrections, they had the opportunity to discuss the findings. Also a presentation of key findings was held with the choir group post data collection where participants were invited to share their comments.</td>
</tr>
<tr>
<td>Reporting</td>
<td>29. Quotations presented</td>
<td>Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number</td>
</tr>
<tr>
<td>30. Data &amp; findings consistent</td>
<td>Was there consistency between the data presented and the findings?</td>
<td>Yes.</td>
</tr>
<tr>
<td>31. Clarity of major themes</td>
<td>Were major themes clearly presented in the findings?</td>
<td>Yes. Major themes are presented in the manuscript.</td>
</tr>
<tr>
<td>32. Clarity of minor themes</td>
<td>Is there a description of diverse cases or discussion of minor themes?</td>
<td>Yes. Minor themes/diverse themes are presented in the Results section and further explored in the Discussion section of the manuscript.</td>
</tr>
</tbody>
</table>
Appendix M

Extended Methodology

This appendix provides additional information pertaining to participant recruitment and the initial participant interview to capture demographic and clinical information.

Participants and Recruitment

Participants were recruited following a presentation delivered by two members of the research team and the simultaneous distribution of a Participant Information Sheet (refer Appendix O). There were three inclusion criteria: a formal diagnosis of PD made by a neurologist; a score of 26 or above on the Standardised Mini-Mental State Examination (SMMSE); and nil to mild symptoms of depression and/or anxiety as measured by the Hospital Anxiety and Depression Scale (HADS).

Approval for the research was granted by both the University of Newcastle Human Research Ethics Committee, approval No. H-2014-0284 (refer Appendix A) and Macquarie University Human Research Ethics Committee, approval No. 5201400414 (refer Appendix B).

Initial Interview

Informed written consent was obtained (refer Appendix P) and eligibility criteria were assessed. The initial face-to-face structured clinical interview (approximately 1.5 hours), utilising the Initial Interview template (refer Appendix Q) was held in each participant’s home. Four self-report measures were administered for the qualitative study reported here (SMMSE, HADS, NMSS, PDQ-39). In addition four self-report measures, namely the IPIP, BMRQ, WTAR and the PANAS were also administered to obtain participant information for an additional and separate quantitative research study reported elsewhere. Details of these measures are included below.
Measures

**International Personality Item Pool (IPIP).** Twelve trait characteristics were selected from the personality item pool to measure participant trait personality (Goldberg et al., 2006), a copy of this measure is included in Appendix R. Participants were asked to rate how accurately each statement described their behaviours from 5 response options (1 = very inaccurate, 2 = moderately inaccurate, 3 = neither inaccurate nor accurate, 4 = moderately accurate and 5 = very accurate) to provide two scores: a neuroticism score and an extraversion score. Scores can range from 6 – 30 with higher scores representing higher levels of neuroticism and extroversion. Time to administer was approximately 5 minutes.

**Barcelona Music Reward Questionnaire (BMRQ).** A new self-report measure to explore musical reward (Mas-Herrero, Marco-Pallares, Zatorre & Rodriguez-Fornells, 2013). Twenty statements across 5 factors (musical seeking, emotion evocation, mood regulation, social reward, and sensory-motor) are scored with respect to level of agreement using a 5-point scale (1 = completely disagree; 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = completely agree) and summed for an overall raw score.

A score is calculated for each factor, as well as a total score for the global sensitivity to music reward. The mean value of each factor is 50 and the standard deviation is 10. Therefore, the standard values are located between 40 and 60. Punctuations below 40 indicate low values in this particular facet and values above 60 indicate high values in this facet (the same applies to the global questionnaire). Time to administer was approximately 5 minutes.

**The Wechsler Test of Adult Reading (WTAR).** A list of 20 words to be read aloud and scored for correct pronunciation to obtain an assessment of pre-morbid intelligence quotient (Wechsler, 1997).

**Positive Affect And Negative Affect Schedule (PANAS).** A brief self-report measure of current mood often utilised with PD populations (Watson, Clark & Tellegen,
1988). The measure contains 20 single word items representing a variety of feelings and emotions. Participants are asked to rate each item according to how they feel ‘right now’ using a 5-point scale (1 = very slightly/not at all, 2 = a little, 3 = moderately, 4 = quite a bit, 5 = extremely) to provide two scores: a positive affect score and a negative affect score. Scores can range from 10 – 50 with higher scores representing higher levels of positive affect (mean score = 29.7, SD = 7.9) and lower scores representing lower levels of negative affect (mean score = 14.8, SD =5.4). Time to administer is approximately 5 minutes.
Appendix N

Extended Results

Overview

The following comprises an extension to the results reported in the Journal Article of this thesis; the manuscript titled Group Singing and Health-Related Quality of Life in Parkinson’s Disease. Four sections follow:

- Interpretive Phenomenological Analysis - extended. An overview of all the themes that emerged in the qualitative analysis; eight in total.
- The benefits of group singing - extended. A more detailed account of participant responses to the semi-structured interview are included for each theme.
- Success factors of the choir. Details of two themes that emerged from the IPA to describe important aspects of the choir for participants.
- Immediate impact of group singing. The immediate perceived changes, and the duration of experiences, after attending a choir session are reported.

Interpretive Phenomenological Analysis - Extended

A total of eight themes emerged from the qualitative analysis of participant transcripts (see Table N1). Six themes describe the benefits of group singing as experienced by participants, namely: physical, mood, cognitive functioning, social connectedness, flow-on effects and ‘sense-of-self’.

Two themes emerged from the open ended question: “Is there anything else that you would like to share about the choir?” to describe factors contributing to the success of the choir: the role of the choir maestro and the choir’s versatility to function as a support group for carers/spouses. These additional themes are included in Table N2. A discussion of these themes, in detail, follows with examples provided from participant transcripts.
### Themes and Subthemes Related to Participants’ Experience of Group Singing

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
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<tbody>
<tr>
<td>Benefits of group singing</td>
<td>Physical</td>
</tr>
<tr>
<td></td>
<td>Voice quality</td>
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<tr>
<td></td>
<td>Posture, gait and falls</td>
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<td></td>
<td>Energising experience</td>
</tr>
<tr>
<td></td>
<td>Mood</td>
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<td></td>
<td>Optimism</td>
</tr>
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<td></td>
<td>Cognitive Functioning</td>
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<tr>
<td></td>
<td>Memory</td>
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<tr>
<td></td>
<td>Concentration</td>
</tr>
<tr>
<td></td>
<td>Social Connectedness</td>
</tr>
<tr>
<td></td>
<td>Camaraderie</td>
</tr>
<tr>
<td></td>
<td>Friendship</td>
</tr>
<tr>
<td></td>
<td>PD-specific choir</td>
</tr>
<tr>
<td>Flow-on Effects</td>
<td>Social activities</td>
</tr>
<tr>
<td></td>
<td>Public performances</td>
</tr>
<tr>
<td></td>
<td>Creativity</td>
</tr>
<tr>
<td>Sense-of-self</td>
<td>Self-confidence</td>
</tr>
<tr>
<td></td>
<td>Sense of control</td>
</tr>
<tr>
<td></td>
<td>Independence</td>
</tr>
<tr>
<td>Success factors of the choir</td>
<td>Choir Maestro</td>
</tr>
<tr>
<td></td>
<td>Personality</td>
</tr>
<tr>
<td></td>
<td>Energy</td>
</tr>
<tr>
<td></td>
<td>Professionalism and dedication</td>
</tr>
<tr>
<td></td>
<td>PD-Carer Support Group</td>
</tr>
<tr>
<td></td>
<td>Camaraderie and validation</td>
</tr>
<tr>
<td></td>
<td>Support and respite</td>
</tr>
<tr>
<td></td>
<td>PD-specific choir</td>
</tr>
</tbody>
</table>

**The Benefits of Group Singing - Extended**

**Theme 1 – physical.** Engagement in group singing has a strong physical component, as noted by Participant 3 (P3): “[group singing], it’s a physical activity”.

**Voice quality.** The majority of participants (9) noticed an immediate beneficial effect in their voice quality after singing at a choir session. Various descriptions included: “sharper”, “you can speak clearly”, and “better clarity”, “I feel I’m doing my vocal chords good and potential to have volume”. In terms of strength and volume, three rated their voice as ‘better’ and five rated their voice as ‘much better’ on the rating scale. These changes persisted from half a day to seven days. As noted by P9:
A lot stronger. On the better side of better. Sustained for quite a long period. Easily into the next day; couple of days. When you have a disease, and you are not working, you tend to stay on your own, so when you go out and socialise you get your muscles in your throat working and speech comes ‘a lot easier’.

Two participants reported no improvement in their voice quality; one participant rated their voice quality as worse due to ‘overuse’ at choir practice compared to living alone and seldom speaking at home: “I’ve had the clinic people look at it. But they say it’s nothing it’s just overuse because, again, living by yourself you don’t get to use your voice” (P10).

**Posture, gait and falls.** The majority of participants (nine) did not report any changes in their MS as a result of their ongoing choir participation. Two participants reported significant improvements in their MS, including balance, gait and reduced falls: “Stand better, walk better” (P4), and P11 stated;

The only thing I notice is that I’m less likely to fall over; I’m not controlling my balance while I’m with the choir. I don’t know [why]. That’s more psychological I think. People have told me before when they suffer Parkinson’s when they are up front or doing something that involves them they don’t get the symptoms. Basically the whole time I am there. I have had stumbles, but very few.

P8 highlighted the increase in their tremor when they performed in public: “Although singing is positive it doesn’t actually help the tremor, and in many ways on the performance you become anxious so the tremor is always worse”.

**Energising experience.** The majority of participants (eight) reported that group singing increases their energy. Whilst there are physical, emotional and cognitive aspects within these responses, the overall theme was of additional energy and motivation to engage in physical activities. The effect on energy levels ranged from high: “There is a definite ‘up’ there which lasts, we can go shopping” (P1) to low: “It’s a slight thing, but I don’t describe it
as ‘better’, sometimes I feel free-er about the facial muscles. A heightened awareness is a pretty fair description. It goes more quickly than a feeling of wellbeing” (P6). Energy is dynamic during a group singing session; it is created and exchanged, as further described by P6:

The experience of the choir itself, the music and watching the pleasure that everybody gets out of it. If you watch it, it is undeniable. They get a buzz out of it. As I do. We get a buzz out of watching other people get a buzz. The buzz is we are doing something pleasurable, something that is constructive in the context of Parkinson’s, we are sort of getting out and doing something that is not part of the everyday routine.

**Theme 2 – mood.** The majority of participants reported enhanced mood (better or much better, in six and four participants, respectively) after group singing. This enhancement persisted for a few hours to three days. As described by P3:

There have been times with the choir when I really, really don’t feel up to going along, or I’m tired, but you go, and you are really glad that you went. You feel so much better afterwards. It’s certainly filled a...yeah, it has added to your overall enjoyment of life.

One participant (P7) reported a decline in mood after a singing session due to frustration with operational aspects of the choir: “It’s gone on a long [time], a bit too long”

Nine participants shared that their overall mood had improved since joining the choir, for example:

Complete change of mood. Not that I had a bad mood before. Before I joined the choir I would sometimes think ‘why me?’ and since I have been in the choir those types of thoughts have completely vanished. Acceptance. Mixing with like-minded people. Parkinson’s gradually took its grip. And having an outlet like this choir is fantastic (P9),
Everything is just so much more positive. Choir, for me, you can just go, you don’t have to prove yourself, you don’t have to put on a show, you can just be yourself and I find that gives me more energy and makes me even more positive (P8).

**Theme 3 – cognitive functioning.** Ongoing participation in group singing was identified by the majority of participants (six) as beneficial for their ‘thinking skills’, as summarised by P8:

Yes. They all go together – thinking, memory, and concentration. Because you are doing something where you have to make on effort. It is not just singing. If you are trying to make an effort to remember the words to a song, if you are trying to remember the notes, or the ups and downs, this bit is loud, this bit is higher. I think that’s an incredibly good thing to be doing to keep your brain [healthy]. A mental workout.

**Memory and concentration.** Six participants reported no change in their cognitive functioning. Five participants reported enhanced ‘thinking skills’ immediately after a choir session. Two of these reported experiencing ‘better’ thinking skills and three reported ‘much better’ thinking skills following choir practice, for example: “My memory actually gets better” (P1); “My ability to concentrate would be a little better because I feel more settled after being with the people” (P11) and “I feel like everything is sharper...I feel alert” (P3). Three participants felt that their enhanced cognitive functioning lasted for the remainder of the day (3 participants) and for two participants for up to two days. One participant reported feeling frustrated when choir attendance highlighted the deterioration in their cognitive functioning due to PD: “I occasionally despair about retaining the lines to a song not withstanding that I have sung it heaps of times. Still rely on the lyrics [sheet]. Frustration. A marginal degree of concern about it. Not dramatic” (P6).
Theme 4 – social connectedness. All participants reported social benefits. The initiative to join the singing group was often socially motivated to reduce loneliness and isolation. For example: “I thought it might be a good idea and I would get to socialise. A major way of breaking the cycle of loneliness and creating new friendships. If I didn’t have Parkinson’s I’d probably still be working” (P9) and “What the choir did was to reconnect me with the community, the society. I got very isolated” (P1).

Camaraderie. All participants described a sense of camaraderie that is highly valued. In addition, camaraderie appears to have a cohesive influence on maintaining and sustaining the singing group as shared by P10: “The camaraderie, looking forward to seeing the people that I’ve got to know, and getting to know even better. Yeah that’s what it is all about. It really is a social group, as far as I see it and a support group”. One participant (P10) rated the singing as ‘secondary’ when compared to camaraderie and stated:

I have no interest in singing. I have never participated in any sort of music. It is purely because [a fellow member] forced me into it that I went along. The camaraderie. Yes that’s what it is all about. Singing is secondary. Very secondary.

Friendship. All participants rated choir friendship as highly important. The acquisition of new friends and the role of friendship are valued experiences of the singing group and motivate attendance: “Friendships there, being part of a group. It’s like playing for a team sport, you’re getting benefits from that but you need to, your contribution is regular attendance, support the others with singing” (P3) and “There is a big social aspect to it. The people that are involved have become pretty ‘tight’, isn’t the right word, ‘good friends’. And more importantly good friends who are walking the same path with Parkinson’s” (P6). There was a strong sense of equality and respect amongst the choir members as summarised by P11:
I’m with people who care. So far I haven’t detected any ego, selfishness, I’m better than you. I haven’t struck any of that with this group. Everyone is the same, seems to have the same attitude. It is precious. It’s so precious.

Finally, the composition of the group also motivates attendance as summarised by P10:

A mature group and the other thing that is surprising about the choir, the people who are involved, I don’t know what I expected, but they are intelligent, responsible bunch, articulate, committed people from a variety of vocational backgrounds which is very broad, interesting. They are not a typical group.

**PD-specific choir.** All participants noted that it was important that the singing group was exclusively for people with PD. This sole focus provided additional cohesion and support as explained by P4:

The actual people with Parkinson’s can see how it effects other people, and how they can relate to those people rather than being out in a group where you’re the only one who has a problem. I think with the choir everybody has got the problem and they deal with it;

and P11:

It’s the old dog story, what you see is ten percent of what is going on. We all feel different inside, every single one of us. We are affected in different ways. It [the choir] has the effect of drawing us together, because we all have the same social stigma in a way. But we don’t let that affect us. We are there to do a job. We do the job in various ways because we are all differently affected by Parkinson’s.

Participants also have access to a rich and valued sources of information about PD. P3 highlights the importance of a dedicated PD choir:
I’ve been able to get to know people and have detailed conversations about Parkinson’s medications, symptoms, life, living with Parkinson’s. If it was a choir without the Parkinson’s I don’t think I would probably be there because that’s just like normal people and people who go to that can sing. In this case the commonality, one commonality is that you’ve all got the Parkinson’s and you can empathise with each other, discuss solutions and cures, and symptoms and all that, talk about things that relate well with each other as well as enjoying an activity, the singing – it’s a physical activity, a communal activity.

**Theme 5 - flow-on effects.** This theme is eclectic and includes activities external to the choir that participants engaged in as a consequence of group singing participation. Ranging from spontaneous group activities, to enabling an individual’s creative output, participants enjoy additional social activities in addition to choir attendance.

**Social activities.** A number of activities have evolved including: a weekly bike ride (5 participants attend), tai chi (3 participants attend), group dinners, film nights and an annual Christmas party. There is also a semi-regular social catch-up for spouses.

**Public performances.** Several participants made reference to the ‘performing’ experience that accompanies group singing. The preparation required to sing in front of fellow choir members, at PD support meetings and conferences, provides goal setting opportunities, additional challenges to master, as well as a sense of achievement upon completion. P6 described their experience: “I was all for the concept of a choir, of performance. I wasn’t sure of what it would produce necessarily, but I was pretty confident that it would be good, and it has proved to be”.

**Creativity.** Three participants and their spouses reported increased activity in creative arts, including writing poetry, drawing and painting, and creating greetings cards. Spouse 1 (S1) shared the beneficial effects she had observed for P1 as a result of his poetry writing:
“The poems, kind of illustrate that there is a regeneration. A sense of control, a way of naming, and shaping and controlling. Being able to be a little bit objective. Structure and make choices...through the language, rhythm and emotion”.

**Theme 6 – sense-of-self.** All participants reported at least one psychological benefit that had significantly improved their sense-of-self since joining the choir. As reported by P1: What the choir did was to reconnect me with the community, the society. I got very isolated. This was aggregated by, and added to the paranoia. A problem with the way people were seeing me, and my identity, my sense-of-self, and, worth.

**Self-confidence.** Increased self-confidence was reported by the majority (nine) of participants:

I’ve never been an overly confident type of person. Choir has made me a lot more confident. Especially when you have to sing solos and that sort of stuff. Which I would never in a life time thought that I would be doing at 62. It [choir] has been a real boost to my self-esteem, to my love of life (P9).

The remaining participants reported no change in their self-confidence with some attributing this to their pre-existing high level of confidence: “I have always been self-confident so it hasn’t affected me in any way” (P6). One participant shared a negative impact on their self-confidence as the experience highlighted a decline in their abilities: “Not really because I am doing something now that I used to do better. That doesn’t help your self-confidence” (P7).

**Sense of control.** Eight participants reported an increase in their sense of control over day-to-day activities, for example: “It does give me a sense of control if only because of the steps I take to get there. I can control. I can control my movements to get there” (P11). A sense of control over PD from the group singing experience was also shared:
I think if you do something you are taking control. You are accepting. It takes a while to accept that you have Parkinson’s. And you go through that whole grief, anger, whatever until eventually you get to the point where you have accepted it. And then you think….well is it going to dominate my life? Am I going to carry on doing things that I really want to do? (P7), and,

It gets back to yes [sense of control] because all information is valuable. Again what I’ve learnt talking to people, through being involved with the choir means that you are gaining knowledge in all sorts of ways. Every time you go there are little bits of knowledge you gain or information. You can empathise with someone over a symptom. (P3).

Three participants reported no change in their sense of control.

**Independence.** Three participants reported an increase in their independence: two participants attributing this to the challenge of coordinating transport to the singing sessions: while the other participant attributed their independence to the support network provided by the members: “A bit. When [spouse] went away, that helped me. Keeping in touch with the choir. The choir was a ‘life raft’ for me. So many people said if you need help, ring me up. Lovely having that. A fall back” (P1). Eight participants reported no change to their independence with five elaborating that they felt independent regardless of their choir attendance.

**Success Factors for the Choir**

**Theme 7 – choir maestro.** All participants emphasised the significant role of the choir maestro in the choir’s success. The qualities mentioned included her gregarious personality, high energy levels, maturity, dedication, empathy, and a high degree of technical competence, along with her understanding of PD symptoms. Participants attributed the
success of the choir to the qualities of this choir maestro: “The choir is as good as it is because of her” (P8).

**Professionalism and dedication.** The choir maestro is committed to the success of the choir as well as ensuring that the participants enjoy themselves. Her performance in the role was described as follows: “Professional and provides professional instruction” (P7); “She has credibility. We all went to see her perform” (P5); “She has skills in teaching non-musicians” (P10);

She is putting so much into it, she is the choir. She is the major influence. She takes it more than seriously I am sure. It is more than a job for that person. And I guess we are reaping the benefits of it (P10), and

[She] has a lot to do with it [success of the choir]...the way she encourages us all, it might be a major factor too, it is hard because I have no experience of anyone else. [She] has put her heart and soul into it and they make us all feel like we are doing well. [She] is brilliant at encouraging us (P3).

**Energy and cohesion.** The choir maestro injects energy into the choir that captivates the participants and contributes to group cohesion. Participants and spouses described their experience of the choir maestro as: “Energised, energy personified” (S1); “Amazing presence” (P8); “A very positive person” (S4); “a bit of a comedian” (P2); “Bubbly personality” (P5); “Nothing negative about her” (S5); “She is brilliant at encouraging us” (P3) and “Tremendous heart” (P9). The choir maestro’s contribution to the group cohesion is highlighted in the following comments: “And these are all types of things that attract other people to her” (P2); “[She] has got us together and [she] keeps us together” (P10) and “And of course don’t leave [choir maestro] out. [She is] very good at drawing us together” (P11).
Theme 8 – PD-carer support group. Four spouses, who provide additional support and care to their partner with PD, also attend the ‘Shake Rattle and Roll’ choir. The choir has provided an unexpected support group for these carers/spouses. The support group theme emerged during the interviews with PD participants, regardless of their spouse’s presence. An advantage for participants whose spouse is also a choir member is the additional motivation they provide to attend on a weekly basis. Spouses enthusiastically described their group singing experiences as: “validation”, “respite”, “shared activity with spouse”, “reduces isolation”, “companionship and connection with other spouses”. S4 described her experience of the choir: “support, motivation, education, vent for feeling, all important for Carers. PD is isolating and frustrating and can tap into self confidence”.

Camaraderie and validation. For some spouses, attending the choir was their first exposure to other cares/spouses. Attending the choir and mixing with other carers was validated their experience in the role of carer: “The camaraderie of the people in the same situation as yourself” (S4) and “[Partners name] mentioned earlier physical contact, hugging, important for me as well. That connection is part of it; part of our existence” (S1).

Support and respite. Some spouses were instrumental in seeking out the choir as an activity for their partner with PD, as well as themselves. “And I’ve got to admit I thought that’s [the choir] another avenue to meet a group of people who are in the same situation as [spouse’s name ] and me as far as the carer goes as well” (S5). Spouses also reported that additional activities, beyond the choir sessions and exclusively for spouses, were in the planning stages: “I get on very well with the other carers. And we are organising coffee” (S4).

PD-specific choir. The importance of a choir for PD was highlighted by spouses: The actual people with Parkinson’s can see how it effects other people, and how they can
relate to those people rather than being out in a group where you’re the only one who has a problem. I think with the choir everybody has got the problem and they deal with it (S4).

**Immediate Impact of Group Singing on Parkinson’s Disease**

Participants were asked to describe the magnitude of both the severity and duration of any immediate perceived changes across physical (body and voice), emotional and cognitive domains after group singing. Specifically, they were asked how they felt in their body, voice, mood and thinking skills immediately after attending a choir session, and to estimate the duration of any perceived positive change. These results are presented in Figure 5 and Figure 6.

The colours used in both Figure 5 and Figure 6 correspond to the severity of the impact experienced by participants on body, voice, mood and thinking (orange = worse, grey = no change, blue = better and green = much better). These immediate impacts (severity and duration) on body, voice, mood and thinking skills have also been matched with individual participant scores for symptom severity (HY, PDQ-39, NMSS) in Table N2.
Figure 5. The severity of the impact of group singing on body, voice, mood and thinking skills.

**Physical impact: body.** Six participants noticed an immediate positive change in their body after attending a choir session: two rated their body as better (shown as blue in Figure 5) and four rated their body as much better (shown as green in Figure 5). Five of these six participants reported sustained positive changes: for the remainder of the day (three participants) and between two and three days (two participants) (refer Figure 6). Three participants experienced no change in their body. Two participants rated their body as worse; a feeling sustained for the remainder of the day (refer Figure 6). One participant attributed their “discomfort” to an irritated throat after singing, due to overuse. The other participant stated a “lack of confidence” made them feel worse however was unable to elaborate further. One participant shared the issues of medication and sleep quality as factors influencing the sustainability of positive changes in their body.
Figure 6. The duration of the impact of group singing on body, voice, mood and thinking skills.

**Physical impact: voice.** Eight participants noticed immediate positive changes in the quality of their voice, namely strength and volume, after attending a choir session: three rated their voice as *better* (shown as blue in Figure 5) and five rated their voice as *much better* (shown as green in Figure 5). Descriptions used by participants to describe their experience included: “sharper”, “you can speak clearly”, “better clarity”, “I feel I’m doing my vocal chords good” and “potential to have volume”. Seven of these participants reported sustained positive changes for the remainder of the day (five participants) and for two to three days (two participants) (refer Figure 6). Two participants experienced *no change* in their voice. One participant rated their voice quality as *worse* and this experience was sustained
for the remainder of the day (refer Figure 6). This participant was the same participant who cited voice overuse at the choir due to living alone and seldom speaking.

**Emotional impact: mood.** Ten participants experienced an enhanced mood immediately after a choir session: six felt that their mood was *better* (shown as blue in Figure 5) and four felt that their mood was *much better* (shown as green in Figure 5). This enhanced mood was sustained in all ten cases: for up to half a day (six participants), for one day (two participants) and between two and three days (two participants) (refer Figure 6). One participant experienced a small decrease in mood that was not sustained beyond the choir session (refer Figure 6). They attributed this decrease in mood to operational aspects of the choir:

> It’s gone on a bit too long. I’m wondering why I care to do it. I don’t care for the songs we are doing. Feel much the same but not in the euphoric mood. I feel a little bit ‘I wish they wouldn’t bother, or I wish they wouldn’t do that’ (P7).

When explored further P7 shared that it was their commitment to the group and the social aspect of the choir that kept them returning: “Commitment. Once I have started to do something I can’t justify in my mind to say I’m not going any more” and “Certainly has been helpful [attending the choir]. Sounds as if I don’t but I do enjoy it. The people are great. I’m not very gregarious. I don’t mix very well but everybody is easy to get on with.”

**Cognitive functioning: thinking skills.** Five participants reported enhanced cognitive functioning immediately after attending a choir session: two participants experienced *better* thinking skills (shown as blue in Figure 5) and three participants experienced *much better* thinking skills (shown as green in Figure 5). Descriptions shared by participants to describe these positive changes included: “my memory actually gets better” (P1); “My ability to concentrate would be a little better because I feel more settled after being with the people” (P11) and “I feel like everything is sharper...I feel alert” (P3). This
enhancement to cognitive functioning was sustained in all five cases: for up to half a day (three participants) and between two to three days (two participants) (refer Figure 6). Five participants reported no change to their cognitive functioning. One participant rated their thinking skills as occasionally worse due to memory decline that was sustained for the remainder of the day (refer Figure 6):

No not really [any change] except in a negative sense in that I occasionally despair about retaining the lines to a song not withstanding that I have sung it heaps of times. Still rely on the lyrics. Frustration. A marginal degree of concern about it. Not dramatic (P6).

When this response was explored further P6 shared that their motivation for returning to the choir in spite of the frustrations around memory: “The experience of the choir itself. The music and watching the pleasure that everyone gets out of it.”
Table N2.


<table>
<thead>
<tr>
<th>Participant</th>
<th>HY</th>
<th>PDQ-39</th>
<th>NMSS</th>
<th>Change</th>
<th>Duration</th>
<th>Change</th>
<th>Duration</th>
<th>Change</th>
<th>Duration</th>
<th>Change</th>
<th>Duration</th>
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<tr>
<td>2</td>
<td>1</td>
<td>7.55</td>
<td>Very Severe</td>
<td>Same</td>
<td>N/A</td>
<td>Better</td>
<td>Half Day</td>
<td>Better</td>
<td>Half Day</td>
<td>Same</td>
<td>N/A</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>22.08</td>
<td>Severe</td>
<td>Much Better</td>
<td>2-3 days</td>
<td>Much Better</td>
<td>Half Day</td>
<td>Much Better</td>
<td>1 Day</td>
<td>Much Better</td>
<td>2-3 Days</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>22.66</td>
<td>Severe</td>
<td>Much Better</td>
<td>N/A</td>
<td>2-3 Days</td>
<td>Better</td>
<td>Half Day</td>
<td>Same</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>22.97</td>
<td>Severe</td>
<td>Much Better</td>
<td>Half Day</td>
<td>Much Better</td>
<td>Half Day</td>
<td>Better</td>
<td>Half Day</td>
<td>Same</td>
<td>N/A</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>9.64</td>
<td>Moderate</td>
<td>Better</td>
<td>0</td>
<td>Better</td>
<td>0</td>
<td>Better</td>
<td>Half Day</td>
<td>Worse</td>
<td>Half Day</td>
</tr>
<tr>
<td>7</td>
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<td>Severe</td>
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<td>Same</td>
<td>N/A</td>
<td>Worse</td>
<td>0</td>
<td>Same</td>
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<tr>
<td>10</td>
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<td>Worse</td>
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<td>Better</td>
<td>1 Day</td>
<td>Same</td>
<td>N/A</td>
</tr>
<tr>
<td>11</td>
<td>3</td>
<td>6.93</td>
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<td>N/A</td>
<td>Much Better</td>
<td>Half Day</td>
<td>Much Better</td>
<td>Half Day</td>
</tr>
</tbody>
</table>

*Participant 4 appeared to not understand the question. No rating obtained.

Note: N/A = Not Applicable; HY = Hoehn & Yahr Scale; PDQ-39 = Parkinson’s Disease Questionnaire -39; NMSS = Non Motor Skills Scale.*
Appendix O

Participant Information Sheet

Group singing in Parkinson’s Disease: Immediate cognitive and emotional effects

Investigators: Amee Baird, Nicolas Bullot (Department of Cognitive Science, Macquarie University), Bill Thompson (Macquarie University) & Maggie Haertsch (Arts Health Institute).

The aim of this research study is to investigate the immediate cognitive and emotional effects of singing in a group in individuals with Parkinson’s disease (PD). Previous studies have documented beneficial effects of singing on gait and voice parameters in PD but there has been no study to date of how group singing could affect cognition (thinking skills such as memory) or emotion (mood and processing of prosody or emotional tone in speech).

Participation in this study will involve completing 3 brief assessments of approximately 30 minutes each (total of 1.5 hours). These assessments will occur on 3 separate occasions, the first at a time arranged with the chief investigator at Newcastle Family Practice (205 Hunter St Newcastle) and on two other occasions during or immediately after the group singing sessions. The assessments will involve tasks assessing your thinking skills (such as memory and attention), mood symptoms and emotion (ability to detect emotional tone in speech) and your knowledge of the songs you have learnt in the group singing session.

The only potential discomfort associated with participation in this study is fatigue but given the short time duration for each assessment there is minimal risk of this. Rest breaks can be taken if required.

Your assessment results will be entirely confidential. Your name will not appear on any assessment forms, as you will be assigned a participant number. Only the chief investigator will have access to the document linking names to participant numbers. The
results may be presented at a conference or published in scientific journal but you will not be identified.

Feedback about your individual results can be provided to you at the completion of your 3 assessments by the researcher in the form of brief verbal feedback. At the conclusion of the study the chief investigator will provide a summary of the findings in an oral presentation to all participants who are interested.

Your participation in this study is entirely voluntary and you have the right to withdraw at any time without having to give a reason and without adverse consequences. If you agree to participate you will be asked to sign a consent form and given a copy of the signed form for your records.

The Macquarie University Human Research Ethics Committee has approved the ethical aspects of this study. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the committee through the Director, Research Ethics, (phone 02 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated and you will be informed of the outcome.
Appendix P

Participant Consent Form

Group singing in Parkinson’s Disease: Immediate cognitive and emotional effects

Investigators: Amee Baird (Macquarie University), Nicolas Bullot (Macquarie University), Bill Thompson (Macquarie University) & Maggie Haertsch (Arts Health Institute).

I agree to participate in the above titled research study. I have read the participant information sheet and understand that participation in this study involves me completing 3 brief assessments of my thinking and emotional skills.

Participant’s signature………………………………………………………………………..

Date……………………………………

Witness/Investigator’s signature…………………………………………………………

Date……………………………………
Appendix Q

Initial Interview (template)

Interviewer ___________________________________ Date __________________

• Introduce interviewer and provide contact details. Clarify any questions/concerns regarding the study.
• Reiterate confidentiality of information
• Reiterate voluntary nature of participation and the ability to withdraw participation at any time.
• Request permission for a telephone contact # if follow up required.

Name __________________________________________

Participant # _____________________________________

Phone (in case I need to make follow up contact) ________________________________

Email __________________________________________

Age ____________________________________________

Gender Male / Female

Education - total years of education ________________________________

Employment - Employed occupation/role ______________________________________

Retired main occupation while working _______________________________________

Volunteer work type/role/frequency ___________________________________________

Marital Status Single? Number of years _______________________________________

Married? Number of years _________________________________________________

Widowed? Number of years ________________________________________________

Divorced? Number of years ________________________________________________

Family - Tell me about your family

Number of children _________________________________________________________

Number of grandchildren ____________________________________________________

Number of great grandchildren ______________________________________________

Who lives at home with you? _______________________________________________

Friends ________________________________________________________________

Interest/hobbies - Share with me how you spend your time ______________________
Parkinson's Disease Diagnosis

Tell me about your Parkinson's diagnosis__________________________________________

When were you diagnosed with PD? Date: ____________________________________________

How old were you when you were diagnosed? Age: ________________________________

How did you feel when you were told? ____________________________________________

What are your main symptoms? _________________________________________________

Do you take medication for your PD? Yes / No Type? ______________________________

Do you find your medications effective? Yes / No

Do you have any other medical conditions or health concerns?_____________________

Have you ever been diagnosed with:
• Depression? Yes / No
• Anxiety? Yes / No
• Any other kind of mental illness? ______________________________________________

Hoehn and Yahr Scale - Interviewer to rate at end of interview
1 Only unilateral involvement, usually with minimal or no functional disability
2 Bilateral or midline involvement without impairment of balance
3 Bilateral disease: mild to moderate disability with impaired postural reflexes, physically independent
4 Severely disabling disease; still able to walk or stand unassisted
5 Confinement to bed or wheelchair unless aided 3

Neurological episodes
Have you ever lost consciousness Yes / No Year________ Hospitalised Yes / No
Rehabilitation details ____________________________________________________________

Have you ever had a head injury Yes / No Year________ Hospitalised Yes / No
Rehabilitation details ____________________________________________________________

Have you ever had a stroke Yes / No Year________ Hospitalised Yes / No
Rehabilitation details ____________________________________________________________

Have you ever had a seizure Yes / No Year________ Hospitalised Yes / No
Rehabilitation details ____________________________________________________________

Recent Past Events

Have you experienced any major events, or stressful occasions in the past 4 weeks: e.g. loss of family/friend, accident, tragedy, etc.. OR positive events e.g. wedding, birth, celebration, birthday, etc..__________________________________________________________
Writing ability
Participating in this research will require you to respond, in writing, to various questionnaires, will this be difficult for you?  Yes / No
What level of support would be helpful?  

Support
What level of support/assistance do you require on a daily/weekly basis?  
Do you have a carer?  
Formal organisation  
Informal family member / other  

What Medical Specialists do you visit?
- General Practitioner  Yes/No  Frequency  
- Neurologist  Yes/No  Frequency  
- Psychologist  Yes/No  Frequency  
- Other  Yes/No  Frequency  

Are you engaged with any Allied Health Professionals?
- Psychologist/Counsellor  Yes/No  Frequency  
- Speech Pathologist  Yes/No  Frequency  
- Physiotherapist  Yes/No  Frequency  
- Dietician  Yes/No  Frequency  
- Other  Yes/No  Frequency  

Do you engage in any exercise activities?
Formal  
Informal  

Besides the choir, what other support groups, or group activity do you attend?
(PD Specific or others)  
Frequency of attendance  
Telephone support e.g. Parkinson's NSW, Lifeline, etc  
Online support email, Parkinson's NSW, Parkinson blogs  

How supported do you feel overall?
1  2  3  4  5  
Not at all  moderately supported  Very supported  all needs met
**Previous musical experience**

Have you ever sung in a choir before now?  
Yes / No

If yes, for how long? (months, years, etc.) _______________________________________________________

Please describe the choir: number of participants, frequency of practice, performances, etc. ______________________________________________________

Do you play, or have you ever played a musical instrument?  Yes / No

If yes, for how long? (months, years, etc.) _______________________________________________________

Please describe which instrument(s) and did you perform for others?  __________________________

Did you ever have formal singing lessons?  Yes / No

If yes, for how long? (months, years, etc.) _______________________________________________________

Did you ever have formal musical tuition?  Yes / No

If yes, for how long? (months, years, etc.) _______________________________________________________


Appendix R

International Personality Item Pool (IPIP)

Participant Number: ____________________________ Date: __________

Instructions:
- On the following pages, there are statements describing people's behaviours.
- Please use the rating scale below to describe how accurately each statement describes you.
- Describe yourself as you generally are now, not as you wish to be in the future.
- Describe yourself as you honestly see yourself, in relation to other people you know of the same sex as you are, and roughly your same age.
- So that you can describe yourself in an honest manner, your responses will be kept in absolute confidence.
- Please read each statement carefully, and then circle the number that corresponds to the number on the response options.

Response Options

<table>
<thead>
<tr>
<th>Statements - N</th>
<th>Please Circle</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I often feel blue.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>2 I dislike myself.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>3 I am often down in the dumps.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>4 I have frequent mood swings.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>5 I panic easily.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>6 I rarely get irritated.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>7 I seldom feel blue.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>8 I feel comfortable with myself.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>9 I am not easily bothered by things.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>10 I am very pleased with myself.</td>
<td>1 2 3 4 5</td>
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</tbody>
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<table>
<thead>
<tr>
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</thead>
<tbody>
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<td>1 2 3 4 5</td>
</tr>
<tr>
<td>12 I make friends easily.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>13 I am skilled in handling social situations.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>14 I am the life of the party.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>15 I know how to captivate people.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>16 I have little to say.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>17 I keep in the background.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>18 I would describe my experiences as somewhat dull.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>19 I don't like to draw attention to myself.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>20 I don't talk a lot.</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>

International Personality Item Pool: A Scientific Collaboratory for the Development of Advanced Measures of Personality Traits and Other Individual Differences (http://ipip.ori.org/), Internet Web Site.