THE DEVELOPMENT AND PROCESS EVALUATION OF A CO-LED MUTUAL SUPPORT GROUP IN LONG-TERM CARE FACILITIES

by
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Abstract

This thesis describes the development of a new intervention involving co-led mutual support groups in long-term care facilities and the evaluation of its process, structure and content. Tom Kitwood’s Model of Personhood was used as the basis for developing The Little Java Music Club, a weekly discussion group using themes chosen by participants and supportive materials such as related music and photographs. A mixed methods qualitative process evaluation was used, utilizing focus groups, systematic observation of six resident groups, individual resident and staff interviews in three facilities in British Columbia, Canada. A majority of the residents reported positive benefits with themes generated around support, companionship and empowerment. Group observations showed increased participation during and after the sessions. In their interviews, staff revealed an overall positive experience and described how the unique program structure fostered sharing on a deeper level and how it empowered residents with moderate to severe cognitive impairment.

Keywords: Support groups; long-term care facilities; empowerment; personhood; mutual support; nursing homes
Dedicated with much gratitude to my husband, Clayton MacKay:

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<tbody>
<tr>
<td>BC</td>
<td>British Columbia</td>
</tr>
<tr>
<td>CEO</td>
<td>Chief Executive Officers</td>
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<tr>
<td>GDS</td>
<td>Geriatric Depression Scale</td>
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<tr>
<td>LTCF</td>
<td>Long-term Care Facilities</td>
</tr>
<tr>
<td>MMSE</td>
<td>Mini-Mental State Examination</td>
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<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
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CHAPTER 1. Introduction

1.1. Background

1.1.1. The Aging Population in British Columbia

British Columbia (BC) has one of the most rapidly aging populations in Canada. Between 1971 and 2002, the number of persons over 65 years of age grew from 9% to 13.3% (BC Stats, 2006). By 2031 seniors will represent more than double the number today at an estimated 23.7% of the total population of BC. Older adults are much more likely to have chronic health conditions, in part because the prevalence of dementia and other illnesses increase with age. In BC, it is estimated that over 50,000 people currently have dementia (Ministry of Health Services, 2004). Those who enter residential care today are presenting with more complex health needs and levels of disability. Twenty-nine percent of women and 17% of men over 84 years of age live in residential care institutions. Thus, in the near future BC will have both a high overall proportion of seniors and a high number of institutionalized residents. This necessitates a closer examination of available resources to meet current and future needs.

With these changing demographics, the rationing of healthcare resources will continue. The Ottawa Charter states: “Health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances....” (Canadian Public Health Association, Health and Welfare
Canada, & World Health Organization, 1986). Pertinent to this study, well-being and quality of life for residents living in long-term care facilities (LTCF) are an ever-increasing concern in BC and other Canadian provinces. This has led to a new interest in the quality of activity programming.

1.1.2. Social Activities and Well-being in Long-term Care Facilities

Residents are rarely part of planning, preparation or leadership of the social events. Most activities tend to be non-participatory and do not enable residents to relate beyond surface social interactions. In addition, the planned activities are limited by low staffing levels, and activity providers tend to use a combination of tradition and consensus in choosing programs rather than empirical evidence (Kellen, 2003). There is increasing evidence that not all activities are created equal and that some programs thought to affect well-being actually have an adverse effect (Davis & Friedrich, 2004; Garcia-Martín, Gomex-Jacinto, & Martíimportuges-Goyenechea, 2004). An ethnographic study revealed objections expressed by older adults attending an adult day program, stating that the activities offered to them were “childlike” (Tse & Howie, 2005). This study addresses in part, the need to empower LTCF residents by means of fostering a sense of dignity, belonging and self-determination through mutual support groups.
1.2. Mutual Support Groups

Surprisingly, social relationships that residents forge in facilities are believed to have a greater impact on loneliness and depressive symptoms than the relationships with those outside, such as family and friends (Fessman & Lester, 2000). When comparing giving versus receiving support and the effects on well-being, being a giver of support is shown to have 7.6 times more effect, as measured by changes in depression, anxiety, satisfaction and happiness (Schwartz, 2007). Mutual support groups offer an opportunity for individuals to give emotional support to one another and to develop their social relationships.

1.2.1. Why Mutual Support Groups in Long-term Care Facilities?

Group work with older adults has been used in a variety of settings (Abrahams, 1972; Christenson, 1984; Davidson, Chinman, Sells, & Rowe, 2006; Toseland & Rivas, 2005; Wang, Mittleman, & Orth-Gomer, 2005). Toseland and Rivas (2005) list the advantages and disadvantages of group treatment versus individual efforts to meet social or emotional needs. Some of the advantages include: receipt of empathy from multiple sources, feedback, mutual help, the instillation of hope, normalization, role modelling, social support, validation, and the vicarious learning of coping skills. Yet groups also have potential disadvantages including member conformity, member dependency, breaches of confidentiality, and scapegoating. However, in a review of group treatment studies for older adults it was found that group treatment was more effective than individual treatment in 25% of the studies reviewed (Toseland & Siporin, 1986).
Roselle Kurland writes about the empowering effects of group work in the following way:

Mutual aid is at the very heart of good group work practice. The expectation that members of a group will be able to help one another - in fact, that they will be expected to do so—is a statement to each person in the group that she or he has strengths to offer to others. (Steinberg, 2004, p. xi)

Silverman (2004) maintains that the best caregiver for those suffering losses (e.g., widows) is another who has gone through a similar experience. Although the positive effects of mutual support groups, such as self-help groups have been documented among older adults with cancer, depression and with widows (Christenson, 1984; Silverman, 2004; Ussher, Kirsten, Butow, & Sandoval, 2006), there is a paucity of substantive research examining these groups in LTCF. Davidson, Chinman, Sells and Rowe (2006) defined mutual/self support groups as “…groups in which the relationships peers have with each other are thought to be reciprocal in nature; even though some peers may be viewed as more skilled or experienced than others, all participants are expected to benefit” (p. 444). This study therefore, has developed a model that provides a framework in which residents living in LTCF can potentially give and receive support.

1.2.2. The Inclusion of Music and Other Related Materials

The inclusion of music and related materials potentially enriches the mutual support group experience for group participants. Including the arts (such as music and poetry) in activities can increase the active involvement of older
adults (Erikson, Erikson, & Kivnick, 1986). Music provides a vehicle through which people “…can explore who they are and express themselves to others” (Hays & Minichiello, 2005). The intent of adding music to a discussion group is to allow participants to bring their level of sharing from an intellectual perspective to one that is based more in their emotional being. Furthermore, according to Hays and Minichiello (2005), music promotes wellness and helps to connect people to one another and social life.

The use of music as a therapeutic medium with older adults is well-documented. Studies assessing the effects of music therapy suggest, for example, a decrease in depressive symptoms (Ashida, 2000; Shergill, Murray, & McGuire, 1998); slowing the progression of high systolic blood pressure (Takahashi, 2006); and increased melatonin levels, which may contribute to an increase in relaxation and calmness in patients with Alzheimer disease (Kumar et al., 1999). In a Swedish study of 500 community living older adults, it was found that the effects of listening to music is associated with positive emotional functions and belongingness (Laukka, 2007). In addition, a recent study suggests that actively listening to music can assist elderly people with cognitive impairments to maintain purposeful selective attention (Gregory, 2002).

Similarly, the use of poetry, storytelling and related activities have long been used as a therapeutic media in numerous settings including nursing homes (Mazza, 1999; Reiter, 1994). Other components included the Native American
talking stick as a vehicle for discussion. The talking stick is a unique approach to this type of intervention but has an important role in Native American traditions:

The Talking Stick is a tool used in many Native American traditions when a council is called. It allows all council members to present their Sacred Point of View. The Talking Stick is passed from person to person as they speak and only the person holding the stick is allowed to talk during that time period. (First People - Native American Legends, 2007)

1.3. The Process Evaluation

A process evaluation involves looking at why a program was or was not successful (Saunders, Evans, & Joshi, 2005). As this was a pilot of a new program, an evaluation of the structure and content was used in order to assess the implementation of the mutual support group intervention. Both formative and summative evaluation elements were used. The purpose of a formative evaluation is to help to shape the program for the purpose of improving it and the purpose of a summative evaluation is to look at the effectiveness of a program and whether or not it should be continued (Patton, 2002). According to Saunders and colleagues (2005), process evaluations can combine both formative and summative approaches.

1.3.1. Formative Purposes

In this study, formative elements of a process evaluation were used to keep the programs on track. To avoid contamination, no changes were made to components of the intervention during the 3-month study. It was not the intent to
generalize findings beyond the setting of LTCF where this study took place, but to use the information to fine-tune the program for future expansion.

1.3.2. Summative Purposes

Summative uses of the process evaluation include making a judgement about the extent to which the intervention reached the intended participants (in this study via residents and staff questionnaires), and the extent to which the intervention was implemented as planned (Saunders et al., 2005). Summative evaluations are usually used to evaluate the effectiveness of a new program using standardized outcomes with controlled comparisons (Patton, 2002). However, as stated in Patton (2002), summative evaluations are also used to assess merit and worth using qualitative fieldwork data, such as interviews, focus groups and observations. In the current study, information from the data gathered was used to analyze why the program worked (or did not work) and used to make summative judgements whether or not to expand the program in the future (see Chapter 4). This evaluation did not look at outcomes, but focused instead on the processes of implementing the program and how staff and residents felt about specific components of the program.

The process evaluation was based on a comprehensive six step process proposed by Saunders, Evans and Joshi (2005). The approach included evaluation components designed to keep the program on track and to assess the extent to which the program was implemented as planned, and the extent to which it reached the intended participants (Saunders et al., 2005). In addition, the
surrounding social systems were taken into account, such as the existing structures of the organization, characteristics of the staff delivering the program and the external environment. Details of the evaluation process are provided in the research methods section in Chapter 3.

1.4. Purpose of the Study

The main purpose of this study was to present a rationale and detail the development of a new intervention involving co-led mutual support groups in LTCF, and to evaluate its process, structure and content. The intervention was based on a pre-pilot group described in detail in section 2.4.1. Specifically this report consists of two parts:

1. A comprehensive description of the development of the intervention and support group manual, including the theoretical and evidence-base supporting program elements; and

2. A description of the piloting of the intervention combined with the initial process evaluation. The process evaluation includes both formative and summative components: formative evaluation elements were used to fine-tune the intervention and summative evaluation elements were used to assess the extent to which the intervention was implemented as planned, the extent to which it reached the intended participants, and whether it is feasible.

The following chapter outlines some of the challenges facing LTCF, the theoretical foundations for the intervention and the study, a review of the literature, goals and objectives for the groups and a description of the conceptual map built on the theoretical foundation.
CHAPTER 2.

Development of a Mutual Support Intervention in Long-Term Care Facilities

2.1. Challenges in Long-term Care Facilities

Well-being and quality of life have become important concerns in the forefront of debates on the care of those living in LTCF (Ice, 2002; R. L. Kane & West, 2005; Maslow & Heck, 2005). Although significant advances have been made in terms of improved health-related quality indicators and safety measures, other quality of life domains and programs are still minimized in the current culture of LTCF, for example, meaningful activities in which residents have a voice and can develop their social relationships.

2.1.1. Background

Thomas (2006) argues that in spite of well-maintained facilities, excellent medical care and dedicated staff, LTCF residents still suffer from loneliness, helplessness and boredom. There is a persistent feeling within our culture that one cannot expect good quality of life within care facilities (R. A. Kane, 2001). A study of ill older people living in the community showed that 30% of them would “rather die” than have to live in a nursing home (Mattimore et al., 1997). These issues plus the association between social involvement and positive health outcomes (i.e. improved health in relation to social support) highlight the potential
importance of research in this area (Tomaka & Thompson, 2006; Wang et al., 2005).

2.1.2. Definitions in Long-term Care

One of the challenges in writing about well-being in LTCF is the variation in usage of names and definitions. Across Canada there is a range of terminology for homes providing care (e.g., nursing home, intermediate care facility, long-term care facility). For the purposes of this study the term long-term care facilities will be used and defined as residential care for people with complex care needs who require 24-hour supervision, personal nursing care and/or treatment by skilled nursing staff (Ministry of Health Services, 2007). These facilities are not publicly insured under the Canada Health Act; instead, they are provincially managed or privately owned and provide professional health services, personal care, meals, laundry, housekeeping and additional therapeutic services (Health Canada, 2007). The term “residents” will be used as opposed to the term “patients”, as the former reflects their ongoing living situation rather than the more transient hospital setting.

2.1.3. Identified Problems in Long-term Care Facilities

In 2004, the Canadian Healthcare Association published a policy brief outlining four problems concerning LTCF: (a) lack of federal funding for long-term care institutions and health services, which means that the standards of affordable care for older people vary across provinces; (b) inconsistent quality of care across provinces and accountability with inadequate staff training and staff
levels; (c) lack of resident dignity and choice, and appropriate end-of life care; and (d) lack of respect of volunteers and families— their role is to provide support, not do the work of paid staff (Health Canada, 2007).

Hirdes, Cormack and Perez (2004) presented five quality of care issues that lack evidence based practices in long-term care: lack of ongoing comprehensive assessment and care planning; lack of a common language across the healthcare system to enable direct comparisons; lack of evidence-based decision making regarding the complexity of care; improved mechanisms for accountability and funding; and additional funding for nursing, personal care and therapies.

It is beyond the scope of this study to address all of these issues; however, identifying the problems in LTCF provides a framework of the challenges encountered. This study will look specifically at the issue of lack of resident dignity and choice and associated resident well-being and the lack of evidence-based decision-making within activity programming in LTCF. Obtaining adequate individualized therapeutic services is not possible with the currently available funding within long-term care (Hirdes, Cormack, & Perez, 2004). However, creating an environment that encourages residents to support themselves within an evidence-based intervention such as a mutual support group, is a potentially effective approach to addressing this identified problem.
2.1.4. The Myths of Aging and the Medical Model of Long-term Care Facilities

Aging myths and the medical model currently used in residential care both contribute to the challenges faced by the facilities. The National Advisory Council on Aging published a bulletin in 2003 delineating the negative myths of aging that influence public policy (National Advisory Council on Aging, 2003), such as “to be old is to be sick” or “seniors are too set in their ways to undertake new things.” Furthermore, there exists a common assumption that aging is a disease that requires medical treatment. According to the National Advisory Council on Aging (2003), education for policymakers, the public, caregivers and professionals is paramount in discounting these myths. In this study, giving voice to the seniors themselves through the mutual support group framework, is another possible approach.

The focus on meeting the medical needs of LTCF residents continues to predominate with safety as a pivotal point in chronic care (R. A. Kane, 2001). This medical model standard is one of the elements that drives the development of the policies in institutions and has far-reaching impact on the well-being for those living in facilities. Under this umbrella, the recipient of care has moved historically from being a vagrant to being an unproductive member of society and a helpless victim of the aging process (Forbes, Jackson, & Kraus, 1987). An example of this in LTCF is holding safety as a priority over the individual beliefs and preferences. This is not to say that the advances that have occurred in improving the medical care of residents are not important or valued, but that the
adherence to disease-based models of care do not empower residents to take an active role in their own care (Kitwood, 1997). Thus, bringing added focus of care in facilities to one that empowers residents is an important move towards enhancing quality of life (R. A. Kane, 2001). An alternative approach includes the least restrictive environment possible and goes further than the traditional health and safety outcomes. When asked, older people consistently report their preferences for fewer years of higher quality of life over more years with a lower quality of life (Lawton et al., 1999).

Mutual support groups can provide a framework wherein residents can express preferences and wishes in a supportive environment. The choices made by residents may perhaps not always be safe in terms of the traditional healthy and safety norms in LTCF (e.g., a desire to on a boating trip); however, groups can give residents a chance to be heard within the often rigid and hierarchical medical system.

2.2. Theoretical Foundations

The concept of “personhood” as put forth by Tom Kitwood (1997), is used extensively in the literature and is the theoretical foundation for this study. Kitwood focused on personhood within dementia care. Personhood as defined by Kitwood (1997), is “...a position or social relationship that is bestowed on one human being by ‘others’, in the context of relationship and social being” (p. 8). Personhood includes the importance of social relationships and the value of
Mutual Support Groups in Long-term Care Facilities

individual beings regardless of their disability (Kitwood, 1997). There are a number of philosophical positions that challenge Kitwood’s approach (Dewing, 2008), however, his work has made a significant contribution to awareness of the lived experience of those with dementia. At the core is a moral concern for others and a conviction that personhood need not be based on the presence of cognitive ability.

2.2.1. Personhood in Long-Term Care Facilities

Within the culture of a LTCF, the focus on traditional medical care often depersonalizes and disempowers residents (R. A. Kane, 2001). As described by Dewing (2008), Kitwood contends that there is a malignant social psychology in our society—one that places higher values on intellectual functioning than on non-cognitive attributes. Kitwood (1997) argues that in many instances the social positioning that occurs around residents with losses in functioning and capacity, results in loss of personhood. Within LTCF, this is demonstrated by staff who often inadvertently place persons with dementia in a position of ‘other’—someone with less ability and status. This positioning can occur in a myriad of subtle ways, between both the staff and residents and between the residents themselves, even when the intention is caring and positive (Dewing, 2008).

The present study expanded Kitwood’s key concepts beyond dementia care to include the care of residents living in LTCF with a range of disabilities. In addition, it expanded the concept of care given from the staff to the residents, to care given from the residents to one another in developing positive interpersonal
relations. Just as putting the person first is an important healthcare professional practice with clinical interventions, so is putting a fellow resident’s personhood first a potentially important relationship-building practice. The mutual support group setting offered a structure in which this behaviour was be modelled and supported.

According to Kitwood (1999), three psychotherapeutic interactions that facilitate positive relationships include: (a) Validation: acknowledging person’s emotions and feelings and responding to them, (b) Holding: providing a space where the individual feels comfortable in self-revelation, and (c) Facilitation: enabling person to use their remaining abilities. Thus through the positive interactions, stability and secure relationships that can develop in the mutual support groups, the personhood of the individual residents is reinforced (Kitwood, 1999).

The mutual support model in this study was based on aspects of reciprocal altruism (Trivers, 1971), pseudo-reciprocity (Conner, 1986) and the helper-therapy principle (Riessman, 1965). Residents living in LTCF share challenges in living with a disability as well as numerous losses related to moving into an institution (Guse & Masesar, 1999). As reported by Guse and Masesar (1999), an example is loss of control over everyday decision-making, which has a significant impact on resident well-being. Park and Schaller (2005) purport that empathy for others that are in similar challenging situations can act as an emotional cue and foster feelings of closeness (Park & Schaller, 2005).
2.2.2. Reciprocal Altruism

Reciprocal altruism is a form of helping in which the benefactor does not expect any form of immediate return (Trivers, 1971). Within this theoretical framework, altruistic behaviour involves an expectation that the benefits received will be larger than the costs. Trivers (1971) outlines a regulating system that balances giving and taking. This regulating system is complex and involves several aspects: emotion (the tendency to like others and form friendships); gratitude and sympathy (sensitivity to the recipient's needs), and trust and the formation of friendships that are balanced with aspects of 'cheating'. In this case, cheating refers to the extent to which people do not return the benefits, e.g., giving back only partially or even mimicking altruism (Trivers, 1971). Although there is a temporary expense expected, there is also a long-term expectation of benefit.

In a close living environment such as a long-term care facility, reciprocal altruism is played out in resident interactions. Residents learn from one another and act together to form exchange systems of giving with agreed upon rules. The regulating system works so long as the system keeps the 'cheating' (i.e., failing to reciprocate) at a minimum.

2.2.3. The Helper-Therapy Principle

As described by Riessman, in 1937 Alfred Adler proposed that social interest or altruistic helping is innate to the human condition and results in enhanced life satisfaction (Riessman, 1965). The 'helper-therapy principle' put
forward much later by Riessman (1965) expanded this Adlerian view to theorize that helping those in need also leads to self-validation and increased self-worth.

2.2.4. The Helper-Therapy Principle and Groups

In addition to individual benefits, Riessman (1965) contends that through helping others, not only do group members benefit but so does the group as a whole, creating a group synergy. The helper-therapy principle is similar to the concept of social support from peers but includes group members giving as well as receiving help from one another; the group as whole benefits from this unidirectional supportive structure. This assertion is empirically supported by numerous studies with different populations (Kyrouz, Humphreys, & Loomis, 2002).

The mutual aid group structure highlights three important aspects of therapeutic group work: (a) the traditional support group helper-helpee ratio is shifted and the number of helpers increases and the number of helpees decreases; (b) the loss of status experienced when receiving help is gone as the helpee knows that s/he will also be giving back in the future; and (c) the combined perceived power of many group members being of service to one another expands the power of the groups as a whole, that is, with so many residents taking on a helping role, the ability of each member to be of help is strengthened (Riessman, 1965).

More recently, Riessman (1997) described 10 principles that drive self-help groups: (a) social homogeneity, peers are more influenced by one another
than an authority figure; (b) *self-determination*, group activities are determined by group members themselves; (c) *helper therapy*, giving help is the best way to receive help and reduces dependency; (d) *group members as prosumers*, as consumers of help (accepting support from fellow group members), group members also produce help (supporting fellow group members) and therefore increase consumer capital; (e) *strength versus pathology*, focus is on inner strengths of group members, not their disability; (f) *non-commodification*, help provided is not bought or sold, it is freely given; (g) *social support*, supportive relationships within the group buffer against stress and allow for new interpretations; (h) *ethos*, values are created and practiced within the group (e.g., giving help); (i) *the self-help solution*, belief in group wisdom and experiential learning as opposed to seeking expert help; and (j) *internality*, internal healing done by the individual within the group versus a cure provided to a patient by a physician or therapist (Riessman, 1997).

The culture of LTCF can create barriers and constraints on resident’s struggles for autonomy (Garmonth & Semradek, 1995). In the mutual support groups residents can both receive help and experience being of help to one another, in spite of their disability. The practice of helping one another as opposed to relying solely on staff for assistance may be an antidote to the traditional role of a resident in an institutional setting. Through the weekly sharing of their stories, residents may discover that whatever their problems, it is possible
that they are not alone. The act of sharing and listening to one another can potentially reinforce each member’s value and wisdom.

2.2.5. Empowerment and Groups in Long-term Care Facilities

According to Rappaport (1987), empowerment is a process in which people gain mastery over their affairs and increase their sense of effectiveness within their community. The concept of empowerment can provide a guide for developing interventions in which participants have a stake (Rappaport, 1987), and link well-being with mental health, mutual help and the desire to create a community that is responsive to individual needs (Perkins & Zimmerman, 1995). According to Berman-Rossi (2005), not only are residents naturally drawn to each in their common need, but a support group provides a source of hope. As opposed to creating passivity (Beckingham & Watt, 1995), the goal of empowerment is “to encourage older persons to discover their strengths, talents, and solutions and to enhance the possibilities for them to meet their identified needs and exert control over their own lives” (p. 484).

2.2.5.1. The Myth of Empowerment in Long-term Care Facilities

Developing a culture that allows for the resident’s voice to be heard is being advocated in LTCF (R. A. Kane, 2001; Thomas, 2006), and a number of indications in the research point to the practical potential of groups to achieve this aim. For example, Paterson (2001) describes “the myth of empowerment” perpetuated in healthcare through time-limited structured approaches that assume that patients are empowered only through a professional, individual
intervention. In addition, it is at times mistakenly assumed that residents, if offered the opportunity, would become active agents in their own lives, that is, to assume that all a healthcare professional needs to do is make choices available (Paterson, 2001). Findings indicate that if people do not feel prepared and are not given sufficient time they will likely rely on someone else to make decisions for them (Paterson, 2001). Research also suggests that interventions that are embedded within ongoing supportive interpersonal relationships (e.g., groups) have the similar results as one-on-one counselling (Gitterman & Shulman, 2005; Gottlieb, 2000; Kyrouz et al., 2002; Paterson, 2001).

2.2.5.2. **Empowerment through Groups**

Self-reported results in an Australian study indicated increased empowerment and agency (compared to family/friendship support) with no differences reported between the professionally-led and peer-led groups (Ussher et al., 2006). The mutual support group is a format that naturally creates a group synergy (Riessman, 1997) and empowers individual members. With a structure in place that facilitates all members participating, frail residents are more likely to engage with the process, speak up and feel empowered to make choices and decisions. The mutual support group offers a powerful process that can act as a buffer to offset the passivity and dependence fostered in the culture of LTCF and foster ‘collective empowerment’ (Berman-Rossi, p. 501).
2.2.6. Assumptions

The process of reflexivity on the part of the researcher is one in which the social background and assumptions are examined and included in the research (Hesse-Biber & Leavy, 2006). It is important to be aware of the relationships and situations between the residents in the care facilities and the researcher in the creation of the intervention and the process evaluation. Therefore, the researcher’s assumptions are examined here and will be included in the results.

The ontological position held here is that there is a reality that many residents living in LTCF do not have a voice in their daily lives, suffer from significant loneliness and lack a sense of belonging to their communities. However, the position also held is that there are individual as well as shared constructed realities and that mutual support groups can allow for new meanings to arise through social interactions. Epistemologically, the investigator and the object of the investigations are interactively linked. In this study, the researcher developed the co-led mutual support group intervention through a process of co-creation with the residents. The shared construction of realities can only be understood in a naturalistic setting, meaning the groups are developed, held and understood within the institutions themselves. The findings were created as the investigation proceeded, meaning that although research questions were posed, open-ended questions at the beginning of the interviews and focus groups left room for alternative findings. Process changes over time and although this is not included in this process evaluation, the belief held is that resident’s definitions of meaning within these groups will evolve and change over time. Thus it would be
useful for future research to examine the groups over a longer period of time. Lastly, the research is pragmatic and the development of the intervention was meant for ongoing practical use in LTCF.

A number of assumptions are acknowledged here. The first assumption is that there is no understanding without interpretation (Angen, 2000) and the belief that people co-create their reality each day with others. The advantage this researcher held in co-creating the intervention, was many years experience working in a LTCF which contributed to insider trust and understanding. It is acknowledged that there was a simultaneous disadvantage in this experience, in that assumptions could have been made when participants said things like: “...you know what I mean.” Other researcher assumptions acknowledged here include: people are influenced by the culture around them; older people and those with disabilities are capable of growth and change; people are active agents in their daily lives; people grow when they engage in mindful interactions with others; and finally, people strengthen their own well-being when they support and encourage others.

2.3. The Literature

2.3.1. Terminology in the Literature

The terminology used in the literature to define the support group format varies and, in some cases, implies different approaches. Terms used include “mutual aid”, “self-help”, “peer support” and “mutual support”. Mutual aid is found
most often in the literature (Gitterman & Shulman, 2005; Gottlieb, 2000; Kelly, 1999; Lee & Ayon, 2005; Steinberg, 2004). Self-help groups is found less often and tends to focus on patient-led change-organisations (Dibb & Yardley, 2006) and provision of social support, education and information (Christenson, 1984; DeCoster & George, 2005; Dibb & Yardley, 2006; Gottlieb, 2000; Kyrouz et al., 2002; Stewart, Craig, MacPherson, & Alexander, 2001). Several studies used “peer support” in groups with older adults with psychiatric issues, cancer patients and visually impaired older persons (Davidson et al., 2006; Ussher et al., 2006; Van Zandt & Van Zandt, 1994). Peer support tends to be conceptualized as groups that are led by participants who offer support to those who are not as far along in their own recovery process (Davidson et al., 2006).

2.3.2. Mutual Support: Conceptualization and Definition

Although the term “mutual support” is used the least often in the literature it will be used for the purposes of this thesis. It will be used to describe the supportive process in groups where “…the relationships peers have with each other are thought to be reciprocal in nature; even though some peers may be viewed as more skilled or experienced than others, all participants are expected to benefit” (Davidson et al., p. 444). Stewart and colleagues (2001) used the term to describe the emotional, practical, informational and affirmational support provided by peers and professionals. Three integral processes were outlined that make up mutual support within a group: (a) social comparisons that validate and normalize experiences, (b) supportive bi-directional social exchanges, and (c) the
sharing of first-hand experiences among group members that strengthen learning and enhance self-efficacy.

There are two reasons why this term has been chosen for this thesis. The first reason is the term “aid”, which describes helping or giving support to, but is also associated with medical terminology (e.g., a “nurses aide”). Thomas (1996) contends that people thrive in home-like surroundings and therefore medical terminology and medical practices are best redefined as much as possible in order to best create this environment. Choosing the term mutual support over “mutual aid” may seem to be a subtle difference, but does contribute and hold true to this contention. The second reason mutual support has been chosen, is to highlight the shift in leadership from the typical mutual aid support group where the role group worker is to conduct treatment to the role of one who facilitates a setting in which participants can learn to support one another (Room & Kaskutas, 1998).

2.3.3. The Effects of Mutual Support Groups in Different Contexts

There were a number of studies found in this literature search around the topic of support in a group format (Gottlieb, 2000). Due to the paucity of studies done on mutual support in LTCF, this literature review will draw largely on pertinent aspects of studies done with adults in community settings.

The effects of mutual support/mutual aid groups have been documented among individuals with a variety of problems or life crises, including bereavement, alcoholism, mental illnesses, visual disabilities and depression.
Two areas that are of interest to this study include: (a) mutual support groups with adults in the community including people with chronic illnesses (Dibb & Yardley, 2006), widowed seniors (Abrahams, 1972; Stewart et al., 2001), adults with mental illnesses (Davidson et al., 2006), older people with visual disabilities (Van Zandt & Van Zandt, 1994); and (b) Mutual support groups in LTCF, including adults with depression (Christenson, 1984).

2.3.4. **Mutual Support Groups with Adults in the Community**

In a review of the literature on mutual support groups, Gottlieb (2000) found 53 intervention studies since 1985; only a small number were specific to older adults. Two studies with older adults compared the effects of a group intervention to a no treatment (control) group with bereaved older adults. The first study focused on widows and widowers and found a significant difference in adjustment and psychological stress between those who formed friendships within the group relative to those in the control group (Lieberman & Videka-Sherman, 1986). The second study included bereaved older women that met for 12 sessions; the results showed statistically significant improvements in stress and psychiatric symptom relief compared to the group participants (Marmar, Horowitz, Weiss, Wilner, & Kaltreider, 1988).

A number of published studies examining the efficacy of mutual support groups in the community focus on coping with a loss and/or a disability. Van Zandt and Van Zandt (1994) examined the effects of peer support groups with 231 older visually impaired American adults (50 to 96 years of age). This study
employed a quasi-experimental design that compared peer support group with two other groups: a) one with peer support and rehabilitation services, and b) one with neither peer support or rehabilitation services. The second group with both peer support and rehabilitation services reported success in coping and satisfaction with level of activities and had a more positive outlook on life (Van Zandt & Van Zandt, 1994). It has been noted that the format and structure of mutual aid groups should not be generalized to all populations (Kelly, 1999). For example, older adults with a mental illness experience different problems and issues than younger adults or those in the same cohort but with other non-psychiatric conditions. This suggests the need to tailor to needs of a specific population and to target specific conditions.

In the Netherlands, 112 patients with chronic rheumatic disease participated in a randomized control trial using self-report questionnaires and group interviews following attendance of mutual support groups (Savelkoul & DeWitte, 2004). Patients reported satisfaction with the intervention and felt supported but only one statistically significant effect was found, and that was a reported increase in social skills (i.e., an increase in expressing positive feelings towards others). In a convenience sample of 13 seniors, DeCoster and George (2005) sought to empower elders and increase diabetes self-care behaviours. This study used a quasi-experimental design. A true posttest measure was not obtained as the participant’s group continued to meet (DeCoster & George,
2005). Significant improvements in self-efficacy and self-care behaviours and a reduction of glycosolated haemoglobin were reported.

A larger control study of nine cancer peer-support groups with 93 participants in Australia was carried out with survey interviews, focus group interviews and participant observations (Ussher et al., 2006). Results indicated increased empowerment and agency (compared to family/friendship support) with no differences reported between the professionally-led and peer-led groups.

### 2.3.5. The Effects of Mutual Support Groups in Long-term Care Facilities

The group format as therapeutic intervention in LTCF makes sense on several levels: social isolation continues to be a documented concern; groups allow one staff member to work with a number of residents simultaneously; and residents in long-term care share similar concerns about adjusting to institutional living (Molinari, 2002). A review of the literature, however, shows that although reports exist of mutual support group work with older people, the majority are small, single-group cross-sectional studies using un-standardized measures lacking control or comparison groups (Gottlieb, 2000; Kyrouz et al., 2002; Toseland & Rivas, 2005). Even though the overall findings specific to mutual support group work are positive, most findings were anecdotal and therefore unreliable.

Initial reports of group work in the homes for the aged tended to focus on issues of helping residents adjust to the home, increase social contacts and
enhancing well-being (Konopka, 1954; Shore, 1952). More recently, a US study was conducted with a small self-help group for the depressed elderly living in a nursing home (Christenson, 1984). Staff leaders chose the topics of the group discussions and focused almost exclusively on goal setting. Although the purpose was to encourage the depressed elderly to regain control over their lives, elements of this group structure may have run counter to that purpose.

In a discussion of the challenges that institutionalized residents face, Berman-Rossi (2005) describes the need for mutual aid groups. He states that the institutions bear the responsibility of providing means to support residents in dealing with institutional stressors as well as ways to empower them to engage with the institutional decision making (Berman-Rossi, 2005). He contends that the mutual aid group potentially provides such a structure and gives residents a means to foster resiliency in a supportive environment of their peers. Therefore, developing a vehicle for residents to participate in such a group and providing the necessary support from staff, can address this need in LTCF.

2.3.6. The Benefits of Co-leadership in Long-term Care Facilities Mutual Support Groups

Thomas (1996) contends that a long-term care facility honours its elders by de-emphasizing top-down bureaucratic authority, seeking instead to place the maximum possible decision-making authority into the hands of the elders or into the hands of those closest to them. Although the presence of a staff facilitator may be vital to the regular functioning and maintenance of mutual support groups in LTCF, Thomas (2006) argues that the extent to which staff members place
decision-making into the hands of the residents, is the extent to which they will flourish.

Shared leadership is a common theme running through much of the literature (DeCoster & George, 2005; Savelkoul & DeWitte, 2004; Ussher et al., 2006). In their study of a support intervention with widowed seniors, Stewart and colleagues (2001) initially provided joint training for selected group members and for the recruited professional leaders. The Widowed Service Line was co-led by two coordinators at the laboratory of Community Psychiatry, Harvard Medical School, and the telephone calls were handled by 18 widowed volunteers (Abrahams, 1972). The volunteers had responsibilities in supervising, training and public relations. In a nursing home study, co-leadership was shared equally in the initial stages and the role of the facilitators decreased over time as group members were empowered to take on increasing leadership and decision making roles (Christenson, 1984). As previously noted, in groups with adults with serious mental illnesses, those who are further along in their recovery offered support to peers in the earlier stages (Davidson et al., 2006). Similarly, in the widow support groups, peer leaders had been widows for a least 2 years with demonstrated increased leadership skills (Stewart et al., 2001). In another study of the arthritis self-management program developed at Stanford University, patients who participated in 6-session self-management classes patients showed a noted improvement in being able to cope with their chronic conditions (Holman & Lorig, 2004; Lorig, Mazonson, & Holman, 1993).
Studies have suggested the benefits of taking on the role of being a “peer supporter” versus being the receiver of support (Schwartz, 2007), and the positive effects on participants taking on a leadership role (Lorig et al., 1993). The current study will build on the above noted research and use a co-leadership model for the mutual support groups in order to empower group participants. All the participating residents will be offered opportunities on a rotating basis to make decisions about the group processes (such as choosing a theme) and to co-lead the group along with the staff facilitator.

2.3.7. Preparation for Long-term Care Facilities Mutual Support Groups

Initial planning before a group begins is critical. It is helpful if the staff member is aware of cohort effects and has some awareness of their own reactions to aging, their own stereotypes about aging and illness in general. An example of cohort effects could be 80- to 90-year-olds that share the economic depression years of the 1930s and World War II service rationing and other related factors. Also of note, older adults raised in that era tend to have less education; mental illness and counselling was seen as a reflection of personal weakness (Toseland & Rivas, 2005). Residents from that cohort may therefore be more hesitant to accept help in any form.

Steinberg (2004) suggests four guidelines to help group facilitators prepare themselves for leading a support group:

1. the facilitator needs to be cognizant of individual group members and remain aware of the group process as a whole;
2. the facilitator is not regarded as the primary helper but rather one of many. The facilitator supports an exchange of stories and spontaneous communication among members;

3. the facilitator ensures that every group member has an opportunity to participate (even if in a limited capacity);

4. the facilitator ensures that the group has a common cause or purpose and assists the group in choosing and developing clear guidelines.

2.3.8. What is the Ideal Length of Long-term Care Facilities Mutual Support Groups?

Studies suggest that the length of time group members are involved is associated with levels of satisfaction (Van Zandt & Van Zandt, 1994). Review of the literature specific to older adults regarding the ideal length for mutual support groups suggest that short term groups achieve little or no sustainable results whereas groups that meet for 6 months or longer tend to show superior efficacy (Gitterman & Shulman, 2005; Gottlieb, 2000; Kyrouz et al., 2002). This suggests a slow and delayed process of change over time (Gottlieb, 2000). However, due to the high attrition rates in LTCF, there is also a turnover of residents within that same period of time. This study will focus on the process of the early formation stages of a new mutual support group over a period of 3 months.

2.3.9. Music and Other Related Materials in Mutual Support Groups

The purpose of adding music to the mutual support group structure in this study is 4-fold: (a) to bring a focus to the group as an enjoyable and relaxing entity, (b) to help group members include an emotional component in their sharing through listening to songs/music related to a chosen topic, (c) to assist
group members in extending their boundaries and exploring new ways of viewing a particular challenge through a discussion of the lyrics or other aspects brought up through listening to the music, and (d) to assist participants in maintaining their attention on the chosen topics. Participants will be able to choose songs related to the topic from an available list which includes a recording, the music and the lyrics.

Other related materials that can serve to enhance the topics will also be available to the groups. These include poetry, affirmations and quotes that can be used in conjunction with the music and the sharing. Some members may prefer music and others may relate more to literary media. Choices may enable residents to participate more fully in the group discussions than they might otherwise.

2.4. Process Evaluation of the Mutual Support Groups

The process evaluation of the mutual support groups in this thesis was based on a combination of descriptive and qualitative methods. The use of focus groups, descriptive survey results, and observation was used in order to more accurately study the complexities involved in the mutual support group processes (see details in Chapter 3).

2.4.1. The Little Java Music Club Program

Using the 10 helper therapy principles outlined above, a mutual support group structure was developed called The Little Java Music Club. The history of
this group dates back to 2004 when an informal discussion group was formed within a facility in response to a need expressed by residents living there. The residents in this group wanted a place to meet and a format that would allow them to get to know each other better. The group was facilitated by the author who worked there in the role of a music therapist. The group met weekly, named themselves The Little Java Music Club, had coffee and tea, sang songs and discussed a wide variety of themes. Within the first year the group wrote an original opening song named after the group’s title, and a closing song entitled: “I’ll be there for you”.

Over the next six years the group developed a more formal structure, becoming the pre-pilot used to establish guidelines and a manual to help the groups function. A list of discussion themes grew out of the topics suggested by the participants as well as staff facilitating the group. Quotes, photographs, readings and songs were collected that supported the topics.

The title, The Little Java Music Club, reflects an informal non-threatening approach to support groups, involving coffee and music in an attempt to invite and sustain resident participation (as opposed to calling it a Mutual Support Group). From the success of the pre-pilot group, it became apparent that the mutual support group format could be a potentially effective approach that would have an impact on resident well-being. Calling it a club seemed to provide residents with an opportunity to join something and foster a sense of belonging. The title of the group was provided for organizational purposes of this study and
to promote the program to facilities and the staff who implemented it. Study
groups were encouraged to add a unique name for their own groups once they
started, (e.g. Heart to Heart: The Little Java Music Club) and there was a place
for that within the opening song. The original pre-pilot group continues to meet
weekly and still has several of the original members participating.

In the study, groups also met on a weekly basis. The groups had a
participatory format in which residents had opportunities to share issues focusing
on their experience of living in the care facility. It was expected that they would
look to one another for role models and validation of their experiences, and to
learn coping skills. The group format included use of themes chosen by the
residents and related materials such as music and poetry. A staff member co-led
the groups with a resident group member, arranged for the set-up of the group
and acted in the role of a facilitator to assist with any special needs of the
residents.

A typical group session of The Little Java Music Club starts off with eight
to 10 resident group members sitting at a table. Background music is playing and
coffee or tea is offered as well as some form of refreshment (cookies or fresh
fruit). While coffee is being served, the staff facilitator invites one of the residents
to co-lead. The resident co-leader then chooses a theme for the discussion that
day from a list provided or a theme of their choice. After the opening song is
sung, the resident co-leader reads the group guidelines from the manual
provided. Guidelines refer to the purpose of the group, the purpose of the talking
stick and other issues such as keeping sharing to five minutes so that all members have an opportunity to share (see Appendix G). Group members are invited by the staff to share how their week has been. Those sharing hold the Native American talking stick provided as a visual cue and a reminder to respect other’s opinions. Questions pertaining to the chosen theme are available in the manual and are posed to the participants - those who wish, offer thoughts on the topic. From time to time, other topics arise and group allows for this diversion so that the topics are pertinent to the current issues of the group members.

After a few of the participants share, the resident co-leader either chooses a theme-related song which is played on a CD player, or asks another group member to read a theme-related quote or reading. Both are provided in a kit with the manual. This gives the group a break from talking and also provides potential mental and/or emotional stimulus for the discussion. When appropriate, the staff facilitator also shows theme-related photographs which often stimulate memories or story-telling. The discussion continues until all the group members have shared or until about 45 minutes have passed. Participants are invited to help with clean up and to aid fellow group members requiring assistance back to their rooms.

2.4.2. Goals and Objectives of The Little Java Music Club

The primary goal of The Little Java Music Club intervention was to enhance residents’ overall well-being and quality of life through their participation in weekly group sessions. The specific objectives for The Little Java Music Club
were generated directly from Riessman's principles. Table 1 is based on these principles and illustrates the essential differences in characteristics between a mutual support group and a typical social group activity in a LTCF.

**Table 1. Mutual Support Groups versus Typical Groups in Long-term Care Facilities**

<table>
<thead>
<tr>
<th>Mutual Support Groups in LTCF</th>
<th>Typical Activity Groups (e.g., Current Events Group)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social homogeneity:</strong> Residents are more influenced by one another than by staff</td>
<td>Staff member in role of leader has more influence on residents than residents do with each another</td>
</tr>
<tr>
<td><strong>Self-determination:</strong> Residents set-up, choose group topics, songs and activities</td>
<td>Staff members set-up group structure: Offers the activity and leads the group</td>
</tr>
<tr>
<td><strong>Helper therapy:</strong> Residents supporting each other reduces feelings of dependency</td>
<td>Residents dependent on group leader for support</td>
</tr>
<tr>
<td><strong>Group members as 'prosumers':</strong> Group members give help and also need help—increases opportunities to give help</td>
<td>Staff members give help and residents remain receivers of help</td>
</tr>
<tr>
<td><strong>Strength versus pathology:</strong> Focus is on resident's inner strength, not disability</td>
<td>Being receivers of help from staff reinforces disability</td>
</tr>
<tr>
<td><strong>Non-commodification:</strong> Help is freely given</td>
<td>All help given has a cost (e.g., activity staff wages)</td>
</tr>
<tr>
<td><strong>Social support:</strong> Supportive actions in the group create a stress buffer and allow for new interpretations of life within LTCF</td>
<td>Focus of a current events' group is typically on events outside of the care home</td>
</tr>
<tr>
<td><strong>Ethos:</strong> Values are discussed and practiced within the group e.g., giving help to one another</td>
<td>Focus is on events outside of the home, not necessarily values held by residents or the home</td>
</tr>
<tr>
<td><strong>The self-help solution:</strong> Belief in group members wisdom—not outside help</td>
<td>Residents seek expert help: Within the home (e.g., nursing) or outside (e.g., resident doctor)</td>
</tr>
<tr>
<td><strong>Internality:</strong> Residents find support through the group processes</td>
<td>Residents seek outside professional therapeutic help</td>
</tr>
</tbody>
</table>

*Note.* Based on Riessman's (1997) self-help principles.

Based on these principles, five specific objectives of this mutual support group were developed. The objectives related to different group members based on their individual characteristics, personal goals and preferences:
1. to increase self-determination through taking on leadership and making choices (groups members had an active voice in choosing themes, songs and other activities);
2. to increase giving and receiving help (groups members were given opportunities to offer advice and wisdom to one another as well as opportunities to receive);
3. to increase their focus on inner strengths, beliefs and abilities (themes, quotes and songs were available that foster discussion around inner growth and exploration of current abilities);
4. to strengthen supportive relationships with one another (themes, quotes and songs were available that encourage discussion about and the development of supportive relationships); and
5. to increase expression of challenges faced in a way that allow for new interpretations (themes, quotes and songs were available that foster discussion on alternative ways of looking at or coping with challenges).

2.5. Conceptual Map

The foundation of this thesis was built on a long-term care facility mutual support model based on concepts of personhood (Kitwood, 1997), reciprocal altruism (Trivers, 1971) and the helper therapy principle (Riessman, 1965). The model (see Figure 1) describes this format as a vehicle for residents to support one another through participation in the mutual support group framework.

As specified in Figure 1, the theoretical foundation is personhood—validation, holding and facilitation. This leads to reciprocal altruism, balanced giving and taking which leads to trust which, in turn, predicts reciprocity (Trivers, 1971). When reciprocity is expressed in groups (within the Helper Therapy Principle framework), helping benefits both the individual and the group (Riessman, 1997).
Figure 1. Conceptual Map

Ongoing Participation in Co-led Mutual Support Groups

- Increase in Resident Empowerment and Well-Being
- Increased Focus on Inner Strength
- Increased Giving and Receiving Help
- Strengthened Supportive Relationships
- Increased Self-Determination

Helper Therapy Principle:
- Reciprocity as Experienced by Group Members
- Helping Benefits Individual and the Group
- Helper as Self-Aware, Caring, and Empathetic
- Social Support Created as a Stress Buffer
- Residents Feel Belonging, Experience Empowerment

Reciprocal Altruism:
- Trust Produces Reciprocity
- Balanced Giving and Receiving

Personhood: Validation, Holding and Facilitation

Focus on Strengths and Resilience
- Other Values Are Discussed & Practiced

Promote Residents' Belief in Their Ability
- "Program" Residents: Give Help & Need Help

Self-care
- Social Support Creates
- Internalized Resilience
- Support Through Group
The following 10 principles are components that are expressed in varying degrees in the groups: social homogeneity, self-determination, helper therapy, residents as “prosumers”, focus on strength versus pathology, non-commodification, internality, social support, self-help solution and ethos. Activity staff working at the facilities will assist the residents in starting the groups and in co-leading them. The residents will learn how to support each other in what may be an unfamiliar group format and hopefully take on more leadership as befits their comfort level. Based on these principles, participation in the co-led mutual support groups potentially leads to five objectives: increased focus on inner strength; increase in giving and receiving help; strengthened supportive relationships, increased self-determination and; increase in expression of coping alternatives. As shown in Figure 1, the ultimate goal of improved resident well-being feeds back into these five objectives which in turn lead to continued participation in the groups.
CHAPTER 3.

Methods

3.1. Overview of the Research Design

The process evaluation used as the foundation for the study was based on a six step process proposed by Saunders, Evans and Joshi (2005). The six-step approach included evaluation components designed to keep the program on track and to assess the extent to which the program was implemented as planned, and the extent to which it reached the intended participants. This chapter will provide an overview of the research design, discuss the use of observations, interviews and focus groups as an approach, provide details of the group design including the group manual and structure of the mutual support groups, a description of the setting and sample participants, data collection procedures, details of the process evaluation plan and the analysis plan.

A mixed methodological approach utilizing descriptive, qualitative and focus group methods was used in order to conduct a multimodal evaluation of the processes involved in implementing mutual support groups within LTCF. The need for the integration of research approaches as complementary paradigms has been identified (Denzin & Lincoln, 2005). This study focused on the use of dissimilar but complementary methods, called method triangulation (Mitchell,
Method triangulation allows for the use of multiple perspectives to collect and interpret data, providing corroborating evidence of findings. Specifically, the methods in this study included systematic observation of the groups, resident and staff individual interviews and resident focus groups (see Table 2).

**Table 2. Evaluation Methods Summary**

<table>
<thead>
<tr>
<th></th>
<th>Month 1</th>
<th>Month 2</th>
<th>Month 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>wk 1 wk 2 wk 3 wk 4</td>
<td>wk 1 wk 2 wk 3 wk 4</td>
<td>wk 1 wk 2 wk 3 wk 4</td>
</tr>
<tr>
<td>Observation Groups (6)</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Informal Feedback Staff (7)</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Program Evaluations All residents</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Program Evaluations All staff</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Focus Groups All residents</td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

3.1.1. **Observation as an Approach**

While individual interviews allow participants to speak freely about their experiences, structured observation is an important method used to record whether what group participants say they do is the same is what they actually do. Observation in the field allows the researcher to better understand the context of the field of inquiry (Patton, 2002). It allows a researcher to describe what happens outside of the formal group structure, to be open and ‘discover oriented’ (Patton, 2002), and to observe non-verbal interactions and behaviours as well as the influence of the environment (Mulhall, 2003). Although observers using an unstructured observation method enter the field with some ideas of what to
observe, there is room for undetermined behaviours or events, and allowance for the researcher to adopt roles, such as that of the “complete participant” (Mulhall, 2003, p. 307). This study used a combination of structured and unstructured observation in an attempt to record both the physical and verbal behaviour of participants and to capture the whole picture or context of the mutual support groups. The researcher adopted the role of ‘observer’ whose role is known to the group participants. The observation checklist has pre-determined sections that are based on the theoretical foundation, but each section begins with a space with general observations.

According to Mulhall (2003), in the role of the unstructured observer it is not possible to separate the researcher from that which is being observed. It is important to keep a personal/reflective diary including an accounting of the experience of being in the LTCF and how the researcher’s life experiences influence the way the observations are filtered (Mulhall, 2003). Therefore a reflexive diary was kept in this study and the researcher acted in the role of an observer who undertakes both observation and interviewing. The researcher is also a staff member in one of the LTCF with a number of years of experience working directly with residents as an accredited professional music therapist. In some ways, this is a drawback as the observational data was likely influenced by this experience in what is observed and how the information is filtered and analyzed. However familiarity with LTCF was also an asset in that the context was much clearer at the outset and the comfort level of the researcher in this
field had a positive impact on the comfort level of the participants in the study. Other aspects which will be accounted for include the researcher bias as developer of the program and the effect of observation on the group participants.

### 3.1.2. Focus Groups as an Approach

Within a multi-method study, use of a focus group can not only contribute supplemental information, but can also provide something unique to the understanding of the topic (Morgan, 1997). Focus groups can be a more effective method of reflecting the residents’ perspectives and experiences over the researcher’s agenda (Barbour, 2007). The open-ended questions may lead to in-depth discussions that produce surprises and highlight unexpected issues. As cited in Patton (2002), Richard Krueger (1994) describes how the interactions among the participants enhance the discussion as the group members are influenced by one another (Patton, 2002).

According to Morgan (1997), the main advantage of a focus group is that it enables a researcher to collect a large amount of data on a topic over a limited period of time. The group’s moderator nurtures the flow of the conversation and provides a permissive, safe environment for the group. Allowing the focus to shift within the focus group process enables participants to move the discussion in a direction that is of importance to them and helps to understand why participants think as they do (Barbour, 2007). Focus groups also open up an alternative method that allow participants who find individual interviews difficult, a place
where their ideas can be heard along with others who may share similar concerns or ideas (Patton, 2002).

The observations taken early in the study provided direction for the interviews and focus groups that happened later. Issues identified from the responses to the individual interviews also provided direction for the subsequent focus groups. The focus groups allowed exploration of salient topics arising from the interviews in an in-depth and interactive manner and the open ended questions provided information about topics initially overlooked.

In this study, focus groups took place in the last two weeks of the 3-month period. It was hoped that the focus groups could be made up of residents from each group as this approach will help to prevent a skewed distribution of responses and would avoid a repetition of group dynamics that may be occurring in the already formed groups. However, moving residents from each unit of the facilities was too big of a challenge for the activity staff and the residents. Therefore, a focus group was held for each group that participated for a total of six resident focus groups in the three facilities. The focus group topic guide was informed by data gathered during the observation and from the data gathered from the resident and staff program interviews.

Employing a combination of observations, individual interviews and focus groups, rich data was collected. Six co-led mutual resident support groups from three facilities were set-up for this purpose. A manual for the groups was developed (see Section 3.2.1) based on available empirical mutual support group
literature and the researcher’s experience as music therapist facilitating a similar pre-pilot group.

3.2. The Group Design

3.2.1. The Group Manual

The group manual (see Appendix G) provided consistent structure for the groups in both of the facilities. It outlined group formation, number of participants, suggested theme topics (total of 35 available) and provided supportive materials. With some minor changes, the staff co-leaders adhered to the structure provided in the manual throughout the 3-month study period. At the same time, some flexibility was available in terms of choice of topics and other elements such as the songs and quotes. The structure and format of the groups enabled the inclusion of residents with different levels of ability.

3.2.2. Staff, Co-Leadership and Program Components

Seven staff were referred by the CEO’s of the participating facilities made up of two activity aides, two therapeutic recreational directors, two rehabilitation assistants and one music therapist. The structure of the groups consisted of the following: groups met on a weekly basis for a period of 3 months (a minimum of 12 sessions); each group session lasted for approximately 45- to 90-minutes; co-leadership consisted of rotating leadership between the group members with a staff member in a supportive facilitating role; discussion themes were chosen by
the residents as were the provided supportive materials such as music, photographs and quotes (with some assistance by the staff).

To avoid contamination of the process evaluation, the program components were not changed throughout the 3-month period of the study. However, informal feedback was given to the staff leading the six groups. Feedback came from the observations held in the first month and was used to assist the staff in staying close to the format of the manual and providing support where it was needed to keep the program on track. At the same time, the staff had opportunities to give their feedback and ask questions that had come up. There were only a few changes that staff made to the program that required correcting. For example, one staff had the group sitting in a semi-circle with the staff member in the centre in a leadership formation facing the residents. The staff member was asked to change the format to a less formal arrangement around a table with the staff being seen as more of a group member than a leader.

Precise planning is important with new interventions, but there are always unintended consequences. The researcher anticipated some potential problems with the facilitation of the groups by the activity staff members. Therefore these had been written out in detail for the staff in Chapter 2 of the manual (Appendix G). Examples of these problems include dealing with the dynamics of a group process over time (i.e., a group developing in maturity and ability) and dealing with conflict within the group.
3.3. The Setting

Three residential care facilities were selected in the Fraser Health Authority in British Columbia, Canada. Under the auspices of the Ministry of Health, the Fraser Health Authority serves the largest of the six geographic regions of British Columbia, Canada (Fraser Health Authority, 2007). It integrates all healthcare services for the area that extends from Burnaby to White Rock and the Boston Bar with over 140 care facilities. Residential care is defined as 24-hour personal assistance and support provided in a secure living environment to adults who require skilled nursing care and can no longer safely live at home (Fraser Health Authority, 2007). Of the three facilities initially invited, one was not able to arrange for consent within the required time, therefore a fourth facility was invited to participate. This created a delay of approximately 2 months for the last two groups and therefore the three month study extended over a period of 6 months with the six groups starting at different times. Two of the three participating facilities were privately owned and one was a publicly funded not-for-profit. All three facilities were in a single geographical region and classified as complex care. Complex care, as defined by the Fraser Health Authority (2007), is provided in a community care facility and is for people who require 24-hour supervision, personal nursing care and/or treatment by skilled nursing staff. The largest of the three (Facility A) was a 236-bed residential care home with Groups 1, 2 and 3 in the study held there; the smallest (Facility B) had 62 beds with group 4; and the second largest (Facility B) had 142 beds with Groups 5 and 6.
Two of the six groups were held in a secured special care units, three in complex care (formerly classified as “intermediate care”), and one in an adult day program within Facility A. Although adult day programs are not defined as part of a LTCF, these programs are often held within facilities and the participants in these programs are often involved in the activities offered within the care homes. The adult day program was included in the study in order to see if there were significant differences in the participant's experiences of the mutual support groups.

3.4. The Sample

3.4.1. Participant Recruitment and Attrition

Residents in each facility were recruited based on their willingness and ability to take part in an ongoing group process. A verbal invitation was used as a written invitation may have created barriers due to potential visual acuity and literacy problems (Parnell, 2005). To facilitate an invitation to participate in the study, activity staff familiar with the residents and their abilities informally invited as many residents as was feasible in the unit/area to take part in an initial meeting about the study. Using purposive sampling, staff invited residents who were deemed able to communicate verbally within a group discussion format to some extent, that is, at least be able to answer yes and no to questions and to be able to track other group members sharing. At this initial meeting the study was explained and the researcher formally introduced. After an explanation of the study, the researcher answered questions that the potential participants had and
informed the participants of confidentially and reviewed the consent form. Those residents who said they wished to participate then remained present after the meeting to sign consent forms. Some signed that day and some chose to take the form with them to review. They were also informed that participation was voluntary and that they could choose to withdraw from the study but still participate, even after the study was in process and the consent forms were signed.

Residents with pronounced aphasia and residents on temporary respite were excluded. Also excluded were those residents whose needs could not be met by a single activity worker (e.g., those with behavioural needs requiring frequent attention). To account for attrition, the initial sample size was augmented from the previously mentioned ideal group size of 8-10 members to about 12-14 members. With this in mind, staff invited more residents to participate in the study groups than would be ideal. With the high attrition rates in LTCF, it was initially estimated that an average of 8-10 residents would end up taking part in each group. However the attrition rate was much lower than expected (see Figure 2), and in some groups there was no attrition.

Although this was beneficial in terms of having a larger sample for the evaluation, it also meant that two of the groups were too large (13 members in each). Concerns about the unmanageability of groups this size is discussed further in Chapter 4.
3.4.2. Participant Retention

Retaining the resident’s participation was handled in specific ways and these are outlined in detail in the manual. Examples of this include the use of weekly written invitations or the practice of hosting a special event every month, such as a party, with the group participants inviting other residents or family members as special guests. At these special events, group participants could also visit those residents that have dropped out of the group with an invitation to come to a party. One of the six groups initiated two special events (an invited
Mutual Support Groups in Long-term Care Facilities

speaker and a pizza party) within the 3-month study period. A second group used weekly written invitations. Staff facilitating the program kept attendance records as well as tracking reasons for refusals and drop outs.

3.4.3. The Mini-Mental State Examination

The Mini-Mental State Examination (MMSE) is a widely used screening measure of global cognitive function with scores that range from 0 to 30 with a higher score indicating better cognitive functioning (M. Folstein, Folstein, & McHugh, 1975). In 2001, Folstein recommended the following which will be used as a screening measure for the purposes of this study: \( \geq 27 = \) normal; \( 21-26 = \) mild; \( 11-20 = \) moderate; \( \leq 10 = \) severe (M. F. Folstein, Folstein, McHugh, & Fanjiang, 2001). Significant cognitive impairment is therefore suggestive as a MMSE score of less than 21. Given high rates of cognitive loss among residents in LTCF, this brief cognitive screening measure was administered to all participants prior to the beginning of the groups. Consent from next of kin was obtained for residents with significant cognitive loss (MMSE = \(< 21\)). Collecting this cognitive status data was for descriptive purposes and although MMSE scores are meant to serve as an indicators only (Kim & Caine, 2002), the resulting data can point the way for further study.

3.5. Data Collection

Data collection from residents was undertaken on-site with health, functional status and demographic information obtained from reviewing the
resident charts. There were three additional methods used to collect data: observation, individual resident and staff interviews and resident focus groups (Appendices E to H). The observations took place during the first month. Data gathered from the group observations was used to inform the focus group topic guide. Resident and staff interviews were administered individually at end of the second month and information from these interviews was used to inform the focus group questions. The focus groups occurred near the end of third and last month. This approach to methodological triangulation provided replication of results and maximized trustworthiness and credibility.

To avoid a skewed distribution of responses, the plan was to interview those residents that dropped out of the program. However, the five residents that initially agreed to be a part of the study but refused to attend the groups were not able to remember either agreeing to participate or remember being invited. Two of the residents had sudden increases in agitation and confusion and were not able to participate in a group setting or answer questions at all and three of the residents were discharged before an interview could take place. Therefore information regarding the drop outs was not available from the participants themselves. In reviewing their characteristics however, no significant differences were noted from the overall sample in terms of demographics, activity levels, health, GDS or MMSE scores.

Problems anticipated included challenges in data collection such as facilitating the focus groups (Parnell, 2005). As reported in Parnell (2005),
examples include: (a) dealing with domineering or shy participants in the focus groups by making note of this during the prior resident interviews and placing those residents close to the moderator and maintaining maximum eye contact with those who are shy; (b) making sure the group stays on topic by repeating questions and giving residents time to focus; (c) drawing additional information on topics by probing with questions such as, “Could you tell me a little more about that”; (d) reminding participants of the importance of hearing from everyone in the group and; (e) pausing the focus group if uninvited guests enter the room (e.g., a staff member or another resident).

3.5.1. Procedure and Ethics Approval

Chief executive officers (CEOs) of three of the four facilities contacted, consented to take part in the research project. Ethical approval from Simon Fraser University was obtained, then a follow-up phone call was made to the CEOs and written permission received. Referred staff were contacted and the study was explained to them in detail. A meeting was set up with the residents and participating staff and the study explained according to the university’s ethical guidelines, including permission for the administration of the MMSE and the GDS and collection of data from the resident charts. In the following weeks, consent forms for the participating residents (and next of kin if MMSE ≥ 21; see Appendix E) and staff (see Appendix F) were signed.
3.5.2. **Sociodemographic and Supplemental Data**

Sociodemographic information questions were obtained from the resident charts including age, sex, ethnic background, and education level. Additional information was also obtained regarding length of stay, cognitive status, functioning level, diagnoses and program participation rates. Supplementary information from participants was gained including levels of social support and health. The self-assessed health measure was taken from the Canadian Study of Health and Aging (Canadian Study of Health and Aging Working Group, 1994a); social support was measured by a single-item question. In addition, the Geriatric Depression Scale short form (GDS) was administered for descriptive purposes (Sheikh & Yesavage, 1986). All data was collected from individual interviews and the resident charts prior to the beginning of the study.

3.5.3. **Observation Checklist**

The observation checklist (see Appendix B) was based on previously developed evaluations from a program called “Fit and Strong!”, and adapted with permission for this study (Hughes et al., 2006). While triangulation provides corroborating evidence, observation allows identification of characteristics, attributes and traits that are most relevant to emerge as well as providing confirmation of the resident and staff reports from the individual interviews (Denzin & Lincoln, 2005). The observation checklist contained questions based on the objectives of The Little Java Music Club and includes aspects of: program attendance (e.g., how many attended, how many left during the program); the
environment (e.g., the space provided for the program, privacy); materials used 
ed (e.g., were the materials provided used in the program); group discussion 
components (e.g., did the staff appear comfortable facilitating the group or did 
residents participate in leadership roles); changes to the format and residents’ 
overall reaction to the program. The observation checklist included space for 
unstructured observations.

3.5.4. Resident and Staff Process Program Evaluations

The resident interview schedule (see Appendix C) and the staff interview 
schedule (see Appendix D) were also based on the Fit and Strong evaluation 
format (Hughes et al., 2006) and on the objectives of The Little Java Music Club. 
During the third and fourth week of Month 2, interviews with both the staff 
delivering the program and residents receiving the program were carried out. The 
questions addressed aspects of the program such as: the environment (e.g., was 
the space provided for the program comfortable, was there enough privacy); 
materials used (e.g., did they like the kinds of materials used in the program, 
such as the talking stick, the music, the themes); group discussion components 
ed (e.g., did they like taking an active leadership part, did they like themes 
available); and their reaction to the program. Overall, the questions were related 
to the extent that the intended activities and processes were delivered and/or 
received. The interview schedules had space available for comments and/or 
reflections. Most of the participant interviews took place in the rooms of the 
residents, and staff interviews took place in their offices. Notes were taken during
the interviews in order to have direct quotations and most lasted an average of 30 minutes.

3.5.5. Process Evaluation Plan

This process and program evaluation plan was based on a systematic approach developed by Saunders, Evans and Joshi (2005). Their design was built on a previous model developed in 2002 by Steckler and Linnan, which included five primary elements consisting of fidelity, dose, reach, recruitment and context. The process evaluation was created for public health interventions and research in the medical field. In keeping with the move away from a disease-based model of care within a medical system to a resident empowered model of care in this study, the word “dose” was replaced with the word “program”.

The six steps consisted of: (a) a description of the program, (b) a description of the complete and acceptable delivery of the program, (c) a list of potential process-evaluation questions, (d) determination of methods for the process evaluation, (e) consideration of the program resources and program characteristics and context, and (f) finalization of the process evaluation plan.

3.5.5.1. Step 1: Program Description

A brief program description is provided in below in Table 3. It includes the purpose, underlying theory, objectives, strategies and the expect impacts and outcomes of the mutual support groups.
Table 3. Program Description: The Little Java Music Club

The Little Java Music Club is a long-term care facility based program designed to provide residents with an opportunity to participate in co-led mutual-support groups. The overarching concept is that with ongoing involvement in these groups, residents can enhance their well-being. In The Little Java Music Club format, a staff member will co-lead the groups with a resident group member, arrange for the set-up of the group which includes coffee, and act in the role of a facilitator in order to assist with any special needs of the residents. These groups will meet on a weekly basis and use a participatory format in which residents have opportunities to share issues surrounding their living situation, look to one another for role models and validation of their experiences as well as learning alternative coping skills from one another. The group format includes the use of themes chosen by the residents and related materials such as music and poetry.

The theoretical framework of the program is based on personhood (Kitwood, 1997), reciprocal altruism (Trivers, 1971) and the helper therapy principle (Riessman, 1965). Personhood is maintained through the attendance to the value of the person regardless of disability. Altruistic behaviour is affected by the expectation that the rewards of giving will be great than the cost. In a LTCF, residents learn from one another and act together to form exchange systems of giving with agreed upon rules. The helper therapy principle proposes that individual benefits are gained through helping others (Riessman, 1997). However, not only do the group members themselves benefit but the group also benefits as a whole. The primary constructs of this principle are similar to the concept of social support from peers but includes group member giving as well as receiving help from one another. The group as a whole benefits from this two way supportive structure. The ultimate goal of The Little Java Music Club intervention is to increase the resident’s well-being. Specifically the objectives include an increase in self-determination, an increase in giving and receiving help behaviours, an increase of focus on inner strengths and beliefs, strengthened supportive relationships and an increase in the expression of coping alternatives. The Little Java Music Club logic model is provided in Figure 3.

3.5.5.2. Step 2: Complete and Acceptable Delivery of the Program

As reported by Saunders and colleagues (2005) the specific details that made up the elements of the intervention are described in more detail in this second step of the process-evaluation planning. These elements were based on the program components of the logic model (Figure 3), and of the recommended elements of a process-evaluation plan as well as an additional evaluation component.
Figure 3. Logic Model
These elements included fidelity (extent to which the program was accurately delivered, program delivered (to the residents), program received (by the residents), and reach (degree to which the residents participated in the intervention). In addition, recruitment (what procedures were followed to recruit activity workers and residents), was added to these four elements.

A description of what comprised a complete and acceptable delivery of the program is in Table 4.

Table 4. Complete and Acceptable Delivery of the Program

<table>
<thead>
<tr>
<th>The Little Java Music Club program consists of an environmental component (focuses on creating a supportive social structure that enables co-led mutual support groups to function within a care facility) and the intervention component (includes a manual with guidelines for facilitators and the group setup criteria).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The Environmental Component</strong></td>
</tr>
<tr>
<td>The groups are formed at three LTCF with the staff delivering the weekly program as laid out in the manual and according to the intervention component below. The program is presented as a social, fun music and coffee ‘club’. The facility is supportive of the program by providing: a comfortable and private space for the groups to meet; materials needed to inform residents of the program (as well as staff and families), and beverages and fresh fruit for the weekly programs.</td>
</tr>
<tr>
<td><strong>The Intervention Component</strong></td>
</tr>
<tr>
<td>The program is designed as an ongoing group delivered on a weekly basis with an average time of 45 minutes to 1 hour. It is meant to be highly participatory with the staff member arranging for the set-up of the group which includes:</td>
</tr>
<tr>
<td>1. informing the staff and families of the group in advance and arranging for a suitable meeting place according to the facility’s current schedule.</td>
</tr>
<tr>
<td>2. placing orders with the facility kitchen for coffee, tea and fresh fruit;</td>
</tr>
<tr>
<td>3. inviting prospective residents to take part, according to the criteria set out in the manual;</td>
</tr>
<tr>
<td>4. holding the groups on a weekly basis; and</td>
</tr>
<tr>
<td>5. encouraging those residents who wish to take on leadership roles and volunteer for set-up and clean up.</td>
</tr>
<tr>
<td>The groups will contain at a minimum the following:</td>
</tr>
<tr>
<td>1. weekly meetings;</td>
</tr>
<tr>
<td>2. activity staff and residents co-leading the groups, according to the resident’s abilities and desires;</td>
</tr>
<tr>
<td>3. the activity staff encouraging residents to choose the themes for each week and the supportive materials provided, e.g., songs, poetry, quotations etc.;</td>
</tr>
<tr>
<td>4. the activity staff encouraging residents to take on increasing leadership roles and volunteering to help with set-up and clean up;</td>
</tr>
<tr>
<td>5. the use of the talking stick (a native North American tradition used at council meetings) to enable groups members to listen to one another in a supportive and respectful way;</td>
</tr>
<tr>
<td>6. the activity staff ensuring that the group’s guidelines are read at the beginning of each group; and</td>
</tr>
<tr>
<td>7. the activity staff dealing with any conflicts and challenges that arise between residents (as outlined in the manual).</td>
</tr>
</tbody>
</table>

*Note.* Adapted from Saunders et al. (2005).
3.5.5.3. **Step 3: List of Potential Process-Evaluation Questions**

In the third step of the process-evaluation a potential wish-list of possible questions is drafted (Saunders et al., 2005). The questions were based on the underlying theory stated in Table 3. As reported in Saunders and colleagues (2005), the components of the process evaluation plan include fidelity, dose delivered (program delivered), dose received (program received), reach, recruitment and context. Table 5 includes the potential questions and information needed to answer each question and Table 6, the evaluation questions.

**Table 5. Formative and Summative Applications**

<table>
<thead>
<tr>
<th>Component</th>
<th>Purpose</th>
<th>Formative Uses</th>
<th>Summative Uses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fidelity (quality)</td>
<td>Extent to which intervention was implemented as planned</td>
<td>Monitor and adjust program implementation as needed to ensure theoretical integrity and program quality</td>
<td>Describe and/or quantify fidelity of intervention implementation</td>
</tr>
<tr>
<td>Program delivered (completeness)</td>
<td>Amount or number of intended units of each intervention or component delivered or provided by interventionists</td>
<td>Monitor and adjust program implementation to ensure all components of intervention are delivered</td>
<td>Describe and/or quantify the amount of the intervention delivered</td>
</tr>
<tr>
<td>Program received (exposure)</td>
<td>Extents to which residents actively engage with, interact with, are receptive to, and/or use materials or recommended resources; can include “initial use” and “continued use”</td>
<td>Monitor and take corrective action to ensure residents are receiving and/or using materials/resources</td>
<td>Describe and/or quantify how much of the intervention was received</td>
</tr>
<tr>
<td>Program received (satisfaction)</td>
<td>Participant (primary and secondary audiences) satisfaction with the program, interactions with staff</td>
<td>Obtain regular feedback primary and secondary targets and use feedback as needed for corrective action</td>
<td>Describe and/or rate participant satisfaction and how feedback was used</td>
</tr>
<tr>
<td>Reach (participation rate)</td>
<td>Proportion of the intended priority audience that participates in the intervention; often measured by attendance; includes documentation of barriers to participation</td>
<td>Monitor numbers and characteristics of participants; ensure sufficient numbers of target population are being reached</td>
<td>Quantify how much of the intended target audience participated in the intervention; describe those who did/did not participate</td>
</tr>
</tbody>
</table>
### Mutual Support Groups in Long-term Care Facilities

<table>
<thead>
<tr>
<th>Component</th>
<th>Purpose</th>
<th>Formative Uses</th>
<th>Summative Uses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>Procedures used to approach and attract participants at individual or organizational levels; includes maintenance of participant involvement in intervention and measurement</td>
<td>Monitor and document recruitment procedures to ensure protocol is followed; adjust as needed to ensure reach</td>
<td>Describe recruitment procedures</td>
</tr>
<tr>
<td>Context</td>
<td>Aspects of the environment that may influence intervention implementation</td>
<td>Monitor aspects of the physical and social environment and how they impact implementation and attend to needed corrective action</td>
<td>Describe and/or quantify aspects of the environment that effected program implementation and program impacts</td>
</tr>
<tr>
<td>Evaluation of Program</td>
<td>Procedures used to achieve optimal administration of the program</td>
<td>Not applicable (program evaluation administered at 3 months)</td>
<td>Describe and/or quantify how the program was delivered/received</td>
</tr>
</tbody>
</table>

**Note.** Adapted from Saunders et al. (2005).

### Table 6. Evaluation Questions for Fidelity, Program Delivered, Program Received, Reach, Recruitment and Context

<table>
<thead>
<tr>
<th>Possible Question</th>
<th>Information Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fidelity</td>
<td></td>
</tr>
<tr>
<td>1. To what extent was the intervention implemented consistently with steps outlined in the manual?</td>
<td>1. What constitutes high-quality delivery for each component of The Little Java Music Club? What specific behaviours of staff reflect the theoretical foundation?</td>
</tr>
<tr>
<td>2. To what extent did the manual provide adequate guidance to the staff?</td>
<td>2. What behaviours of the staff convey that this guidance was given adequately?</td>
</tr>
<tr>
<td>Program Delivered</td>
<td></td>
</tr>
<tr>
<td>3. To what extent were all the intended components of the Java Music Club delivered to the residents?</td>
<td>3. How many components are there to The Little Java Music Club?</td>
</tr>
<tr>
<td>4. To what extent were all the materials designed for use in the Java Music Club actually used?</td>
<td>4. What specific materials are supposed to be used and when should they be used?</td>
</tr>
<tr>
<td>5. To what extent were all the activities described in the manual used?</td>
<td>5. What specific activities should be used and in what way?</td>
</tr>
<tr>
<td>Program Received</td>
<td></td>
</tr>
<tr>
<td>6. To what extent did the residents attend the Java Music Club?</td>
<td>6. What constitutes adequate attendance in order for the residents to receive the benefits of the program?</td>
</tr>
<tr>
<td>7. To what extent were the residents present at the program engaged?</td>
<td>7. What participant behaviours indicate being engaged?</td>
</tr>
</tbody>
</table>
### Possible Question | Information Needed
--- | ---
8. How did residents react to specific aspects of the intervention? | 8. With what specific aspects of the program (e.g., activities, materials etc.) do we want to assess resident reaction?

**Reach**

9. What proportion of the priority targeted residents participated in (attended) each group offered? How many participated in at least 6 of the 12 possible groups? | 9. What is the total number of residents in the priority population? What proportion of the group members dropped out and why?

**Recruitment**

10. What planned and actual recruitment procedures were used to attract facilities in providing the program? | 10. What mechanisms should be in place to document recruitment procedures for facilities?

11. What planned and actual recruitment procedures were used to attract staff in providing the program? | 11. What mechanisms should be in place to document recruitment procedures for activity staff?

12. What planned and actual recruitment procedures were used to attract residents in attending the program? | 12. What mechanisms should be in place to document recruitment procedures for residents?

13. What were the barriers to recruiting facilities, staff and residents? | 13. How will barriers to participation be systematically identified and documented?

14. What planned and actual procedures were used to encourage continued involvement of residents in the groups? | 14. How will encouragement by the activity staff for continued involvement of the residents in the groups be documented?

15. What were the barriers to maintaining involvement of the residents? | 15. What mechanisms should be in place to identify and document barriers encountered in maintaining involvement?

**Context**

16. What factors in the facilities social/political context or other situational issues could potentially affect either the Java Music Club’s implementation or the outcome? | 16. What approaches will be used to identify and systematically assess organizational, social/political and other contextual factors that could affect the intervention? How will these be monitored?

**Evaluation of Program**

17. How successful is the program from the activity staff’s perspective? | 17. What specific aspects of the program worked well and what suggestions are there for improvement?

18. How successful is the program from the resident’s perspective? | 18. What specific aspects of the program worked well and what suggestions are there for improvement?

---

**Note.** Adapted from Saunders et al. (2005).
3.5.5.4. **Step 4: Methods for Process Evaluation**

In this step, the methods are laid out that will be used to answer each question in the list of process-evaluation questions. The available resources are considered in deciding which methods to use in carrying out the plan and issues to consider include design (where is the data collected); data sources; tools or measures needed to collect data; data collection procedures; data-management strategies, and data-analysis or data synthesis plans (Saunders et al., 2005).

Following is a list of evaluation methods for The Little Java Music Club program (see Table 7) and a process evaluation methods summary (see Table 8).

Because the process evaluation of intervention was used for formative purposes (see Table 1), a data-collection, analysis and reporting scheme was developed that would assure that the staff received formative feedback in a timely manner so that they could make adjustments as necessary.

**Table 7. Issues to Consider for Process Evaluation Methods**

<table>
<thead>
<tr>
<th>Methodological Component</th>
<th>General Definition</th>
<th>Quantitative and Qualitative Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td>Timing of data collection: when and how often data are to be collected</td>
<td>Observe each group over the 3 designated months: in first month and again in the 2nd or 3rd month</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Conduct focus groups with residents in 3rd month</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Conduct individual interviews in the 2nd month</td>
</tr>
<tr>
<td>Data sources</td>
<td>Source of information (e.g., who will be surveyed, observed, interviewed, etc.)</td>
<td>Data sources include residents and staff delivering the program, and the environment</td>
</tr>
<tr>
<td>Data collection procedures</td>
<td>Protocols for how the data collection tool will be administered</td>
<td>Detailed description of how to do qualitative group observation, focus groups and individual interviews</td>
</tr>
<tr>
<td>Data management</td>
<td>Procedures for getting data entered; quality checks on raw data forms and data entry</td>
<td>Staff turn in participants sheets weekly; interviews will be checked before data entry</td>
</tr>
<tr>
<td>Data analysis/synthesis</td>
<td>Statistical and/or qualitative methods used to analyze, synthesize, and/or summarize data</td>
<td>Statistical analysis (see logic of analysis above) and SPSS will be used to analyze quantitative data</td>
</tr>
</tbody>
</table>

*Note.* Adapted from Saunders et al. (2005).
Table 8. Process Evaluation Methods Summary

<table>
<thead>
<tr>
<th>Evaluation Method</th>
<th>Data Sources and Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implementation fidelity</td>
<td>Possible data sources and methods include reports from activity workers implementing the program and observation of the programs: both require developing a checklist of expected characteristics of implementation.</td>
</tr>
<tr>
<td>Program delivered</td>
<td>Possible data sources and methods include reports (from staff implementing the intervention) and program observation: both require developing a checklist of content to be covered and methods to be used in the program.</td>
</tr>
<tr>
<td>Program received</td>
<td>Possible data sources include residents and staff. Methods and tools include observation, administering the individual survey questionnaire and conducting focus groups.</td>
</tr>
<tr>
<td>Reach</td>
<td>Data sources are the attendance records kept by the activity workers and percentage of attendance from the overall target population within the care facility.</td>
</tr>
<tr>
<td>Recruitment</td>
<td>Activity workers document all activities involved in identifying and recruiting residents for the program. Data from recruitment of care facilities and staff within those facilities will also be gathered.</td>
</tr>
<tr>
<td>Context</td>
<td>Possible data sources include, activity staff and supervisors of the staff (activity coordinators). The primary method and tools are interviews with open-ended question to assess barriers to implementation.</td>
</tr>
<tr>
<td>Program Evaluation</td>
<td>Possible data sources include residents attending and staff co-leading the program.</td>
</tr>
</tbody>
</table>

Note. Adapted from Saunders et al. (2005).

3.5.5.5. Step 5: Consideration of Program Resources

In reviewing the resources available for this intervention there were a number of considerations as well as a number of built in positive characteristics within the current care facility structure. First of all, all these care facilities had activity staff who were able to implement all aspects of The Little Java Music Club program. The program manual was designed for them and there were few anticipated barriers, as they already had varying degrees of experience in implementing a variety of programs. Thus, this new intervention was not disruptive to the facilities regular operations and well within their current budget. The burden on the activity staff delivering the program was light, given the willingness of the staff to try the program and their willingness to fit the program in their schedule. Encouragement was given to not add this program to their existing schedule, but rather to replace something already in existence (that was
perhaps not working as well), so that it would not add to an already busy schedule.

A resource consideration was help and time needed for data collection, entry, analysis, and reporting. Volunteers were found to become research assistants for the focus groups and training was provided. These volunteers assisted with taking notes during the focus groups and with debriefing after the groups as well.

Lastly, the resource consideration of available time to complete this study was an important issue. Although doing focus groups and open-ended individual interviews was ideal in terms of gathering in-depth data, doing both was beyond the scope of this project. Therefore, only the focus groups were conducted and the individual perspectives were gained from the resident interviews, which include some open-ended questions.

3.5.5.6. **Step 6: Finalization of the Process-Evaluation Plan**

The final evaluation plan is detailed in Table 9.
## Mutual Support Groups in Long-Term Care Facilities

### Table 9. Final Evaluation Plan for The Java Music Club Program (Step 6)

<table>
<thead>
<tr>
<th>Fidelity</th>
<th>Data Sources</th>
<th>Tools and Procedures</th>
<th>Timing of Data Collection</th>
<th>Data Analysis or Synthesis</th>
<th>Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>To what extent was the program implemented consistently with steps outlined in the manual?</td>
<td>Residents, staff &amp; research assistants</td>
<td>Resident Focus Groups (FG), observation checklist, program evaluation</td>
<td>Resident &amp; staff FG (month 3), group observation (months 1 &amp; 3), program evaluation (month 2)</td>
<td>Themes, Logic of analysis, (SPSS, see Ch.3), calculate scores based on number of intended activities and processes included</td>
<td>Formative; feedback to staff months 1 &amp; 3; and final report (info from final analysis)</td>
</tr>
<tr>
<td>To what extent did the manual provide adequate guidance to the activity staff?</td>
<td>Staff</td>
<td>Observation checklist, resident FG and resident &amp; staff interviews and program evaluation</td>
<td>Group observation (months 1 &amp; 3), program evaluation (month 2)</td>
<td>Calculate scores based on number of intended activities and processes included; themes from focus groups &amp; interviews</td>
<td>Final report (info from final analysis)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Program Delivered</th>
<th>Data Sources</th>
<th>Tools and Procedures</th>
<th>Timing of Data Collection</th>
<th>Data Analysis or Synthesis</th>
<th>Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>To what extent were all the intended components of the Java Music Club delivered to the residents?</td>
<td>Staff, residents and observation</td>
<td>Observation checklist, resident FG and resident &amp; staff interviews and program evaluation</td>
<td>Group observation (months 1 &amp; 3), resident and staff FG (month 3), program evaluation (month 2)</td>
<td>Calculate scores based on number of intended activities and processes included; themes from focus groups &amp; interviews</td>
<td>Formative; feedback to staff months 1 &amp; 3; final report (info from final analysis)</td>
</tr>
<tr>
<td>To what extent were all the material s designed for use in the Java Music Club actually used?</td>
<td>Staff, residents and observation</td>
<td>Observation checklist, resident FG and resident &amp; staff interviews and program evaluation</td>
<td>Group observation (months 1 &amp; 3), resident and staff FG (month 3), program evaluation (month 2)</td>
<td>Calculate score based on number of intended activities and processes included; themes from focus groups &amp; interviews</td>
<td>Formative; feedback to staff months 2 &amp; 3; final report (info from final analysis)</td>
</tr>
<tr>
<td>To what extent were all the activities designed for the Java Music Club actually used?</td>
<td>Staff, residents and observation</td>
<td>Observation checklist, resident FG and resident &amp; staff interviews and program evaluation</td>
<td>Group observation (months 1 &amp; 3), resident and staff FG (month 3), program evaluation (month 2)</td>
<td>Calculate score based on number of intended activities and processes included; themes from focus groups &amp; interviews</td>
<td>Formative; feedback to staff months 2 &amp; 3; final report (info from final analysis)</td>
</tr>
</tbody>
</table>

**Note.** Saunders et al. (2005).
<table>
<thead>
<tr>
<th>Process Evaluation Question</th>
<th>Data Sources</th>
<th>Tools and Procedures</th>
<th>Timing of Data Collection</th>
<th>Data Analysis or Synthesis</th>
<th>Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Received</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To what extent did the residents attend the Java Music Club?</td>
<td>Staff</td>
<td>Attendance records</td>
<td>Weekly</td>
<td>Calculate percentage of full attendance</td>
<td>Final report (info from final analysis)</td>
</tr>
<tr>
<td>To what extent were the residents present at the program engaged in the activities?</td>
<td>Staff, residents and observation</td>
<td>Observation checklist, resident FG and resident &amp; staff interviews and program evaluation</td>
<td>Group observation (months 1 &amp; 3), resident and staff FG (month 3), program evaluation (month 2)</td>
<td>Calculate score based on number of intended activities and processes included; themes from focus groups &amp; interviews</td>
<td>Formative: feedback to staff months 2 &amp; 3; final report (info from final analysis)</td>
</tr>
<tr>
<td>How did the residents react to specific aspects of the intervention?</td>
<td>Staff, residents and observation</td>
<td>Observation checklist, resident FG and resident &amp; staff interviews and program evaluation</td>
<td>Group observation (months 1 &amp; 3), resident and staff FG (month 3), program evaluation (month 2)</td>
<td>Calculate score based on number of intended activities and processes included; themes from focus groups &amp; interviews</td>
<td>Formative: feedback to staff months 2 &amp; 3; final report (info from final analysis)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reach</th>
<th>Data Sources</th>
<th>Tools and Procedures</th>
<th>Timing of Data Collection</th>
<th>Data Analysis or Synthesis</th>
<th>Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>What proportion of the priority targeted residents participated in (attended) each group offered?</td>
<td>Staff</td>
<td>Attendance taken</td>
<td>Weekly</td>
<td>Calculate score based on number of total possible targeted participants</td>
<td>Final report (info from final analysis)</td>
</tr>
</tbody>
</table>

Note: Saunders et al. (2005).

Table continued ↓
<table>
<thead>
<tr>
<th>Process Evaluation Question</th>
<th>Data Sources</th>
<th>Tools and Procedures</th>
<th>Timing of Data Collection</th>
<th>Data Analysis or Synthesis</th>
<th>Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What planned and actual recruitment procedures were used to attract residents in providing the program?</td>
<td>Staff</td>
<td>Program evaluation</td>
<td>Program evaluation (month 2)</td>
<td>Calculate scores based on number of intended recruitment approaches included</td>
<td>Formative: feedback to staff months 2&amp;3; final report (info from final analysis)</td>
</tr>
<tr>
<td>What were the barriers to recruiting residents?</td>
<td>Staff</td>
<td>Program evaluation; staff interviews</td>
<td>Program evaluation (month 2); Staff FG (month 3)</td>
<td>Calculate scores based on number of barriers to recruitment; themes from focus groups &amp; interviews</td>
<td>Formative: feedback to staff months 2&amp;3; final report (info from final analysis)</td>
</tr>
<tr>
<td>What planned and actual procedures were used to encourage continued involvement?</td>
<td>Staff</td>
<td>Program evaluation; feedback from staff interviews</td>
<td>Program evaluation (month 3); Staff FG (month 3)</td>
<td>Calculate scores based on number of procedures used to encourage continued involvement; themes from focus groups &amp; interviews</td>
<td>Formative: feedback to staff months 2&amp;3; final report (info from final analysis)</td>
</tr>
<tr>
<td>What were the barriers to maintaining involvement of the residents?</td>
<td>Staff, residents and observation</td>
<td>Observation checklist, resident FG and resident &amp; staff interviews and program evaluation</td>
<td>Group observation (months 1&amp;3), resident and staff FG (month 3), program evaluation (month 2)</td>
<td>Calculate score based on number of intended activities and processes included; themes from focus groups &amp; interviews</td>
<td>Formative: feedback to staff months 2&amp;3; final report (info from final analysis)</td>
</tr>
</tbody>
</table>

*Note.* Saunders et al. (2005).
<table>
<thead>
<tr>
<th>Process Evaluation Question</th>
<th>Data Sources</th>
<th>Tools and Procedures</th>
<th>Timing of Data Collection</th>
<th>Data Analysis or Synthesis</th>
<th>Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Context</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What factors in the facilities social/political context or other situational issues could potentially affect either the Java Music Club's implementation or outcome?</td>
<td>Staff</td>
<td>Staff Interviews</td>
<td>Staff Interviews</td>
<td>Discuss barriers and facility supports in place from interviews</td>
<td>Final report (info from final analysis)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Program Evaluation</th>
<th>Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did the staff and residents evaluate the program</td>
<td>Group evaluation of intended activities and processes included</td>
</tr>
</tbody>
</table>

Note. Saunders et al. (2005).
The data analysis plan was based on the theoretical foundation and objectives of this group and included a summary of the final decisions made according to the complete and acceptable delivery of the program, the formative application, the process evaluation questions and the issues to consider for the process evaluation methods.

### 3.6. Data Analysis

#### 3.6.1. Overview of Analysis Plan

The evaluation analysis plan includes a summary of the observations, the individual resident and staff interviews and the focus groups. Scores were calculated based on the number of intended activities and processes included in the programs. Substantive themes were generated and synthesized from the focus group data.

#### 3.6.2. Descriptives

The observation checklist, the residents and staff interviews and the focus groups generated data that was analysed and summarized. Analyses were conducted to identify characteristics of both the individual facilities and the resident respondents using the software program SPSS™ (Version 18). There are a number of challenges relating to comparative analyses in research in residential care facilities (Maas, Kelley, Park, & Specht, 2002), therefore data collected included self-assessed health, length of stay, social support, depression and cognition. In addition, results were compared across groups and
across facilities. It was predicted that there would differences between the six groups and between the three facilities.

3.6.3. Focus Groups

Using an interpretive approach, the researcher in this study played an active role in constructing the understanding arising from the focus groups. With the social constructionist assumption that the reality is co-created, the researcher needs to ensure that the topic is relevant and beneficial (Angen, 2000) and allow space for the participant’s voice. The data was therefore co-constructed between the researcher and the participants. The assumptions in this study was that there is no understanding without interpretation (Angen, 2000) and that the researcher was responsible for the choices made from the beginning of the study. Thus, in developing codes, the data in this current study was analysed by which things fit together and what patterns need to be sorted into categories. Patton (2002) describes the criteria by which categories should be judged: internal homogeneity (the extent to which data belongs together in a meaningful way); and external heterogeneity, the extent to which the differences are clear. Once the categories were chosen, they were prioritized according to utility, salience, credibility, uniqueness, heuristic value, feasibility and finally, completeness (Patton, 2002). The data in this study was examined closely using the above priorities.

The researcher was also responsible for addressing considerations of validation in order to provide trustworthiness (Patton, 2002). The approach taken
in this study was to include ethical and substantive validation for the focus group data collection and analysis. According to Patton (2002) this includes questions around how solid and consistent is the evidence; to what extent do the findings increased understanding; to what extent are the findings consistent with existing literature; to what extent are the findings practical and useful. Aspects of ethical validation that were addressed in the study included ensuring that no one participant’s voice was excluded or demeaned; that the research generated new possibilities beyond the present understanding of the topic of mutual support in LTCF; that lastly, that it opened possibilities for effective change in how group activities are approached in LTCF.

As reported in Angen (2000), substantive validation involves providing a chain of interpretations so that the reader can judge the trustworthiness of the conclusions drawn from the data. Similarly, as reported by Rabiee (2000), in order to establish rigor and minimize the potential bias introduced by the researcher and the subjective selection and interpretation, an audit trail of evidence needs to be provided. The data analysis consisted of a number of stages. These stages included examining, categorizing and tabulating the evidence in order to meet the original intentions of the study (Denzin & Lincoln, 2005).

With the above information in mind, the data analysis in this study followed the series of steps outlined below:
3.6.3.1. **The Focus Group Process**

The focus group processes included the following four components:

1. Recorded and transcribed spoken language in the focus groups;
2. Observations capturing the non-verbal communication of group members recorded by note-takers (volunteer research assistants);
3. A reflective diary kept by the moderator of the focus groups; and
4. Reflection of the focus groups written immediately after each group with the moderator and the note-takers. (Rabiee, 2004)

3.6.3.2. **The Data Analysis**

A framework analysis described by Krueger (1994) with key stages described by Ritchie and Spencer (1994), was used for the purposes of this analysis. The framework includes five key stages of focus group data analysis:

- **Stage 1:** Familiarization: listening to recordings, reading the transcripts and observational notes;
- **Stage 2:** Identifying a thematic framework: writing memos from ideas and concepts arising from the text—beginning development of coding and categories;
- **Stage 3:** Indexing: sifting data, making comparisons within and between cases;
- **Stage 4:** Charting: lifting quotes from original context and rearranging them under themes; and
- **Stage 5:** Mapping and Interpretation: making sense of the relationships between the data as a whole used the following established criteria: words, context, internal consistency, frequency and extensiveness of comments; specificity of comments; intensity of comments, and big ideas. (Krueger, 1994; Ritchie & Spencer, 1994)
The analysis also explored any potential variations of themes across the two facilities and between groups within each facility.

3.6.3.3. **Coding**

The use of labels to classify and assign meaning to the data helps to make sense of the large amounts of text and to uncover patterns.

1. **Initial Coding:** This is the first stage in which meaning is assigned to pieces of information and then classified. A number of codes were generated and after reading through the data several times, data was at times assigned to more than one category.

2. **Focused Coding:** This is the second stage that happens after the initial coding in which classification and the assignment of meaning is applied to the data. When a large number of responses were found, they were subdivided into several categories and less useful codes were eliminated. Repeating ideas and larger underlying themes were identified that connected the codes.

3. **Identification of Initial Themes:** Themes are developed from the bigger ideas generated in the focus groups as well as the categories that have been developed. The intent of this analysis was not to find out how many or to make generalizations but rather to find out why participants felt as they did about the issues raised. (Morgan, 1997)
CHAPTER 4.

Findings

The main purpose of this study was to present a rationale and detail the development of a new intervention involving co-led mutual support groups in LTCF, and to evaluate its process, structure and content. As this was a pilot of a new program, a process evaluation of the structure and content was used in order to assess the implementation of the intervention. A process evaluation involves looking at why a program was or was not successful. This evaluation did not look at outcomes, but focused instead on the processes of implementing the program and how staff and residents felt about specific components of the program. A mixed methodological approach was used to conduct the multimodal evaluation of the processes involved. Due to the small numbers of participants involved, it is not the intent to look at statistical differences but rather to describe and assess the delivery of the intervention and compare what was intended with what actually happened.
4.1. The Process Evaluation

4.1.1. Recruitment

4.1.1.1. Planned and Actual Recruitment Procedures of Facilities and Staff

Obtaining approval from all three facilities took much longer than intended. There were some barriers to receiving approval from two of the facilities as they required their family council’s approval before granting permission. The family council of one facility was unexpectedly not able to convene at all and the second family council had a full agenda and was not able to discuss the application for several months. This created lengthy delays and therefore data collection for what was a 3-month study took place over a total of six months. However, it is noted that the focus of the research was welcomed and appreciated by all four, even though one was not able to participate.

CEOs referred staff to the researcher and after the study was explained to them, all the staff that were invited agreed to participate. Training for the program was provided from the previously described manual. Time was spent with each staff member discussing the study, answering questions about the program and going over the manual together. Staff began the programs without the researcher present in order to allow them to explore the program components on their own. The researcher came to observe near the end of the first month and went over questions that had arisen and made a few requests regarding corrections to the program delivery.
4.1.1.2. **Planned and Actual Recruitment Procedures of Residents**

The intended plan was for the activity staff familiar with the residents to informally invite residents to take part in an initial meeting about the study. Letting the residents know that coffee and treats would be served potentially helped to bring more residents to this meeting. At the initial meeting the study was explained and the researcher formally introduced. For the most part, residents were able to understand the project and after questions were answered, most were willing to sign the consent forms and answer questions around their health and the GDS and MMSE forms. Some residents preferred to take time to think it over and some refused. In some cases the consent forms were reviewed with the resident and their significant other before the signing occurred. As a significant portion of the participants had moderate to severe cognitive impairment, consent was also obtained from the family members.

The process happened quickly in *Facility A* as the residents and staff were familiar with the researcher (as it was her place of employment). In the other two facilities, recruitment took a little longer as there were more questions and residents needed additional time to think it over before signing. It worked well to have the activity staff present the researcher and stay with the group while the questions were being answered. This appeared to provide legitimacy to the project and to reassure the residents. Two concerns that were brought up were whether it would cost them money, and what would happen if they couldn’t attend every week for 12 weeks of the study. Residents were assured that there was no cost involved and were encouraged to participate even if they were not able to attend...
every week. It was emphasized that they could withdraw from the study at any
time, even after it commenced.

4.1.1.3. Sample Characteristics

Of the total number of participants (\(N = 65\)), the majority were female (54
or 83.1\%), with two of the groups having no male participants (Table 10).

Over half of the participants were 85 years of age and older (36 or 55.4\%)
with a small minority (4 or 6.2\%) who were 64 years of age and younger.
Significant proportions of the participants lived at (or, in the case of the adult day
care, attended the facility) for 2 or less years (50 or 77\%), were Caucasian (58 or
89.2\%) with an elementary or high school education (45 or 69.2\%). Although the
sample was primarily made up of Caucasians it is to be noted that this does not
necessarily reflect the overall ethnic population distribution within the three
facilities.
## Table 10. Facility and Group Comparisons

<table>
<thead>
<tr>
<th>Overall Totals in all 3 Facilities (within category)</th>
<th>New Vista Care Home (n=32)</th>
<th>Harmony</th>
<th>Carlton Gardens (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Willow Place</td>
<td>Cypress Grove</td>
<td>Cranberry Cottage</td>
</tr>
<tr>
<td></td>
<td>(n = 10)</td>
<td>(n = 13)</td>
<td>(n = 9)</td>
</tr>
<tr>
<td>Gender (female)</td>
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<td>7 (70)</td>
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<tr>
<td>Age</td>
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<tr>
<td>64 &amp; under</td>
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<tr>
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<td>2 (15.4)</td>
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<td>75 - 84</td>
<td>17 (26.2)</td>
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<td>4 (30.8)</td>
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<td>85 &amp; over</td>
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<td>Stay</td>
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<tr>
<td>2 or less years</td>
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<td>8 (80)</td>
<td>9 (69.2)</td>
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<td>3-9 years</td>
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<td>Overall Totals</td>
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<td>----------------</td>
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<td>f (%)</td>
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<td>Impaired</td>
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<td>Impaired</td>
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## Mutual Support Groups in Long-term Care Facilities

### Overall Totals in all 3 Facilities (within category)

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<tr>
<th></th>
<th>Willow Place (n = 10)</th>
<th>Cypress Grove (n = 13)</th>
<th>Cranberry Cottage (n = 9)</th>
<th>New Vista Totals (n = 32)</th>
<th>Overall Totals</th>
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<td>f (%)</td>
<td>f (%)</td>
<td>f (%)</td>
<td>f (%)</td>
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<tr>
<td>Like the talking stick?</td>
<td></td>
<td></td>
<td></td>
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<td>1 (15.4)</td>
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<td>44 (67.7)</td>
<td>6 (46.2)</td>
<td>8 (88.9)</td>
<td>25 (78.0)</td>
<td>9 (69.2)</td>
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<td>15 (23.1)</td>
<td>4 (30.8)</td>
<td>2 (21.9)</td>
<td>6 (18.8)</td>
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<tr>
<td>Like the music?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>11 (84.6)</td>
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<td>2 (15.4)</td>
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<td>Like to help with set up</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>No</td>
<td>8 (12.3)</td>
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<td>4 (30.8)</td>
<td>1 (11.1)</td>
<td>2 (15.4)</td>
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<tr>
<td>Attendance</td>
<td></td>
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<tr>
<td>6-9 groups</td>
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<td>10-12 groups</td>
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<td>Dropped out</td>
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<tr>
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### New Vista Care Home (n=32)

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<th></th>
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<th>f (%)</th>
<th>f (%)</th>
<th>f (%)</th>
<th>f (%)</th>
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</thead>
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<tr>
<td>Like the talking stick?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
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### Harmony

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### Carlton Gardens (n=20)

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</tbody>
</table>

Note: 3 facilities and 6 groups (N = 69).
A total of 42 (64.6%) participants had some form of dementia, and 23 (35.4%) had other disorders, for example, heart disease, psychiatric disorders, musculoskeletal disease (Table 10). Of the 65 participants, 10 (15.4%) had scores indicating possible mild to moderate depression (GDS scores of 5-11) and three (4.6%) indicating possible severe depression (GDS scores of 12-15) (Brink et al., 1982). The results of the depression indicators were relayed via email to the staff at the facility and followed up with a personal communication in order to be sure that this information was known to the care staff. MMSE score indicators ranged from severe cognitive loss, (MMSE scores of 10 or less): 6 or 9.2%, to moderate cognitive loss (MMSE scores of 11-20): 30 or 46.2% and mild cognitive loss, (MMSE scores of 21-26): 22 or 33.8% (M. F. Folstein et al., 2001). Although participants with severe cognitive loss were initially excluded as it was thought they would not benefit from a verbal discussion group, the activity staff found six of these residents were socially closely connected with study participants. As it would not have reflected the reality of life in the care home and as it would have created potential distress for those residents to separate them for the duration of the mutual support groups, it was decided to seek permission from next of kin, include them in the study and observe their participation.

Participants were asked to rate their health, 2 (3.1%) rated their health as excellent, 36 (55.4%) rated it as good to very good and 19 (29.2%) rated their health as satisfactory (Table 10). Eight participants (12.3%) rated their health as poor. Some of the participants were in wheelchairs (19 or 29.2%) and a small
portion had a visual impairment (8 or 12.3%) or a hearing impairment (5 or 7.7%). When asked how many close friendships they had in their lives, 47 (72.3%) said they had three or more friends, 17 (26.2%) said they had one or two friends and one participant said none. The levels of active involvement of the participants in activities ranged from 44 (67.7%) who were active (13 or more activities per month), 16 (24.6%) who had some level of activity (4-11 activities per month) and 5 (7.7%) who had little or no participation in activities (0-3 activities per month).

4.1.1.4. **Planned and Actual Retention Procedures**

The planned retention procedures included holding special events chosen by the group members and/or making written invitations to the participants. Only one of the staff were able to coordinate holding a special event. The others said they were not able to find the time to coordinate an additional event. However in the individual interviews, all of the staff felt that it was a good idea in terms of keeping the energy of the group going and said that they would likely being doing that in the coming months. One staff member (Group 5) encouraged their group to choose what kind of event to hold and ended up holding two special events within the study period, both of which the residents enjoyed. For the first event, a long-time staff member in the care department was invited to come to the group and share the history of the care facility with group members and the second special event was a pizza party.
The staff of Group 4 chose to use the group invites provided on a weekly basis. The invites were given to the residents in the morning and served as a reminder to not just the group participants but also as a reminder to the care staff. One staff commented that the invitations became like a ticket to an event and became very important to the residents. Once when a group participant was inadvertently missed, they still attended the group but arrived asking where their invitation was.

...just the fact from a special invitation that went out...they knew they were invited to something special. It wasn’t just an everyday activity that was happening, this was something very special. Each person, I think felt an accountability in that group to...to contribute. They held onto their invitation—it was like their ticket to get into the room. That made a big difference. They would be up and ready to go,...like in most programs we’d have to get them out of bed and ask.....like yesterday Irene said..."I didn’t get my invite!" It’s a bit of work to write them out—but it makes it easier on the other hand.

4.1.1.5. Barriers to Maintaining Involvement

In order to discuss barriers to maintaining involvement it is important to look at the context in which the groups took place. Staff talked about the typical challenges involved in maintaining resident’s involvement in social groups in LTCF and an overall feeling of a lack of time. In addition to a variety of conditions that create barriers to ongoing participation such as illness, doctor’s appointments, etc., some residents also struggled with motivation, lack of energy or getting along with others. Inviting residents to a program took a considerable amount of time—some needed to be found, some are not quite ready and needed quite a bit of assistance, some required time to understand what they
were being invited to, and the list goes on. This created a barrier for some residents to participate as it took up time for example, if a resident was napping in bed and needed a two person-assist to get up. It was not possible to rush this important inviting process. Therefore, staff needed to plan on at least a ½ hour before a group started to assist residents to the program and another ½ hour after the group for clean up and to help them back to the lounge or their rooms. Furthermore, overall interest in the best of the weekly social activities often wanes over time, creating more of a challenge. Thus, even though the special events were only carried out in one group, the concept was seen as an integral a part of the intervention.

In the individual interviews, staff commented on some of the differences that they found in conducting the mutual support groups versus other comparable social groups:

*It draws out the best of the residents. I see all the programs that they do and this is the one where we don’t have the bickering and the fighting and everything...this is the one where they are being supportive...a lot of the of time we’re seeing the opposite...so a sacred place is there. Our various programs, for example the folding program, some of the discussion programs, craft groups, we get....”So and so isn’t working over there.” You know, there’s a pecking order in any group and uh...that that just wasn’t happening here.*

*I always get the impression they just want somebody to come and...just to sit with them and talk. So this is a good opportunity with music to have a group where you can focus the one-on-one attention—to sit with them and hear what they have to say, what they’re feeling, thinking. I think it’s really good—we try to do this with the programs we have now, but often there is not enough opportunity for that and I’ve seen....I just see the difference....especially Walter. He’s opening up more than he used*
to. Relationships are developing—it’s nice—I like that. It’s been good, very good.

4.1.2. Reach

The targeted groups of residents for this intervention were those who were able to communicate verbally within a group discussion format to some extent. In LTCF there are an increasing number of residents with cognitive impairment and also with visual and hearing challenges. Therefore, although many of the participants had MMSE scores \( \leq 21 \) (indicating moderate cognitive impairment) and some MMSE scores \( \leq 10 \) (indicating severe cognitive impairment), the focus was more on their willingness and ability to take part in the groups processes, than their cognitive and verbal abilities.

Degree of involvement was noted by attendance and participation in the group processes, for examples sharing with the talking stick, singing along with the music and/or listening to others share. In the observations, it was clear that although the verbal responses of those with lower cognitive functioning was often jumbled, their intent was not. Facial expressions and body language demonstrated their focused social and emotional involvement.

It was hoped that some of the residents who tended to be more isolated would attend the program regularly and to some extent this occurred (5 or 7.7% of those with little or no attendance in facility programs and 16% or 24.6% of those with some attendance). It is noted that there were a few residents that attended the groups who were not in the study. Although these residents were
not formally included in the study, they were a part of life in the LTCF and staff chose to allow them into the program as it did not feel right to exclude them from the social event.

4.1.3. Program Delivered

Of the 23 environmental and intervention components, 17 of the 23 were achieved (Table 11). Group 3 (adult day program) did not have a private space to meet; Groups 1 and 5 did not have access to a table for the residents to sit at and therefore used a coffee table in the centre of the room; Groups 2 and 4 were too large with 13 participants each and both had challenges with residents being able to hear; only Groups 6 held a party or celebration; and only Group 4 used the written invitation as a retention tool. Of the total sample, 55 (84.6%) of the residents attended at least the minimum number of groups (6 out of 12 sessions) and 48 (73.8%) attended most of the groups (10-12 sessions).
### Table 11. Completed Environmental and Intervention Components

<table>
<thead>
<tr>
<th>Environmental Components&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Achieved (Yes, No, Fraction)</th>
<th>Intervention Components&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Achieved (Yes, No, Fraction)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Groups take place with residents living within a residential care facility</td>
<td>Yes</td>
<td>1. Based on the manual provided</td>
<td>Yes</td>
</tr>
<tr>
<td>2. A required ability to communicate verbally within a group discussion format to some extent i.e. be able to answer yes and no and track other group members sharing</td>
<td>Yes</td>
<td>2. Groups meet once a week</td>
<td>Yes</td>
</tr>
<tr>
<td>3. No other specific resident membership requirements (i.e. any age or disability)</td>
<td>Yes</td>
<td>3. Groups last for approximately 45 minutes to 1 hour</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Private space to meet (i.e. a room with doors or a partitioned area)</td>
<td>5/6 groups</td>
<td>4. Staff member acts as facilitator and organizes time and place</td>
<td>Yes</td>
</tr>
<tr>
<td>5. Takes place for a minimum of 3 months</td>
<td>6/6 groups</td>
<td>5. Staff encourage residents to assist with set up and clean up</td>
<td>Yes</td>
</tr>
<tr>
<td>6. Facility provides coffee and tea and treats (in the form of fresh fruit or cookies etc.)</td>
<td>6/6 groups</td>
<td>6. Staff assist resident to take on leadership roles and choose the weekly theme and/or music (co-leadership)</td>
<td>Yes</td>
</tr>
<tr>
<td>7. The facility provides a CD player for use</td>
<td>6/6 groups</td>
<td>7. The group guidelines are read</td>
<td>Yes</td>
</tr>
<tr>
<td>8. The facility provides a table for residents to sit at and put coffee, songbooks, rhythm sticks etc.</td>
<td>4/6 groups (no table)</td>
<td>8. ‘Talking stick’ is used weekly</td>
<td>Yes</td>
</tr>
<tr>
<td>9. Appropriate group size (8-10)</td>
<td>4/6 groups</td>
<td>9. Music is used weekly, song lyrics and rhythm sticks provided as appropriate</td>
<td>Yes</td>
</tr>
<tr>
<td>10. Sitting arrangement supports all residents being able to hear and see facilitator</td>
<td>4/6 groups</td>
<td>10. Photos, quotes and readings are used as appropriate</td>
<td>Yes</td>
</tr>
<tr>
<td>11. Residents attend a minimum of six of the 12 groups over a 3-month period</td>
<td>55 (84.6%) (N = 65)</td>
<td>11. A party or celebration is held once a month where group participants invite other residents as special guests</td>
<td>1/6 groups</td>
</tr>
<tr>
<td>12. Invitations are issued to participants and/or guests invited</td>
<td>1/6 groups</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup> Focuses on creating a supportive social structure that will enable the co-led mutual support groups to function.

<sup>b</sup> Guidelines for facilitator and group set up criteria.
4.1.4. Fidelity

In order to assess to what extent the program was implemented consistently with the steps outlined in the manual, scheduled observations took place in the first and last month. The program was implemented as outlined in the manuals provided with some minor changes. All used the weekly opening and closing songs; the residents chose the weekly themes and songs; the talking stick was used; quotes and photos were used where appropriate; and the guidelines were read out by a resident and repeated by the staff member so that all could hear. Some of the changes include not always putting out the rhythm sticks and not using the general song lyrics in the secured unit groups (Groups 1 and 6). On the whole, the staff said in their interviews that the manual provided adequate guidance and that the materials provided were excellent.

Some challenges in the layout of the manual and the songbooks were brought up. The songbooks contained alphabetical dividers and this created problems for some residents who had a hard time finding the songs. The directions for the staff facilitator were found to be a bit too lengthy and a shorter version was created. Some of the lyrics in the songbooks did not match the recordings and although all the guidelines were useful and applicable, they were a bit too long. Recommendations for program refinement are discussed in Section 5.4.
4.1.5. Program Received

Although the staff had some time challenges in assisting the residents to the program each week, the attrition rate was remarkably low (15.4%; see Figure 2). Only 5 of the participants refused invitations to attend but of those 5, 4 attended no programs and one attended sporadically. The refusals for this participant centred on not being physically well and/or not wanting to leave their rooms. Of those who did attend, only 2 were not able to continue; 1 due to increased confusion related to the progression of their dementia and 1 due to low blood pressure and dizziness. Three residents moved to another facility (were discharged) before the individual interviews could take place. It was the intention to interview those who dropped out of the program, but of the 5 that were available to interview, none were cognitively able to remember that they were invited to participate in the study, nor could they remember what the program was about.

Moving on to the extent to which residents were engaged in the activities provided, it was apparent from the observations in the first and third month and, from the individual interviews, that residents actively participated and enjoyed the program. For all the groups, there was a distinct difference between pre- and after-group resident interactions. Before the groups, it was noted that the residents mostly just sat and waited—with some occasional glances at each other and few verbal interactions. At the beginning of the groups residents were mostly quiet but as the music began and the discussion ensued, residents became more animate and spontaneous. After the groups were done, the
residents looked at one another often and chatted freely as they were preparing to leave the room. They all clearly liked the music. Most sang along with the songs and toe-tapping and movement to the rhythm of the music was often noted.

Almost all the residents listened attentively to one another’s sharing, leaning in closer hear, making compassionate responses such as “…me too,” laughing or responding with suggestions etc. Only a few residents were not engaged: two residents were extremely hard of hearing; a third spent time talking to herself and looking through the songbooks; and on occasion, some of the residents fell asleep from time to time (see Section 4.4).

Comments that the residents made during the observation periods included: “…So meaningful,…so full of meaning (waving a hand at the whole group)..coming here, I am learning from a group like ours, how to adapt”; “It’s the only good thing around here!”; “The talking stick, I’ve got the knocking stick (group laughter)”; “I like coming to this group”; and “I enjoyed this evening very much...this afternoon, whatever it is!”

One participant with a low MMSE score (4/30) was observed to be actively engaged in both the verbal discussion and the music. For example, one group member commented: “He’s a nice fellow, when he behaves himself”; he laughed and replied: “OK, OK, OK.” When questions were posed to him his responses were sometimes jumbled, but there were also times when his answers were startlingly clear. An example was when the theme question was asked “What do
you like about yourself?," he responded, "I’m like other people here, I don’t." He then laughed and looked to others for confirmation. When asked what he thought about the talking stick he responded: “It’s not about showing who’s best.” Other times his responses were incomplete but he interacted and responded throughout the group session from beginning to end. The other group members did not appear to mind that he needed extra time to respond or that his responses did not often make sense. He smiled and laughed from time to time, snapped his fingers and almost always sang along with the music. He was also able to quickly learn the original opening and closing songs, reading along with the lyrics provided with only a few errors. It was clear that he was enjoying himself. When the group was over he walked out arm in arm with another female group member, smiling and looking around. When asked in his interview how the group could be improved, he responded: “You don’t want to be shy....it shows that we’re all pretty OK.”

4.1.6. Context

Hirdes, Cormack and Perez (2004) pointed out the need for additional funding for nursing, personal care and therapies. Staff talked about the stress of trying to meet the needs of too many residents and how often there could be a ratio of up to 50 residents to one activity staff. In a recent publication, Thomas (2006) identified an important and over-looked need in promoting the well-being for those working and living in LTCF. In order for any changes to the quality of life of the residents to be effective, the institutions must care for the caregivers
themselves. There are more and more expectations that front line staff will effectively carry out a myriad of time-consuming regulated tasks as well as dealing with increasingly complex health conditions of the residents. The stressful working conditions and the low resident/staff ratios coupled with a lack of on-going adequate education has led to ongoing staff burnout and turnover (Woods, 1999).

These problems highlight some of the challenges that the staff faced in implementing a new program and in recruiting and inviting residents on a weekly basis. However, developing more intimate relationships with residents in their care led to increased personal satisfaction on behalf of some staff. The supportive nature of the groups deepened the relationships between residents as well and staff said they felt good that it also helped to preserve the identity of the more vulnerable residents.

4.2. Evaluation of the Program

Overall, participating in the mutual support groups was a positive experience for the majority of the residents. Of those interviewed ($n = 55$), 96.4% said they enjoyed the groups (Table 10). One resident who attend the adult day program said that she didn’t enjoy the group: “No, I do many things at home—my husband is sick. It’s not for me.” When asked why it wasn’t for her, she explained that she couldn’t sing. Analysis of the individual resident interviews and focus group themes was done separately but as there was a substantial overlap
a decision has been made to present the combined results instead dividing the
data up. In addition, the salient themes were identified and a comparative
analysis completed of the cognitively higher functioning residents (MMSE scores
≥ 21) and the cognitively lower functioning residents (MMSE scores ≤ 20). This
was done in order to see if there were comparative differences in the
experiences of these two groups of residents. There some divergences and
these seemed to centre around some of the challenges they encountered (see
Section 4.4). Where they were similar was in the benefits that they experienced.

4.2.1. Group Characteristics

The characteristics across the six groups had several noteworthy
distinctions (Figure 2). Two of the groups were smaller and were held in secured
units (with 10 participants in each group). Three were with relatively higher
functioning residents in unsecured units: 1 with a smaller group of 10, and 2 with
larger groups of 13 participants in each. The sixth group (with 9 participants) was
held in an adult day program.

4.2.1.1. Group 3: Adult Day Program (Facility A)

The youngest contingency in the six groups was the adult day program
which also had the highest percentage of male participants and activity levels
(Table 10). As these were participants from the community still living in their
homes, this was to be expected.
4.2.1.2. Group 5 and Group 6 (Facility C)

When looking at the education levels across the groups, the two groups at Facility C had the lowest education levels: 40.6% had elementary school education compared with 23.1% at Facility B and 15.6% at Facility A. Both of the groups at Facility C had the highest percentage of dementia (80% and 90% compared to 46.2%, 55.6% and 46.2%), the only exception being Group 1 (Facility A) with 80%. These two groups also had higher indicators of moderate levels of depression (e.g., GDS [8-11]: 30% and 20% compared to none in the other groups); and more participants with severe cognitive loss.

4.2.2. Facility Characteristics

When comparing the three facilities there are several characteristics which stand out. The first characteristic (outlined previously), is that the education levels at Facility C were somewhat lower. This facility also had the highest prevalence of indicators of dementia (85% compared to 46.2% [Facility B] and 59.4% [Facility A]) and the highest prevalence of indicators of depression (45% as compared to 23.1% at Facility B and 18.7% at Facility A). The other noteworthy distinction is the comparatively high level of active participation in activities of the group participants of Facility A (90.6% as compared to 46.2% [Facility B] and 45% [Facility C]).

4.2.3. Emerging Themes of Residents Interviews and Focus Groups

The data of the resident interviews and focus groups was analysed and the eight emerging themes are listed below. Upon analyzing the transcripts,
significant and consistent overlaps were discovered between the interview and focus group data, therefore, the data was combined and will be presented below as such.

4.2.3.1. “Coffee and Camaraderie”

The first theme that emerged centred on being with others as opposed to being alone. Some said that they enjoyed getting together, drinking coffee, singing and just being together. Others talked more about the feelings of being alone in their rooms and the chance to get out.

I like it…the coffee and camaraderie...that people stay in contact with each other.

It’s nice to be with other people… I think my room is at the end of the world.

It’s like brothers and sisters that you don’t have.

A frequent comment that occurred within this theme was how friendly the group members were towards one another:

I like it the best….because they're all friendly. And the coffee and the cookies....

They’re friendly—sometimes it is hard to sit through the whole group—I have a lot of pain. But, it takes my mind off the pain.

To get along together with so many people in this group is something good—it’s hard enough to be away from home.

This has changed quite a bit—when I first started, it had not much going—then it grew sort of. I definitely do like it—they’re all nice people. You get into other people—from here to the other end. I have a problem…I banged my head…I don’t know.
4.2.3.2. “Getting to Know You”

The second theme that emerged was similar to the first but focused on the contradictory experience of living with so many people and yet not being able to get to know them. Group participants found they liked the deeper levels of sharing that occurred and the beginnings of new developing friendships.

*People open up in this group—normally they don’t, everyone is afraid of saying something. You only see people at lunch or dinner and you otherwise don’t talk other than “How are you doing?*

*People here—they are always in a hurry—they pass you by and say “How are you” and then keep going. No one has time...to look, to talk. Here we get time and more time—and we listen.*

*You get to know people. After the group, three of them came up to me at mealtime, because they know me from the group....normally they don’t talk to me.*

*I find this group meaningful...very much. To get to know everybody...sometimes when you're walking,...well, I'm not walking but sometimes in my wheelchair...I pass people I don't know who they are...but this way I get to know everybody...and then you say hello.*

Another frequent comment was about learning from one another and the wisdom and understanding that they gained from being together:

*I enjoy the wisdom—you click with some and some not. It's informative—to help us to understand one another.*

*I think other places should have this group. You get to, not only listen to others, you respect others more because of their different things that come out. You get to know them better—little things—it gives you a new respect.*

4.2.3.3. “Don’t Worry, Be Happy”

The third theme was around the giving and receiving of help and support.

This was encapsulated in one resident’s comment “Don’t worry, be happy”: 
We help each other—I like that. People listen to you here.

It’s just a comforting feeling that people care about me in this group.

Everybody needs someone. If somebody is crying you put your arm around their neck and say: “...tomorrow you’ll feel much better.”

They’re friendly and they’ll talk to you and listen to what you have to say. It makes me feel that I belong here.

4.2.3.4. “Get Things Off Your Chest”

Theme number four highlighted the importance residents attached to sharing their troubles and what was going on for them. Although this theme is somewhat similar to the previous theme in terms of receiving support, the comments focused more on the feelings associated with unburdening:

It’s something to look forward to...to do. Try get things off your chest...chat about things...makes you feel much better.

It’s very nice—it’s like a day off. I like it because if we have any problems we can share it—that really helps. You keep so much stuff to yourself...so when you unburden, you kind of go....aaaaaah.

4.2.3.5. “A Little Bit of Something Else”

Boredom is a frequent complaint in LTCF (Thomas, 1996) and the fifth theme centred on the change of pace that the groups offered and participants commented frequently on this:

It’s to me,... the only group where we sit and talk about different things....here it’s....different—we’re not going to know what we’re talking about each week.

I love it—‘cause it’s new...the set-up—it switches...not one boring thing. It switches from talking to quotes to music....
I enjoy it as a matter of fact. It’s something to do—just being part of something going on. It’s like you belong to a club.

Life can be very monotonous—you go from breakfast, lunch, coffee and dinner—it can be very monotonous. People suffer here from anything from Alzheimer’s to a broken leg. So the group—it does give people something to think about—it stimulates them.

4.2.3.6. “Always Have Music!”

The sixth theme was around music. Of those who were interviewed, 51 or 92.7% said that they liked the music, 3 or 5.5% were unable to answer and one said no. Those who liked the music were enthusiastic and effusive about their enjoyment of music:

It’s so good—always have music.

When there’s music you don’t think of anything else. Whatever bothers you is not so bad when there’s music.

The singing is what I like most. It brings us closer together.

Wonderful—powerful. I’m not feeling well sometimes and a little music kind of... perks me up and it feels happy.

It brings everybody close together. It gives us a chance to expound how we feel. That’s why I came when I was invited.... ’cause of the music.

4.2.3.7. “A Million Things to Say” (The Talking Stick)

The seventh emerging theme was about the Native American talking stick which was an object of much interest. While most of the residents interviewed (n = 55) liked it and wanted to keep it (44 or 80%), a few didn’t like it (6 or 10.9%) and some just didn’t understand it (5 or 9%). The concerns around the talking stick will be discussed further in Section 4.4. In all cases the stick provided an interesting topic of conversation. Some saw the stick as an imaginary
microphone and used it to address their fellow group members, and some held on to it closely like a safety rope:

The stick…ah…now I feel like I have a million things to say (group laughter).

It’s quite fascinating—some people have nothing to say and you give them the talking stick…and off they go!

I never had anything like that, the stick. It gives you a purpose…something to hold on to.

The talking stick—it’s very good—the longer we have it the easier it will be to get used to it. At first you think: “Oh, I can’t share my problems,”…but then they share theirs and before you know it, you do too.

I think it makes order in the place, when it’s lively. I think it’s wonderful. It brings attention when you’ve holding the stick…but it does it lightly.

4.2.3.8. “My Moment in the Sun”

The eighth, final and most controversial theme centred around leadership and assisting with the program. Of those interviewed, 23 (41.8%) enjoyed being in a leadership role, 25 (45.5%) didn’t enjoy it, and 7 (12.7%) chose not to or were unable to answer the question. The concerns around being a leader will be discussed both in Sections 4.4 and 4.5. As might be expected those who enjoyed leadership were a little more outgoing:

Yes, I’m very jolly! When everybody is silent I like to talk.

Some people don’t like it but I do…I do a lot of listening here and in this group I get my moment in the sun and they listen to me.

I’m not a shy type—it (being the leader) didn’t bother me at all. I got them all laughing and kept things going pretty good.

I like being the boss.
Figure 4. “My Moment in the Sun”
Mutual Support Groups in Long-term Care Facilities

Giving and receiving support was considered under leadership in that those who became actively involved in the functioning of the group, took on a type of leadership, in that they helped others in ways that was possible for them. Sometimes this meant listening or giving suggestions and sometimes it meant getting someone a cup of coffee. The participants were asked how they felt about giving and receiving support from one another:

- *It’s a paradox…when we need help the most, that’s when we have the hardest time asking for it. This group is so good for you that way.*
- *I like receiving suggestions….that is what people learn from—give a little take a little.*
- *It’s just a comforting feeling that people care about me in this group.*
- *When others give you suggestions, it gives you a bit—maybe things you’ve never thought of.*

Participants were also asked if they like to help the staff with the set-up and clean up of the program and 44 (80%) said they did and 8 (14.5%) said no. Many had concerns about their ability to help (discussed further in Section 4.4).

When questions were asked around the group components such as the guidelines residents found them important and helpful saying that the guidelines gave them an understanding what the group was about: “I think they’re good—I think we need them.” Other components such as the quotes, readings and photographs were also liked: “I especially like the quotes...and the poems.” When asked if they planned to continue attending the program after the study was complete 100% of those interviewed said yes, even those who said they did not
like the program. Concerns around the group components are also discussed further in Section 4.4.

### 4.3. Topics of Discussion

Participants were asked which topics would be of interest to them or which topics would they find important from their perspective of living in a LTCF. The strongest theme that emerged from this was “family”. Staff commented on this as well, stating that for some residents that would be their preferred topic of choice every week. Many of the topics mentioned were already on the themes list, but some were not. Salient topics include: family, kids, expectations, a whole new life, fear, getting older, being alone, dying, moving in here, day to day challenges, struggles with family, getting along, pain, missing our husbands, being heard, and restlessness.

### 4.4. Resident Concerns and Challenges

Many of the residents with lower cognitive functioning had concerns that were different from those in the higher cognitive functioning groups. These differences are important as they provide insight for further program refinement.

#### 4.4.1. Concerns of Those with Lower Cognitive Functioning

Those with lower cognitive functioning seemed to be able to adapt to the program and its components even though they did not always appear to understand what was going on. A typical comment when they entered the room
and saw the table set-up would be “What this now? This looks nice.” However, staff commented that it was not hard to invite them to sit at a table and enjoy a cup of coffee or tea. When the music started they would sing along even with the opening and closing songs that were new and original and they would not have known previously.

4.4.1.1. **Remembering Names**

One of the concerns raised by the participants in the individual interviews and in the focus groups was the challenge of not remembering names. One commented “I don’t know their names—but it feels like home.” Another said: “We should, I think we should, start wearing our names...oh they are terrible things—trying to remember them.”

4.4.1.2. **Concerns about the Talking Stick**

The talking stick did not work as well for everyone in the two special care units. Some of the residents liked it but some expressed confusion and concerns about the purpose of the stick and did not seem to be able to grasp what it was for. It seemed that the stick at times came across as a kind of disciplinary tool to keep people in line: “This is the stuff to, um, you know, uh, get to go with them, so that nobody will be, uh, get out of hand or anything like that,” and “You can use it for hitting the kids.” It also sometimes diverted the group participants from the topic of discussion and added confusion. Others misunderstood the purpose even after it was explained: “When they go home they might buy a candle—it
looks like one. It’s a good sign—now everything comes back from the old days."

Another perception was that it could be dangerous:

> It’s alright….unless somebody gets bad tempered…that would be dangerous. Maybe we could wrap it with velvet—for when you get mad if you give someone a little swat. People consume a lot of alcohol—you’ll never know what they’ll do. But I think most people don’t go out of their minds.

Staff from both of these groups felt the talking stick as it was, did not work well with those with the lowest cognitive functioning levels.

4.4.1.3. **Fears around Leadership**

Most of the residents in this category did not like the thought of being a leader. When probed they talked about not being sure they would know what to do and that they wouldn’t remember things right:

> Well, I’m,…I’m not a leader, I’m a follower.
> I would rather not be a leader—I like to listen. I’m not as good at it—I sometimes remember but not as well as I used to.
> I’m not a leader. But I can say what I think but I’m not a leader no. But I share.

4.4.1.4. **Helping with Set-up and Clean-Up: Not Knowing What Is Needed**

Most of the participants with lower cognitive functioning said they would like to help out with what needs to be done, they also expressed concerns that they would not know what to do:

> As long as somebody can tell me what needs to be done I’d be happy to help out. I don’t have much idea—what to do….
Well, I guess, if you’re assigned something it’s better. Somebody tells you who you do this...they need help with that.

Other concerns expressed were that they didn’t know anyone there in the group, that they had only come once or twice and didn’t remember, and that they were not the type of person to join a group or be talkative. Two opposing suggestions were given for improvement: one was to slow down the pace of the group overall and the other suggestion was to pick up the pace.

4.4.2. Concerns of Those with Higher Cognitive Functioning

Participants with the higher cognitive functioning had some concerns around the talking stick they also expressed somewhat different concerns.

4.4.2.1. Not Being Able to Hear

Two residents in Group 4 were very hard of hearing and expressed their frustrations about not being able to enjoy the group:

Some of them are hard to hear. I have hearing aids but I don’t wear them very often.

I haven't....I have hearing aids...but I haven't gotten them in...so I can't hear a thing...I understand that...I got the odd word but it's terrible when you're with a group you can't hear. I'm always embarrassed...it's frustrating.

4.4.2.2. Not Being Able to Sing

A number of residents talked about wishing that they had the ability to sing. However, they enjoyed the music and liked to listen to it:

I cannot sing…but I can talk. And yeah, I like to listen.
Oh I like the group—but I can’t sing—wish I could…I used to be able to.

4.4.2.3. Not Being Physically Able to Help

Quite a number of participants had concerns about not being physically able to help with the set-up and clean up of the programs or about being too old:

I like to help….I’m in wheelchair, but I would if they asked me.
Not any more, not at 94 years of age.

4.4.2.4. Concerns around the Talking Stick

Some of the residents in this category shared the worries and/or confusion around the talking stick and three did not care for it for a variety of reasons:

You can choose with...for 5 minutes for you...without uh...without uh...interruption. If there's interruption, you can hit them with it (group laughter).

It’s a club—it’s heavy! Boy, that would kill you—you’d see a few stars. Hmmm…it doesn’t hurt anything though.

I don’t see the good of it….I don’t think it’s necessary….the only use I can think for it is that you know who’s doing the talking.

To be very honest with you I don’t really care for the talking stick....but it’s OK. But I don’t know enough about what it is—I don’t have negative thoughts about it.

The talking stick is a little silly but it’s alright. I don’t pay much attention to those actually. It’s a stick.

4.4.2.5. Dying as a Topic

When the discussion of topics was brought up in the focus group, one resident said that they would find dying a difficult topic and is would be depressing. Other group members disagreed and found that it was important for them to talk about controversial subject matters such as dying. One resident
shared a personal story about the time when her husband had died, and that her son had not been able to talk about it. She shared how hard that was on both of them and that she wished he had an outlet like this group to share with during that period of time.

### 4.5. Staff Interviews

A total of seven staff members were interviewed individually near the end of the second and third month of the group processes. As with the residents, the overall staff experience of the mutual support groups was a positive. Three rated the program as very good; three rated it as excellent and one as superb. Two talked about the problems the large size of the group created but otherwise found the actual program very good. In the interviews they described how this program was different than other social programs at the facility, what the program meant for their relationships with the residents and the changes they saw in the residents. When asked what it was like to be a facilitator of the group, staff described first what they liked about it:

*I knew this was a positive program. How positive it was going to be I couldn't have even imagined. I think so many of the residents in that group have just benefited not only directly from that program but it has had overflowed to other programs. Just their lives in general...really positive, really positive.*

*I enjoy it myself. I am amazed at how others have responded even though they have dementia...short, simple, yet profound answers. Others are so vulnerable and at times pass or try to…but once encouraged, would share something meaningful. The program is a great idea….it's unique—it makes them feel more like themselves.*
This is a good opportunity with music to have a group you can focus the one-on-one attention—to sit with them and hear what they have to say, what they’re feeling, thinking. I think it’s really good—we try to do this with the programs we have now, but often they’re not enough opportunity for that and I’ve seen….I just see the difference. It’s their group and it’s something they do every Thursday morning at 10:00. That we share—it’s nice. Relationships are developing—it’s nice—I like that. It’s been good, very good.

4.5.1.1. The Environment: The Good and the Challenging

Staff also shared some of the challenges they faced in facilitating the groups. Five of the six groups were able to hold the groups in a separate room with closed doors. All the staff said that a closed off room was preferable as it helped to reduce distractions and contributed to the intimacy and the level of sharing. One staff member described it like this:

It’s good and I like being the small area as opposed to being in a big area. You know, we had a little of bickering that uhhhh…in some of our other groups and…why isn’t so and so working harder or you know….I think there was a special…it was almost a sacred room, there was a sacred “this” in the room. They knew that this was a positive environment where they were there to support each other. And little bickerings that sometimes happen in our groups wasn’t happening.

One group was held in a partitioned area that afforded some privacy but was still mostly in an open area. The staff talked what occurred when people went in and out while the group was in session and about the noise:

I would have liked it to have been quieter…because there was two programs going on at the same time because um…the other staff member had to do things with the people that weren’t involved in…in the music program…right? So there was a lot of noise coming from different places…where it would have been nicer if it was a little bit more of a quieter environment. But overall it still worked out
okay. More of a closed environment would be better...so it wouldn't be open to everybody wandering through...a closed group.

One of the challenges that occurred was that two of the groups were simply too large with 13 members each. This came about in part from over sampling as a much higher attrition rate was expected and in part because of the success of the program—more residents wanted to join the groups after they started. It meant that there was not enough space in the rooms and that often times the activity staff felt the stress of not having enough time for each group member to share and of trying to keep the program a reasonable length of time:

*We don’t have enough space to have everyone, we always have to move tables and chairs have someone new comes in because of the wheelchairs, walkers and furniture in the room to work with....which makes it challenging. The door is open and people kind of wander in at any time—it can be a little distracting and disruptive.*

*Some staff not aware of it would just bring in residents to join or encourage others to join, which is hard because it is full already. Most days there were 15, close to 15 people in that room…and hard for the facilitator right?*

**4.5.1.2. The Low Attrition Rate**

All of the staff commented how few residents dropped out of the program and how many of them were interested and kept coming back:

*No drop outs yet....some residents have refused once or twice—and maybe sick or sleeping at one time out of nine meetings that have had...all of them are interested.*

*The interesting thing on that note...we didn’t really lose anybody other than the one person who moved. One client in the group is bipolar and she would come resentfully, but she was coming....and wouldn't share. She sat with her arms crossed, saying “No, I don’t want the talking stick that is being passed.”...and that was*
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acceptable. It is interesting to see because she’s in a good place right now and I know that she was very happy to share this week…the topic was happiness. A very different place for her.

Nobody dropped out…no! A few came more sporadically; we had a couple of residents in hospital and a few away…not because ‘I don’t want to come to the program’ that certainly wouldn’t be a reason.

4.5.2. What Makes this Program Different

There were specific differences that staff found in this program compared to other social programs that they offered in their facility. The differences included the focus on the experiences of the residents here and now, having the time to talk about things that were important to them on a deeper level, not being forced to do anything and having fun:

I think it’s different from reminiscing groups—more….more applicable to what they’re feeling at that moment. Reminiscing will take you back to the days but this is different—this is sort of what’s happening for them in the here and now. How they’re feeling coming here now, adjusting to a new place, fears they have, and it’s fun! Like, they’d go back but it’s different. It’s not like reminiscing. Also days that are hard, and they don’t feel like sharing…that’s OK. There’s no being forced to do anything you don’t want to do. And I think that sometimes being here and they’re pushed a bit to come to things.

I think, …often residents—they’re sitting there and they see you buzzing around doing a thousand different things at once and I think just to have that time where they know that at this day and this time,…and they do look forward to certain things…they can come here. And it’s very relaxed setting, it’s very inviting and just the chance to get whatever’s on their mind off their chest. And whatever it is to them…I mean, it may be something that’s not life altering or…that we know, but to them it’s very real and so to have that opportunity to talk about it.

Our programs are pretty structured…you know…we’ll have laughs and bring out things. But you can tell when residents are preoccupied. They’re there but they’re not there. And you can tell
4.5.2.1. The Combination of Program Components

The combination of program components was useful for the functioning of the groups. Staff found the components such as the music along with the weekly themes, the guidelines, the photos and quotes all helped to keep the pace moving along and to keep program interesting from week-to-week:

*It is a good program—the residents like it….and it is a good combination of music (song) and discussion which they really like doing. They love the quotes…we elaborate on them—they want to take them home.*

*It’s interesting how they choose different ones each week...guidelines and topics. And the photos are cool…I like the photos. They’re always talking about what each person thinks of that photo and what comes to mind when they look at it.*

*I found the quotes to be good. It was a breaking up of the sharing…the music was another…it was nice to have that little bit of a rest from people sharing.*

4.5.2.2. Evaluation of the Music

Staff also found the music to be a positive contribution to the energy within the groups, both for themselves and for the residents. The music provided some context to the themes and helped to keep the focus of the discussion:

*MUSIC transcends everything; I think it reaches every soul. I can’t think of anybody in that group who didn’t connect at some point to the music. Depending on what the theme is, and the resident’s mood—they may get a little off track and it sort of breaks…it keeps the group on task and sort of…and then we move on.*
I love the music part of it. That's the most fun. I think all the music picked out was really good. Music is a good break from sharing—it uplifts, encourages, and is therapeutic.

Usually when I play the songs they get quiet and listen—sometimes ask to play it again.

The music is good. Sometimes we would go over the lyrics…and sometimes we talk about how it connects to the topic. It’s unlike any other program we have—including music in with the emotional topics—it’s nice.

Six of the seven staff members had no musical skills and although they said that the recorded music worked well, one stated that live music from time to time could add to the program. Facilitating the groups with no musical experience was described as easy and workable:

I thought it was going to be a lot more challenging...but actually the way it's all laid out it's really easy, anybody could run it…I think whether you can play music or not it really doesn't matter.

Easy—you don't need to have a musical background to do it...anybody can put a CD on…(laughs)...like we always do. I thought we would do a lot of it without the CD but we used the recordings for all of it.

4.5.2.3. The Talking Stick

The use of the Native American Talking Stick was very successful in four of the six groups with residents with higher cognitive functioning levels. On the whole the staff liked it and found the residents liked it as well:

I think it's holding it—it's very tactile. ‘Cause if you watch them,…they don’t just hold it—like Joan pulls it into her. She'll be talking about something in her little voice—she’s not many words but she’s holding it…..it’s interesting—hanging on for dear life.

A fantastic tool; a very fantastic tool. I think it’s says to everybody that you’re accountable to contribute to the group. The stick is now yours, the floor is yours. And it’s acceptable absolutely to pass. I
did notice that there were a few people who absolutely get lost in the rush, never ever speak their minds here...and with the talking stick...spoke out and it was great to hear them. I'm yeah...yeah!

I think it’s having respect for each person and their opinion...so what they have to say is important. And to give them that time to share. Everybody will have their chance to share. Sometimes, like I say, other programs we don't have that. And so I always try to offer the opportunity. But people get lost—they’re not heard.

Well it’s very important. I find that it’s kind of soothing—when somebody’s sharing they’re always kind of touching it—it feels good in their hands. They’ve never had anything like that in their program. But now they look for it.

You see like that they’re looking for something to grab on to....I've had people reach for a stuffed animal...not in this group—but different...that’s what we do—we put a little, to ...it’s very important, it’s nice. It’s neat and when they hear where it’s come from and the message behind it—that’s important to tell them.

However, in the two special care unit groups (Groups 1 and 6), staff found the talking stick was at times, more of a distraction than a help. Residents found the stick a source of concern: “You could hit someone with it,” or didn’t understand what it was for:

That was a hard one for people to grasp onto what the meaning of that was...every time I explained it I think I didn't do a good job of explaining it—every time you have the stick you have the floor...what’s the floor?...OK,...you have the right to talk...well doesn’t everyone...OK...I found it hard to explain. Then I finally said...when you have the stick...basically just don’t interrupt when someone is talking, when they have the stick. Also, everybody said yes, every time...I don’t want to hit anyone with this stick...and it would go on a huge tangent and they would talk about how the sticks and how bad they are and they just didn’t quite get it...or they would start talking about how lovely the wood is...so sometimes a little distracting. And I didn’t find that it worked. I found that it...otherwise we would just say, we would just ask the question “How are you doing?”...just for this group...because of the dementia.
4.5.2.4. The Monthly Social Get-Togethers/Parties

Although all the staff agreed with the concept of keeping the spark going for the groups, most had not yet tried this concept out. The one staff who did found it was effective:

*I wanted to say the special events...are great. We’ve had a pizza party—I didn’t do any music while we were eating because it was so messy for the first ½ hour. The next thing we’re going to do, Brenda (resident) suggested this....everyone is going to bring in something from their childhood and we’re going to talk about that. The first one we had a speaker, then the pizza party. I think it’s nice to, it’s a group their,...its a group that’s jelled for them...in the addition to the business of, of sharing, getting down solving all, you know all that good stuff. All those important topics...remembering every so often, not every so often, I think on a schedule basis, once a month to have a fun activity.*

4.5.3. Suggestions for Improvements

Staff were also asked to keep a journal of the process and through this and through the individual interviews a number of suggestions were offered for program refinement:

- Not to mix residents of differing cognitive abilities:
  You know, if I were to re-evaluate the program I would not include them in the program....because of just the level of the level of their cognitive abilities—it just doesn’t jive with the other ones...that’s the only thing I would look at. I’d have a separate lower functioning Java Club....and the focus would be on a little bit lighter things—like showing the pictures.

- Smaller Groups (8-10):
  In a smaller group we could be spending more time. I’m looking at the clock and we’ve been at it for 45 minutes and we still have six people to get to...you know what I mean. We could do more songs...it almost feels like a time crunch in there.
• **Numbering the Songs:**
  Residents had a hard time finding the songs—numbering them would make it easier.

• **Live Music:**
  It would be nice to have live music—maybe once a month. It’s just nice to have live music as opposed to the stereo.

• **A Private Space with a Closed Door:**
  At the start of the program there were residents who were joining in that were not part of the program—which makes others unsure of sharing because someone is new. The call bells at times are disruptive—someone would like to go inside in the middle of the program, some members come in late, other volunteers would come and take residents for another program.

• **A Volunteer to Help with Coffee and Songbooks:**
  A steady volunteer is an essential resource which I wish I had. A volunteer would be helpful to set-up coffee and help serve it—it would be more efficient. You have to set aside ½ to 1-hour before and ½-hour after.

**4.6. Reflections**

The purpose of reflection on the part of the researcher is to demonstrate trustworthiness and to voice the “unspoken” (Finlay, 2002). It is not the intent to engage in self-analysis but rather to acknowledge the presence of the assumptions and to add depth and richness to the analysis. For example, the development of this intervention presupposes a strong belief in the effectiveness of the mutual support group process and that is acknowledged here. The choices of themes that were used in the groups point to the researcher’s decisions made about salient issues experienced by residents living in LTCF. The evaluation has shown that the residents experienced a strong connection to these groups and the themes chosen.
There were a number of stages to reflect on in the development and process evaluation in this research. These included: the development of the intervention, the manuals, songbooks and recordings; setting up the project with three LTCF; and the experiences of conducting the observations, residents and staff interviews and the focus groups.

4.6.1. Development of the Intervention

The development of the intervention took place over a 6-year period. It began with a pre-pilot group that emerged out of a need for a supportive discussion group in a LTCF. This group became the model used to develop the manual and to experiment with a variety of approaches and tools, such as the talking stick and the choices of music, quotes and photographs. Thus the development of the manual was based on the co-creation of the residents and the researcher as music therapist and facilitator for the group. The manual included a collection of 36 themes and each of these themes were supported by specific songs, quotes and photographs and a lyric book for the group members etc.

The actual writing up of the manual and the collection of needed materials took well over a year. However, because the materials were tested on the pre-pilot group, there were only a few errors made, for example, some of the song lyrics did not perfectly match the recordings. In addition to this, although there was financial support for data collection, the costs of printing the materials were
substantial and the assembly of the materials took a great deal of time and
without the help of recruited volunteers, the study would not have been possible.

4.7. The Process of Data Collection

The study overall was a very large project for one researcher. Collecting
the sociodemographic information from the charts, doing the first interviews to
establish cognitive levels and gathering other data with the sample of 65
residents spread out over three facilities, took time. It did allow the researcher to
become familiar with the group participants before the study began. Observing
the groups was a relatively straightforward process. It was clear that the group
components were working well, even with staff who had no musical skills. With a
few minor exceptions, it was observed that the staff had grasped the facilitation
process and how to help co-lead the groups. It was also clear that the residents
were taking to the group processes and appeared to enjoy the groups.

The individual interviews were a little more complicated as it was apparent
early on that even though the interview schedules were reduced after a pilot
interview, they were still far too long and had to be abbreviated to keep the
residents and staff focused. Other challenges around the residents interviews
was finding quiet places to interview, finding the participants who at times were
sick, or out for family visits etc.; keeping the interviews short as many of the
residents would go off on tangents about family or health concerns. The 62
resident and staff interviews each took an average of 30 minutes. Therefore this portion of the data collection took up considerable time.

The six focus groups went well overall and once the purpose of the focus groups was explained, the residents appeared to enjoy being asked their thoughts and opinions. The topic that posed a challenge for participants was around expressing concerns or offering suggestions for improvements. Although some did when asked, it often required one participant to step forward and then others seemed to find the courage as well. Some subject areas were very challenging for the residents to grasp, both in the individual interviews and in the focus groups. These topics included: the focus on inner strength and abilities (e.g., “Do you find it helpful to share about ways you find inner strength?”) and increasing coping alternatives (e.g., “Does sharing in the groups help you to deal with issues or challenges that you have?”). It may be that the questions were not worded in a way that residents could comprehend the concepts. However, even when the questions were reworded or approached from a different angle, these topics did not elicit much response. It may be helpful in the future study of these groups to create a focus group around these topics to explore the concept from different perspectives on a deeper level.
CHAPTER 5. Discussion

5.1. Introduction

The goal of this study was to present a rationale and detail the development of a new intervention involving co-led mutual support groups in LTCF and to evaluate its process, structure and content. To this end the study was divided into two parts: a description of the development of the intervention and a pilot of the intervention. This discussion will look at the implications and limitations of the findings and make recommendations for program refinement and future research.

5.2. Results and Theoretical Integration

Almost all the participants in this study had some form of cognitive impairment and close to half had moderate to severe cognitive impairment. Although this is not meant to be a representative sample in this region, it does highlight one of the trends in LTCF, that is, the gradual increase of those with cognitive impairment (Canadian Study of Health and Aging Working Group, 1994a). The trend impacts all aspects of care and pertinent to this study, the nature of activity programs that are feasible. Although it would seem that a verbal discussion program such as a mutual support group would not work well with this population, observations of and interviews with participants reveal that not only
did those with mild-moderate cognitive impairment actively participate and appear to benefit, but those with severe cognitive impairment did as well.

These findings are supported by other studies suggesting that frail older adults with mental illnesses benefit from involvement in support groups (Kelly, 1999; Lee & Ayon, 2005; McDonald & Brown, 2008). As Kelly (1999) points out, those with cognitive losses face other losses as well, such as loss of social roles and social support and participation in the support groups foster a sense of self and a sense of belonging. These findings are further supported in a 2-year exploratory study that investigated the experience of belonging among a group of community dwelling people with early stage dementia (Clare, Rowlands, & Quin, 2008). It was found in this group that the mutual support process helped participants to develop a voice and engendered a sense of feeling valuable. The findings also lend support to the theory of ‘collective empowerment’ put forth by Berman-Rossi (2005), suggesting a synergy that empowers individuals that participate in support groups.

Specific observations were made of the six individual residents with indicators of severe cognitive impairment. Although individuals in this group were also interviewed, they were not able to answer some or all the questions posed, therefore they were also observed separately. It was apparent that all six were comfortable in the groups even though their communication skills were limited. They appeared relaxed, smiled at other group members and were almost always attentive to the sharing as it went around the group.
This is in keeping with Kitwood’s theory of the three psychotherapeutic interactions that facilitate positive relationships, namely validation, holding and facilitation (Kitwood, 1997). Validation (an attempt to understand a person’s frame of reference), was accomplished in part by the simple act of listening. Having their emotions and feelings heard was clearly a part of the attraction of the program for the participants. Their reactions to feeling cared about and loved came across when one said it was like brothers and sisters she no longer had and another who said this was a place where he felt listened to. Kitwood also described five psychosocial needs: comfort, attachment, inclusion, occupation, identity - all of which point to a central need for love. The phenomena of caring and being cared about was the most frequently commented on by both the residents and the staff, attesting to the importance of attending to this need.

Holding (providing a safe psychological space where vulnerability may be exposed), was expressed by a number of residents with comments around needing one another, sharing what was on their minds and feeling safe. The combination of the guidelines which emphasized confidentiality and support and the themes and music which focused on expression appeared to help build this safe container in which participants were able to share their concerns. This finding was further confirmed by the observations made by staff around the positive supportive participant interactions.

Facilitation (enabling people to do what they would not otherwise) was created through the use of the talking stick, allowing one another to have
differences of opinions (as emphasized in the guidelines) and offering choices in topics, music and quotes. In addition, having their emotions and feelings responded to in a space that was comfortable and safe seem to empower the group participants to use their remaining abilities. Their responses and interactions were encouraged and supported by staff and other group members and the ongoing weekly sessions provided stability.

This highlights the concerns that despite the advances in our understanding of the dementia process, the abilities of people with moderate to severe dementia are often underestimated (Snyder, Jenkins, & Joosten, 2007). One of the male participants with a low MMSE score (4/30) indicating severe cognitive impairment, would not normally be considered a candidate for a verbal discussion group. However, observations revealed that he listened closely to what others were saying and made comments from time to time that indicated he was tracking the conversation. Staff commented on the remarkable participation of the severely cognitively impaired group and how they were able to respond with short yet profound answers.

Both the staff of the two secured unit groups found that the program worked well with some adaptations. Some of the adaptations included: not using the songbooks (except for the lyrics of the two original opening and closing songs); enhancing the use of the photographs and music; simplifying the guidelines; keeping the question short and concrete (rather than abstract), allowing for “yes” and “no” answers; and clearly repeating and/or paraphrasing
the participants responses in a louder voice so that all could hear and understand.

Other characteristics of the participants included a number of positive attributes: (a) a majority who rated their health good to excellent, (b) a small number in wheelchairs with visual or hearing impairment, (c) a large proportion who had three or more close friends and who were actively involved in activities, (d) and relatively few with GDS scores indicating depression. Thus it could be said that overall, except for the levels of cognitive impairment, the participants from these care homes were socially and physically in moderate health. As stated previously, this was a purposive sample and therefore is not necessarily a reflection of the care homes general population. However, it does suggest that the type of person who is willing to participate in this kind of a social support group is more likely to be someone who is already socially and physically somewhat well. From another perspective some of those who tend to be loners and who consider themselves to be in poor health (i.e., those who potentially benefit the most), may not be willing or able to benefit from this kind of an intervention. In this researcher’s clinical experience there is a proportion of ‘loners’ who do not take part in activities in every facility. There were however, a percentage of participants who were not socially active who did choose to participate in the support groups. Furthermore, in the pre-pilot group, frequent special parties were held and some of the loners came for the food, but would return in subsequent weeks for the group experience, attesting to the potential of
this type of intervention for loners. Finally, the importance of maintaining the well-being of those who are more active needs to be pointed out as it is important and worth attending to in our quest to achieve quality of life for all who live in LTCF.

Moving on to the delivery of the program, it seems that despite a few of the problems encountered with the facilitation, most of the environmental and intervention components were used correctly and the objectives of the intervention were achieved. The active involvement of almost all the participants and the low attrition rate enabled group members to fully experience the benefits of the support available. Although there was no measurement of outcomes, the following was observed over the 3 months in all of the groups: self-determination (taking on leadership), giving and receiving help to one another, discussions of their inner strengths and beliefs; and expression of the challenges they were facing and how to better cope with them.

Almost all the group members interviewed said that they enjoyed the groups. Participation within the groups was high and interest in the groups was evidenced by the low attrition rate. Although there were differences noted across the groups and facilities, these differences were not apparent in the benefits that the participants experienced. Of the eight themes that emerged the first, *Coffee and Camaraderie*, was expressed by almost all those interviewed. This theme is supported in the literature contending that relationships that residents form with one another are a stronger predictor of loneliness and depression than relationships with friend and relatives (Fessman & Lester, 2000). Furthermore,
participation in support groups help participants realize that they are not alone and that others’ struggles with similar challenges (Lee & Ayon, 2005; Roberts, 2009). The findings also lend support to Kitwood’s concept of personhood in the context of relationships that empower residents and specific group components used. The presence of the talking stick for example, attends to the importance and value of each person in the group. It ensures that the social positioning that occurs in the relationship between the staff and residents and between the residents themselves does not come into the equation, as each group member is given an equal voice. The theme of support and camaraderie was expressed through the frequent comments regarding friendliness of their fellow group members. Thus, in spite of the number of activities and social programs offered to residents with LTCF, social isolation is still surprisingly widespread (Molinari, 2002). According to the participants in this study, the mutual support groups are well-suited as an antidote to this condition.

Similarly, the second theme (Getting to Know You) emerged with frequent, extensive comments about finally getting to know those who they have often seen in the hallways for a long time but don’t know. These comments also included frequent comments of feeling more at home. The support group appears to play a significant role in making social contact and in developing ties with other residents. Two related issues are explored in the literature: (a) cognitive impairment prohibits some residents living in LTCF from participating in social events and connecting with others (Mason, Clare, & Pistrang, 2005); and (b)
social positioning occurs once a diagnosis happens, which serves to place residents in a position of being “other”—someone with less social status (Kitwood, 1997). The support groups speak to both of these issues as they allow for the development of positive interpersonal relations that are on an equal basis. In addition, the interactions allow group members to learn from one another leading to increased understanding and respect.

The third theme (Don’t Worry, Be Happy) centred around giving and receiving help and was marked by the intensity of the comments. One participant expressed that it brought feelings of comfort that someone cared about her in the group and another expressed that it was just like having brothers and sisters again. These comments lend support to Trivers (1971) theory of reciprocal altruism involving a number of aspects such as emotion, gratitude and sympathy and trust and the formation of friendships. In the mutual support groups this is played out with residents learning from one another, supporting each other in an exchange system based on agreed upon guidelines of The Little Java Music Club. Being of help to others is not commonly associated with residents in LTCF. However, perceptions of participants in a long-term care facility study highlighted that being helpful to others was very important to their quality of life (Guse & Masesar, 1999). Indeed, in a study of older Canadians in the community suggests that engaging in helping behaviours increases a sense of belonging and feelings of connection to others (Theurer & Wister, 2010). These results revealed a dynamic relationship between altruistic factors and sense of belonging.
Mutual Support Groups in Long-term Care Facilities

to one’s community. It also highlights two of the helper-therapy principles described by Riessman (1965): helper therapy, giving help is the best way to receive help and it reduces dependency and; the self-help solution, a belief in the wisdom of the group as opposed to seeking expert help. The act of sharing and listening reinforces each group member value. When asked, well over half of the participants said they participated with the setup and cleanup of the group sessions saying that it felt good to have a purpose. Those who said they did not help had concerns which centred on not being physically able to or not knowing what was needed. Most expressed the desire to take their turn and to be of help to others.

The fourth theme (Getting Things Off Your Chest) revealed unexpected findings around the importance of the chance to share what was on their mind. This is congruent with Riessman’s tenth principle internality—internal healing done by the individual within the group (vs. continually seeking a medical cure). Although this older generation is not typically as comfortable sharing their troubles, one resident explained that those who were shy or had a harder time expressing themselves were empowered by observing others sharing their burdens. This support of residents for one another is particularly important in light of the time pressures that were expressed by staff and the high staff to resident ratio.

The fifth theme (A Little Bit of Something Else) centred on how the program was something different and unusual in the care home. The participants
liked the variety of the program components, from music to quotes to photographs. As mentioned previously, one of the components of interest was the use of the talking stick. The talking stick not only gives the speaker the sacred power of words, it also gives the speaker courage and wisdom (First People - Native American Legends, 2007). This phenomenon was reflected in the frequency and the depth of the sharing of the group participants. Staff remarked on being impressed with the profound insights expressed by residents during the groups and in particular, the insights of those with severe cognitive impairment.

In keeping with this, the sixth theme of (A Million Things to Say) highlights another of Riessman’s 10 principles, that of a belief in the group member’s wisdom. The talking stick played a significant role here as well. It seemed to give participants the permission to share more than they might normally. One resident described the stick as an “imaginary microphone,” and several residents used it to address the group as though they were speaking from a podium. In addition, it seemed to provide a sense of safety. Staff described how some residents would stroke the stick continually during their sharing and others appeared to be hanging on to it like a safety rope.

Staff also shared the perception that this program had significant differences from others that were offered in the home. Some of the differences included: the specific time allotted to each participant’s sharing until they were done; the focus on what was going on for them here and now; a chance to get
whatever’s on their mind off their chest; and the resident leadership of the
groups, for example, theme content and song choices

*My Moment in the Sun* was the most divisive theme that emerged with
over half of those able to answer “loving being in a leadership role” and the rest
not liking it or even being afraid of it. Not surprisingly, those who liked it were
more outspoken, and some cheerfully acknowledged that they liked being “boss”.
Many spoke to the benefits of sharing the leadership around the group. Some
however, found a leadership role challenging and believed it was not in their
make up as a person. With some fears of being a leader was more about making
a mistake, about their mind not working as well or about their lack of education.

As one of the objectives of The Little Java Music Club was to empower
residents to increase self-determination, staff found that removing the word
“leader” from the equation made all the difference in uptake. Thus when inviting
resident to help co-lead, staff found that using phrases such as “Can you help me
pick out a theme” or “I need some help figuring out which song to pick” helped
most participants feel more comfortable. This supports Paterson’s (2001) “myth
of empowerment” contention, that patients will not become active agents in their
own lives merely because the opportunity is give to them. Rather, they become
empowered if sufficiently prepared. This is further supported in the literature
where, given the right environment, older people will discover and use their
strengths to make choices in their lives (Beckingham & Watt, 1995).
The eighth and final theme (Always Have Music) was a frequently, extensively and intensively expressed by all except for one of the participants interviewed (98.1%). The one participant, who didn’t like the music aspect was only concerned about her ability to sing. Thus including music served to meet a number of the objectives of this intervention: to increase self-determination (residents chose the songs), to strengthen supportive relationships (it brought them closer together) and to increase expression of challenges (it enhanced self-expression). Literature also supports this premise that the purposeful use of music facilitates responses and increases participation (Clair, Mathews, & Kosloski, 2005).

These findings are also in accord with the use of other components such as the guidelines, the theme-related quotes and photographs. Both the residents and the staff agreed that the guidelines were useful and needed. Having some form of agreed upon ‘rules’ is also mentioned in the literature on group therapy in long-term care. Molinari (2002) put it this way: “Periodically restating group goals and rules of respect for each other go a long way to assure that all members will feel valued and comfortable in risking expressing their true selves to the other residents” (p. 18). However, some participants with lower cognitive functioning had trouble following the guidelines. It was pointed out by staff however, that it became easier for most to grasp as time went on. Those who did understand them demonstrated the spirit of the guidelines for all, for example, respecting
differences of opinion. The behaviours of listening with care and being supportive was observed as being contagious.

The quotes, readings and photographs were all served to increase the participant’s interest in and focus on the theme as well as significantly increasing the participation of those with lower cognitive functioning. The use of photographs bears a special mention as they were particularly helpful for those with severe cognitive impairment. It was observed that when a photograph related to the theme was shown, participants in this group would make up a story about what they thought was happening in the picture. Thus they were better able to participate in the sharing and contribute to the group discussion. The participants were observed to become animated and expressive when looking at the photographs and would “make up” stories about what the characters in the photograph were doing. This phenomenon is supported in the literature in a unique program called “Timeslips”, where people with dementia who participated in a group storytelling program with photographs, demonstrated an increase in alertness and engagement (Fritsch & Basting, 2009).

Although it could be considered ideal to separate residents further along in the dementia process into their own groups, the reality in LTCF is that the levels are often mixed to some degree. An additional complication is the delay in resident transfers to a more suitable unit within the care home as dementia often progresses slowly and the changes can be subtle. Therefore, there are times when residents, who are no longer sufficiently cognitively able, are still mixed in
with those who are. Having group components then, such as the photographs, can serve a purpose to enable those with decreased cognitive functioning to participate in the verbal group discussions in a unique way.

5.3. Limitations of Findings

Despite the attention to methodological detail in this evaluation, several limitations need to be taken into account. This relatively small sample was based in three care facilities within one geographical region. It was predominantly female, had almost no racial/ethnic diversity and most of the participants had varying levels of dementia and moderate to high levels of activity. As this study was not looking at outcomes, the sample was not meant to be representative of the general population nor representative of care facility populations. However, it can be said that some of the characteristics are typical of facilities in this region, for example, a predominance of females and those with dementia. Future research should expand this study in looking at how it can serve all the care home populations. For example those with different cultural backgrounds, those with lower cognitive function and the male or younger populations.

Another limitation is the use of the MMSE scores to determine cognitive status. Although this is common in gerontological research, age and educational status affect the validity of this measurement tool and therefore the scores are meant to serve as indicators only (Kim & Caine, 2002). It is also noted that the MMSE continues to be the measurement tool most commonly used by LTCF in
this health region. A further limitation is the lack of information about the 10 drop-outs of the study. As it was not possible to interview these participants (see Section 4.1.5), the results may be positively skewed.

Secondly, as the intervention was developed through a process of working with a pre-pilot program over a period of 6 years, the theoretical development of the intervention and its components were chosen based on the experience and beliefs of clinical work done by the researcher. This and the use of one person to collect all the data introduce a researcher bias. Furthermore, group members were selected by staff with the sole criteria for inclusion being the ability to participate in some way in a discussion group. Thus further research with other care facilities and populations will be useful. The strength of this process evaluation however, lies in the choice of method triangulation including descriptive, qualitative and focus group methods that provide corroborating evidence of the findings.

5.4. Recommendations for Program Refinement

Upon reviewing the observations, focus groups and resident and staff interviews a number of recommendations have emerged. Some of the recommendations are straightforward changes that can be made to the materials used and others relate more to the approach taken by staff.
5.4.1. Numbered Songs

The songs in the songbooks were organized by alphabetical dividers in order to keep additions simple. However, it quickly became apparent that group participants had a hard time finding the songs this way. It was unanimously recommended that the songs be numbered instead of alphabetized for ease of use.

5.4.2. Revised Recordings

Overall the songs chosen were liked by the residents and by the staff. A number of suggestions were given as to the type of music to include (e.g., more classical, and more country and western). It was also observed that some of the songs were in high keys and, at times, difficult for residents to sing along with, and that a few of the lyrics did not match the recordings. Therefore, it is recommended that recordings be made of the songs in lower keys and somewhat simplified so that singing along worked better. Play recordings or instrumental music before and after the groups each week.

5.4.3. A Separate Song List

The songs related to the themes were listed below the discussion section in the manual. When staff invited a participant to choose a song, they needed to be able to differentiate the songs titles from a page full of other information.
5.4.4. **Removal of the Talking Stick in Special Care**

Due to the confusion that the talking stick creates, it is recommended that future research with these groups remove the talking stick and expand the non-verbal and sensory tactile approaches to the themes for residents with lower cognitive functioning (e.g. the use of photographs or scents).

5.4.5. **Increased Usage of Photographs**

As the photographs were used a great deal, it is recommended that a photograph be available for each theme (only about half of the themes currently have a photograph). The photographs need to be large (at least 8½” x 11”) and tell some kind of an evocative story.

5.4.6. **The Use of Concrete Rather than Abstract Questions**

It is suggested here that questions posed to residents with moderate to severe dementia tend to work best if they are concrete rather than abstract, and if they only require a “yes” or “no” answer. For example the concrete direct question “Do you get lonely?” is easier to answer than the more abstract version, “Has loneliness affected your life here?”

5.4.7. **Changes to Group Set-up**

A number of suggestions are made here to maximize the effectiveness of the groups setup: keep the groups to a small number of residents (8 – 10 maximum); whenever possible keep the group seated at a table to provide a place to put coffee/tea cups, songbooks, rhythm sticks, etc.; keep residents close
together (but not too close); keep residents who are hard of hearing next to the facilitator and the facilitator in the middle if the table as opposed to the end (i.e., if rectangular in shape). Also included under set-up is to keep the staff facilitator role as an active group member who also sits at the table and takes a turn with the talking stick. Provided that the sharing remains authentic, this serves as a model for the group guidelines and assists those who require more guidance.

5.4.8. **Use the Word “Assistant” rather than “Leader”**

It is suggested to find an alternative for the word “leader”. Options include “assistant” or “helper” as these choices appear to be less challenging for many of the residents and, therefore, increase the number who will accept the invitation. It is still in keeping with the concept of co-leading as the staff and residents assist one another to facilitate the group together.

5.4.9. **Use of a Volunteer**

Except for the two smaller groups, all the staff said that a volunteer would be ideal. Someone to help the residents with the set-up and clean up and to assist residents in finding songs would enable the staff to ensure the groups run smoothly with a minimum of distraction.

5.5. **Future Research and Applications**

This study provides support for continued development and testing of mutual support groups both within LTCF and perhaps in the community. Future research might explore a number of options. Of particular interest is a closer in-
depth look at the lived experience of the LTCF group participants. Approaches could include individual in-depth interviewing of those who are participating in the groups currently and/or in-depth observation through current evidence-based observation tools. Also of interest is adaptation of the intervention specific to those living with moderate to severe cognitive impairment taking a closer look at the use of non-verbal components such as the photographs and story-telling. Additionally the use of video and a second person to capture nuances and reduce researcher bias would also contribute valuable information.

A randomized controlled clinical trial design could also be feasible using a larger sample to better understand the effects of this intervention. The findings suggest that this intervention may contribute to the development of new friendships for those living in facilities. This warrants a closer look how friendships are formed in and around the groups and the impact of this on well-being. Also of interest is the concept of empowerment. The resident’s increased participation and decision-making was observed within the group context, indicating that the groups may be offering a process that offsets the passivity and dependence normally fostered within the culture of LTCF. Finally, there is increasing support in the literature contending that relationships older adults form with one another have a significant impact on loneliness and depression (Fessman & Lester, 2000; Lee & Ayon, 2005; McDonald & Brown, 2008; Roberts, 2009) and sense of belonging (Theurer & Wister, 2010). The cognitive difficulties that residents in LTCF experience may mean they require longer to build trust...
and to benefit from support functions, therefore a trial would need to be at least 6 months in length. In addition the literature attests to the importance of using sensitive measures to accurately be able to assess the subtle changes that take place.

It is noted that some residents deemed loners in this evaluation became actively involved over time. Therefore an exploration of their perspective and the potential benefits of their participation would be useful. This research could extend to the development of a community-based program for those with early-stage dementia as well as those living in assisted-living communities. Nonpharmacological evidence-based interventions are showing support for community support group participation including increased cognitive, physical and social functioning (Burgener, Buettner, Beattie, & Rose, 2009).

Finally, it is proposed here that the mutual support group format could be useful in enhancing the effectiveness of resident council meetings within LTCF. In an exploration of institutionalized residents’ experiences and coping strategies based on recording of resident’s council meetings and interviews, data highlighted a range of unmet needs (Timonen & O'Dwyer, 2009). Frustration was expressed by the residents over limited opportunities to participate in decision making concerning their lives. In this researcher's experience, resident councils are not usually a true representation of the residents as a whole and more often than not, the meetings are dominated by a small number of more outspoken residents. The use of a talking stick and the mutual support group guidelines
would serve to empower those that are typically quieter. The potential of the approach used for these groups could be explored further both by researchers and practitioners interested in supporting residents in making choices and shaping their lives.

5.6. Conclusion

This preliminary study is intended to be the first phase of a larger study that will further investigate the experiences of residents in LTCF who participate in mutual support groups. The findings speak to the positive benefits of participation in these groups and the importance of meaningful network systems. Residents have stated that engaging with peers has a strong influence on friendship, companionship and psychological well-being. Thus these results call for further detailed study of mutual support groups including those with different populations within LTCF and with those in other settings. It is hoped that these findings and recommendations will help to shape health care services and research priorities in LTCF with a focus on evidence-based support group programs for those living with dementia and related illnesses.
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References


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Ussher, J., Kirsten, L., Butow, P., & Sandoval, M. (2006). What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science & Medicine, 62*.


Appendices
Appendix A.

Focus Groups Topic Guide

I’m going to ask you a few questions about your experience of The Little Java Music Club program. All your thoughts, ideas and suggestions are helpful to me…there are no right or wrong answers. So you can be comfortable to share freely here—if you disagree feel free to speak up. It’s all good and will be of help to us as we refine the program. Thank you for taking the time to help.

1. So let’s start with…what is it like for you to be in this group?
   
   Probes…
   
   a. As we read in the guidelines each week (hold them up)….the purpose of this group is for us to help and support each other—what is your experience of that?
   
   b. Some of you have told me that it helps you to get to know people better—can you tell me a bit more about that?
   
   c. Do you feel connected to others in the group? Why or why not?
   
   d. Someone has said that you like it that there is no pressure—for example, if you don’t want to say anything you can just pass the talking stick on…is that true for you?

2. Did you find the group activities and interactions personally meaningful? (for example, we talk about a different theme each week, 1 week might be about what it’s like to move in here and get along with others, the next week it might be about feeling lonely and so on….

3. What’s it like for you to have music in the program?
   
   Probes:
   
   a. A few of you have mentioned that you are not singers, but like to hum along or just listen….tell me about that…
   
   b. One person mentioned that the music is uplifting—is that true for anyone else?
4. What’s it like for you use the talking stick in the group? *(hold it up)*
   Probes:
   a. Someone mentioned that it gives you something to hold on to when you’re sharing....gives you a purpose or a safety rope...what do you think? *(question 4 con’d next page)*
   b. Others thought it takes a bit of getting used to, that it’s a new thing..and were not all together sure if they liked it....how is it for you?

5. Some of you have given me excellent suggestions for themes....things that might be important or interesting for you when choosing a theme to talk about each week? What do you think could be a good topic?
   Probes:
   a. Here are some of the suggestions..."Having your own life in a place like this"..."Moving in here"..."Day-to-day challenges"..."Missing your husband"..."Struggles with family."

6. Some of you have been co-leaders of the group—for example, you helped to choose the theme or choose the songs and so on. What was that like for you?
   Probes:
   a. Some suggested to me that it is good to share the leadership—that way everyone gets a chance to pick the topic....Do you agree?
   b. Others have said that they prefer not to be a leader; that they prefer to listen...What do you think?

7. Do you have any suggestions for things we could do differently?
   Probes:
   a. Are there any parts of the program that do not work for you?
   b. Someone mentioned that sometimes the group goes too quickly—that you are not able to keep up with what is going on? Is that true for anyone else?
   c. Some of you have said that you enjoy helping to set up and clean up—others have said they find it too physically difficult...what do you think?
   d. Someone said that they found it hard when people disagree about things in the group? Is that true for you as well?

8. Has being a part of the group, The Little Java Music Club, had an impact on your quality of life here in the home?

9. Is there anything I didn’t ask you that I should have?
### APPENDIX B: Observation Checklist

**Site:**
- Name of Program: The Little Java Music Club
- Start Date of Program:
- Date of Observation:
- Number of Residents in Attendance:
- Measurement Scale (these number are approximate numbers to use when appropriate)
  - None of the time: 0 times;
  - Some of the time: 1-4 times;
  - Most of the time: 5-9 times;
  - All of the time: 10 or more times

### A. General Observations

<table>
<thead>
<tr>
<th>Observation</th>
<th>Yes</th>
<th>No</th>
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### B. The Physical Environment

1. Was the room private e.g., a door or partition available? 

2. Was the room quiet overall? 

3. Did the staff and residents have all the resources out during the program:
   - 3a. Coffee/tea was served 
   - 3b. The java club sign was displayed on the table 
   - 3c. The talking stick 
   - 3d. The CD player 
   - 3e. The songbooks 
   - 3f. The guidelines for the residents to lead with 
   - 3g. The themes for the residents to lead with 

4. Expanded descriptions on Questions 1-3:
APPENDIX B: Observation Checklist - Page 2

C. Program Components: General Observations

<table>
<thead>
<tr>
<th>Program Components Con’d:</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>1. Did the group appear well organized?</td>
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<td>2. Were the themes used?</td>
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<td>3. Were the quotes used?</td>
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<td>4. Were the photographs used?</td>
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<td>5. Were the following musical components used?:</td>
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<td>5b. The songbooks</td>
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<td>5c. The CD recordings</td>
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<td>5d. The sheet music</td>
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<td>6. Were the guidelines were read at the beginning?</td>
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<td>7. Did the staff invite a resident to take on a leadership role?</td>
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<td>8. Did all the residents have an opportunity to share?</td>
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<td>9. Were the opening and closing songs used?</td>
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<tr>
<td>10. Expanded Descriptions of Questions 1-9:</td>
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</table>
### The Staff Con'd:

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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<tbody>
<tr>
<td>1. Did the staff appear comfortable working with the residents varying functioning levels?</td>
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<td>2. Did the staff modify the program?</td>
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<td>3. Did the staff appear comfortable using the music components?</td>
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<tr>
<td>4. Did the staff appear comfortable using the quotes and poetry components?</td>
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<td>5. The staff kept the group discussion moving at a good pace</td>
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<tr>
<td>6. The staff were able to engage the residents in the discussion portion of the group</td>
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<td>7. Did the staff offer the residents choices in choosing songs or themes?</td>
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<td>8. Did the staff play an instrument and/or sing along with the music?</td>
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<td>9. The staff appeared comfortable supporting the residents when stronger emotions were expressed</td>
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<td>10. The staff appeared comfortable when problems or arguments arose between residents</td>
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<tr>
<td>11. Expanded Descriptions on Questions 1-10:</td>
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</table>
APPENDIX B: Observation Checklist - Page 4

E. The Residents: General Observations

<table>
<thead>
<tr>
<th>The Residents Con’d:</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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<tbody>
<tr>
<td>1. Did the residents appear to enjoy <em>The Little Java Music Club</em>?</td>
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<td>2. Did they sing along with the songs?</td>
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<tr>
<td>3. Did they participate in the discussion?</td>
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<td>4. Did they assist with the set up and/or clean up?</td>
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<td>5. Did it appear that they could hear what was going on?</td>
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<td>6. Did they use the songbooks?</td>
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<tr>
<td>7. Did the resident who was co-leading, appear comfortable?</td>
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<tr>
<td>8. Did the residents offer advice or support to one another?</td>
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<tr>
<td>9. Expanded Descriptions on Questions 1-9:</td>
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</tr>
</tbody>
</table>
### F. General Comments

<p>| | | | |</p>
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<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1. Did any problems occur during the group?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1a. If yes, please describe...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Was the format changed in any way?</td>
<td></td>
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<tr>
<td>2a. If yes, please describe...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Other Comments:</td>
<td></td>
<td></td>
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</tbody>
</table>
## APPENDIX C: Resident Interview Schedule

**Please have available a copy of:**  1) the response options: “None of the time” & “Yes/No”  2) the guidelines and  3) topics list

### Site:

<table>
<thead>
<tr>
<th>Name of Program</th>
<th>The Little Java Music Club</th>
</tr>
</thead>
</table>

### Start Date of Program:

### Date of Evaluation:

Thank you for helping us to complete this survey. It will help us evaluate the program that you have participated in.

All information is confidential and you do not need to sign your name.

The following statements focus on various parts of the program - please tell us which response best reflects your opinion.

There are no wrong answers - we value all your thoughts and opinions just as they are.

The feedback you give will help us to make positive changes to the program so that others can benefit from it in the future.

**Reminder:** Hand out the responses options to the resident before the interview

### A. General Comments

Do you have any comments or thoughts on the group that you are taking part in?

<table>
<thead>
<tr>
<th>Comments</th>
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</tbody>
</table>
B. The Staff: General Comments:

1. Do you have any comments or thoughts about the staff member that helps with the group?

<table>
<thead>
<tr>
<th>The Staff Con'd</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
</table>

2. Do you find the staff member a good co-leader of the group?  
*Please elaborate...*

3. What do you like most about the staff member?

4. Is there anything that they are doing that doesn't work well?

5. Do you have any suggestions for the staff member to improve the groups?
APPENDIX C: Resident Interview Schedule - Page 3

C. The Program: General Comments

1. Do you have any comments or thoughts about things that are used in the program...for example, the talking stick, the quotes read etc.?

<table>
<thead>
<tr>
<th>The Program Con’d</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Do you enjoy <em>The Little Java Music Club</em>?</td>
<td></td>
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<tr>
<td><em>Why or why not....please elaborate....</em></td>
<td></td>
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<tr>
<td>3. Do you like having music as a part of the program?</td>
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<tr>
<td><em>Please elaborate...what parts do you like, singing, choosing a song, playing rhythm sticks, etc.?</em></td>
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<tr>
<td>4. Do you like the guidelines for the group?</td>
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<tr>
<td><em>Any suggestions for a guideline?</em></td>
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<tr>
<td>5. Do you have any suggestions how we could improve other parts of the program, like the music, or the themes chosen, etc.?</td>
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<tr>
<td><em>Please say what you think is an important theme to talk about from a resident’s perspective living in a facility like this one?</em></td>
<td></td>
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</tbody>
</table>
### APPENDIX C: Resident Interview Schedule - Page 4

#### D. Self-Determination: General Comments

1. Do you have any thoughts or comments about the leadership in the groups, for example residents and staff co-leading the groups?

<table>
<thead>
<tr>
<th>Self-Determination</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

2. Have you helped with leading the group? (for example choosing the theme, or songs…)

*Please describe a little more…*

| 2a. If so, did you enjoy doing that? *(Please describe a little more about what you liked)* |
|----------------------------------|-----|

<table>
<thead>
<tr>
<th>2b. Is there anything you found that didn’t work so well when you were helping with leading?</th>
</tr>
</thead>
</table>

*Please elaborate…*
### APPENDIX C: Resident Interview Schedule - Page 5

#### E. Giving and Receiving Help: General Comments

1. Do you have any thoughts or comments about sharing wisdom, giving help or advice to others in the groups?

   

---

#### Giving and Receiving Help

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Do you like giving advice or suggestions to others in the group?</td>
<td></td>
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<tr>
<td><em>Please elaborate...</em></td>
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<tr>
<td>3. Do you like receiving advice or suggestions from others?</td>
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<tr>
<td><em>Please elaborate...</em></td>
<td></td>
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</tr>
<tr>
<td>4. Do you like to help with set up and clean up of The Little Java Music Club?</td>
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<tr>
<td><em>Please elaborate...</em></td>
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</tbody>
</table>

**Totals:** 0 0 0 0
APPENDIX C: Resident Interview Schedule - Page 6

F. Focus on Inner Strengths and Abilities

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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</thead>
<tbody>
<tr>
<td>1. Are there opportunities to share about your inner strengths and abilities in the group? Please elaborate....</td>
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<td>Total:</td>
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</tbody>
</table>

G. Focus on Strengthening Supportive Relationships: General Comments

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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</thead>
<tbody>
<tr>
<td>1. Have you developed any friendships or relationships from being in the group? Please elaborate....</td>
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</tbody>
</table>

2. Do you feel supported by other residents in the group when you share? Please elaborate....

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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<td>Total:</td>
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</table>
APPENDIX C: Resident Interview Schedule - Page 7

H. Increasing Expression of Coping Alternatives: General Comments

1. Do you have any thoughts or comments about sharing issues or challenges that you might be facing personally in this type of a group?

<table>
<thead>
<tr>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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</table>

Increasing Expression of Coping Alternatives Con’d

2. Does the sharing in the groups help you to deal with issues or challenges that you have?
   *Please elaborate....*

<table>
<thead>
<tr>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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</table>

3. Do you get some new perspectives from listening to other group members share?
   *Please elaborate....*

<table>
<thead>
<tr>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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**Totals:** 0 0 0 0

I. General Questions

1. Did any problems occur when you were in the group?
   1a. If yes, please describe...

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</table>

2. Do you plan on continuing to attend the *The Little Java Music Club*?
   2a. If yes or no, please describe why...

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</tr>
<tr>
<td>J. Overall Reaction and Comments</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
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<tr>
<td>----------------------------------</td>
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<td>------</td>
</tr>
<tr>
<td>1. Please rate your overall reaction to The Little Java Music Club program...</td>
<td>Yes</td>
<td>No</td>
<td></td>
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<tr>
<td>Please elaborate...</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>2. Is there anything we didn’t ask you that we should have?</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>If yes, please elaborate...</td>
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</table>

Thank you very much for taking the time to answer these questions. Your comments and thoughts are of value to us. If you have any questions about this evaluation, please contact Kristine at 604-535-1917 or email her at kristine@kristine.ca
APPENDIX D: Staff Interview Schedule

<table>
<thead>
<tr>
<th>Site:</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Name of Program: The Little Java Music Club</td>
<td></td>
</tr>
<tr>
<td>Start Date of Program:</td>
<td></td>
</tr>
<tr>
<td>Date of Evaluation:</td>
<td></td>
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</tbody>
</table>

Thank you for helping us to complete this survey. It will help us evaluate the program that you have helped to co-lead. All information is confidential and you do not need to sign your name.

The following statements focus on various parts of the program - please tell us which response best reflects your opinion. There are no wrong answers -- we value all your thoughts and opinions just as they are.

The feedback you give will help us to make positive changes to the program so that others can benefit from it in the future.

A. The Environment

1. Do you have any comments or thoughts on the group setting or the environment?

<table>
<thead>
<tr>
<th>The Environment Con’d</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. In your opinion, does the space for your group give enough privacy? <em>Please elaborate...</em></td>
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<tr>
<td>3. Is the room often noisy or are there a lot of interruptions during the groups? <em>Please elaborate...</em></td>
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<tr>
<td>4. Do you find other facility staff are supportive of this program? <em>Please elaborate...</em></td>
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<tr>
<td>5. Do you feel you had all the resources you need to conduct the program? <em>5a. If not, please describe what might be helpful to you...</em></td>
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</tbody>
</table>
APPENDIX D: Staff Interview Schedule - Page 2

B. Attendance

1. How many residents started in your program?

2. How many residents are still in your program?

3. Please check the reasons for drop outs: (list all that apply):
   3a. Health problems/illness:
   3b. Time conflict (e.g. other programs):
   3c. Not interested:
   3d. Moved out of the facility:
   3e. Deceased:

3f. Other (please specify below):

4. Which two reasons were the most common for drop outs?
   4a. Number 1 reason:
   4b. Number 2 reason:

5. Do you have any suggestions or ideas on how to better support the attendance of those residents who might be interested?
### APPENDIX D: Staff Interview Schedule - Page 3

#### C. The Program Components

1. Do you have any thoughts or comments about the Little Java Music Club as a program?

#### The Program Components Con'd

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Do you enjoy The Little Java Music Club? Please elaborate...</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>3. Do you think it is helpful to have the guidelines read out each week? Please elaborate...</td>
<td></td>
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<tr>
<td>4. Do you feel that residents have enough time to share in the groups? Please elaborate...</td>
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<tr>
<td>5. Do you like having music as a part of the program? Please elaborate...</td>
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<tr>
<td>6. Do you like having the talking stick as part of the program? Please elaborate...</td>
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<tr>
<td>7. Do you like having the quotes and readings as part of the program? Please elaborate...</td>
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<tr>
<td>8. Do you find that having a monthly social get-together or parties as part of the program is helpful? Please elaborate...</td>
<td></td>
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<tr>
<td>9. Do you have any suggestions with regards to the music or other components of the program?</td>
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<tr>
<td>10. What do you think might be the three most meaningful topics to discuss as a group?</td>
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</tbody>
</table>
## Facilitating The Program

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What has been your experience in facilitating the Little Java Music Club up until now?</td>
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<tr>
<td><strong>Facilitating The Program</strong></td>
<td></td>
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<tr>
<td>2. Do you enjoy facilitating and co-leading The Little Java Music Club?</td>
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<tr>
<td><em>Please elaborate...</em></td>
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<tr>
<td>3. Do you feel confident working with residents of varying physical functioning levels?</td>
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<tr>
<td><em>Please elaborate...</em></td>
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<tr>
<td>4. Do you feel confident working with residents of varying cognitive functioning levels?</td>
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<td><em>Please elaborate...</em></td>
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<tr>
<td>5. Are you comfortable arranging for and setting up the groups?</td>
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<td><em>Please elaborate...</em></td>
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<tr>
<td>6. Are you comfortable inviting (and motivating) residents to come to the group?</td>
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<td><em>Please elaborate...</em></td>
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<tr>
<td>7. Do you feel confident using the materials provided for the program?</td>
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<td><em>Please elaborate...</em></td>
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<tr>
<td>8. Do you feel confident supporting the residents as co-leaders in the groups?</td>
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<tr>
<td><em>Please elaborate...</em></td>
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<tr>
<td>9. Do you think the materials used were appropriated for the residents in your group?</td>
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<tr>
<td><em>Please elaborate...</em></td>
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</tr>
</tbody>
</table>
### D. Facilitating The Program Continued....

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. Is it easy for you to keep the group discussion moving at a good pace?</td>
<td></td>
<td></td>
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<tr>
<td><em>Please elaborate...</em></td>
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<tr>
<td>11. Do you feel you have time to give each of the residents enough time to share?</td>
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<tr>
<td><em>Please elaborate...</em></td>
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<tr>
<td>12. Are you able to engage the residents during the discussion portions of the group?</td>
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<tr>
<td><em>Please elaborate...</em></td>
<td></td>
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<td></td>
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<tr>
<td>13. Do you think the residents understand the themes and concepts during the group discussions?</td>
<td></td>
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<tr>
<td><em>Please elaborate...</em></td>
<td></td>
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<tr>
<td>14. Do you feel confident facilitating the group if/when problems arise between residents?</td>
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<tr>
<td><em>Please elaborate...</em></td>
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<tr>
<td>15. Do residents volunteer when you ask for help with set-up/clean-up?</td>
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<tr>
<td><em>Please elaborate...</em></td>
<td></td>
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<tr>
<td>16. Do you feel comfortable facilitating the music portion of the format?</td>
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<tr>
<td>16a. If no, please say why....</td>
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<tr>
<td><em>Please elaborate...</em></td>
<td></td>
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</tr>
<tr>
<td>17. Do you have any suggestions with regards to the themes (theme ideas, types of themes etc.)?</td>
<td></td>
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<tr>
<td>18. Do you have a musical background? If yes, please describe...</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>18a. If so, are you using your musical skills in the groups?</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>18b. If not, do you feel it is necessary to have a musical background or musical abilities to facilitate these groups?</td>
<td></td>
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<td></td>
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</tbody>
</table>
**APPENDIX D: Staff Interview Schedule - Page 6**

### E. General Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have any unanticipated problems occurred during the group?</td>
<td></td>
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</tr>
<tr>
<td>1a. If yes, please describe...</td>
<td></td>
<td></td>
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<tr>
<td>2. Did you adapt the format in any way?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2a. If yes, please describe...</td>
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</tr>
<tr>
<td>3. Do you think the length of the program is adequate?</td>
<td></td>
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</tr>
<tr>
<td>3a. If no, please say what length you would prefer...</td>
<td></td>
<td></td>
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<tr>
<td>4. Is once a week appropriate for the program?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4a. If no, please say how often you think the group should meet</td>
<td></td>
<td></td>
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<tr>
<td>5. Do you plan on continuing to facilitate the The Little Java Music Club at your facility?</td>
<td></td>
<td></td>
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<tr>
<td>5a. If yes or no, please describe why...</td>
<td></td>
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</tbody>
</table>

### F. Overall Reaction and Comments

<table>
<thead>
<tr>
<th>Question</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Please rate your overall reaction to The Little Java Music Club program...</td>
<td></td>
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<td></td>
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<tr>
<td>2. Is there anything we should have asked you but didn’t?</td>
<td></td>
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<tr>
<td>3. Do you have any suggestions for improvements?</td>
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</tbody>
</table>

Thank you very much for taking the time to answer these questions - your comments and thoughts are valued. If you have any questions about this evaluation, please do not hesitate to contact Kristine at 504-535-1917 or email her at kristine@kristine.ca
Appendix E.

Resident Consent to Participate Form

My name is Kristine Theurer and I am a Masters' candidate with the Gerontology Program at Simon Fraser University at Harbour Centre in Vancouver, BC.

You are invited to participate in a research project looking at the well-being of residents living in long-term care facilities such as this one you live in. You have been invited to take part as you have expressed a willingness to be a part of a special new discussion group here at your home. We value your thoughts and opinions and the information you provide can benefit others like yourself.

You will be one of approximately 80 people participating in these groups. All participation is voluntary. Once the opinions of people have been gathered and summarized, a report will be written and you will have access to it if you should wish to read it.

We will be interviewing you once and the interview will last about 20 minutes. We will also have a focus group where we will be meeting with some members of the group for a discussion. During the interview and the groups, we will ask you to describe and any thoughts and opinions you might have about the groups and your personal experiences. We will be observing the groups, making an audiotape recording of the focus groups and will take notes to make an accurate record of what is said. There are no right or wrong answers to any of the questions and all of your opinions are valuable and appreciated.

Our notes and the information you provide us in this project will be kept confidential. Only the researchers involved in this project will have access to the information we collect and the information will be kept in a locked place. No one else will see your responses. We will only report summarized results, so your identity will be unknown. We will not disclose any information that can be identified with you, nor connect your name to any information we present. The results will be submitted for future publication in a research journal and a book.

Your decision whether or not to participate will not affect any services you now receive. If you decide to participate, you are free to discontinue participation at any time. You can also let me know if you are uncomfortable or need a break. There are no known or anticipated risks associated with participation in this study.

If you have any questions, please don't hesitate to ask me. If you have any questions later, I will be happy to answer them. You can reach me at ____________ or email me at ______________. If you have any concerns you can also contact Dr. Andrew Wister at Simon Fraser University at 778-782-5044.

Your signature indicates that you have read and understood the information provided above and have decided to participate. Your signature also indicates that you have given permission to be recorded during the focus groups and that the results of this study can be published.

You are welcome to request a copy of this form and thank you for your participation in this study.

___________________________________________  __________________________
Signature of Participant                      Date

___________________________________________  __________________________  __________
Signature of Explainer                        Date                        Participant #
Appendix F.

Staff Consent to Participate Form

My name is Kristine Theurer and I am a Masters’ candidate with the Gerontology Program at Simon Fraser University at Harbour Centre in Vancouver, BC.

You are invited to participate in a research project looking at the well-being of residents living in long-term care facilities such as this one you work in. You have been invited to take part as you have expressed a willingness to facilitate a special group here at your home over a period of 3 months. We value your thoughts and opinions and the information you provide can potentially benefit many other residents living in long-term care facilities.

You will be one of 6 staff and 80 residents participating in the study. All participation is voluntary. Once the opinions of staff and residents have been gathered and summarized, a report will be written and you will have access to it if you should wish to read it.

We will be interviewing you in the second month and the interview will last about 20 minutes. We will also have a staff focus group in the third month where we will be meeting with the other staff as a whole for a discussion. During the interview and the focus groups, we will ask you to describe and any thoughts and opinions you might have about the groups and your personal experiences. We will be observing the groups in the first and third month, making an audiotape recording of the focus groups and will take notes to make an accurate record of what is said. There are no right or wrong answers to any of the questions and all of your opinions are valuable and appreciated.

Our notes and the information you provide us in this project will be kept confidential. Only the researchers involved in this project will have access to the information we collect and the information will be kept in a locked place. No one else will see your responses. We will only report summarized results, so your identity will be unknown. We will not disclose any information that can be identified with you, nor connect your name to any information we present. The results will be submitted for future publication in a research journal and a book.

Your decision whether or not to participate will not affect your staff position in any way. If you decide to participate, you are free to discontinue participation at any time. You can also let me know if you are uncomfortable or need a break during the interview. There are no known or anticipated risks associated with participation in this study.

If you have any questions, please don’t hesitate to ask me. If you have any questions later, I will be happy to answer them. You can reach me at ________________ or email me at _________________. If you have any concerns you can also contact Dr. Andrew Wister at Simon Fraser University at 778-782-5044.

Your signature indicates that you have read and understood the information provided above and have decided to participate. Your signature also indicates that you have given permission to be recorded during the focus groups and that the results of this study can be published.

You are welcome to request a copy of this form and thank you for your participation in this important study.

______________________________  ____________________________
Signature of Staff  Date

______________________________  ____________________________  ______________________
Signature of Explainer  Date  Participant #
Appendix G.

The Little Java Music Club Manual

THE LITTLE JAVA MUSIC CLUB

The Manual

by

Kristine Theurer

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CHAPTER 1:

INTRODUCTION AND BACKGROUND

1.1 Introduction

1.1.1 Welcome and Thank You

Thank you for being a part of this research project. Your participation in this study will potentially help to improve the quality of life for people living in long-term care institutions in British Columbia and elsewhere in Canada. The input you provide is highly valued and will be kept strictly confidential. With your help, we will be examining the processes of mutual support groups in order to better understand the elements of this type of group and how they are perceived by both the residents and the staff in long-term care facilities.

Following is a brief outline of the study for your interest. Please feel free to ask for additional information at any time throughout and I will be happy to provide it for you. I have also included more detail in the next section entitled: ‘Background’. In the following outline, however, I will keep things brief and practical so that it is not too cumbersome to read initially.

1.1.2 What is the Study about?

This study is looking at the processes involved in conducting and participating in mutual support groups within LTCF. These groups potentially offer an opportunity for residents to provide social and emotional support to one another. The groups will meet on a weekly basis for three months or 12 weeks for 45 to 60 minutes each week.

This manual is the basis for the mutual support group format and will provide a consistent structure. There will be three measurement periods: the first will occur in the first month with some observation, the second will be resident and staff interviews in the second month and the third will be focus groups with the residents in the last month. Both the residents and the staff will have an opportunity to share what the experience has been like. We are hoping that the information we gain will be of much practical use in the development of the format and of use to other activity workers such as you. This in turn will assist residents living in facilities to help themselves achieve the quality of life that they deserve through participation in groups like these.

1.1.3 How to Use this Manual

Please feel free to skim over the material in the early section of this manual. It is there to provide you with background and support information and you can refer back to it for more detail. Chapter 1 gives you a quick overview and some background information that might be of interest to you. Chapter 2 helps you to prepare for this new group including information about your role, how to set up the group and group guidelines. Chapter 3 gives some information that
might be of help to you about special challenges of groups, communication suggestions and more.

The appendix includes information about the group set up, group guidelines as well as the themes and supportive materials. The key elements that you need to run the groups are in this appendix. Each of the themes suggested for the groups give a list of related songs. CD’s with recordings of the suggested songs are provided. The lyrics to all the songs are also provided so that those group members who wish can read or sing along with the recordings. In addition, the music charts and chords to the songs are provided if live music is an option (e.g. if you or a volunteer or a group member are able to play an accompanying instrument such as guitar or piano). It also works to play the recordings on a CD player.

1.1.4 The Staff Notebook

Your thoughts and ideas are an invaluable resource for future study. A notebook is provided for you to keep track of any thoughts, opinions or feelings as we go along. This information will be helpful as we evaluate the program and will be used to revise and refine it for future use. Examples of notes can include observations of the things that you notice worked well, or did not work well; perhaps patterns of things that keep happening, any unusual events you think might be important; any strong reactions from the residents or yourself to themes, or strong reactions to specific aspects of the program; antidotes of specific events that are noteworthy. Small things are as important as the seemingly ‘big’ things. The notes can be very brief and in point form.

1.2 Background

The following is more detail on the background of this study … grab your favourite beverage and read on to find out exactly why we are doing this study and why it is so important.

1.2.1 Well-being and Social Activities in Long-term Care Facilities

Well-being and quality of life for residents living in long-term care facilities (LTCF) is a rising concern in recent decades. This is particularly important in British Columbia where the population is aging at a rate faster than most other provinces (BC Stats, 2006). Surprisingly, social relationships that residents develop in facilities are believed to have a greater impact on loneliness and depressive symptoms than the relationships with those outside, such as family and friends (Fessman & Lester, 2000). This aim of this study is to develop a mutual support group intervention for long-term care residents and to conduct a preliminary process evaluation based on a pilot study.

Roselle Kurland writes about the empowering effects of mutual support group work in the following way:

Mutual aid is at the very heart of good group work practice. The expectation that members of a group will be able to help one another – in fact, that they will be expected to do so – is a statement to each person in the group that she or he has strengths to offer to others (Steinberg, 2004, p. xi).

The positive effects of mutual support groups have been documented among older adults but there are very few studies reported in long-term care facilities. There is increasing evidence that not all activities have the same effect and that some programs intended to
improve well-being, actually have an adverse effect (Davis & Friedrich, 2004; Garcia-Martin, Gomex-Jacinto, & Martíimportugues-Goyenechea, 2004). For example, a recent ethnographic study revealed objections by older residents attending an adult day group to the activities offered claiming that they were 'childlike' (Tse & Howie, 2005).

1.2.2 Long-term Care Facilities: Increasing Challenges

Although significant advances have been made in terms of improved health-related quality indicators and safety measures, other quality of life domains e.g. meaningful activity, social relationships, enjoyment or privacy, are still minimized in current assessment processes (Kane, 2001). Thomas (2006) argues that in spite of well-maintained facilities, excellent medical care and dedicated staff, residents in LTCF are still suffering from loneliness, helplessness and boredom. A study of ill older people living in the community showed that 30% of them would "rather die" than have to live in a nursing home (Mattimore et al., 1997). There is a pervasive sense that one cannot expect good quality of life within the culture of a medical institution (Kane, 2001). The association between social involvement and positive health outcomes highlight the potential importance of research in this area of long-term care facilities (Tomaka & Tompson, 2006; Wang, Mittleman, & Orth-Gomer, 2005).

1.2.3 Why Mutual Support Groups?

Belongingness support in older people (from friends and social groups) has been associated with various health outcomes such as diabetes, hypertension, liver disease, arthritis and emphysema (Tomaka & Tompson, 2006) and coronary heart disease (Wang et al., 2005). This has implications for healthcare funding, in part because Canadian demographic trends indicate we are about to face significant increases in the population of persons over 64 years of age from 13.2% of the population in 2005 to 24.5% of the population in the year 2036 (Turcotte & Schellenberg, 2007).

The positive effects of self-help groups have been documented among older adults with cancer, depression and with widows (Christenson, 1984; Silverman, 2004; Ussher, Kirsten, Butow, & Sandoval, 2006); there is a lack of substantive research, however, for these groups in LTCF. Davidson, Chinman, Sells and Rowe (2006) defined mutual/self support groups as "...groups in which the relationships peers have with each other are thought to be reciprocal in nature; even though some peers may be viewed as more skilled or experienced than others, all participants are expected to benefit" (p. 444).

This study proposes to look at the processes that occur within mutual support groups in long-term care facilities. An activity staff member (like yourself) will co-lead the groups with a resident group member (rotating co-leadership) and act in the role of a facilitator in order to assist with any special needs of the residents.
CHAPTER 2:

PREPARING FOR A NEW GROUP

“Although the world is full of suffering…it is also full of overcoming it.”
(Helen Keller)

2.1 Group Benefits, Criteria and Set Up

2.1.1 The Benefits of Being in a Mutual Support Group

Following is a list of some of the many benefits of participating in a mutual support group (Toseland & Rivas, 2005). You likely have some of your own ideas to add to this list. A mutual support group can provide…..

- empathy from multiple sources
- mutual help
- the instillation of hope
- normalization (for living in a facility)
- role models
- social support
- validation of experiences and..
- vicarious learning of coping skills.

2.1.2 The Group Criteria and Size

Residents in each facility will be invited to participate based on their willingness and ability to take part in an ongoing group process. The residents who will not be included are those with advanced dementia or pronounced aphasia who would not be able to participate in verbal discussions. Also not included in this study are temporary respite residents and those whose needs cannot be met by a single activity worker. To account for the number of residents that will not be able to participate for the full three months (residents move, become ill or unable to take part for a multitude of reasons), the initial recommended number of residents to invite is approximately 12 - 15. An ideal group size is about 8 – 10 members.

For the purposes of this study only, the group will be closed in the sense that once the group has started new members will not be able to join the group until the study is complete. Once the study is complete, you are welcome to continue the group and to invite new members. As previously noted, start out inviting at least 12-15 members as it is very unlikely that all will accept or come each week. I usually have about 20 on a group list that I go out and invite, but they are never all able to come and participate at the same time.
2.1.3 Setting-up the Group

From many years of leading groups, I have found that most successful way to start up a group is to offer a safe, non-threatening environment, personal invitations and most of all....treats! It really is as simple as that. Food is a familiar and comforting aspect to social gatherings and "warms the soil" (Thomas, 1996). Just as the seed of a flower will not grow in frozen soil, we too need a warm space in which to grow. Suggestions for treats include coffee and tea, warm cookies from the oven and fresh fruit, but you can offer whatever feels right for your group.

For the first meetings I set up the room to make it as warm and inviting as possible. As the group progresses over time, I invite group members to help me prepare the room each week. We push several tables together in a rectangle shape so that we can all sit close together and hear one another share. We make the room inviting by playing music right before and after the group and ....by setting up the following:

1. tablecloths on the tables and napkins
2. a "talking stick" (a large piece of driftwood, approx. 2-feet long, sanded down and varnished)
3. the "Group Guidelines" and the "Little Java Music Club" sign inside plastic display holders
4. flowers (real if possible, otherwise dried or silk flowers)
5. condiments for coffee/tea
6. warm cookies or fresh fruit and coffee and tea
7. lyrics to the songs (songbooks) and sheet music (if needed)
8. rhythm instruments if possible (e.g. simple rhythm sticks/ maracas)
9. CD player and CD's.

2.1.4 Meeting Place and Times

Generally speaking, late mornings (10:30/10:45 am) tend to be the best meeting times. If that is not possible another time that works well is just before supper (e.g. 3:30/3:45 pm). The time I try to avoid is right after lunch as this is often a time when people are sleepy or low in energy. A room that is separate where you can close doors is ideal as it cuts down the distractions.

2.1.5 Publicizing a New Group

Before advertising the group to the residents, it is important to let all the staff in the facility know that you are starting a new group and what the purpose is. If you are able to attend nursing/care team meetings and share the information there, that is even better. Generally speaking, staff tend not to like surprises. Asking for their suggestions in advance about the time or place where the groups could be held might benefit the group as a whole. This invitation can also go the group, as it fosters their support and involvement. Have posters ready to hand out as well as invitations for the staff to come to the groups to observe.

To let the residents know that this group is happening, several things can be done in advance:
1. Put up posters that include a very brief description of what the group is and who can come (feel free to use the attached sample and simply rewrite the information to suit your circumstances)

2. Distribute the signs to the key areas of your home e.g. nursing stations, information boards, elevators etc.

3. Include the poster in your long-term care facility newsletter (if possible)

4. Make up invitations and hand them out personally (feel free to use the attached sample)

5. Offer warm apple pie and ice cream for the first group meeting (or anything that will get people’s attention...hint, chocolate is a sure thing, or Nanaimo bars etc. etc.).

When I invite residents to participate I simply say something like this: “Hello __________. I’m so glad I found you! Come join me for a cup of coffee or tea – a few of us are getting together and there will be some good music there as well”. I do not use terms such as mutual support, groups or a club or anything that might feel uncomfortable for someone who has not already been a part of a mutual support group.

2.1.6 The ‘Talking Stick’

The ‘talking stick’ is a Native North American tradition used at tribal council meetings. In this tradition, the ‘talking stick’ is a ceremonial tool that reminds council members not to interrupt the stick holder and to listen closely. The tradition is based on honouring each member’s sacred point of view even though they may disagree (First People, 2007). For our purposes, we will use the talking stick in a similar way. The group member holding the talking stick shares, and when they are finished, they pass the stick on to the next member. The purpose of the group is explained each time during the group guidelines are read (guideline #1) as well as one of the other seven guidelines.

2.1.7 Themes, Music and Supportive Materials

There is a group leader binder put together that includes the group leader guidelines, set up/clean up checklists, a themes index and the themes themselves. Please look through this binder before starting the first group. The group leader guidelines will serve as a guideline for you to start the group and to, over time, support the residents to take on more and more leadership roles. Each of the themes have related songs listed as well as affirmations, sayings, poetry etc. attached. The themes are suggestions only - residents may have other topics that may be of interest to them. Please also feel free to add songs not listed in the song index that the residents and/or you may want to include.

2.2 Guidelines for Facilitators

"Full inclusion for all; the belief that there is not social justice until each belongs and has an equal place in our home"

(adapted from Newton & Wilson, 1999).

In order to help the groups begin their journey as a mutual support system, a tentative format is presented so that the group has a solid start (Steinberg, 2004). It takes time for a
group to develop the capacity for support and to develop leadership strengths. The role of the facilitator is to provide an initial structure and to help the group develop cohesion and strength. As the group progresses the facilitator’s role is to ‘decentralize authority’ (Steinberg, 2004). This means encouraging the group members to make as many decisions and choices as possible within the group-parameters. The parameters include things such as staying within the group time-frame (approximately one hour); respectful treatment of one another and allowing each group member a chance to share. The partnership role of the facilitator and the group members is outlined by Steinberg (2004) where the facilitator supports the group in having a ‘real say’ by saying things such as: ‘How do you see things?’, ‘What should we do at this point’, ‘How should we go about this?’ (pg. 147).

2.2.1 Your Role

Your role is of an advocate for the group as a whole and for all the group members, so that even the most vulnerable members have an equal place within the group. You have the very important position of being a supportive facilitator, but not of being the group leader. In order to empower the residents, this group is structured to allow decisions to be placed in the hands of the residents. Through your encouragement the group members, if they choose, eventually become the group leaders.

This manual has guidelines and details to help you with the process. The group is not meant to be a treatment group, therefore you can rest assured (and relax!)... your role is not to be a therapist, but rather a support person who handles the logistics of putting a group together and helping it to function. The details of how to do this, are coming up. All the ingredients for a successful group are there – you don't need to figure them out, it has been done already for you and tested out with a group.

It is important that all who participate in these groups feel secure that the sharing that they do is treated with respect and will be held in confidence. This is a part of the eight suggested guidelines that will be laid out in this chapter (see 2.3.2 Suggested Group Guidelines). Once your group has agreed to the guidelines, it is helpful to ask one of the group members to read out the suggested guidelines at the beginning of each group. As all eight of the guidelines are a bit long to read each week, it is recommended that you read the first guideline every week (which states the purpose of the group) and one of the remaining seven. The group leader is provided with a “Checklist for the Group Leader” form will allows the rotating leaders to keep track week to week which guidelines were read the previous week. In addition this form helps the leader to track which residents didn't get to share (due to time restrictions). These residents could be asked to share first the following week.

2.2.3 Changes to the Format

For the purposes of this research project it is important to keep the processes of the groups as similar as possible. Therefore, please make as few changes as possible to the format for first 12 sessions (that is approximately 3 months) so that the groups remain comparable. Thank you in advance for this. After that time-period, of course, you are welcome to make whatever changes feel right for your group. Having asked this, if the group strongly feels a need to make a change, then that is more important than this research project. In that case please go ahead and make the change and keep a record in your notebook.
2.3 The First Group Sessions

2.3.1 The First Group

For the first meeting it is likely you will need a little more time than usual. Try to keep the meeting as simple as possible as everything is new on this day and too much information can be hard to assimilate. Here is a proposed format: (please see the “Group Leader Outline”):

- Have background music playing as people come in.
- Share the purpose of the group and the talking stick (#1 & #2 of the guidelines).
- Play/sing the opening song: “The Little Java Music Club” — invite group members to sing along and/or play the rhythm sticks.
- Invite one of the residents to choose a theme for the list of ideas provided. Give them the talking stick and invite them to share how they are doing and then any thoughts they might have around the theme. After they have shared, ask them to pass the talking stick on to the next resident. Go around the group inviting each member to share.
- When using the themes, feel free to use only the first question. The other questions can be used as needed or if they are particularly interesting to the group leader. Please note that if not everyone got a chance to share, it could be appropriate to use the same theme two weeks in a row to enable everyone to participate.
- After a couple of the residents have shared, invite one of them to choose a song, or pick one of the quotes attached to the themes. Then go on with the sharing around the circle, until each resident has shared or the one hour is over.
- When choosing songs, please note that the first group of songs listed are ‘older’ songs and the second group are more recent.
- Ask for resident volunteers to help with clean up after the program, someone to help lead the group for next week (see form provided to keep track).
- Invite the group to help sing the closing song: “I’ll be there for you” and thank everyone for taking part. Invite residents to come again the following week.
- Turn on the background music and help the residents with clean up, etc.

2.3.2 About the Group Guidelines

Rather than calling them ground rules or restrictions, I like to call the suggestions ‘guidelines’ as it keeps the focus is on the positive. The following guidelines are suggestions — please offer them to your group. Let them know that these are guidelines that other groups have used and ask the group members if they would like to adopt them as well. They may want to add additional guidelines or reword these later. They are printed out as a separate attachment for your group. Here are the proposed guidelines:

1. The purpose of the Little Java Music Club is for us to help one another and to support one another’s strengths.
2. We keep things we hear here confidential. That means we keep the stories but leave the names behind.
3. We use the Native American traditional ‘talking stick’ as a way to honour one another. We do this by not interrupting and by doing our best to listen with care.
4. We are respectful of one another’s sharing, even if we disagree on things. That way that we can all feel comfortable to freely share our ideas, thoughts and feelings.

5. We are respectful of one another’s time and keep our sharing to about five minutes so that everyone gets a chance to share.

6. We allow each other the right to “pass” if we do not feel like sharing at any time.

7. We understand that this group is not a substitution for professional help or advice … we encourage each other to seek support services or counseling as needed for more difficult situations.

8. Our rotating group leaders are entrusted with our guidelines only. We have but one ultimate authority and that is loving kindness.

As the groups continue, encourage those residents that appear comfortable, to take on more leadership within their group. Examples of leadership include choosing a theme, reading the quotes, leading the groups, setting up and cleaning up, etc.

2.3.3 The Monthly Party or Special Event

It is highly recommended to have a party once a month. The social aspect of coming together for groups is very important and in previous similar groups, I found that the parties kept the spirit of the group alive. It is a way of motivating residents who initially came to the group but dropped out, and a way of re-motivating those who have been participating. The reason for the party is not important, it can simply be … “We’re having a party!”. The key component is… you guessed it…food. Order apple pie and ice cream, buy a box of chocolates, or order pizza for after the group…anything that is a little unusual for the group to have. Invite the group members to invite other residents that don’t normally come as special guests, and/or to invite the staff in to take part (see resident invitations format attached). All of the above help to build group cohesion and strength. Do it any time the group energy appears to be flagging and in any case, do it once a month. Any excuse for a party is a good one! The group format still works, (i.e. passing the talking stick around etc. etc.)…but just add in the extra special food and/or new people.
CHAPTER 3:

WORKING WITH GROUPS

3.1 Special Challenges of Groups

Groups fill an important need for many residents living in LTCF. Social isolation is a common problem for residents even though they are living in what appears to be a highly social environment (Molinari, 2002). A group can enhance a sense of belonging and provide a structure whereby residents can get to know each other on a more intimate basis than in the usual social gatherings. However, the groups also create some unique challenges for the group members and for the facilitator. Residents live with a wide range of cognitive and physical limitations and following is suggestions and selected information about groups and group work for facilitators.

3.2 Group Dynamics

The dynamics which occur within groups over time vary from group to group, but also illustrate some common aspects. Bruce Tuckman (1965) developed a 4-stage model of group development. This model outlines the process of a group developing in maturity and ability. It is not always a linear model. In other words, the four stages often overlap and/or the group will move back and forth between the stages.

1. **Forming**: The participants come together and get to know one another and form as a group. At this early stage, the group is more dependent upon the facilitator until the vision of the group and the member’s roles become clearer.

2. **Storming**: The second stage is where the group establishes how leadership is handled and chooses guidelines to follow. Clarity is increasing but there are still uncertainties and it is helpful to the group if the facilitator coaches group members on how to take on more leadership.

3. **Norming**: The third stage is where agreement is eventually reached on how the group operates. Responsibilities and roles have become clear and accepted and commitment and unity is stronger. This is the stage where the group begins to plan fun activities and try new things.

4. **Performing**: The group practices its craft and becomes effective in meeting its objectives. It likely has a shared vision and is able to stand on its own feet with minimal support from the facilitator.
3.3 Mutual Support and the Role of the Facilitator

At first glance, mutual support (also often referred to as ‘mutual aid’ in this section) may be construed as a simple exchange of support within a group setting. However, there is a multitude of dynamics that occur and it is helpful to identify them as a group facilitator, in order to support the ones that contribute most to the well-being of the group and the participants. In her book, *The Mutual-Aid Approach to Working with Groups: Helping People Help Each Other*, Steinberg (2004) outlines 9 mutual aid dynamics identified by Shulman (1999). Following is a brief description of these dynamics along with a suggestion of the supportive role the facilitator can take.

1. *Sharing Date:* Mutual support is based on a belief that every group member has a rich resource of life experience to share.
   - The facilitator encourages the group members to share their wisdom with one another, rather than looking to the facilitator for answers.

2. *The Dialectic Process:* The dialectic process within a group format often calls for the exchange of arguments to arrive at a new truth. The format of the mutual support group does not include the interruption of sharing. However, the dialectic process of change through the expression of opposing ideas as the group members continue to share one at a time, allows each participant to arrive at their own truth.
   - The facilitator reminds participants that each person is allowed their own viewpoint and that it is alright to agree to disagree.

3. *Discussing Taboos:* So-called taboo subjects such as prejudice, sexuality and income are generally taboo subjects in our society. As respectful honesty is a part of the group guidelines.
   - The group facilitator models the process of being open and honest and that gives the members permission to do the same. This allows participants to experience commonality, keeps the sharing at a real level.

4. *All In The Same Boat:* There is a strength in numbers and as time goes on, group members derive strength from each other and from knowing that they are not alone in their struggles and challenges as well as in their victories and achievements.
   - The facilitator models acceptance, support and compassion thereby coaching participants to do the same.

5. *Mutual Demand:* As the group takes form, a process called ‘mutual demand’ occurs where the members acknowledge in their own way, a commitment to the deeper level of respectful sharing within the safe structure of the group. This means that as participants are ready, they will share on more than a superficial level.
   - The facilitator encourages this process when it happens by thanking them for their openness and trust.

6. *Individual Problem Solving:* As individuals bring their problems to the group, the members have an opportunity to look to their own experience to be of help to one another, rather than give advice.
   - The facilitator encourages participants to thoughtfully reflect on their own experiences with the issue and share with the intent of being of service to one another.
7. **Rehearsal:** The mutual support within the group provides a safe place for individuals to try out new ways of thinking, expressing their feelings, taking risks, making mistakes and expressing dreams.
   - The facilitators models this by sharing their own risk taking, mistakes and dreams and actively showing support for trying and failing, rather than not trying at all.

8. **Strength In Numbers:** Individual group members gain strength, courage and hope from the support of other group members that are experiencing similar challenges as themselves. The group can choose to address problems within their living space as a collective, or use it's strength to help an individual face a special challenge.
   - The facilitator encourages members to support one another by helping them to think of specific ways in which they can do that, by talking about ‘strength in numbers’ and praising it whenever it is seen in action.

3.4 **Dealing with Conflict in the Group**

Conflict will arise from time to time and is a natural part of any group process. There are ways to handle conflict but of course, each situation will be different. However, there are early indications of developing conflict that can be helpful to recognize. Some of these are withdrawn body language, disagreements regardless of what is shared and increasing lack of respect for other group members.

There are several positive approaches to this that can help group members work through this together and result in resolutions.

1. Encourage residents to agree to disagree
2. Encourage residents to share concerns honestly and respectfully
3. Encourage following the guidelines adopted by the group
4. Follow up concerns after the group is over with the resident expressing conflict to ensure that they have the support they need
5. Listen carefully to the other person and make certain they feel understood.
6. Provide more information that they might need to resolve the issue

3.5 **Ways to Strengthen Social Support in Groups**

1. Establish a code of behavior by introducing the guidelines in the first meeting.
2. Model supportive behavior by showing a high level of support and caring.
3. Encourage physical contact as the group is comfortable with one another. For example, if a resident is struggling with an issue, model hugs and caring and encourage group members to do the same throughout the week.
4. Positive comments: provide and encourage genuine positive feedback. It will help raise general self-esteem.
5. The group is only for individual sharing and group issues. If group members are having problems between each other, encourage them to sort out the problems after the group is over.
6. Encourage individual sharing outside of group time for issues that are very difficult to handle. If a group member’s behavior significantly disrupts the group ask the resident to leave and meet after the group to discuss the problem.

Conflict can be seen as an asset rather than something to be avoided as long as the resident is able to behave in a respectful manner.

3.6 Mutual Support and the Role of the Facilitator

The key role of a group facilitator is unconditional positive regard, a term coined by Carl Rogers (1951). A way to do this, is to ‘mirror’ back what is heard. This means to restate what the resident has said, either exactly (if it is short) or to paraphrase. This serves a number of purposes:

1. It helps the resident to clarify what they are feeling.

2. It helps the resident know that they were heard and that what they have to say is of value.

3. It helps other residents hear what was said.

This simple process validates whatever is being shared without placing any judgement. At the center of these mutual support groups is a belief of the importance of valuing and actively supporting each member of the group. In his book A Way of Being, Rogers (1980) states: “As persons are accepted and prized, they tend to develop a more caring attitude towards themselves” (p. 166).

As the group facilitator sees the world through the group member’s eyes so the member will come to see his or her view of reality as having value.

I hope this manual is helpful to you and I thank you for taking part in this study.

Kristine Theurer