THE VALUE OF RECREATION THERAPY FOR INDIVIDUALS LIVING WITH DEMENTIA

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The Value of Recreation Therapy for Individuals Living with Dementia

By

Danielle LeDrew

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I would like to dedicate this thesis to my parents, Dennis and Wanda LeDrew. I am extremely thankful for your endless support and encouragement. Even when I doubted myself you always believed in me. You will never know how much you both truly mean to me, I love you.

Abstract

The purpose of this research was, first, to examine the meaning of recreation participation for individuals with Alzheimer's disease; and secondly, to examine the provision of recreation therapy on a dementia care unit as experienced by recreation therapy practitioners. Qualitative methods included observations of programs, interviews with residents, family members and recreation therapy practitioners, and the maintenance of a reflective journal.

The findings suggested that participation in therapeutic recreation (TR) programming was important for a number of reasons. In addition to experiencing feelings of enjoyment, engagement and meaning, of primary importance was the relationship development between resident and practitioner. Issues of the TR practice were also examined and discussed. Recommendations for practice and future research are highlighted.

From this research it was suggested that there should be more communication between the practitioners and the family members as well as between the staff. Increasing communication between the practitioners and the family members will allow for the practitioner to learn more about the residents and provide programs that are focused on residents' personal preferences and past activities.

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History of this Research

In the winter term of 2006 I began an internship with a long term care home that is part of a Regional Health Authority in eastern Canada, as part of a course requirement. When I began my graduate work in the fall of 2005, I planned to carry out my thesis research on some aspect of the provision of therapeutic recreation[1] services for a special population. One population I was particularly interested in was individuals with Alzheimer's disease and associated dementia. While completing my internship I spent a great deal of time on the dementia care units and my desire to complete research in the area of dementia grew. After working closely with the residents of both units and engaging in their activities I knew for certain that my focus would be on them and their lives. Thus began the collaboration between the long term care home and the School of Human Kinetics and Recreation at Memorial University of Newfoundland.

Having decided that I did want to complete my thesis research in this area, I met with the recreation therapy practitioners along with my academic advisor to discuss the possibility of carrying out some kind of applied research at the facility. One Recreation Therapist and two Recreation Therapy Assistants agreed to participate in the study. Given the nature of the collaborative work proposed, an action research framework was dictated. Action research allows for the involvement of participants as co-researchers and in this instance, the practitioners assumed the roles of co-researchers and they were involved in all aspects of the research from

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[1] The terms therapeutic recreation and recreation therapy will be used interchangeably throughout the thesis because the literature often used the term therapeutic recreation while the department within the regional health authority is called Recreation Therapy.

conception to dissemination. It is important to note that without the involvement of the co-researchers this research would not have been possible. This study was a direct result of their involvement in the lives of the resident participants and their family members.

The study focused on the lives of the residents who lived at the long term care home, their family members and the recreation therapy practitioners.

Chapter 1: Introduction

1.1 Introduction

"Alzheimer's disease (AD), a degenerative disorder that attacks the brain and leads to dementia, is one of the most common dementing disorders of old age" (Khachaturian & Radebaugh, 1996, p.4). Unless an individual knows someone living with Alzheimer's disease they may not be aware of the growing incidence of this disease. It has been estimated that there will be approximately 97,000 new cases of dementia diagnosed in Canada in 2006. Further, almost 25% of Canadian families have a family member living with Alzheimer's disease (Alzheimer's Association, 2006). It is anticipated that the cases of dementia will surpass the estimated cases of people diagnosed with any other disease during this year. One of the reasons for the rise in number of people diagnosed with Alzheimer's is because of the aging population.

While a great deal of information is know about various aspects of Alzheimer's Disease including symptomology, variations of the disease, and changes in brain functioning of those with dementia, there is no known cure for the illness and confirmation of such a diagnosis can only occur post-mortem (Khachaturian & Radebaugh, 1996). Though there is no cure for the disease, there have been some indications that individuals with AD can benefit from continued recreation participation as a means of maintaining and improving quality of life and activities of daily living (Sullivan, Pedlar, & Miller, 2002). "Recreation therapy is a profession that uses various activities to improve the physical, cognitive, emotional, and social functioning of individuals disabled as a result of trauma or disease" (Long, 2002, p.1). The activities implemented by recreation therapy practitioners serve to relieve symptoms associated with the disease. Further therapeutic recreation (TR) practitioners provide education for participants and family members regarding coping strategies that may benefit those living with AD. Finally TR is used to promote socialization. TR practitioners follow a resident focused care philosophy in which the resident and their wishes are the center of the practitioners planning and implementation of activities. A number of positive outcomes for residents in long term care facilities involved with therapeutic recreation have been identified. For example, in a study conducted by Geiger and Miko (1995) it was found that residents who participated in recreation therapy programs experienced a sense of continuity and security, a desire to learn, and it allowed them to fill their desire to interact socially with others. Similarly, Sullivan and colleagues (Sullivan et al., 2002) suggested that access to leisure opportunities enabled residents to contribute to their "community," belong to a group, and gain a sense of achievement by helping others.

1.2 Purpose of the Study

If people who are diagnosed with Alzheimer's disease or other forms of dementia have no choice but to accept the diagnosis and recognize that it will become a part of their life, then why has research into the experience of dementia, including quality of life issues been slow to evolve (Cahill, Begley, Topo & Saarikalle, 2004)? The lack of attention in the area of quality of life for people with AD has left people with more questions than answers. Additional research in this area could substantially benefit individuals with Alzheimer's disease as well as their caregivers. The purpose of the current research then was twofold, first, to examine the meaning of recreation participation for individuals with Alzheimer's disease; and secondly, to examine the provision of recreation therapy on a dementia care unit as experienced by recreation therapy practitioners.

This research was the start of collaboration between the School of Human Kinetics and Recreation at Memorial University and the Department of Recreation Therapy in the regional health authority to formally evaluate the services offered. The current research was conducted to examine the experience of the residents with regards to the recreation offerings from the perspectives of all those involved. The focus of the research was to evaluate the services provided during recreation therapy in a long-term care facility in Eastern Canada. The ultimate goal was to provide the recreation therapy practitioners with an in-depth understanding of the services offered and to determine whether these services were meeting client goals.

1.3 Research Questions

Given the purpose of the current research, the following research questions were used to guide the study:

1. What meaning does recreation therapy have for residents?
    - What is the perspective of the resident?
    - What is the perspective of family members?
2. What is the experience of the recreation therapy practitioners in the provision of the recreation activities on a dementia care unit?

These questions were formulated in conjunction with the recreation therapy practitioners (all co-researchers) from the long term care home to ensure that the findings resulting from the research would be valuable to the recreation therapy practice in the complex. Two copies of the final thesis will be provided to the long term care complex. As well, the co-researchers will be invited to participate in any presentations or publications resulting from this research.

Chapter Two: Review of Relevant Literature

2.1 Introduction

Information and experience combines to create each individual's unique view whenever anything is encountered. We look within ourselves to make sense of situations as they are presented. According to Creswell (1994), in qualitative research the role of the researcher is as the primary data collection instrument. As the researcher, it is necessary to outline any "personal values, assumptions, and biases at the outset of the study" (Creswell, 1994, p.163). By acknowledging this role, I hope to provide the reader with a clear picture of the lens I used to carry out this research. The following sections will address concepts that I have identified as having a potential impact on the study. The following sections will outline both my personal experiences that have brought me to this research and the literature I reviewed in preparing for this study.

2.2 Personal Experience

Growing up with a great aunt who was diagnosed with Alzheimer's disease, I experienced first hand the dramatic effects of the disease. From a young age I asked questions and was curious about what Alzheimer's was and how it affected the person and their loved ones. As I grew older I expressed my curiosity through writing papers and asking questions. Once I started at Memorial University and began working towards my Bachelor of Kinesiology (co-op) my time spent studying and researching Alzheimer's subsided for two reasons. Firstly, because the focus in Kinesiology is not on diseases and disorders but more on understanding the body in general and secondly because my great aunt had passed away. While working on my Kinesiology degree I had many accomplishments but always felt that there was more to be discovered about how people live with various illnesses and diseases. After many work related experiences and further exploration of my options, I decided that I wanted to complete a graduate degree that would allow me to focus once again on how people actually experience living with disabilities and illnesses. During my second term as a graduate student I completed an internship as part of a course requirement at the long term care home. I worked closely with many residents of the long term care facility and became especially interested in the residents with dementia. After helping with the provision of the recreation therapy activities I immediately knew that the focus of my thesis research would be on some aspect of the quality of life for persons living with AD.

2.3 Understanding Dementia

In today's society every effort has been made to understand the causes as well as possible treatments for people with dementia. It is known that Alzheimer's disease has multiple causes (e.g. Gilster, Accorinti, & Dalesssandro, 2002). Some possible causes noted for AD are toxic exposure and oxidative stress (e.g. Khachaturian & Radebaugh, 1996). It is important to note that Alzheimer's disease which is known as the most common form of dementia accounts for 64% of all dementias in residents of Canada (Alzheimer's Society, 2006). This is why it is essential to understand Alzheimer's disease when researching dementia.

Approximately 18 million people with dementia are living in the world today (Gigliotti, Jarrott, & Yorgason, 2004).

The Alzheimer's Society defines dementia as a syndrome that consists of a number of symptoms that may include memory loss, and changes in mood and behaviour. Parker and Penhale (1998) viewed dementia as a progressive illness and at the present time it is seen as an illness from which people do not recover. Although there are variations of the definition of the illness, the symptoms of the disease have been established, for example; confusion and memory loss. In general AD eventually impacts all aspects of the person's life (Alzheimer's Society, 2006). It is also worthy to note that because dementia typically is recognized in the later years of life, the signs and symptoms can and have been mistaken for indicators of old age (Khachaturian & Radenbaugh, 1996). Some other diseases that may result in dementia include Pick's disease, Huntington's disease, Korsakoff's syndrome and Parkinson's disease.

2.4 Understanding Therapeutic Recreation

To understand the value of recreation and leisure opportunities for individuals with dementia it is important to consider what is meant by therapeutic recreation. When TR first emerged it was viewed as a rather new profession (Gunn & Peterson, 1978, p 8). According to O'Morrow (1976) the term therapeutic recreation was not found in the literature until the late 1950's. Prior to this time the prevalent terms were; hospital recreation, medical recreation and recreation for the ill (O'Morrow, 1976). Recreation therapy today is viewed as a treatment that uses education and recreation services to help people with varying illnesses, disabilities and other conditions. It helps people to develop then use their leisure in ways that can enhance their health, functional abilities, independence and eventually their quality of life (National Therapeutic Recreation Definitions, 2000).

It was during the Greek and Roman times that people began to desire a good mind in a good body. This "seems to have been responsible for a great shift in the philosophy of care for the sick and disabled" (O'Morrow, 1976, p. 85). It was during this time that rehabilitation activities were recognized to help a variety of people. This is when the healing arts were practiced. During this period of time people recognized that there was a way of helping 'disabled' people by means of therapy.

In today's society recreation has been viewed as a key element to ensuring that people with disabilities have the highest possible quality of life (Kraus & Shank, 1989). Therapeutic recreation is a form of treatment or intervention that has a specific goal or set of goals in mind, because of this recreation therapy is very different from recreation for leisure (Mactavish & Mahon, 2007). Recreation therapy practitioners work with various special populations to allow them to enjoy their leisure participation. There are many settings in which therapeutic recreation may be applied. According to Kraus and Shank (1989) some of these settings may include: hospitals, nursing homes, schools, penal institutions, programs for volunteer agencies, after-care centers, public recreation and settings serving the elderly and centers for physical medicine and rehabilitation. Depending on the setting the recreation therapy can be applied in various manners.

The Canadian Therapeutic Recreation Association "identifies functional interventions, leisure education, and participation as key elements in therapeutic recreation programming" (Mactavish & Mahon, 2007, p. 248). Mactavish and Mahon (2007) go on to state that functional interventions are used to address daily living skills to allow people independence in everyday functioning, while leisure education is about educating the person so they are aware of the 'self' in leisure, they learn skills and self-determination, while finally participation simple refers to allowing the person to participate in personally meaningful recreation.

2.5 Importance of Recreation Therapy

2.5.1 Benefits of recreation therapy

Recreation therapy has been found to improve physical, cognitive, social, and emotional functioning; provide individuals with disabilities mechanisms to prevent declines in physical, cognitive, and psychosocial functioning; and consequently reduce the need for healthcare services (Long, 2002). Research has suggested that recreation participation for individuals with dementia results in improved quality of life, specifically in terms of social and emotional health (e.g. Fisher & Mitchell, 1998; Sullivan et al., 2002). With numerous studies supporting the benefits of recreation for people with dementia it would be expected such activities would be incorporated into the lives of all of those suffering from dementia; however, this is not always the case (Nystrom & Lauritzen, 2005).

Personal accounts of dementia give a different perspective and help in providing a greater understanding of the illness. For example, Robert Davis, a gentleman diagnosed with AD commented on the continued need for activity by stating "whether living in one's own home or in a care facility, persons with dementia retain a desire for activity that is personally meaningful" (Kuhn, Fulton & Edelman, 2004, p.144). Similarly, Marilyn Truscott, author of *Adapting Leisure and Creating Activities for People with Early Stages of Dementias*, was also diagnosed with the early stages of Alzheimer's. Speaking about the value of recreation in her own life she states: "what a sense of accomplishment, and re-enforcement of self-worth it is, to make something, paint something, and finish something, in spite of cognitive problems" (Truscott, 2004, p. 3). She then goes on to express from her personal experience how activities such as playing music, writing and painting have improved her life. These stories are important to consider because they highlight the value of continued leisure opportunities for those living with AD.

Gigliotto, Jarrott & Yorhanson (2004) conducted a study to examine the benefits of horticultural activities (cooking, crafts and planting) for people with dementia, and found that all three types of horticultural activities resulted in high levels of positive effects for the people engaged. Further, they reported that planting activities were just as effective at engaging participants as other more familiar activities such as crafts and cooking (Gigliotto, Jarrott, & Yorganson, 2004). Another less common activity that promotes communication skills for persons with dementia is group dance therapy as a form of expressive therapy

(Nystrom & Lauritzen, 2005). Further, Simmons and Andel (2006) found that there is growing evidence to support the notion that physical activity can offset age-related decline and can preserve an individual's independence.

2.5.2 Recreation therapy programs & activities

There are numerous activities that are of benefit for people with dementia (Phinney, 2006). There are a large variety of activities available for people with dementia to participate in that are also viewed are therapeutic. For instance it has been established that observing and interacting with animals and birds has been shown to be rewarding for people with dementia (Cantley & Wilson, 2002). Dowling (1995) suggested that word games, such as tongue twisters, enable people with dementia to have fun, experience cognitive stimulation, and be encouraged to make mistakes in a non-threatening environment . Another word game involves participants having to finish famous slogans such as "Maxwell House coffee: Good to the last drop." Simple table games can be self-motivating and self-involving. Such as, magazine scavenger hunts, giant puzzles, folding towels, and sorting nuts and bolts. Social gatherings should also be planned for people with dementia because social interaction has been found to have a number of benefits including security (Dowling, 1995), and a feeling of belonging and connectedness to other individuals (Sullivan et al., 2002). While most group activities have some social elements, in many instances, social interaction is the primary purpose for the activity, such as socializing over a cup of tea, discussion groups or larger events including music programs and special occasion events.

There are also a number of physical activities that involve some form of exercise. Much of the literature that is available recommends exercise, as a tool in releasing energy, maintaining physical fitness and promoting a sense of well-being (Dowling, 1995). Physical activity can involve anything from a simple exercise routine that can be followed as the residents sit or stand, to doing the hokey pokey. Walking is generally the easiest, most natural, and possibly the most beneficial exercise of all (Dowling, 1995). Again this can range from walking around the house to exploring the great outdoors.

Of all the therapies available to people with dementia, music offers the best hope of providing a generally effective set of techniques and tools for people with dementia (Dowling, 1995). One great aspect of music is that it is easily incorporated into almost any activity. Live forms of entertainment can provide music along with the ability to socialize with others. Music can also be provided simply as background to another activity or allowing participants to engage in a singing group or choir or possibly play instruments.

Art is another possible recreational activity that can be beneficial for people with dementia. However Dowling (1995) notes that the literature available on the benefits of art for people with dementia often focuses on individuals who had previously participated in art related activities. Often this is because too many people art and drawing is alien. Some ideas for art related activities that can be easy for anyone to try are colouring, shape tracing, mixing colors, and even trying your own signature.

One interest that is not often thought of as a recreational activity is cooking. The tasks involved in cooking or baking can be easy tasks and gratifying to some people with dementia. These can involve peeling vegetables, mixing ingredients, or even making a whole desert. It is also essential when planning recreational programs to allot time for spirituality. As Dowling (1995) suggests no single activity creates more peacefulness than spiritually-oriented activities. Another reason for allowing time for spirituality is that having a belief in God or some other form of Supreme Being provides individuals with a sense that all is not lost and allows them to believe that because someone else in charge of their fate, everything may work out in the end (Stuckey & Gwyther, 2003).

2.5.3 Requirements of programs & activities

Whatever the activity, when providing recreation for people with dementia it is important to remember that structured activities share two sets of characteristics if they are to provide beneficial outcomes: first they are familiar and secondly they allow the person to feel successful (Dowling, 1995). As well, Dowling (1995) points out that the task should not be new to the client, rather such tasks should be recognizable to the client. Possible examples include folding clothes, chopping vegetables, or wiping a table, but again it depends on the individual. Usually tasks that are familiar are also tasks that can bring success. For example, a resident may have spent a lot of their time baking for their family. The residents can still participate in baking and it is a task that is familiar to them. When they contribute to the baking process and see the end result they also feel that they have had success.

As noted, research has suggested that various forms of activity are necessary elements of health and well-being for individuals with dementia for a variety of reasons such as benefits to health, promoting socialization and allowing for people with dementia to cope (Green & Cooper, 2000; Sullivan et al., 2002). Existing research that explores the subjective experience of dementia has found that decreasing participation in activities is a major concern of persons with the disease (Phinney, 2006). A guideline when planning recreational activities is to keep in mind that it is important for persons with dementia to participate in activities throughout the day that provide pleasure, a sense of usefulness and trigger memories of familiar activities from his / her past (Alzheimer's Association, 2006).

2.6 Providing Long Term Care

Often the burden of caring for a loved one with dementia becomes overwhelming. Many family members who are caring for older adults experience physical, psychological, emotional, and even possible financial problems (Khachaturian & Radebaugh, 1996). In many instances, families eventually face the possibility of having to place the loved one in a long term care facility.

Obviously, there cannot be a debate about the rapid growth in the elderly population world wide (Hornum, 1989), and with an aging population a definite barrier in the selection of a long-term care complex is availability. As people age and suffer from chronic illnesses and can no longer care for themselves they must look for facilities that provide long term care (Bayne, 2006). Often these facilities have limited availability and a reality is it may take years before being accepted into the facility. While the specific medical attention provided by a long term complex is a primary priority, many families want to ensure that the complex offers recreational activities, social relationships, good company, visitors, opportunities to receive spirituality and a good atmosphere (Cantley & Wilson, 2002). Some families will also look to place their loved on in a complex which has a Special Care Unit.

Special care units are usually located in long term care complexes and are floors or units which are designated specifically for one population, such as residents with dementia. Special care units have had increased interest over the past few years, resulting in research on special care units (SCUs) for people with Alzheimer's disease and dementia growing dramatically in the decade from 1990–2000 (Maslow & Ory, 2001). By the time the late 1980s had arrived there were strong debates about the effectiveness of special care units (Maslow & Ory, 2001).

According to Maslow and Ory (2001) more recent studies have distinguished various types of SCU's, including:

- Discrete units that are bounded by physical barriers for entry and exit and limited to people who meet specific admission criteria;
- Cluster units, where people with dementia are concentrated in an identified section of a traditional nursing home unit;
- Programs that bring residents from different units.

One recent study focused on a special care unit which was designated for residents with dementia. Grant, Pothoff, and Olson (2001) stated that staffing and administrative practices in dementia special care units in nursing homes and assisted living facilities are critical to organizational performance in terms of finance, human resources, level of quality, and satisfaction of staff members, residents, and family caregivers.

It is important for the facility to recognize that good dementia care is tailored to the interests, likes, dislikes, and values of each person (Cantley & Wilson, 2002). While individual care is the ideal, this process can be time consuming and at times impossible given the nature of the disease process of dementia. It is important that staff become as familiar as possible with each individual but this will take time and outside resources may be needed, including family members and other staff working with the individual (Cantley & Wilson, 2002). One way to become familiar with the residents is the use of life story books. This book is made with input, primarily from the resident, but also in conjunction with key workers and relatives. The book contains pictures, descriptions of favourite activities and personal memos.

There are many issues facing providing care for those with dementia. Communication has been cited as one of the greatest challenges facing people providing care for persons with dementia (Cantley & Wilson, 2002). One possible reason for this challenge is that many people with dementia have behavioral changes which can include hallucinations, delusions and / or agitation (Khachaturian & Radebaugh, 1996). Khachaturian and Radebaugh also suggest that the most difficult challenge in treatment of behavioural problems is the need for human resources. Of course inadequate number of staff would pose the biggest dilemma in providing recreational programs to people with dementia. This would be a major concern in any setting including long term care facilities.

Staff should be properly trained in a number of issues including communicating with the residents, respecting these individuals as contributing persons (Kitwood, 1997), as well as providing a culture in which communication and interaction is encouraged and valued. Wilkinson, Kerr and Cunninghan (2005) pose that the knowledge, experiences and skills of the staff working in long term care home settings are essential in ensuring a good quality of life for people with dementia. After the care givers get to know the residents and have faced possible barriers to recreation, specific recreation activities should be chosen.

2.7 Conclusion

The above has outlined the key concepts and terms which related to this research. Based on the available literature and the input of the co-researchers the research questions were developed.

Research, has mainly focused on the causes and treatment options for dementia, and has minimally looked into the benefits of recreational programs for people with dementia. Minimal research has explored the benefits of recreational programs for people with dementia and people often fail to determine which individuals are most likely to benefit from certain programs (Gilster et al., 2002). The current research examined leisure participation from the perspective of the residents living on a dementia care unit. Essentially, the study evaluated recreation therapy offerings from the perspectives of the residents themselves, their family members and the practitioners providing recreation services. Further, few studies have captured the experience of persons living with dementia from their perspectives; much of the information available comes from caregivers, family members and staff working with these individuals. While information from these sources is valuable and was used in this research, every attempt was made to accurately capture the residents' perspectives.

Chapter 3: Study Design

3.1 Introduction

Based on the need identified by the recreation therapy practitioners and the literature reviewed, the present study was exploratory in nature and employed qualitative methods. The purpose of the research was to examine the meaning of recreation participation for residents on a dementia care unit from the perspective of the residents and their alternate decision makers. In addition to the experience of residents, the experiences of recreation therapy practitioners in providing these services were also examined.

3.2 Research Questions

As previously noted, the research questions that guided the study were developed in collaboration with the co-researchers. These questions were as follows:

1. What is the experience of the residents regarding their participation in recreation therapy?
    - What is the perspective of the resident?
    - What is the perspective of family members?
2. What is the experience of the recreation therapy practitioners in the provision of the recreation activities on a dementia care unit?

To obtain the answers to the research questions multiple qualitative methods were employed including observations, informal (conversational) interviews with residents, in-depth interviews with recreation therapy practitioners and family members, and the maintenance of a reflective journal by myself, the primary investigator.

To answer the first question, "What is the experience of the residents regarding their participation in recreation therapy?" observations and interviews were conducted. First, there was direct observation of resident participation in a variety of recreation programs. Detailed field notes including the activity, the number of participants, the staff involved, resident interactions with one another, the practitioners and volunteers, the physical environment, and anything else deemed relevant to the program were recorded. In addition, I kept a written record of my own feelings, thoughts and questions related to the programs. Immediately following the therapeutic recreation program being observed I spoke with residents using a more conversational approach to the interview. The interviews took place where the resident was most comfortable (e.g.: recreation room, living room, common room) and all conversations were audio recorded. Field notes were also made during the interview or immediately following the interview depending on the comfort level of the resident with the process. The residents were asked questions with the intent of understanding their recreation experience. Interview questions were focused on the residents' feelings towards the program, their reasons for participation, and the value of the programs in their lives (See Appendix E). Depending on how the interview progressed, other questions were asked based on the resident's activities, preferences, communication, and relationships. To further gain insight into the resident's experience a family member (the alternate decision maker) was interviewed. The family members shared with me their opinions on the recreation therapy programs, the activities, and the overall service at the long term care home. They also gave me insight into what the residents did for enjoyment before they lived in the complex and what they felt should be done to improve their loved ones quality of life. The questions included: Does 'the resident' speak to you regarding leisure participation here? What kind of activities does 'the resident' participate in here? (See Appendix I for details).

To gain insight into the second research question "What is the experience of the recreation therapy practitioners in the provision of the recreation activities on a dementia care unit?" the recreation therapy practitioners participated in group and individual interviews to examine their experience with regards to the provision of recreation programs for this particular population. The interviews took place in their common area, which is where the practitioners feel most comfortable. The group interview allowed the practitioners to talk about the delivery of recreation programs from their own experiences, their perception of the impact of recreation participation on resident quality of life, as well as barriers to providing these programs and possible implications for improvement (See Appendix H). There was one group discussion with the therapeutic recreation practitioners during the time at the long term care home. As well, direct observations of the recreation programs occurred where the focus was on practitioner involvement in the program.

3.3 Rationale for Chosen Methods

A phenomenological approach is used as an "umbrella term covering styles of research that do not rely on measurement, statistics, or other things generally associated with the scientific method" (Denscombe, 2003, p. 96). This approach was employed because in phenomenological research the researcher works to identify the essence of experiences that concern a particular phenomenon (Creswell, 2003) as well because a phenomenological method is directed towards uncovering meaning as humanly experienced (Becker, 1992).. Because of the potential communication challenges often associated with this particular population, multiple methods were employed. Triangulation was used by employing various methods such as interviews, group discussions and observations. Using various methods can compliment each other and aid in the research findings (Denscombe, 2003).

Action research has been described as having four characteristics; it is practical, it creates change, it endures a cyclical process and it involves participation (Denscombe, 2003). Because of the interest of the therapeutic recreation practitioners in evaluating existing services offered by recreation therapy, an action research framework allowed for their involvements as co-researchers. Co-researchers for the current study included two Recreation therapist and two Recreation therapy assistants. These four individuals were involved in the proposal of the study. After the proposal was complete there was some relocation of positions. Because of this relocation one recreation therapist was not included in the rest of the study. The other therapist and recreation therapy assistant continued with the process. By involving therapeutic recreation practitioners as co-researchers, it was hoped that the research conducted would be beneficial to the practitioners, the residents and family members they work with as well as the therapeutic recreation profession as a whole.

3.3.1 Action research

Action research is a strategy used in research rather then a specific method (Denscombe, 2003). The action research process consists of four defining characteristics: (1) "practical" – it is used to study real life issues or concerns usually found in the work place; (2) "change" – it can be used to identify solutions to problems, or to gain in depth understanding of a particular phenomenon of interest and subsequently result in changes to practice as a result of this understanding; (3) "cyclical process" - it occurs in a cyclical form involving an examination of practice, reflection, inquiry, planning and acting; and (4) " participation" – it depends on the active involvement of the practitioners as co-researchers (Denscombe, 2003, p.77) .

3.4 Preliminary Observations

In order to gain some familiarity with the proposed environment for this research as well to develop a rapport with the therapeutic recreation practitioners and clients, preliminary observations were carried out over a three month period as part of a graduate course requirement designed to introduce me to various aspects of therapeutic recreation. These observations consisted of observing various recreation programs offered at the complex, meeting the therapeutic recreation practitioners, as well as beginning to introduce myself and become comfortable with the residents. By conducting preliminary observations, the initial stages of the research will not have to be used to gain the trust and openness of both the recreation therapy practitioners and the residents.

3.5 Participants

The long term care facility where this study was conducted is home to 377 residents and is located in Eastern Canada (See Appendix A for more details). This facility is home to mostly older individuals of all abilities. While many of the residents have some form of dementia, others have physical disabilities such as Multiple Sclerosis and many residents cope with developmental disabilities. To be eligible for participation in this study, participants were required to meet the following criteria:

- The resident must have been currently involved in recreation therapy;
- The resident must have had the ability to communicate for interview purposes;
- The resident's alternate decision maker must agree to provide informed consent for the resident's participation in the study. (See Appendix C); and
- The alternate decision maker must agree to participate in an in-depth interview regarding their perceptions of the resident's recreation participation.

Because the primary purpose of the study was to evaluate recreation therapy from the perspective of residents and practitioners, it was necessary that participants be involved in TR (for sample calendar see Appendix J). It was also imperative that residents be able to verbalise something about their involvement in TR in order to interview individuals. Because the recreation therapy practitioners work closely with the residents everyday they were asked to select possible participants based on the criteria. After this I contacted each of the alternate decision makers to explain the study to them and asked to meet with them for further information. During this meeting the alternate decision maker and the resident were be given the opportunity to ask any questions they may have about any aspect of the study. Family members were involved in two ways; they provided consent for the residents and they were interviewed to provide additional information regarding the residents and their participation in TR. Further, they could provide information on the resident's life before living in the long term care complex and they were able to clarify unclear statements made by the residents.

Due to the potential decline in physical or cognitive abilities associated with AD to ensure adequate participation in the study, all residents meeting the criteria outlined above were invited to participate. To avoid the possibility of feelings of exclusion some individuals were included in field notes but they were not approached for follow up interviews. In some instances, during the observations, I included notes about residents who were not formal participants in the research but it was necessary to include them in observation note to provide the context of some of the data. These individuals were not assigned pseudonyms and will be referred to as "a resident" where necessary.

As previously noted, the therapeutic recreation practitioners occupied two roles in the present research. As participants, they were being asked to participate in both observations and interviews. Consequently, they were asked to sign consent forms (See Appendix G). Family members provided consent upon the initial meeting and they will be invited to participate in one or two in-depth interviews throughout the research process.

3.6 Data Collection

As noted previously, data collection involved multiple qualitative methods including observations, conversational interviews with residents and family members, in-depth interviews with therapeutic recreation practitioners, and the maintenance of a reflective journal of the entire process. The interviews with family members and practitioners were semi-structured while the resident's involvement in the conversation was dictated by the flow of each individual exchange with residents. Observations were recorded and confirmed for completeness and accuracy with the practitioners and residents where possible. In addition to these two methods, I kept a reflective journal throughout the process to track personal observations and feelings that may have influenced the data analysis and interpretation. The journal entries were also treated as data and are presented in this thesis to assist the reader in understanding how I made sense of the data as it was collected, analyzed and interpreted.

The conversational interviews provided an insight into how the residents felt about the recreation programs. Conversational interviews were used because it has been found that engaging people with dementia in long in-depth interviews is likely to be unsuccessful. Also, because people with dementia are interested in talking about their situations, these interviews gave them a chance to express how they felt. The group discussions with the recreational therapy practitioners allowed them to express how they felt as a team so that a single person would not sense that they were only expressing their own opinion. The group discussions also allowed the recreation therapy practitioners to support each other in what they said. The use of triangulation with various data collection methods assisted in gaining a deeper understanding, as well as ensuring the authenticity and trustworthiness of the findings.

3.6.1 Observations

The observations focused on the recreation therapy programs that were offered at the long term care facility. Although the main observations were focused on the participants of the research at times other residents were observed and notes were taken if their engagement was seen as something that was interesting to the study. I aimed to keep an open mind during the observation period.

Detailed field notes were taken during the observations regarding the interactions between the practitioners, residents, volunteers and family members.

These records also indicated the response of the residents to other aspects of the activity such as physical setting, the number of residents present, and the type of activity that were provided.

3.6.2 Interviews

Because of the varying communication abilities of the participants in this research, a combination of conversational interviews, in-depth individual and group interviews were used. Conversational interviews were used rather than in-depth interviews when speaking with the residents because of the challenges associated with dementia. The interviews with the residents were designed to gain the understanding of their enjoyment and satisfaction with regard to the programs that were provided to them by the therapeutic recreation practitioners. This data was crucial to the study as the study was focused on them. These interviews were done when and where the resident felt the most comfortable.

In-depth individual interviews took place with the resident's alternate decision maker, who were quite often, but not always a family member. These interviews helped to better understand the resident and gave the interviewee the chance to elaborate on what the resident had suggested; especially where the resident had trouble communicating or when I was uncertain of what meaning was expressed. These interviews were taped via a digital voice recorder to ensure that the information was accurately captured and interpreted.

A group interview also took place with the two recreation therapy practitioners. This interview helped to gain an understanding of the issues and barriers that face the practitioners when planning and implementing the programs.

I also spoke with the practitioners informally during observations and noted what was said at these times. One of the interviews was done individually with the recreation therapist. This interview focused on the primary work that is done before the planning and implementing the programs as well as issues and concerns at the specialist level.

3.7 Approach to Data Analysis

As previously stated data was collected until there was no longer any new information being added to the study. As the data was collected it was transcribed. The interviews were recorded and then transcribed verbatim. Following this, the transcribed data was read through carefully. After reading through the data, data bibbets (small bits of the data) were noted as having similarities and being able to fall into categories (such as non-verbal communication and the support of loved ones). From these categories three themes emerged. The data was initially placed into categories, after the categories were formed they were grouped together to form the three themes listed below. After the initial coding, I stepped back and reflected on the data. Following this reflection I continued to code the remaining data into the categories (all of which are explained below). After this the co-researchers were asked to consider the findings and if they had any suggestions regarding the categories or themes. It was anticipated that data collection and analysis would occur simultaneously during the research (Creswell, 1994) to allow for theoretical saturation to be reached. Saturation is achieved when the researcher reaches a point in the study where the collection, analysis and interpretation of data no longer add new information to the study (Strauss, 1987).

The data from the interviews, observations and group discussions were looked at independently and were analyzed using Kirby and McKenna's (1989) approach to organizing and understanding the data. As the data is collected it was organized in the form of bibbets and then coded into categories. Bibbets are chunks of data that are combined to form categories. From the categories themes emerged. After the initial coding, I stepped back and reflected on the data. Each of the field notes and interview transcripts were examined independently and then used to understand the experience as a whole. During the second reading of these documents, preliminary patterns were identified. After this the co-researchers were asked to consider the findings and they were asked if they have any suggestions regarding the themes or patterns.

3.8 Ethical Considerations

To ensure that the study was conducted in an ethical manner, all those who participated received an information letter describing the purpose of the research. All potential participants were given an opportunity to ask questions and all were asked to sign a consent form prior to participation. In the case of residents, the alternate decisions makers were asked to provide written consent. This proposal received clearance from the Interdisciplinary Committee on Ethics in Human Research (ICEHR) at Memorial University as well as the ethics committee at the Regional Health Authority prior to the start of participant recruitment.

Chapter 4: Findings

4.1 Introduction

Data was collected over a period of four months, from November, 2006 to March, 2007, and consisted of observations, conversational interviews with residents, and in-depth interviews with family members and practitioners. In addition, I maintained a reflective journal throughout the study that captured my own reflections on the process and these entries have been included as data for analysis and interpretation. Time on the unit before starting the study allowed me to become comfortable with the day-to-day ongoings on the unit and I was also somewhat familiar with the staff and residents.

Findings from the data are presented in this chapter. Direct quotations from the various interviews and field notes are presented in relation to the findings of the study.

4.2 Research Participants

As indicated previously, the participants consisted of three recreation therapy practitioners who acted as co-researchers in this investigation, seven residents from two dementia care units, and seven alternate decision makers. The primary focus during the data analysis was the data gathered from the residents and the recreation therapy practitioners. The alternate decision makers provided supplemental information regarding their perception of the residents' experiences. The names of all participants have been changed to protect their identity. As previously noted although the majority of the participants that will be discussed in this research were participants, on a few occasions the research will speak of other residents. These other residents will simply be referred to as 'a resident'; including the other residents in the observations and notes was of great importance because all of the residents contributed to the programs and overall atmosphere. While every effort was made to protect the identity of the practitioners, they were informed that in some instances their colleagues may be able to identify them because of the unit involved or comments they may have shared.

4.2.1 Recreation therapy practitioners

As noted, three recreation therapy practitioners agreed to participate as co-researchers and participants in this study. As a result their involvement as co-researchers meant they contributed to all aspects of this research from inception to the preparation of the final thesis. As well, they will be invited to participate in any presentations or publications stemming from this research. As participants, they allowed me to observe them on a regular basis while they worked with the residents during the recreation therapy programs, and they participated in the group discussions to explore their experiences as recreation therapy (RT) practitioners.

Angela is a Recreation Therapist at the long term care home. She has been working in that facility for only a short period of time, approximately a year. She meets with the family members to discuss the residents and their preferences. She was responsible for conducting individual assessments and developing care plans with residents on a referral basis. She is also the clinical supervisor of the

Recreation Therapy Assistants. She observes activities on all floors and has interaction with all residents and practitioners. Before working with this long term care home she worked in another long term care home elsewhere in the province.

Sarah is a Recreation Therapy Assistant at the long term care home. She has worked at the complex for 23 years. Previous to working at the long term care complex she worked at another long term care complex also involved with recreation therapy. Sarah plans and implements the activities for 3 West with residents with dementia. This floor was open to both men and women of varying abilities.

Claire is a Recreation Therapy Assistant at the long term care home. She has been working with the long term care home for 20 years. Prior to this she was employed at another long term care facility. Claire plans and implements the programs for residents on 2 North with the majority of residents experiencing some degree of dementia. This was an all female floor that was open to only female residents with some degree of dementia.

4.2.2 Residents

Seven female residents from the long term care home participated in the research. All of these residents had some degree of dementia. All of the residents who participated in this study were female. The residents were not chosen based on gender. After the alternate decision makers were contacted and had confirmed that their permission was given for the resident to participate in the study it was noticed that all residents who were participating were female. I will now introduce each resident that participated.

Eve was the first resident to become a participant for the study. She was a vibrant 91-year-old woman. She was just recently admitted to the complex (in September of 2006) before I began my observations. Although she was new to the surroundings, she actively participated in many activities especially the outings. Eve is an outgoing woman who was very easy to speak with.

Elizabeth was the second resident to become part of the research. Elizabeth is a quiet lady at the age of 88. She has lived at the complex for almost one and a half years. She enjoyed walking around the complex and socialized with the other residents. She participated in such activities as outings, going to the salon, dinners, baking and going outside. Prior to coming to this complex she actually spent a lot of her time hooking mats. Elizabeth also mentioned how important the social aspects of leisure were prior to her admission to the complex.

Deborah was the third resident I had the opportunity to meet. She is an 88-year-old woman who has been living in the complex for almost two years. Prior to this she lived in an apartment building and prior to that she lived alone in another province. She enjoyed gardening, reading, watching television, knitting, sewing and doing crosswords. When I met Deborah she was having evening tea with the other ladies of the unit and working on a word find. She seemed to be enjoying herself.

Later in the same week I had the opportunity to meet Avril. She is 87 years of age and has been in the complex for almost a year. Prior to this she lived in another long term complex and prior to this she lived with her son for 12 years, so it has been a long time since she has been on her own. When I met Avril she was eating her dinner and continuously telling me how wonderful the food was. She was sitting with her son Pat and it was obvious her family was very important to her.

I also had the privilege to meet Ina. She is an 87-year-old woman who is living in the complex. She was ill the day I met her. She had an upset stomach and was lying in bed. Her daughter and granddaughter were sitting with her. She is an active resident who enjoys baking, bus rides and going to get her hair done. Even though she was not feeling well she was very pleasant and a joy to speak to.

May was one of the women that I saw almost everyday. She was an energetic 76-year-old who loved participating in a variety of recreation programs. I observed May in such programs as; baking, scrap-booking, evening mug up's, morning tea, and beauty culture. She was always excited to leave the floor and participate in programs. She was happy to sit and talk with me whenever I asked her to do so. She also enjoyed sitting in the cozy corner and spending time with the other women.

I met Olivia one night at the evening mug up program. Despite her age of 85 and her stage of dementia, she was able to answer Claire's (the recreation therapy practitioner) many questions and riddles. Claire was trying to solve a crossword and Olivia could tell her almost every answer. Quite often she had answers to the questions that I would never have known. Olivia loved to socialize and sit with the other women. She appeared to be eager to participate in the programs and was excited to attend. I observed her in the evening mug up's and sitting with the other ladies in the cozy corner quite often. She was a delight to speak with.

4.2.3 Alternate decision-makers

There were also seven alternate decision makers, one for each resident that participated in the study. Each alternate decision maker was interviewed about their loved one. For this study the alternate decision makers were all family members of the residents. The individuals and their relationships with the residents are described below.

Bob is the son of Eve. Bob said he visits his mother about once a week. He also noted that his sister visits his mother quite often. Bob appeared to have a close relationship with his mother and often spoke to her about the past, refreshing her memory of years gone by. When I met Bob his mother had just recently been admitted and he was eager to learn what the complex had to offer.

Elizabeth's daughter June visited her mother almost everyday. June was sitting with their mother and keeping her company when I met her. June was knowledgeable about the programs at the complex, as she could tell me the many programs that were available to her mother. June commented on the strong bond she has with her mother.

Denise is Deborah's daughter. When I met Denise she told me that she has a close relationship with her mother and she visits three to five times a week. She said that her mother did not speak to her regarding her leisure activities and she also noted that she did not know what her mother did at the complex for leisure.

She took the time to comment on the great staff that work at the complex and had some suggestions for changes.

Avril's son Pat was helping his mother to eat dinner the first time I met him. He was eager to answer all of my questions and help in any way. He said he usually visits every week and he tries to get his mother out of the complex as well. Avril had previously lived in another long term care complex and Pat took the time to comment on how he has seen a positive change in her since she has moved to this complex. Pat lives in St. John's with his family and his daughter just recently gave birth to a baby girl. He mentioned this because he noted that often Avril remembered the baby.

Florence is the granddaughter of Ina. I met her in Ina's room one day when Ina was not feeling well. Also with Florence was her mother (Ina's daughter). The family sat with Ina and showed her concern and compassion as Ina lid in bed trying to calm her stomach. Florence said she gets to see her grandmother every week and is so close to her that she actually thinks of her as her second mother. It wasn't hard to tell how close this family is. Florence knew what her grandmother participated in at the complex and she had lots of praise for the staff of the unit.

Sherry is the daughter of May. Sherry had travelled from Nova Scotia to visit her mother when I met her. We gathered in May's room as she spent her last few moments with her mother before she would have to go to the airport. Sherry explained to me that she visits once every three months. May also has a son in Gander who visits quite often and an ex-daughter-in-law that comes to see her every week. It was easy to see that May had a strong support system. Sherry explained that she is glad that May participates in all the activities that are offered. She finds that it keeps her mind busy. Sherry also took the time to comment on the wonderful staff.

The last alternate decision maker I met was Victoria. Victoria is the grand daughter of Olivia. Victoria was happy to sit with me and discuss the programs that her grandmother participates in. She was happy to hear about the many things Olivia has done at the complex and commented on the wonderful staff. Victoria mentioned that she would like to see more programs that involve word games or other puzzles. She also mentioned that she would like Olivia to go out for walks more in the summer. She said that since her grandmother has been here she has learned to socialize well and gets along with the other women. It was great to meet Victoria and tell her some of the programs I have seen Olivia participate in at my time at the complex.

4.3 Overview of Findings

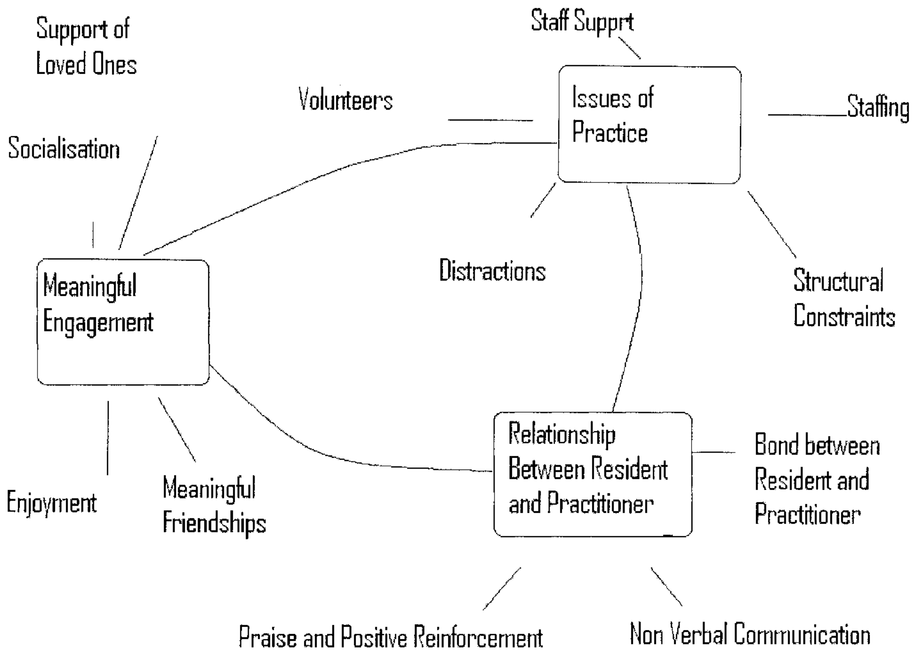
As I gathered the data and began the analysis I found myself often referring back to the research questions to ensure that I was maintaining focus. The first research question "What meaning does recreation therapy have for residents?" was reflected through meaningful engagement. I relied heavily on observations and field notes in answering the research questions due to the previously noted identified difficulties with communicating with the residents. The resident's interviews while important, did not always provide the most meaningful data, but the data was included when it was appropriate. The related patterns are further discussed in section 4.4

For this research question I also relied on the information that was provided from the family members. I interviewed family members to gain insight into the resident's life prior to admission to the complex. Also, I hoped to better understand the resident from their perspective.

The second research question "What is the experience of the recreation therapy practitioners in the provision of the recreation activities on a dementia care unit?" also required heavy reliance on observations and field notes as well as the interviews with the practitioners. The practitioner's experience is described in detail in section 4.5. Although some ideas in this section may appear to be negative it is important to recognize these challenges as they related to the practice.

To make sense of the data I used hurricane thinking as suggested by Kirby and McKenna (1989). Figure 1 is a result of this process and is included to allow the reader to understand how the themes were created.

Figure 1: Hurricane Thinking



One aspect of this research explored the resident's experience, while another aspect of it looked at the experience of the practitioner. The experience of the residents was, at times quite different, and at times quite similar to that of the practitioner. To look at how the experiences were different the themes of the residents experience and the practitioner's experience remain independent themes. To look at how the experiences of both are similar, related and sometimes dependent on one another, there is also a theme that looks into the relationship between the two.

The following themes emerged from the data gathered during this study:

- Meaningful Engagement
- The Practitioners Experience
- The Relationship between Resident and Practitioner

Each of these themes and the associated patterns will be described in sections 4.4 through 4.6 below.

4.4 Meaningful Engagement

The experience of the residents was one of the primary interests when embarking on this research. To understand their experience, I observed them in a number of different recreational activities and I interviewed them to chat about these experiences. The main patterns that emerged based on the residents' experiences were:

- Feelings of enjoyment
- Socialisation
- Meaningful friendships
- Support of loved ones

These patterns will be discussed in the following sections.

4.4.1 Feelings of enjoyment

This pattern was constantly noted during the observations of the various recreational programs. The residents found joy and pleasure in participating in the activities and they showed their emotions in various ways. Some residents expressed their enjoyment vocally during the program. For example, some commented on how much they enjoyed listening to the singers; as well some residents expressed joy by shouting when they won bingo. Others were more nonverbal in their communication of enjoyment. These residents smiled, nodded their heads, or clapped their hands to show that they were interested and enjoyed what they were doing. Below are some specific examples of enjoyment displayed in a number of the activities I observed.

Scrap-booking was open to female residents of two units. There were seven women seated around tables. They participated by cutting, colouring and stamping paper. With help from the recreation therapy practitioner and volunteer each resident made her own Christmas card.

> After seeing her finished product one woman exclaimed "It's wonderful," you could see the pure delight in her face (Field note, November 21).

Sing along programs were larger in nature and involved residents from various floors. Here they listened to a church group sing carols and gospel hymns. I had the opportunity to observe two such musical activities and on both occasions the residents expressed the enjoyment they were experiencing.

> Many residents sang along while some tapped their feet or clapped their hands. Some just nodded their heads but you could still see the enjoyment in their face. One woman never spoke a word, but she constantly nodded her head. One woman looked at me and smiled throughout the songs. The smile was one that seemed honest and full of emotion. Her happiness seemed to be pure and sincere (Field note, November 25).

> Much like last weekends gospel sing-a-long the residents sang, clapped their hands, nodded their heads and stomped their feet (Field note, December 2).

Bingo, an activity often criticised as part of the recreation therapy offerings, was an interesting program to observe. Bingo was a popular activity and residents attended for any number of reasons, to socialise as well as to play the game. However, a primary motivation is likely the same as the motivation of any individual participating in such an activity. They came together and played for monetary prizes. Although many did not win, they enjoyed playing. The following note suggests that while it may not be the number one activity on the list of practitioners, it was important to the residents.

> The women were quite engaged in the bingo. One woman would look at me ever so often and just smile. She made me feel like she really enjoyed what she was doing and was happy. The prizes for winning bingo were monetary and the women/men were very excited when they won. At the end of the program one woman exclaimed 'it's good fun' (Field note, November 25).

'Evening Mug Up' is a program where the residents gather in the common room to have coffee or tea in the evening. They spend time speaking with each other and playing games or riddles. It is a completely different environment from bingo; however, residents also enjoyed these evening chats immensely. This activity was implemented in different ways depending on a number of factors. While residents were guaranteed to have a cup of tea or coffee and a chance to chat, other activities included reading, telling stories and completing cross word puzzles. During one Evening Mug Up, Claire decided to read stories based on families and all had a strong meaning in them.

> After Claire had read the second story the women said "that was nice" Claire said to one resident "you like the stories don't you Lori?", "Yes I love them", the resident replied (Field note, November 28).

In addition to the activities that have been discussed above, where appropriate, activities were delivered in resident rooms. One such activity was Bedside Baking which was conducted in the resident's room. It allowed residents who are not able to get out of bed, or are not feeling well enough to do so, to participate in recreation therapy. The recreation therapy practitioner brought a toaster oven and cookies into the resident's room and invited other residents to participate. Then as the cookies were baking the residents participated in various activities with each other and the practitioner. On one of these occasions Sarah had six female residents involved and once the cookies were in the over she read a book on Newfoundland places.

> The women seemed to enjoy hearing about where they came from. The women would often smile at me while Sarah was reading. One woman smiled with glee when Sarah mentioned her hometown (Field Note, December 4).

The fun and fitness program was an active program that the residents of two units participated in together. The residents gathered in the common room of one of the units and Claire sang songs and asked the residents to sing along with her. As well Claire asked them to carry out various actions, such as nod their heads, and stomp their feet.

> Everyone moved about. The residents sang along and smiled. You could tell they enjoyed the exercises by the smiles on their faces. They did the hokey pokey, which the residents seemed to love. This program is beneficial to the residents in many ways (Field note, December 15).

Generally people would agree that to be considered recreation an activity must be enjoyable to the person participating. Enjoyment was clearly an important element of recreation therapy in the lives of the women in this facility. While enjoyment is crucial, another equally important element is one of engagement. While participating in recreation, people look for opportunities to engage in a meaningful way both with the activity and with each other. The following section describes the importance of engagement for these women.

4.4.2 Socialisation

All programs that I observed offered opportunities for socialisation between residents, volunteers, family, visitors, and staff. There were small groups that focused on particular tasks and larger groups where the focus was often on some kind of entertainment, such as bingo, musical activities, or outings.

As previously mentioned, the Evening Mug Up program addressed a number of resident needs. One of the main focuses of this activity was that of socialisation. The women gathered in the common room and sat together to have coffee and to talk with each other.

> The women choose to participate in the program and enjoyed the tea and word games and reminiscing. They also watched televisions and chatted with each other (Field note, November 21).

> During the Gospel sing-a-long residents gathered to listen to a church group sing Christmas carols.

> Residents from three East, three North and three West gathered in the third floor to sing hymns. Slowly more and more residents entered the lobby. Residents came from different floors. Soon the lobby was full (Field note, November 25).

This gave the residents a chance to socialise with residents from many other units.

At bingo, again residents from all floors attended. This program was open to all residents. At one bingo game I observed there were two male residents and sixteen female residents participating. Here residents had the chance to socialise with residents of other floors, and the opposite gender.

> The women were quite engaged with the bingo. Some women spoke about bingo and other topics, they used this time to socialize. Some ladies quietly sat and concentrated on their bingo while others spoke to Sarah, the volunteers, and each other (Field note, November 25).

At another evening mug up program seven women sat and had their tea or coffee. The women sometimes sat quietly and enjoyed their beverage and snack.

Quite often however, they would also use this time to socialise and speak with one another.

> The women sat and chatted about different things. They talked about having their hair done, the news, and the weather. Two women joked around together (Field note, November 28).

One evening I attended the Evening Mug Up. Residents met in the common room on the unit for tea or coffee and a small snack. But of great importance was the opportunity to socialise with others. In addition to general conversation between residents, the recreation therapy practitioner also used some of this time to read stories and complete cross word puzzles with residents. During this program it was noted:

> The recreation therapy practitioner asked the women the possible answers. She asked questions then gave some hints and allowed the women time to think about the answers. The women seemed engaged in the activity as they all contributed to guessing the answers. They were excited when someone guessed a correct answer (Field note, November 21).

During another program, Beauty Culture, the women all gathered in the 'cozy corner'. This program allowed the women to sit together in their common area and have their nails polished along with other beauty regiments. The cozy corner is an area at the end of the unit which has chairs, a television set, a table, a couch and for the season, a Christmas tree. This area was developed because they recognized that the women on the unit enjoyed socialising with one another but only have the small common area to do so. I noted the following during this program:

> The atmosphere was fun and open today. Christmas music was playing while the ladies spoke to each other as they gathered in the cozy corner while Claire painted their nails (Field note, November 29).

During the same program a man wandered onto the unit. He walked around and did not really say much. A resident was sitting, folding towels, in the cozy corner. It was noted:

> A gentleman that was wondering around came to her and took a hold of her hand. Neither of them spoke they just held hands (Field note November 25).

Although neither of them spoke a word both residents continued to hold hands.

I also asked their residents during their interviews about the time they spend socializing. During a conversational interview with a resident I had the following conversation:

> Danielle: You like sitting and chatting with the other ladies hey? Sitting and having a chat?
>
> Elizabeth: yeah

Elizabeth enjoyed sitting in the common room by the window and talking with the other ladies of her floor.

I asked the residents about how they enjoyed spending time with other residents and they all told me that they enjoyed that time. I asked May what her thoughts were:

Danielle: Do you like being with the other women and speaking with them?

May: yeah

Again the same conversation with another resident:

Danielle: Do you like getting out with the other women and doing things? Having a bit of company and some women to speak to?

Ina: yes I love that. Yeah I enjoy it. It makes me feel good.

When I asked another resident, Denise about what she enjoys she said she occasionally enjoys baking. I asked her as well about socializing with the other residents. She had the following to say:

Danielle: what else do you like to do?

Denise: talk to the boys

A little later in our conversation I asked Denise what else she liked to do and she again jokingly said she liked talking to the boys. She expressed that she liked socializing with the residents and having someone to speak to.

The above has demonstrated the importance of social opportunities. Further to being social, the residents clearly felt that it was more than just being social, it was about having friends. The following section highlights the development of friendships on the units.

4.4.3 Meaningful friendships

The women and men of the facility have lived together for varying lengths of time and subsequently have developed friendships. The residents enjoy time spent socialising with friends. In the programs that were observed it was often noted how well the residents got along with one another and the types of things they would do for each other. The women I observed appeared to have a special bond. Although they may not call each other by name all the time, they recognize each other and feel comfortable together. It was during an evening mug up one night that I first saw the special bond that the residents have.

> One woman was wandering in and out of the room; another woman was upset when her table with her coffee on it had to be moved away from her. She got upset and began to sob. Another resident sitting next to her touched her on the shoulder and reassured her that it would be ok. The woman began to sob again and the other resident once again comforted her by holding her hand (Field note, November 21).

At the gospel sing-a-long residents from all floors gathered together. One man and woman who I had seen together on previous occasions appeared to be good friends and they sat together on the couch and sang along with the music. Two ladies entered the lobby together in their wheel chairs. They asked the nurses that were bringing them into the lobby to put them closer together; it was immediately evident that they were also friends. The following note describes my observations of their interactions:

> One resident was given a song book to follow along and she followed along then asked the woman next to her if she would like to share (Field note, November 25).

During the programs it was often noted that the women praised each other for doing well. During bingo the residents would congratulate each other on their winnings, during baking the women would praise each other for a task done correctly and during the evening mug up the women would praise the others for correct answers to the word puzzles. The residents showed genuine concern and compassion for each other. Often during the evening mug up the friendships between the residents were easily observed.

> The women sat and chatted about different things. The women joked around with each other. You could tell they all felt comfortable with each other (Field note, November 28).

On any given day when I would walk onto the unit women would be gathered in the 'cozy corner'. The residents sat together and talked, watched television or just looked out the window. One day Claire had the Beauty Culture program scheduled and when she entered the floor all the women were already seated together in the cozy corner, so she decided to carry out the program in the corner rather than ask the women to move. As previously noted, a gentleman entered the floor and approached one of the residents, Lori, and held her hand. They remained holding hands for a few moments. Another resident of the same unit as Lori, Olivia sat next to her. Olivia kept her eye on the gentleman to make sure he was not doing anything to hurt Lori. After a while Olivia motioned for the man to leave and be on his way. I thought Olivia's actions were that of a true friend.

During activities that involved a number of residents from various floors, I often noticed that the women would be seated together. For the majority of occasions the residents were given the opportunity to choose where they sat and who they will sit next to. One day during a sing-a-long:

> I noticed the women from the second floor were sitting up front, they are always seated together even when it is left for them to decide where they want to sit (Field note, December 2).

Residents often sat with other residents from their home unit suggesting these were the people they considered their friends. Further, residents often gathered together in their rooms to watch television or just talk to one another. As well, this floor had a large common room and the residents often gathered there with each other. When I went to speak to Elizabeth she and another woman from the floor were sitting in two chairs by the windows talking.

One day Sarah had a bedside baking program on one of the units. This program was offered in the room of one of the residents and others would be invited. The residents then sat together while the cookies baked in a toaster oven. One woman entered after the program had begun. I noted:

> One woman entered late and took the hand of one of her friends. They held hands for a while and smiled at one another (Field note, December 4).

During the same program one resident had become upset because the nurses put her in her chair although she had wanted to stay in bed.

> Blanche was upset because she did not want to be in her chair. While Sarah spoke she wept quietly and the woman next to her spoke to her and comforted her (Field note, December 4).

The residents also quite often commented on the importance of company and friendships. When I interviewed the residents they sometimes spoke of socialising, spending time with the other residents and the importance of company and having someone to talk to.

From previous interactions with Ina, I knew that friendships and company were important to her. She spent a lot of time being around the other residents and speaking with the other women. Her desire to have friendships is noted in the following exchange:

Danielle: Do you like getting out with the other women and doing things?

Ina: yes I love that. Yeah I enjoy it. It makes me feel good.

Danielle: me too

Danielle: so it's nice to have the women around and have someone to speak to?

Ina: yeah.

Eve was somewhat new to the facility. She had only been living there for approximately two months when I met her. Eve seemed to enjoy her involvement in recreation therapy programs. I often observed her at sing-a-long as well as scrap-booking cards. I suspected that because Eve had only been at the facility for a little while her friendships and other relationships would not be as strong as the other residents who had lived there for some time.

Danielle: do you like being with the other women?

Eve: well yes if I knew who they all were

Danielle: that's right

Eve: if they weren't so different from me

Eve made a very good point. Being a relative newcomer to her surroundings and the other residents she was still settling in. She makes the point that she is still getting to know the women and right now she finds that they are different from her. The residents of both units expressed that they enjoyed being in the presence of other women and being able to just sit and talk with them. When I interviewed Eve she was sitting with her friend in the common room on the unit.

Danielle: you like sitting and chatting with the other ladies hey? Sitting and having a chat?

Eve: yeah

While friendships developed between the residents and they valued time spent with one another, equally important were their relationships with loved ones. Because of the criteria for participation in the present study, all the research participants did have the support of at least one loved one. The following section will speak to the involvement of family members.

4.4.4 Support of Loved Ones

One thing that was evident for all the residents who took part in this research was the wonderful support system they all had. As noted, each resident had an alternate decision maker and in all cases these individuals were family members; often it was the son or daughter of the resident. All the alternate decision makers were eager to meet with me and happy to answer all of my questions. They all showed great support for my research and showed care and concern for their loved ones.

All the family members stated that they visited on some occasions. The biggest factor impacting visits was their home location. Some people lived in other provinces and only had the opportunity to visit once every three months. Other family members reported that they visit once a month, while others visit once or more times a week. All family members said they visit as often as they can and enjoyed spending time with their loved ones.

The family members had some knowledge regarding what their loved one did in the past for enjoyment. Some family members admitted they had had little or no knowledge of the activities available to residents in the long term care facility. However, they did indicate that while they fully support participation in recreation therapy programs some were unaware of what was available.

All family members stated that they felt their loved one was content and comfortable living in the facility. They all took the time to comment on how wonderful the staff are at the facility. When asked if they had ever approached a recreation therapy practitioner regarding their loved one's participation in the recreation therapy programs, all family members reported that they had not.

Although they did not ask about recreation participation, many of the family members had attended some of the recreation therapy programs. Family members attended bingo, sing-a-longs, and other activities. When I first observed the evening mug up I noted that there was a family member in attendance. The family member sat with the resident during the program. As well, nearing the end of the program another resident's daughter came in and sat with her for the remainder of the program. During bingo family members attended to spend time with their loved ones as well to help them with their bingo cards.

While it was imperative that the experiences of the residents be captured from their own perspectives, it is not possible to begin to understand the provision of recreation therapy services without also considering the experiences of the practitioners and how these two come together on a daily basis. The next section will highlight the practitioners' experiences in providing recreation on a dementia care unit. This will be followed with a discussion of the relationships that exist between the residents and the practitioners.

4.5 Practitioners Experience

The second research question was designed to capture the experience of the practitioner. Practitioners are responsible for assessing residents, developing resident goals and then planning, implementing and evaluating programs designed to meet these goals. In addition to these technical skills, the practitioners come to care for these individuals and develop meaningful relationships that impact the delivery of services as well as the residents they work with. To gain an understanding of the practitioners' experiences a variety of programs were observed and notes on the various aspects of the program were recorded. As well the recreation therapy practitioners that conducted the programs agreed to take part in a group interview. I asked them questions about planning and implementing the programs and what they felt were some issues or barriers to the practice.

During the observations I noted some possible barriers or issues related to providing such programs, the practitioners were given the chance to comment on their feelings on the topic. Often I found that they addressed issues that I had not witnessed, and on some occasions, I had noticed possible issues that they did not mention in the group discussion. I went back to the practitioners and asked their opinion on what I had observed. In relation to the practitioners' experiences in practice, the following patterns emerged:

- Structural constraints
- Staffing
- Volunteers
- Staff Support
- Distractions

Each of these patterns will be described in detail below and supporting data from interviews and observations will be provided.

4.5.1 Structural constraints

Structural constraints were noted in some of the field notes recorded during the observations. For this research structural constraints were limitations to the programs based on the lack of physical space or materials. These structural constraints included: adequate space, resources, and equipment/ materials. Each of these issues will be described below.

I observed the Evening Mug Up program. During this program the residents were asked to come to the common room of the unit to have coffee and tea and spend time with the other women. The common room for this unit is a very small room, with one table, one couch and approximately seven chairs. On this particular evening, there were seven residents, the recreation therapy practitioner, myself, a nurse, and two family members present. During the program residents come and go as they feel. At one point a woman wanted to leave the room and in order to do so, she had to move a woman's table away from her to make room to exit. Although she meant no harm and had no other choice but to move the table in order to get out of the room, the woman was upset because she thought that she could no longer have her coffee.

The recreation therapy practitioner that provided that program also recalled that night when I asked her about issues or barriers to implementing the programs.

Claire: the sad thing about [unit] is the space limitations. They are probably one of the, besides for [unit], one of the busiest or active units or could be and they have the smallest sitting room. I don't know if you noticed it the other night but there were a lot of residents I couldn't even take in for tea and then they were talking over each other and Maisy was trying to get in and we had them sat on the couch and sat at the table and there was no space and ....

Danielle: and then one lady got upset because the table had to be moved

Claire: yeah and that's the space that you are working with up there and for that group of residents it's not conducive, not at all

One week later I attended the same program, again the structural issues were evident. The program was one that the residents really enjoyed. In fact there were usually more women wanting to attend then there was room available. On this evening, like the last, some ladies could not attend the program because there was no room available. Women were seated at the tables, in chairs and on couches.

I also attended a Morning Mug up, which was a similar program and was offered in the same room. On this day I noted:

> Morning mug up began at 10:30. Again there was trouble getting all the women in the common area. The room is definitely not big enough for wheelchairs. Women having difficulty walking would have great trouble getting around this room (Field note, November 27).

On that same morning I noted the impacts of the small common room on the residents. The following statements were also made that morning.

> One nurse came into the room and asked "no room left is there?" Another woman wanted to join the group but there was no room left for her in the common room. As much as Claire tried to find a place for her the room was already congested. Because of this small room one woman was excluded from the program. Now I understand why Claire noted this space to be an issue and a barrier to providing programs with this unit (field note, November 27).

Again during the group interview with the recreation therapy practitioners the issue of structural concerns surfaced. However, the major issue with regards to suitable space was the sitting area on one of the units. After Claire shared her concerns, Sarah also described similar concerns.

> Sarah: we've talked before about it and I have mentioned it before when I was up there about if they drop one bed they could open up that wall up, or drop one room a two bed room so they would have to drop two residents but then I guess they are looking at money and you know they are not going to drop down just to get that extra room as they did up on [unit], they have got a beautiful sitting room"

It was good to see that Sarah and Claire supported each other on this topic. Although Sarah does not work on this floor she showed genuine concern for the residents.

On November 25 I attended a beautiful Gospel sing-a-long. Volunteers from a local church came in to lead the group. The joyous music had residents coming from various units. The program took place in the main lobby of the 3rd floor. The main lobby is the area links the three units of the third floor. It also contains the elevators and entrance to the stairs.

During the program many people entered the lobby. Nurses, family members, other residents, and other staff would enter the lobby to get to various units as this is the only entrance to the three units on the third floor. As they would enter via the elevator or stairs they interrupted the program. As well, many people actually had to walk in between the church group and the residents to get to their unit. The staff that entered did so with little remorse or apology for their interruptions. As well, many of the residents in attendance were in wheelchairs. As others entered the floor they often had to move these residents to gain access to the unit.

Another program that I observed on a number of occasions was scrap-booking. For this activity the residents were brought to the recreation therapy practitioner's room. This room is where the practitioners plan the programs for the residents and meet with each other. The residents gathered around the table while the practitioners attempted to do some planning and work.

Baking was an interesting program to observe. On the first floor of the facility there is a beautiful common room with a full service kitchen. Groups came here to cook and bake. The room was rather large and could seat a fair number of residents at the tables. The room was also very open and allowed for wheelchairs and walkers. Although the room was ideal for this type of program, the necessary materials were not always readily available:

> Claire commented on the need for new measuring cups (Field note, November 22)

When I asked the recreation therapy practitioners to identify some of the issues they face them implementing the programs Claire made the following comment.

> Claire: and then for the kitchen area you go down there and some things supposed to be there and its not it's missing

It appears that while the area for baking and cooking is not a concern, there were concerns at times regarding the lack of resources or equipment.

Another issue regarding structural concerns that was noted during the group interview was the use of the bus.

> Sarah: even with the bus, they have the bus and that's a unit that could maybe, not so much in the winter but in the spring summer and fall, they could do with three bus rides a week or two a week now they are getting one a month
>
> Claire: even if it's just for half an hour or 45 minutes
>
> Sarah: it's getting it out of their space it's giving them something different you know and we talked about that before

Both practitioners noted that having the bus available to the residents for outings was a blessing. They mentioned that for some residents having the bus available to them for outings on a more frequent basis would be a great benefit.

4.5.2 Staffing

Another issue that was evident in my field notes and came out in the group interview with the practitioners was related to staffing. Just prior to my observations at the facility, one of the recreation therapy practitioners had been on leave for some time and had eventually extended the leave due to family circumstances. The position had not been temporarily filled, leaving the other practitioners to try to plan and implement their own programs as well as to try to plan and implement some programs for the floors. One day I asked Claire about a program that was scheduled for the next day and she told me she was not sure if she would be able to go ahead with that program because she was trying to provide some activities for Pat's unit because they haven't had many programs since Pat has been gone. It seemed like a vicious cycle. She was trying to provide for the residents of Pat's floor while he was away, but then this would mean her own residents would have to do without her or their programs for that day.

When I asked the practitioners some issues that they face they indicated that staffing issues were second to space issues. When I spoke to them about the issues and barriers the following conversation again showed that the practitioners feel the need for more staff:

> Claire: and with that unit too it's a unit where one staff would be going with them and it's impossible with Alzheimer's because they are wanderers you need the volunteer support or more staff but being realistic you need to volunteer support because you're not getting more staff

Sarah: yeah it's fine if you go on a bus ride you get assistance
getting them all down

Claire: you can't take them off anywhere you can't do it

Sarah: then you don't get off they can't get off anywhere whereas
if you had you know more volunteers or an auxiliary or
something like that you could go to Bowring Park and if
there was four of you take two each and go for a walk

Claire it expands their energy and it helps with the sun downing
but when you don't have that support

Clearly there were a number of key structural concerns impacting the delivery of recreation therapy services at the facility. The next issue of practice related to volunteers working at the facility. This will be described in the next section.

4.5.3 Volunteers

The issue of volunteers was noted in field notes as well from the group interview with the recreation therapy practitioners. It was noted that there is often a lack of volunteers with regards to the recreation therapy programs. Most recreation therapy programs could benefit from the assistance of a volunteer, yet more often then not there is no volunteer present with the programs.

The first program I observed I was very happy to see a volunteer attending to assist Claire with the program and the care of the residents. This particular volunteer came at regularly scheduled times on Tuesdays and Thursdays. As a long term volunteer, she had clearly developed rapport with a number of the residents and felt comfortable working closely with them. In my first observations, I immediately noted the need for volunteers:

> I think the help of the volunteer was desired. She helped the residents come down from upstairs, helped the residents to become comfortable, and helped make the cards (Field note, November 21).

During the Evening Mug Up there was not as great of need for a volunteer as there were only typically seven residents that could attend, however a volunteer's service would be useful in all programs. Only seven residents attended because of the lack of physical space in the common room. While observing that program one evening I noted:

> Although Claire carried on well on her own it appeared that the help of a volunteer would be useful during all activities. On this evening a volunteer could have helped the women into and out of the room, helped with the tea & coffee and socialised with the women (Field note, November 23).

One morning when I observed the baking group only three ladies attended. Just before we went to the program Claire had told me that with this program she was never sure how many women might attend. Quite often women were still sleeping, may be feeling ill or having morning care from the nurses. On this morning there was no volunteer present and since there were only three participants in the particular program, perhaps a volunteer was not necessary.

However, if more residents wanted to participate then she would likely need a volunteer present.

I went in one Saturday to observe two recreation therapy programs, one was bingo and the other was a gospel sing-a-long. The first program I observed was bingo. The residents gathered in the auditorium for bingo. I noted that there were three volunteers at this program. Two of the volunteers were students and one was a woman who had been volunteering for a number of years.

> Sarah mentioned that a Christmas concert was scheduled for the next Saturday. She asked the volunteers if they would be able to attend because she would be the only staff. That's a lot of residents attending a concert for one staff person (Field note, November 25).

Luckily two out of three of the volunteers said they would be able to attend the following Saturday. It would not be possible to offer this kind of large scale program without volunteers. Sarah was the only recreation practitioner working and had to rely on volunteers to porter residents to and from their rooms and help residents with their bingo cards. It is also important to note that although there were volunteers involved, the number of volunteers available is not always adequate.

> One kitchen staff entered and helped a man who was seated by himself. The gentleman from the kitchen returned to check on the gentleman several times to help him with his bingo card and ask him how he was doing. Eventually this gentleman left with the man from the kitchen (Field note, November 25).

When the therapeutic recreation practitioners were asked about the issues and barriers to providing the programs they reported the lack of available volunteers as one of these issues.

Danielle: so as for volunteers there is a lack of volunteers is that what you would say right now

Sarah: well this is probably our better time for volunteers we have like probably six now but I mean there are times when we have had two for the whole year

Claire: or none

Sarah: you might get one regular one ones that you know are coming in every Saturday or they are coming in every Tuesday right now we do have one for Tuesday and Thursday

Claire: it is the same one

Sarah: and one for Thursday mornings with me

Claire: and they and we just have our Saturday morning volunteers which is not a lot

A little later in the group discussion the issue of volunteers arose again.

Danielle: so some of them I guess are doing a program here

Sarah: they are doing a program where they need volunteer hours like 20 hours or whatever so like we got them now but come January we could be down to just [one volunteer] again. Volunteers like you say yes regular, mature volunteers

Danielle: that take it seriously I guess and will come

Claire: yeah and will be committed yeah

Volunteers are an important element of many recreation programs and those offered at the facility needed regular volunteers. So while the efforts of the volunteers involved were praised, it was also noted that there was a great need for additional volunteers. The next issue from the perspective of practitioners related to staff support.

4.5.4 Staff Support

Staff support appeared to be more of a minor issue with regards to the programs for the residents, however, it is still important to address. Throughout my time spent at the facility I met a lot of the staff and observed their interactions with the recreation therapy practitioners and the residents. Overall the relationships I observed between the recreation therapy practitioners and other staff members were that of a supportive manner. The staff of the facility showed great respect for all the residents and treated each of them in a fair and kind manner. When I interviewed the alternate decision makers they were asked about the staff of the complex, and their comments were always positive. When I asked the recreation therapy practitioners to list some issues or barriers to implementing their programs they had this to say with regards to staff support:

Claire: residents being ready is another one [barrier] for programs

Sarah: yeah

Claire: like especially if it's an outing and you put the list up and say you need them ready by such and such a time and you go up and you know the staff say they didn't know anything about it no one is toileted and no one has their coats on and that sort of thing

Sarah: and quite often then we have to go do that because they are on break half down staff and you've got two other units to go to and it delays things

Both recreation therapy practitioners reported that residents not being prepared for an outing was an issue. If the residents are not prepared for the outing by the staff on the floor before the recreation therapy practitioners went to get them then often they were late getting on the bus and consequently late for their program. However, this was an issue that was easily addressed and corrected. Again a little later in the group interview I wanted to address the question specifically of staff support:

Danielle: what about staff support? You mentioned it a little bit. But with any staff, support for the programs, or support for what you do?

Claire: totally depends upon the staff some staff are very supportive and see the benefits of what we do other staff

Sarah: are very negative

Claire: and they let that show to the residents too, some do. They honestly do. And like I said some are very very supportive, they know what we do they understand what we do and they know the benefit that it is to the residents.

Sarah: As for physical support rather then emotional support. You can go to the unit sometimes and certain staff are working and say 'are they ready for the bus ride' and they say 'oh was there a bus ride I didn't know ok um who do you got going? Ok May can you go get Jean's coat' and she's gone to get another ones coat and you'll say 'well I'll check on this one'. But you can go up two days after with another shift maybe and say 'are they ready for the bus' and they say 'oh my dear I didn't even know there was a bus ride sure we haven't stopped here this morning long enough for anything' and you say 'we put it on the board its on the board the list is on the'.. 'I never had a chance to look at that you know'. And they don't get up and help. You can go and gather them all up now. And you know that's frustrating when you know you got another unit yet you got to go to and probably face the same thing

From the group interview there did seem to be an issue regarding staff support for recreation activities. Again during the observations I noted a great deal or respect for each other's profession but the practitioners noted that staff support was an issue in some instances and therefore it warranted inclusion in this thesis.

While staff support was included as a more minor issue, the issue of distractions was a much bigger issue impacting many aspects of recreational programming at the facility. These distractions will be discussed below.

4.5.5 Distractions

The last issue to arise from this research was distractions during programs. This was a re-occurring issue that I noted in observations and although some of these distractions were mentioned by the recreation therapy practitioners they appear to be something that they have learned to live with. Distractions came in a variety of forms. There were distractions from other staff, family members, other residents, noises as well as other interruptions. During my first observations there was a fire alarm.

> During the middle of the activity there was a fire alarm. Claire kept all the women calm and told them not to worry (field note, November 21).

During the same activity a woman entered the room looking for a resident. She said it was time for her to go have her hair done. The resident was enjoying her cards and was a little disappointed that she had to leave.

During another activity in the common room of the unit, people wandered in and out of the room regularly during the program. Staff, family and other residents were constantly entering and exiting the room. Some would enter to get something from the fridge or kitchen area, others would just sit and listen for a while. Although it did not appear to bother Claire I thought this constant traffic interrupted the program.

On the day of the Gospel sing-a-long again space and distractions were reoccurring issues. With the sing-a-long being held in the lobby of the third floor there were constant distractions and interruptions. With the elevator and stairs all opening to the lobby where the residents had gathered, every few minutes there was an interruption. There was also a constant flow of staff walking in front of the choir and distracting the residents as well as the choir.

During another evening mug up interruptions and distractions were again noted.

> A few nurses entered to get some tea. Family members also entered as they pleased. At one point a nurse entered without excusing herself and interrupted the story telling and distracted the residents. At one point a family member entered (who is also staff) and spoke to a nurse about a broken closet. I thought that conversation could have been left for later (Field note, November 28).

When the recreation therapy practitioners were asked about issues or barriers to implementing programs the following statement was made regarding interruptions:

> Sarah: environmental or interference whatever you want to call, because we will be performing, whether its down in the auditorium or up on the units and we can go in and close the door and put a sign on it 'program in progress' but you know the door is still swung open and 'I'm just getting my stuff', 'how ya doing?' 'Oh how ya doing?' And the program is disrupted.

At times I found myself shocked at the number of interruptions in a single program. People came and went as they pleased, at times as if they did not see that there was a program in progress. This section highlighted a number of issues related to practice. The following section will describe how the practitioners managed to overcome these barriers to create opportunities in which residents could experience meaningful engagement.

4.6 The Relationship between Resident and Practitioner

As stated above, the residents and practitioners have their own independent experiences, thoughts and outlooks on the programs they provide or participate in. However, it is also important to acknowledge the interdependence of these. In some instances, residents chose programs because they enjoyed the specific activity; at other times however, they attended activities simply to spend time with the recreation therapy practitioners. There were three distinct patterns that spoke to the relationship between residents and practitioners:

- Praise and Positive Reinforcement
- Non-Verbal Communication
- The Bond Between Resident and Practitioner

These patterns will be described in detail below.

4.6.1 Praise and positive reinforcement

The practitioners often used praise and positive reinforcement when residents attempted or accomplished a specific task. This type of encouragement came in both verbal and nonverbal forms. Residents were often complimented for a task well done. In other instances, they received a pat on the back or a hug depending on the accomplishment. The practitioners frequently told the women that they were proud of their accomplishments and praised them for their work. While various forms of praise and reinforcement were used, it was always done appropriately. At no time did a resident appear uncomfortable with the physical touch used by the practitioners.

An example of this kind of encouragement occurred during the scrap-booking program. The women were asked to do various tasks such as stamp and colour the cards. During that program it was noted:

> Women were often praised for their hard work. On this occasion praise came in the forms of verbal compliments and appropriate touching, such as a pat on the back (Field note, November 21).

The second time the above program was observed the same tactics of praise and reinforcement were used. This appeared to keep the residents interested and they often wanted to put more effort into their activity after being praised.

> The women were given tasks like colouring, stamping and making bows. Claire spoke to the residents and praised them for their hard work (Field note, November 28).

Another program in which praise and positive reinforcement were used was the baking program.

> The women were given instructions and asked to do things like: pour, stir and measure. They were asked to perform all the processes involved with baking. Claire constantly praised the ladies by saying 'good job' (Field note, November 2).

In addition to the smaller programs as noted above, praise was also used in larger groups such as the gospel sing-a-long. The residents were encouraged to sing with the groups and were praised when they actively participated. The group clapped for the residents who sang and encouraged them to sing again. Usually at the beginning of the sing-a-longs only a few residents showed enough courage to sing, but after some reinforcement and the creation of a safe atmosphere, many of the residents sang along.

Like other programs, praise was also used on many occasions with the morning tea and evening mug up programs. After the residents had their coffee or tea Claire engaged them in an activity and would praise the women for their participation.

> Claire asked the women the answers to a find-a-word puzzle. The women enjoyed guessing the words and were proud when they guessed correctly. Claire praised the women for trying even if the answers were wrong (Field note, November 27).

It was interesting to see that quite often the praise and positive reinforcement was in fact reciprocal between the residents and practitioners. The residents often praised the recreation therapy practitioners for doing a good job, or for planning a successful activity. The residents often showed their gratitude for the programs that were provided.

4.6.2 Non-verbal Communication

The varying abilities of the residents to communicate verbally meant that non-verbal communication was essential for interactions between individuals. In addition to the challenges associated with dementia, some residents also had visual and hearing difficulties which further complicated communication. This meant that it was important for me to pay particular attention to all interactions. Non-verbal communication was used to express emotions and show concern. The practitioners used touch in an appropriate manner to enable residents to feel secure and comfortable. For example, when a resident was upset someone would rub her on the back or give her a hug. Similarly, if someone was distraught or having a bad day often the practitioners would rub their arms and shoulders and speak to them quietly.

During the scrap-booking activity I noted that the recreation therapy practitioner and the volunteer used non-verbal communication to demonstrate to the residents that they cared.

> The volunteer constantly spoke to the residents and touched them on the shoulders or arms to show them she cared. Claire constantly touched the residents as well to show them she understood if they were frustrated or did not understand. The touching used by all practitioners is always appropriate and accepted from the residents because of the special bond they have formed (Field note, November 21).

On many occasions the residents used non-verbal communication to show that they were enjoying themselves. Many times during a program the residents smiled to show that they were interested in what they were doing and that the program made them happy.

4.6.3 Bond between resident and practitioner

The bond between the residents and the practitioners was a unique one. Although the residents had dementia they always recognized the practitioners' faces even if they may not remember their names. It was easy to see that there was a great deal of respect in their relationships. The practitioners clearly knew each of the residents on an individual basis. This enabled practitioners to create environments that were meaningful and comfortable for the individual. The comfort level that was established did not exist with all the recreation therapy practitioners; instead it existed mainly with the practitioners and residents that participated in the programs together on a regular basis. Based on my observations, if there were different practitioners involved in the programs everything about the programs would inevitably change. Many times throughout the field notes the importance of this relationship was noted.

As I observed my first program I immediately noticed the relationships of those involved:

> Claire and a volunteer went upstairs to ask the residents if they would like to come downstairs for the program. The women were asked if they would like to participate. Then they were encouraged to attend. They were never pushed to go but they were made welcome (Field note, November 21).

On that same day I first noticed the bond between Claire and the residents.

> Claire constantly touched the residents (on the shoulder or the arm) to show them she understood if they were frustrated or did not understand (Field note, November 21).

I immediately noticed that Claire knew the residents on a personal level. Because Claire worked with the same residents for quite some time, she spent a lot of time getting to know the residents. Claire knew all the residents by name, their family members by name, the activities they enjoyed and the ones they would rather not participate in. She had what I would consider a great friendship with the residents.

> She (Claire) showed a strong bond to the residents by calling them names such as 'sweetheart'. Claire showed she knew the residents by saying "you used to bake" to May and "you used to bake a lot of wedding cakes didn't you" (Field note, November 22).

During the same program, baking, one woman complimented Claire by saying she was a great worker. It was easy to see how much the residents appreciated everything Claire did for them. In response, Claire commented that she would like to take the women home with her.

A few days later I observed Sarah running bingo. The following notes again highlighted the bond between the residents and practitioner:

> Sarah called the residents by name and spoke to them quite often (Field note, November 25)
>
> Sarah used humour and created a fun atmosphere (Field note, November 25)

Sarah, like Claire, appeared to have a meaningful relationship with the residents. The practitioners knew all the residents that attended their programs on a personal level. The relationship between the residents and practitioners was a comfortable and strong one.

Most, if not all relationships take time and attention to develop. Similarly for the residents, it took time for them to feel comfortable with other people. Over the course of data collection, I often noted that the residents seemed to feel more and more comfortable being in my presence. As would be expected when anyone new came into their lives, my presence as an observer in programs would be somewhat intimidating. However, as time went on the women began to recognise me and were not impacted by my attendance in their activities.

The recreation therapy practitioners frequently said things to the residents that lead me to believe that they knew the residents on a personal level and were genuinely concerned for them. It was evident that they knew a lot about the residents and their past but they were also knowledgeable about the resident's current life and preferences. One day during beauty culture Claire sat with May and asked her about the colours of nail polish she liked:

> Claire mentioned to May, 'isn't your daughter coming home this week?' A nurse said 'oh your daughter is coming home this week is she?' (Field note, November 29).

At the end of the same program Claire finished May's nails, put cream on her hands and gave her a little massage.

> May asked Claire, 'how much do I owe ya?' Claire said 'you owe me nothing but a smile' and May put on probably the biggest smile I have ever seen (Field note November 29).

While observing the bedside baking program I thought this program was wonderful for residents who could not get out of their bed very often or for those who felt more comfortable staying in their rooms. Not only did this program have an impact on participants, there was potential for others not directly involved to experience meaning as noted below:

> After the program had started the nurses came in to get one woman (who was not a participant of the study) out of the bed and into her

> chair so she could join the group. After the nurses were finished getting the resident into her chair they left her facing away from the group. Sarah went and turned her so that she could join in the conversation (Field note, December 4).

Sarah showed compassion for the resident by making sure that she was included in the group. Again on that day Sarah showed that she knew the residents well by calling them all by name and knowing their hometowns.

Claire also showed her knowledge of the residents one day during the baking program. She was speaking to May about recipes that May had used in the past.

> Claire said to May ‘I think your favourite recipe used to have raisins in it did it?’, ‘yes’ said May. ‘See how I knew that’ Claire said (Field note December 6).

During the same program I noted that I thought that the residents felt quiet comfortable with Claire.

In addition to the observations, I also asked the practitioners to comment on their relationship with the residents during the group interview. The following conversation with Claire and Sarah supports the observations noted above.

Danielle:	ok what type of a relationship do you feel that you have developed with the residents?
Claire:	I think that we have developed a good rapport with the residents. We’re the ones that they kind of come

to….like well residents comes to you (Sarah) with stuff.

Sarah: yes and may comes to you (Claire) with stuff'

Claire: right

Sarah: that she will not get done or get an answer for anywhere else.

Claire: even with their dementia and everything else they kind of know, well ok that's nursing so you don't go there because they are doing personal care type of stuff.

Sarah: yeah they have a little more of a bond. Even a resident will come to me and say I got to call my son here's his number, will you do it for me? And I'll say you give me his number and I'll do it when I go down in my office. But yeah they do I guess it's because we're the fun people we're the…

Claire: we're the ones that distract them and take them out and we bring them things

Sarah: we're not insistent that they get dressed now or, we're just there to do things and take them places

4.7 Preliminary Conclusions

The current research found that to fully understand the complexity of the recreation therapy programs at a long term care complex, it is vital to understand the views of the practitioners, family members and most importantly the residents.

The current study looked at the residents and practitioners experiences independent from one another as well as the interdependence between the two. Some things that were noted as findings were meaningful engagement, socialisation and friendships. As stated previously these findings were specific to the residents and recreation therapy practitioners in this study, if either of these contexts changed the outcome may have been very different.

The following chapter will attempt to further explain the results as well as how they compare to previous research findings and what this means for society as a whole.

Chapter Five: Discussion and Synthesis

5.1 Introduction

This research was designed to gain an understanding of the value of recreation therapy for residents with dementia from the perspectives of the residents themselves and the practitioners providing therapeutic recreation services. To gain such an understanding observations were made of various programs, interviews were conducted with residents, alternate decision makers, and the recreation therapy practitioners, and a journal was maintained by the primary investigator.

This chapter will highlight the major findings of this research. To allow for an understanding of these findings I will also relate this research to some other major findings within dementia research. This will include: quality of life, negotiating ethics in dementia care, freedom of choice and decision making.

5.2 Quality of life

In the past years, quality of life has been established as a key concept in caring for people who suffer from chronic illnesses (Droes et al., 2006). This also pertains to people living in long term care. It is said that the priority of those working with residents in long term care should be to optimize the quality of life for the elderly people in the final stages of life (Droes et al, 2006). To do this the staff as well as family members should work in collaboration to ensure that the highest possible quality of care is provided to the residents. In this research the main measure of quality of life was observed in terms of the meaning that recreation therapy to the residents.

When the family members in Droes et al's study (2006) were asked what they felt affected the resident's quality of life, they talked about, cheerfulness, happiness, and humour. In the Droes et al. (2006) research, residents also noted the following elements as important to quality of life: being allowed to express all feelings positive or negative or just being approached in a positive manner and loneliness. In the current research the practitioners displayed happiness, cheerfulness and humour that definitely impacted the quality of life of the residents in a positive manner. The residents responded positively when they were greeted in a positive way. As well loneliness impacted the resident's quality of life. In the observations it was noted that one woman asked if she could be taken home, as well one woman expressed that she would enjoy the company of the other women if she knew who they were. This resident has just been admitted to the complex and was experiencing some loneliness.

The residents also noted that involvement in the things around them was important to their quality of life. Phinney (2006) found that most of the families believed that continued participation in activity was necessary for their loved one's quality of life. She further suggested that it is important to reduce the demands placed on the individuals with dementia so that they succeed in the activity and do not become discouraged (Phinney, 2006). The current research showed that the residents of both units were very involved in many aspects of daily living at the facility. Many of the programs allowed the residents to participate in everyday activities. For example, during the baking program the women were given one food preparation task so they could be involved but would not become overwhelmed by the amount of preparation actually needed in the baking process. Participation in the programs was one way to increase the resident's quality of life.

Dores et al. (2006) also found that friendship, communication, and one-on-one contact were all important to resident's quality of life. In the present study, many of the residents commented on how important it was for them to have the other residents around to communicate with. When I asked the residents of one of the units if they liked to have the other women around they almost always answered yes. As well, while observing the programs, it was evident that friendship was an important element of activity. The women held hands, praised each other, comforted each other or just sat and talked with each other. This type of interaction with one another provided a sense of comfort and feeling of belonging.

In addition to friendship and contact with others, it was also important to be social and find joy in various aspects of daily life (Droes et al., 2006). The programs that were provided allowed the residents to socialize with their friends from the same floors and the residents of other floors. This way the residents could meet new people or spend some time with people they already knew. One woman explained that she "likes to chase the boys". Living on an all female floor does not allow her to have much contact with the opposite sex, but a number of the programs allowed her to meet a variety of people including men and women.

Some residents and the family members mentioned spirituality as an important factor in quality of life while other residents of the long term care complex never mentioned much to me about spirituality. One resident did mention her desire to go to church on Sundays. She attends all church services, of all religions. There are services available to the residents of various religions so the residents can continue to attend mass and services and fill their need for spirituality. As well there are gospel sing-a-longs provided to the residents where they can gather with other residents and sign hymns.

There were some similarities and some differences to what Droes et al (2006) noted as having an impact on the residents quality of life. Some similarities between the two were affect, self-esteem, and enjoyment of activities. However there were also differences found in the responses.

One similarity was that both the residents and their family members agreed that social contact was important in the resident's quality of life. However their opinions differed as to what social contact looked like. The family members believed that social contact in general was effective. The residents however, identified specific people as being important in their quality of life. The residents noted: feeling involved in the lives of their family members, along with, loving relationships, true friendships and intimate contacts and true friends, as things that were important in their lives (Droes et al, 2006). The residents in the present study frequently spoke of their relationships with family members including, children, siblings, grandchildren, and spouses, sometimes they spoke about present relationships and were aware of who their family members were, on other occasions the residents spoke of their family members of the past as if they were in the present. The residents as well commented on the importance of friendship and many of the observations noted the close bond the residents seemed to have with each other.

Droes et al (2006) concluded that social contact and enjoyment in activities have been left out of some measurements of quality of life. Based on past research and the findings of the present research, such measures should be included in the analysis of one's quality of life. The residents' participation in recreation therapy programs provided them with much enjoyment and meaning. As well their social contact, especially that of their friends and family, was a major determining factor in the resident's quality of life.

In an attempt to understand the experience of dementia and quality of life issues for persons with dementia, Kitwood (1997) identified five great needs of persons with dementia. These five needs are attachment, comfort, inclusion, occupation and identity, with the central need being, love. The author goes on to explain that people need to feel attachment to feel secure and safe. The residents in the present study found great security in their relationships with the therapeutic recreation practitioners and with the other residents. They also continued to feel attachment with lost loved ones.

Kitwood (1997) explains that people need to feel comfort to have strength. The residents in the current study gave each other comfort and strength and they also looked for comfort from each other in times of need. The women were a source of strength when their friends were upset or scared. Kitwood suggests that the social life of people with dementia tends to dwindle away but they need to be allowed to maintain some social opportunities in order to experience life positively. In the current research the residents were given many opportunities to socialize, and when they were asked if they enjoyed this time they always answered positively.

In addition to these connections with other people, Kitwood (1997) suggested that people with dementia need to be involved in the processes of their lives. That is, they need to experience some form of occupation. The current research found that the residents were involved in many recreation programs such as baking and beauty culture, and where possible they were assigned tasks based on their individual abilities.

The final need suggested by Kitwood is identity. According to the author it is important for people with dementia to maintain some sense of identity. The residents participated in programs that allowed them to engage in activities they previously participated in as well as discuss their past experiences. Residents talked about past lives and traditions in the mug up programs. There were ample opportunities for reminiscence allowing residents to express their individual identities. Again the central need is love, suggesting that above all these needs people with dementia continue the need to feel loved and give love. When the above needs are met they all contribute to the person feeling loved.

The present research clearly demonstrates that the therapeutic recreation practitioners were cognizant of each of the residents as individuals. They knew their names, their family members, and their preferences as related to recreational opportunities and consequently treat residents as persons who are actively engaged in their lives. It was important to go with the rhythms of the residents and their realities on a daily basis. Alzheimer's disease has a significant impact on the person's identity but the practitioners in this study provided opportunities for residents to express their ever changing identities. Further they enabled these individuals to participate in life in meaningful ways.

5.3 Negotiating Ethics in Dementia Care

According to Brannelly (2006) one of the strengths of an ethic of care is the ability to accommodate all those involved, including people with dementia. Further Brannelly notes that to provide the best care to the person with dementia, collaboration is necessary between the key actors that provide the care.

Brannelly (2006) noted that there are four ethical elements: attentiveness, responsibility, competence and responsiveness. The first is Attentiveness. "Attentiveness refers to the ability of practitioners to grasp the needs of the person(s) for whom they provide care, as the person perceives them" (Brannelly, 2006, p 4). In the current research it was evident that the practitioners were attentive in their care. The practitioners showed their vast knowledge of each of the individual residents and their abilities.

Responsibility, according to Brannelly (2006) is when practitioners decide to take responsibility for the means in which they attend to the person's needs. In the current research the practitioners were very responsible in the decisions they made during the care for the residents. The bond between the practitioners and residents clearly speaks to the connection between caregiver and care recipient.

This bond was evident in many situations. The practitioners knew residents by name. The residents, while they may not be able to name the practitioners due to the disease process, clearly knew who the practitioners were and smiled upon seeing them. Although they were not always clear on what they were going to do, they were clear that they expected to enjoy time spent with these women. This research clearly demonstrated that the connection between the residents and the practitioners was of utmost importance in the provision of RT services in this facility.

Competence refers to the ability of the practitioners to plan care, take responsibility for the care then ensure that this care is carried out. "Competence of care is directly affected by the resources of the lack of them" (Brannelly, 2006, p 4). In the current research the practitioners were competent in providing care. However, they often noted the lack of resources which meant that the programs could not be planned or carried out. One such example was the availability of the bus. One practitioner noted that the residents enjoy the outing but because the bus is not as readily available as it used to be such programs have been reduced.

The last is responsiveness. This step allows the person receiving the care to voice their opinions. "The recognition of this position of the person receiving the care is vital" (Brannelly, 2006, p 5). This stage allows the practitioners to understand the feelings of the person and possibly allow the practitioner to understand how the care should be changed or adjusted. Whitlatch, Feinberg and Tucke (2005) looked at the accuracy and consistency of the responses given by people with cognitive impairments. They concluded that "it may be possible for persons with mild to moderate cognitive impairment to discuss their everyday wishes with their family caregiver" (p 179). In the current research the practitioners did spend time after the programs asking the residents as a group about the program. The residents usually responded with verbal information about how they enjoyed the program and what they did or did not enjoy about the program. Most residents had no issues with expressing their thoughts verbally. Other residents would express their thoughts on the programs through non verbal cues like smiling, frowning, falling asleep or leaving the program.

When considering an ethic of care for working with people with dementia Brannelly (2006) found that the majority of the practitioners consistently approached people with dementia with social regard. In the same research it was found that the practitioners were frustrated when other practitioners did not collaborate to achieve good care. As well the practitioners demonstrated ethical care by providing care to the preferences of the person with dementia.

There were some similarities between the above research and the current research. One similarity was that the residents were approached in a respectful manner at all times and when appropriate the approach was individualised based on the preferences of the resident. For example, practitioners may joke with one resident while they may be softer in their approach with someone else. The practitioners noted that the majority of staff were understanding and helpful while others did not collaborate to provide the best care for the residents. In the current research the practitioners showed that they had a vast knowledge of all the residents in their programs as did the practitioners in the previously noted study.

5.4 Freedom of Choice and Decision Making

Tyrrell, Genin, & Myslinski (2006) noted that there are a significant number of people with dementia and this number is growing, yet there is little known about their involvement in decision making with regards to their health care. In today's society there is an increasing emphasis on patient's rights to be involved in this process. When the practitioners of the current study were asked how much choice the residents have with regard to the programs they answered with the following:

> Sarah: With Alzheimer's it's a bit difficult. You do give them the choice. You tell them what's on the go explain it to them. If it were something different like going out somewhere then you need to explain a little bit more about it we are going what you're doing but for the most part they are given a choice.
>
> Claire: Programs that we plan are based on experience and whether they are successful or not. It's not just stuff we want to put on its not about well I want to do this today it's about the residents like this stuff so we try to base it out that way.

The above comments suggested that the practitioners did tell residents about the programs to be offered that day and then asked if they would like to attend. So while residents may not always have the choice of various programs that will be offered on a daily basis, they do get to decide whether they want to participate or not. It is also important to note that the programs are planned in advance based on what the practitioners feel is preferred by the residents. This is based on past success with specific programs as well as careful program planning by the Recreation Therapist.

Forbat (2006) found that the aging population still feel the need for real choice in the services they are provided. He also went on to explain that services should value and encourage the people to make their own choices and decisions. Phinney (2006) also agreed with allowing the participants to make their own decisions, especially when regarding participation in activities. She went on to state that if they choose to participate in an activity and then become overwhelmed or need some guidance, practitioners need to be ready to remind the person what they are involved in and help them through the activity.

Tyrrell, Gein & Myslinski (2006) conducted a study on people with dementia and their freedom of choice. The criteria for inclusion in their study were similar to the current study. The participants were patients with dementia who were also able to communicate verbally and had a caregiver who was also able to be interviewed. When asked about their freedom of choice the majority of the participants said that they had been listened to; however, some participants explained that they felt they had not been heard. When the caregivers were asked if they felt their loved one was being listened to a larger majority of the caregivers said they felt their loved ones were being listened to more then the residents admitted to. I believe that the same knowledge was found with this study. Although these questions were not asked directly the family members commented on the programs and the positive atmosphere and care in the complex. The residents sometimes admitted to not enjoying the program that they had participated in.

Often once someone is known to have dementia they are viewed as needing to have a caregiver to make all their decisions for them. It was noted by Tyrrell, Genin and Myslinski (2006), that people in the early stages of dementia are often unsolicited and unheard. However as long as the person is able to communicate their views, these views should be respected.

5.4.1 Person centered theory

"Human becoming patient-centered care combines the organizational commitment to support professional practices that address and meet concerns, needs, and expectations of persons receiving care with a theory that can provide the knowledge, the know-how, to practice in this way" (Mitchell, Bournes & Hollett, 2006, p. 218). Patient focused care is becoming a widely accepted means of care. The following exchange between the practitioners and I speak to their perceptions of patient focused care:

Danielle: One of the things I read a lot about was patient focused care. So the care that you are providing should be focused towards the patient or the resident so what do you feels about that or what does it mean to you?

Claire: Patient focused care is great if you have got lots of staff but when you have got one staff with 24 Alzheimer's residents it's very hard to do specific patient focus with each resident.

Claire: You try to group them into a category and try to focus on that category rather then each individual person. It's impossible to do it individually.

Danielle: ok so you mean you would like at dementia or Alzheimer's.

Claire: yes

Danielle: in general?

Claire: yeah

The recreation therapy practitioners have the knowledge of the patient-focused theory and admit that it is not always applied to the extent that it would be with additional staff, funding and support. However, when the recreation therapist was interviewed she noted that all residents are assessed individually.

Nolan, Ryan, Enderby and Reid (2002) re-emphasize the importance of person centered care for people with dementia. They explain that practitioners should seek out the views of the people with dementia then reflect these views in their design and services. They go on to comment on the importance of acknowledging the perceptions of the family members as well as the person with dementia.

Mitchell, Bournes and Hollett (2006) indicated that they put nurses through a structured educational program to introduce them to patient-centered care. During this time the nurses attended seminars, meetings, and discussions. From this program the nurses noted that they "learned how to speak with patients and families in ways that are helpful for everyone" (p. 221), "learned that every patient is an individual who has a unique outlook and experience in life" (p. 221), and "respect patients and families and their values, choices, beliefs, and hopes" (p. 221). This could work in all long term care complexes with other practitioners such as recreation therapy practitioners.

Phinney (2006) looked into the strategies for providing meaningful activities for people with dementia. She found that it was essential to have the participants engaged in programs that allowed them to feel as they were the same person they had always been. If person centered theory was practiced then each person would be engaged in activities that they enjoyed and were comfortable with.

With the current research the practitioners noted that it is difficult to constantly practice the person-centered theory. The above education program may allow for all the practitioners and other staff to value the person-centered theory.

5.5 Summary

This study concluded with some major findings. We increased our understanding of the meaning of the recreation therapy practice to the residents with dementia. We now understand the benefits the recreation programs provide to the residents as well how the programs enhance the residents quality of life. We also gained a better understanding of the views of the family members. We explored the residents and the family member's points of view, although we now know that not always are either exactly correct. Lastly, we have discussed the values and issues of practice with the practitioners and learned their point of view.

Chapter Six: Considerations for Practice and Reflections

6.1 Introduction

By reviewing the initial purpose of the study and the research questions, we can see that through this research we have gained an insight on the recreation therapy programs at the facility, learned how the family members view the programs, understood the resident's point of view, and discussed the issues that face the practitioners.

6.2 Recommendations for Practice

I have thoroughly enjoyed my time spent with the residents and practitioners of the long term care home. I would like to take this opportunity to thank them for allowing me to work closely with them and learn so much from them.

As well there were many positive discoveries from this research. All the family members that were interviewed commented on the hard-working, friendly and helpful staff and they indicated how much they appreciated having such a wonderful staff working to care for their loved ones. As well the programs that were observed seemed to be beneficial to the residents and created opportunities for them to socialize, engage in various activities and enjoy their free time. The recreation therapy practitioners also took the time to comment on the great staff support that the recreation therapy practitioners have for each other.

As for recommendations for the practice they are listed as in the following order: structural, staff support, and communication with family members, volunteer recruitment and training.

6.2.1 Structural recommendations

I spent most of my time with the residents from one specific unit. Many times the programs were provided in the common room on the floor. I regularly made notes about the room being too small to hold all the residents that wanted to participate in the programs. As well there were frequent difficulties getting the residents in and out of the room, and on some occasions residents had to be denied access to a program because there was not enough room available. This was rather unfortunate as this particular unit was noted by the recreation therapy practitioners as being one of the more active units. There are many residents on this unit that are able and willing to participate in the programs but sometimes cannot attend if the program is held in the common room of the floor. A larger and more accessible room is necessary so high quality programs can be offered to all interested residents.

6.2.2 Staff support

This issue was discussed by the recreation therapy practitioners and was also noted on occasion during the observations. The majority of the time the staff (recreation therapy practitioners and other staff) support seemed to be very present and noted as such. However, sometimes such things as interruptions from staff of other disciplines were noted. During the group interview the practitioners were asked about staff support from staff in other disciplines then recreation and the practitioners commented on how it varied depending on the staff members. All staff, no matter of what discipline, should fully support each other in their common goal of providing the best care possible to the residents and enhancing the residents' quality of life. Some means of ensuring that there is positive staff support is to provide the staff with the information they require to understand each others role in the resident's life. Then small group discussions may allow all the staff to meet each other and discuss how they can work together to reach their common goal.

6.2.3 Communication with Family Members

As noted before the family members all took time out to give positive comments on the staff. They all stated how they were very pleased with the care their loved ones were given and found the staff very easy to approach and speak to. Often the family members admitted that they did not approach the recreation therapy practitioners regarding loved ones' participation or preferences. To allow the practitioners to meet all the loved ones of each resident would understandably require a lot of time. However, the specialist does meet with the family members to ask them questions on the resident's preferences and past activities. Perhaps twice a year the recreation therapy practitioners could set aside a day to meet with the loved ones of the residents they work with directly and discuss with them what the residents have been participating in and what they see being available to them in the coming year and allow the family to make suggestions. The recreation therapist noted that there are interdisciplinary meetings in which the family members are allowed to attend and discuss issues. However these meetings do not always happen twice a year. My suggestion would be for a more informal meeting to take place and with each of the resident's family members, twice every year.

6.2.4 Volunteer recruitment and training

One major issue that needs to be addressed is the lack of volunteers. This issue was noted by the recreation therapy practitioners on a number of occasions and was noted in most of the observations. Having a volunteer present during the programs would allow the practitioners to focus on their task at hand and ensuring the quality of the programs. Some of the current volunteers are students that are required to volunteer as part of a work placement. One possibility is to speak to other schools with related programs to ask if they would allow their students to volunteer with the regional health authority. There could possibly be an agreement with colleges to have a set number of volunteers for each semester, so in that instance as you lose one group of volunteers another group begins. You could also ask that the students from the schools to remain as volunteers once their work placement has concluded. There may also be a possibility to have extended family members as official volunteers. Perhaps a grandchild or child of the residents would enjoy spending some time with their loved on while helping other residents. More publicity about the possibility of volunteering with such a facility would also aid in the number of volunteers recruited.

Training for the volunteers should be mandatory but at no cost to them. This should involve the major topics that need to be addressed to the volunteers. Issues that may be useful as part of a volunteer training program may include, structural, health mandates, the person centered theory, approaching residents, emotional issues. Allowing volunteers to know they will undergo the proper training will allow them to feel more comfortable in the situation, especially if the volunteer has never worked with such a population.

6.3 Implications for Recreation Therapy

Although this research focused on the dementia care units at one long term care facility, it is likely that many of the findings would in fact be similar in other dementia care units. Further, much of what was revealed in the present study has implications for recreation therapy as a whole. For example, Sullivan et al (2002) found that recreation opportunities were of great value to the individuals living on a special care unit in Ontario. Similarly they noted a number of structural challenges that the TR practitioners had to negotiate that were also found in the present study. Below is a discussion of how the findings of this study can be applied to the field of therapeutic recreation.

It was reported by the family members that they were not approached by the recreation therapy practitioners regarding their loved ones' preferences or past activities. The communication between these two parties can be vital in providing resident focused programs. This line of communication should be opened and maintained. In circumstances where the residents cannot voice their opinions or may be unable to recall their preferences or past activities, the knowledge of the family members may prove valuable. It is also understood that although many times the information provided from the family members is accurate and a true reflection of their feelings, on occasions the family members views are tainted by feelings of guilt from having placed their loved one in the long term care complex. This can apply to almost any long term complex as well we the recreation therapy practice as a whole. It is important for all practitioners to keep the lines of communication open with family members of the residents for numerous reasons.

As well it was noted that there is not always a resident-focused approach in the practice. It is first important for all practitioners to understand the importance of this philosophy so they can fully support it. This can be done through information sessions or discussion groups with varying practitioners. After the philosophy is understood and set as a standard for the practice it is also important to carry it out. This will involve taking the information obtained from the family members and applying it to the practice. Although this is done in many situations it is not always applied. It is also important to obtain information from the residents themselves. Again, it is vital to allow the residents to voice their opinions and have a freedom of choice.

6.4 Recommendations for Future Research

I strongly feel that this collaboration between Memorial University and the regional health authority was a beneficial experience for all parties involved. I believe communication should continue between these parties to allow for the development of future research in this area. It would also be beneficial to have a similar study conducted at other long term care complexes within or outside of the regional health authority. Research based on people with dementia can be very rewarding to the participant, the family members, the facilities involved, the researcher and organizations concerned with dementia care.

One area I think would be interesting for further study is the family member's perceptions. While the family members I spoke to all fully support the recreation therapy program, Angela noted that on some occasions family members did not support their loves ones' participation in these activities. Understanding the family member's perceptions can open the lines of communication between the recreation therapy practitioners and the family members. After understanding the family member's point of view the practitioners can work to educating the family members on the programs, the benefits of the programs and when and why the residents should participate.

If I had the opportunity to do this research over again there are a few things I would do differently. I would first have more residents identified as possible participants. Some alternate decision makers chose not to participate in the study and others were not available. I would also ensure that there were male and female participants included in the study. Lastly I would do a larger group discussion with more recreation therapy practitioners.

6.5 Reflections on the Practice

After just losing my grandfather I have learned that life is a precious gift. I am now more thankful for this wonderful opportunity that I have been given. I began this journey because of many personal interests and end with an even more intense interest.

The three recreation therapy practitioners that I worked closely with aided me every step of the way. These three practitioners brought much knowledge and understanding to the research and I could not have completed this work without their assistance. My supervisor has given me an immense amount of guidance and support. It was her personal interest as well that allowed me to choose this intriguing area to work in.

After getting the proposal approved the data collection process primarily began in November and ended in February. The analysis was done simultaneously with the collection. I enjoyed being able to reflect on what I learned.

Some possible limitations to the study are the number of residents who participated. However, despite the small number of participants all residents who were observed were able to be noted in the observations. This allowed for a more accurate understanding.

Overall I feel that the structure for this research was a success.

6.6 Final Words

This study has only intensified my quest for knowledge about people with dementia. I now understand more about their quality of life, the person centered approach and the lives of the family members.

I have spent the last months getting to know some of the most amazing people. I am ever so thankful for the opportunity that was provided to me by the regional health authority and in particular the long term care home.

I will never forget the knowledge and understanding that was shown to me by the practitioners. Their willingness to help in this project was a critical component. I will continue to be impressed by the things they do.

I am also very thankful to the family members who allowed me into their lives and ask such personal questions. Their words contributed greatly to my understanding.

I hope that this research is a true reflection from the residents, practitioners and family members and that is only helps to increase the quality of care that is provided to these residents.

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Appendix A: Summary of Regional Health Care Complex

The complex has a total of 377 long term care beds with respite. In the east end of St. John's, the Complex is the largest nursing home facility in the region. It has 3 floors which each have a North, East and West wing. Common rooms are present on all units, to varying degrees. It also contains a new 15-bed Transition Unit where patients released from acute care hospitals may stay, prior to moving into a long term care facility. The Complex also has an Achievement Centre for various creative activities, and a Protective Care unit. The complex also hosts a cafeteria, auditorium, foyer, and a kitchen (only on the transition unit).

The purpose of the recreation programs is to allow the residents to enjoy their participation in the programs, to allow them to participate in activities they had previously enjoyed & to allow the residents to engage in activities that allow them to socialize. The goals of the therapeutic recreation programs vary depending on the clientele. However they all have the following in common; they attempt to facilitate positive changes in special-population members and they hope to see the clients eventually enjoying and independently choosing their leisure activities.

There are many recreation therapy programs available. Each unit has an activity calendar stating which programs are available to the residents of that particular floor. Some of the programs offered are: baking, bedside baking, evening mug up, morning tea, men's cooking group, beauty culture, scrap-booking, sing-a-longs, choir visits, bingo, and outings.

Also available at the complex are Physiotherapy, Occupational Therapy, Food & Clinical Nutrition Services, Nursing Services, Social Work Services, Transportation Services, a Beauty Salon, Resident Council, a Public Library and other professional services.

Appendix B: List of Programs / Activities

Programs observed during this research were: baking, bedside baking, scrap-booking, morning tea, evening mug up, beauty culture, choir visits, fun and fitness and bingo.

Some of the other recreation therapy programs that are offered at the complex are: outings, men's cooking group, cards and other games.

Each program differs in length but they all run between 1 and 2 hours long. Most of the programs were observed on more then one occasion, but one program was only offered once during the time of the observations.

Appendix D: Areas for Discussion

Introduction: Hello, my name is Danielle LeDrew, and as you know I am here doing some research as part of my program at Memorial University. I want to find out what you think of some of the recreation programs you take part in and how you feel about them. I would like to thank you for taking the time to meet with me today and I really appreciate your time. I am going to ask you some questions about the program you have just participated in, is this ok? I am also going to write some notes because I want to be sure that I know what you are trying to tell me. Is this alright with you?

Some possible topics for discussion are:

- Enjoyment in the activity
- Participation in other Activities
- Outside of Recreation Activities
- Changes to Programs

Some possible question but not limited to are:

What did you like about the program this morning?

Do you come to this activity often?

Do you like coming to this program?

* If no, tell me what you do not like about it?

What activities do you like most in this program?

What other programs do you attend?

What are some other things you like to do (outside the recreation programs)?

What are some ways to make these programs better?

*** Note: These are some possible questions posed to the residents. However, depending on the resident and the stage of dementia in which they are currently in, the manner in which the questions were asked may have been altered to allow them to comprehend.**

Appendix E: Information Letter for Alternate Decision Makers

Dear Participant,

I am writing to invite you to participate in a study hat I am conducting as a part of my Masters thesis in the Department of Human Kinetics and Recreation at Memorial University. I am also asking for your consent for your family member/ person to which you have power of attorney participation in the study. The reason I am doing this research is to gain a better understanding of the leisure opportunities offered here at the long term care home from the perspective of you, the residents and the recreation therapy practitioners. I am working with the recreation therapy staff to learn about your perception of the activities that are offered and to see if there is any way that we can improve these activities.

If you decide to take part in this study, I will be asking you to sign a consent form for both you and the resident. Of course, you can choose not to participate. You may choose to withdraw from the study at any time. Any decision not to participate in the study will not have any impact on your family member's recreation or any other activities at the long term care home.

For the study I will be asking you if I can observe your family member's participation in the leisure opportunities provided by the recreation therapy practitioners. Also, I would like to be able to chat with him or her about his or her experiences in these activities. However, if at any time he or she wishes to discontinue or postpone the session they can tell me and I will arrange to return at a different time. I will ask for your permission to make notes of my observations as well as of our discussions. The sorts of things that I will be observing include the way therapeutic recreation practitioners relate to the residents and what activities are offered. During the interview I hope to learn how your family member enjoys the recreation activities and what sorts of things might be offered to improve his or her recreation experience. Our interviews would likely be taped by a digital voice recorder to ensure that I have an accurate account of the conversation. Also, I would like to ask your permission to tape and interview with you regarding your perceptions of your family member's experiences in leisure opportunities. Finally, I would like you to know that I will also be interviewing the recreation therapy practitioners about their experiences of providing recreational activities to the residents. Again I will be taping these interviews to ensure tat I have an accurate account of what is discussed. The recordings will be used by only myself and will be kept in a secure place that is only accessible by myself and my Masters supervisor Dr. Anne Marie Sullivan. For the purposes of the final thesis, I ask that I be allowed to include direct quotes from the interviews when necessary; however, people will not be identified by their real name and all comments from individual participants will be combined so that no one person's comments can be identified. Any information provided by you will be treated confidentially and access to specific information that may identify people will be limited to myself and my supervisor.

Appendix H: Discussion Group Guideline

Introduction: Hello everyone, as you know I am doing a qualitative research study to look at the experience of the residents as well as you the recreation therapist practitioners with regards to the recreation programs that are offered here. I want to gain an understanding of the barriers and issues with planning and implementing the recreation programs to this clientele. Feel free to offer any information you feel will be valuable to this study as well to the programs that are offered through this complex. I would like to thank you in advance for your time and your honesty in these answers. I am going to audio tape this conversation so that I am ensure I have accurately recorded what is being said, as well I am going to take some notes as we speak.

How long have you worked with (the long term care complex)?

Before this did you work at another complex within the SJNHB?

What are some barriers you face when planning these programs?

What are some barriers you face when implementing these programs?

Are the programs you offer for this clientele different from the other residents?

How do you feel about the care that you are providing to the residents?

What type of relationship do you feel you have developed with the residents?

What does patient focused care meant to you?

Do you feel the programs are planned to reflect the needs and desires of the residents?

* If no, how can this be changed

Do you think that the principle of patient focused care is implemented differently because of the population you are dealing with?

How much choice is given to the residents with regards to choice in recreation programs?

Do you feel that your practice could be improved at all?

*If yes in what ways?

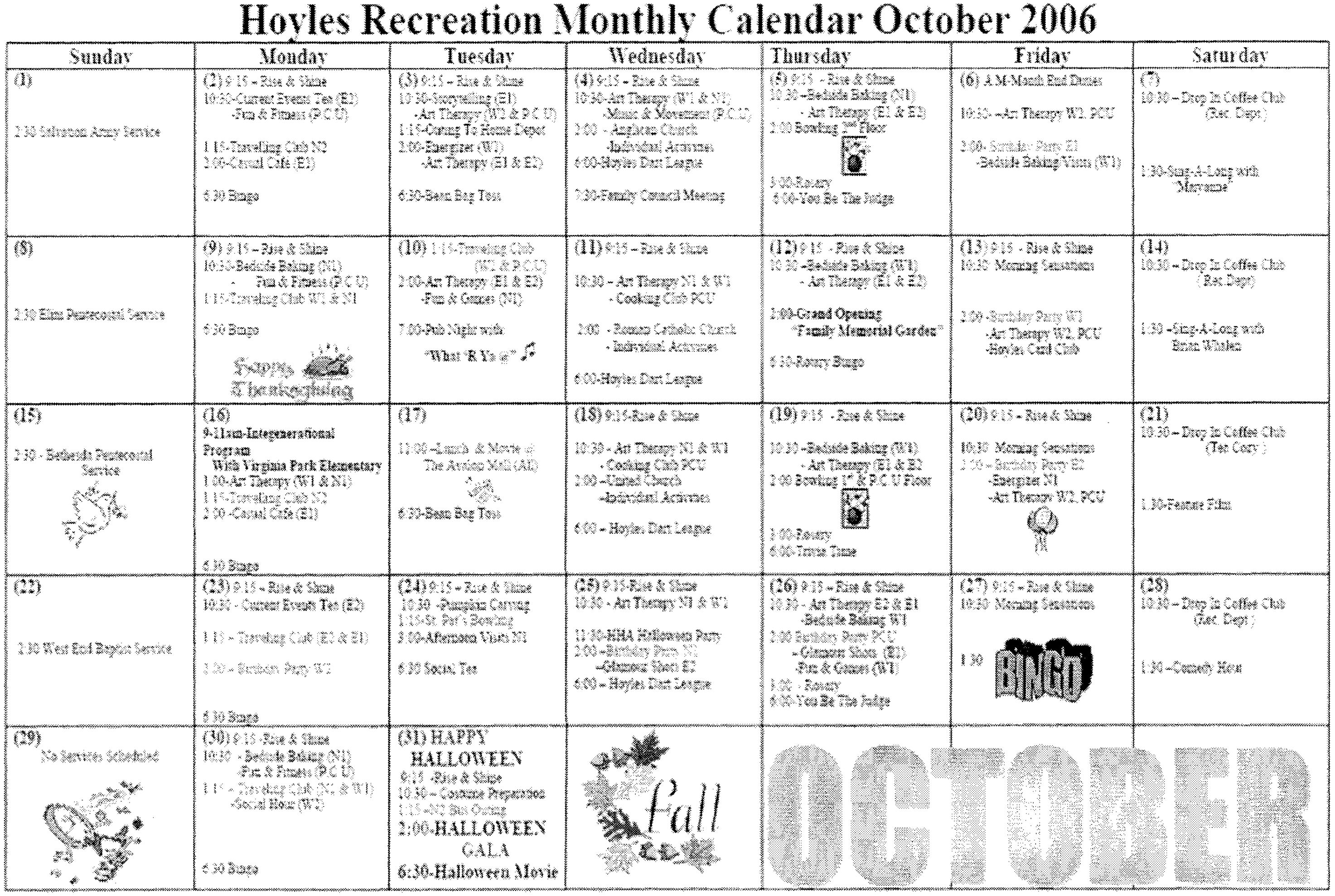
*And on who's behalf?

Appendix I: Family Member Interview Guide

Hi, I am Danielle LeDrew and I am working in conjunction with the recreation therapy department here at the long term care home on a research project. You have already given me consent for _________ to participate in the study and I would like to thank you for you also agreeing to be a part of the study. Before I go any further do you have any questions for me either regarding the study itself or my involvement in it? Ok, well, as the letter had mentioned I am interested in understanding the process of providing leisure opportunities for residents at the long term care home. I want to know what this is like for both the resident and the recreation therapy practitioners. The reason I have also asked that family members be involved is because you know _________ quite well and I think that any information that you may provide will help clarify ___________ responses and it will also contribute to my understanding of __________ perspective. Ok, if it is ok with you I would like to begin recording now?

1. How long has the resident been here?
2. How often do you have the opportunity to visit?
3. Does ______ speak to you regarding leisure participation here?
4. What kind of activities does ____________ participate in here?
5. What did __________ do prior to coming here for leisure?
6. Have the recreation therapy practitioners approached you before regarding ________ preferences and past leisure involvement?
7. Do you feel that this information has been incorporated into ___________ care?
8. Have you ever approached the recreation therapy practitioners regarding _______ involvement?
9. Do you find the staff helpful?
10. Does _________ appear to be happy here to you? Why or why not?
11. What do you think would improve _______ life here?

Appendix:J



Hoyles Recreation Monthly Calendar October 2006

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
(1) 2:30 Salvation Army Service	(2) 9:15 – Rise & Shine 10:30-Current Events Tea (E2) -Fun & Fitness (P.C.U) 1:15-Travelling Club N2 2:00-Casual Cafe (E1) 6:30 Bingo	(3) 9:15 – Rise & Shine 10:30-Storytelling (E1) -Art Therapy (W2 & P.C.U) 1:15-Outing To Home Depot 2:00-Energizer (W1) -Art Therapy (E1 & E2) 6:30-Bean Bag Toss	(4) 9:15 – Rise & Shine 10:30-Art Therapy (W1 & N1) -Music & Movement (P.C.U) 2:00 - Anglican Church -Individual Activities 6:00-Hoyles Dart League 7:30-Family Council Meeting	(5) 9:15 - Rise & Shine 10:30 –Bedside Baking (N1) - Art Therapy (E1 & E2) 2:00 Bowling 2nd Floor 3:00-Rosary 6:00-You Be The Judge	(6) A.M-Month End Duties 10:30- –Art Therapy W2, PCU 2:00- Birthday Party E1 -Bedside Baking/Visits (W1)	(7) 10:30 – Drop In Coffee Club (Rec. Dept.) 1:30-Sing-A-Long with "Maryanne"
(8) 2:30 Elim Pentecostal Service	(9) 9:15 – Rise & Shine 10:30-Bedside Baking (N1) - Fun & Fitness (P.C.U) 1:15-Traveling Club W1 & N1 6:30 Bingo	(10) 1:15-Traveling Club (W2 & P.C.U) 2:00-Art Therapy (E1 & E2) -Fun & Games (N1) 7:00-Pub Night with "What R Ya @"	(11) 9:15 – Rise & Shine 10:30 – Art Therapy N1 & W1 - Cooking Club PCU 2:00 - Roman Catholic Church - Individual Activities 6:00-Hoyles Dart League	(12) 9:15 - Rise & Shine 10:30 –Bedside Baking (W1) - Art Therapy (E1 & E2) **2:00-Grand Opening "Family Memorial Garden"** 6:30-Rotary Bingo	(13) 9:15 - Rise & Shine 10:30 Morning Sensations 2:00 -Birthday Party W1 -Art Therapy W2, PCU -Hoyles Card Club	(14) 10:30 – Drop In Coffee Club (Rec. Dept) 1:30 –Sing-A-Long with Brian Whalen
(15) 2:30 - Bethesda Pentecostal Service	(16) **9-11am-Integenerational Program With Virginia Park Elementary** 1:00-Art Therapy (W1 & N1) 1:15-Traveling Club N2 2:00 -Casual Cafe (E1) 6:30 Bingo	(17) 11:00 –Lunch & Movie @ The Avalon Mall (AL) 6:30-Bean Bag Toss	(18) 9:15-Rise & Shine 10:30 - Art Therapy N1 & W1 - Cooking Club PCU 2:00 –United Church -Individual Activities 6:00 – Hoyles Dart League	(19) 9:15 - Rise & Shine 10:30 –Bedside Baking (W1) - Art Therapy (E1 & E2 2:00 Bowling 1st & P.C.U Floor 3:00-Rosary 6:00-Trivia Time	(20) 9:15 – Rise & Shine 10:30 Morning Sensations 2:00 – Birthday Party E2 -Energizer N1 -Art Therapy W2, PCU	(21) 10:30 – Drop In Coffee Club (Tea Cozy) 1:30-Feature Film
(22) 2:30 West End Baptist Service	(23) 9:15 – Rise & Shine 10:30 - Current Events Tea (E2) 1:15 – Traveling Club (E2 & E1) 2:30 – Birthday Party W2 6:30 Bingo	(24) 9:15 – Rise & Shine 10:30 -Pumpkin Carving 1:15-St. Pat's Bowling 3:00-Afternoon Visits N1 6:30 Social Tea	(25) 9:15-Rise & Shine 10:30 - Art Therapy N1 & W1 11:30-HHA Halloween Party 2:00 –Birthday Party N1 -Glamour Shots E2 6:00 – Hoyles Dart League	(26) 9:15 – Rise & Shine 10:30 - Art Therapy E2 & E1 -Bedside Baking W1 2:00 Birthday Party PCU – Glamour Shots (E1) -Fun & Games (W1) 3:00 - Rosary 6:00-You Be The Judge	(27) 9:15 – Rise & Shine 10:30 Morning Sensations 1:30	(28) 10:30 – Drop In Coffee Club (Rec. Dept.) 1:30 –Comedy Hour
(29) No Services Scheduled	(30) 9:15 -Rise & Shine 10:30 - Bedside Baking (N1) -Fun & Fitness (P.C.U) 1:15 – Traveling Club (N1 & W1) -Social Hour (W2) 6:30 Bingo	**(31) HAPPY HALLOWEEN** 9:15 -Rise & Shine 10:30 – Costume Preparation 1:15 -N2 Bus Outing **2:00-HALLOWEEN GALA** **6:30-Halloween Movie**				