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GROUP INTERVENTION WITH YOUNG DISABLED ADULTS

AND THEIR FAMILIES

by

Cheryl A. Nuytten

A practicum submitted to the Faculty of Graduate Studies of the  
University of Manitoba in partial fulfilment of the requirements of the  
degree of Masters of Social Work 1994

Faculty of Social Work

University of Manitoba

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**GROUP INTERVENTION WITH YOUNG DISABLED ADULTS  
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**BY**

**CHERYL A. NUYTEN**

A practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements of the degree of

**MASTER OF SOCIAL WORK**

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The effects of chronic illness and/or disability and the subsequent reorganization of the family may be more disruptive, functionally and emotionally, to the well-being of family members than to the well-being of the patient (Williamson, 1985 & Stulfbergen, 1987). The impact of chronic illness and/or disability on the individual and the family members can have serious negative effects. Depression, anxiety, reduction in life satisfaction, reduction in socialization, and negative health effects have all been associated with the impact of illness and/or disability, for the individual as well as family members (George & Gwyther 1984; Klien, Bogdonff, & Dean 1975). Supportive group interventions have been found to have positive effects for young disabled adults and for family members who care for a young disabled adult (Powers, 1985; Clark & Rakowski 1983; Hallagher 1985).

This practicum designed and implemented a supportive group intervention for young disabled adult residents and their family members, on the newly developed (December, 1983) young disabled adult's unit at the Tache Nursing Centre in Winnipeg, Manitoba. Four groups were formed, two resident groups and two family groups.

Fourteen residents attended groups, six in Young Disabled Group and eight in the Aphasic Group. The resident groups focused on empowerment of residents by providing information and independence related skills (i.e. negotiating skills). Twelve family members attended the groups, eight in Afternoon Family Group and four in the

Evening Family Group. The purpose of the family groups was to provide education and support through staff presentations and shared experiences.

Assessment of the intervention included; the General Well-Being Scale, which was a reliable and consistent measure of depression and anxiety; the Sheltered Care Environment Scale, which measured respondents perceptions of different aspects of the facility (i.e. Cohesion, Conflict, Resident Influence, and Physical Comfort); and a Support Group Evaluation, which measured consumer satisfaction. Anecdotal data was also collected over the course of the interventions.

The results showed minimal group changes on the two measurement scales, but a number of dramatic individual differences in each of the groups. Members of the resident groups and the family groups felt that the intervention was very positive and should have been available to them long ago.

In conclusion, this practicum was able to identify and highlight an important gap in the provision of social services. The project demonstrated that a generic supportive group intervention for young disabled adults and their family members can provide significant benefits to the individuals, the family members, and the organization. Further follow-up on the subjects in this study was recommended. The regular implementation of groups of this nature should be a part of the services provided in long-term care settings.

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## CHAPTER ONE

### INTRODUCTION

#### 1.1 Brief Overview of Problem Area

Health issues are of major concern in present day society. With the great strides being made in medicine and health care, people are living much longer. This includes the elderly, as well as individuals who are struck down by serious disease or severe injury. Among the Canadian Population, 12% (2,448,000 individuals) report some form of disability. A greater proportion of women, 13.7% (1,339,000) versus men, 11.8% (1,108,000) report disability (Health and Statistics Canada, 1983-84).

In 1985, the Workers Compensation Board of Winnipeg reported 826 permanent disabilities associated with work related injuries. In 1987, permanent disability claims to the Board numbered 4,699 and in 1988, there were 4,774 permanent disability claims (Workers Compensation Board of Winnipeg, 1988). The dramatic increase in permanent disability claims from 1985 to 1986 and 1987 could be explained by drops in employment prospects. Because there are less jobs, people are staying in jobs, even when conditions are unsafe, and thus the likelihood of injuries increases. The numbers for temporary disabilities are well over twenty thousand in 1987 and 1988 (Workers Compensation Board of Winnipeg, 1988).

The Worker's Compensation Board statistics do not indicate whether the disability resulted in a need for a temporary or permanent placement in a nursing home facility.

The Worker's Compensation Board (1983, 1984, 1987, and 1988) statistics provide support for further and more in depth examinations of chronic illness and/or disability and its ramifications for the individual, the family, and the community.

Chronic illness is defined as impairment or deviation with one or more of the following characteristics: permanence; leaves residual disability; caused by a non-reversible pathological alteration; requires special training of the ill individual and/or the family for rehabilitation; and may be expected to require extended periods of supervision, observation, and/or care. The effects of illness and the subsequent reorganization of the family may be more disruptive, functionally and emotionally, to the well-being of the family members than the patient (Williamson, 1985 & Stuijbergen, 1987). Increasingly young disabled adult Canadians and their families are looking to the community for supports, but when these supports are unavailable or become insufficient to help provide needed care, nursing home facilities become one of the last alternatives available to the individual and the family.

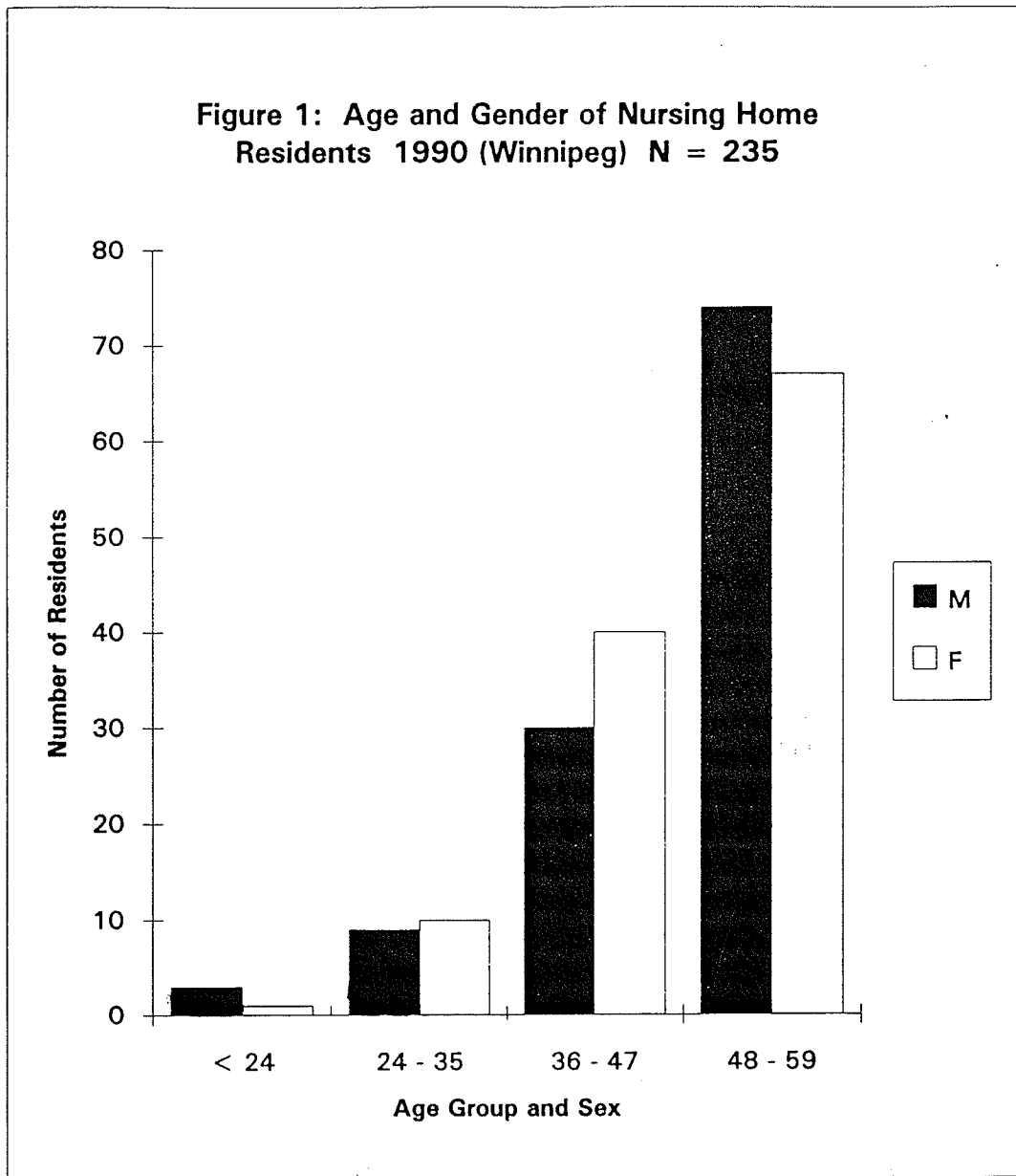
Soltys (1990) studied the needs of the adult disabled persons in personal care homes. This study was based on the Manitoban population, and focused on personal care homes in Winnipeg. Soltys looked at young disabled adult residents (59 years and under) already in personal care facilities, and at the waiting list of young disabled adults (59 years and under) awaiting placement. Although this focus limits the generalizability of the data, one should not minimize the importance of the recommendations it makes, nor the vast need for supportive interventions within the nursing home setting.

In Manitoba there were two-hundred and thirty-five (235) residents of nursing home care facilities, 59 years and under, as of April 1, 1990. Furthermore, there were forty (40) individuals within this age group, who had been assessed and were awaiting placement in a nursing home facility as of April 1, 1990 (Manitoba Health Services Commission, October, 1990).

The average age of the 235 Nursing home residents who were 59 years and under, was 47.9 years, with a fairly equal gender distribution. The majority of these residents were in the 36 year to 59 year age bracket, with the largest proportion between 48 years and 59 years. This information is represented in Figure One (see Figure 1).

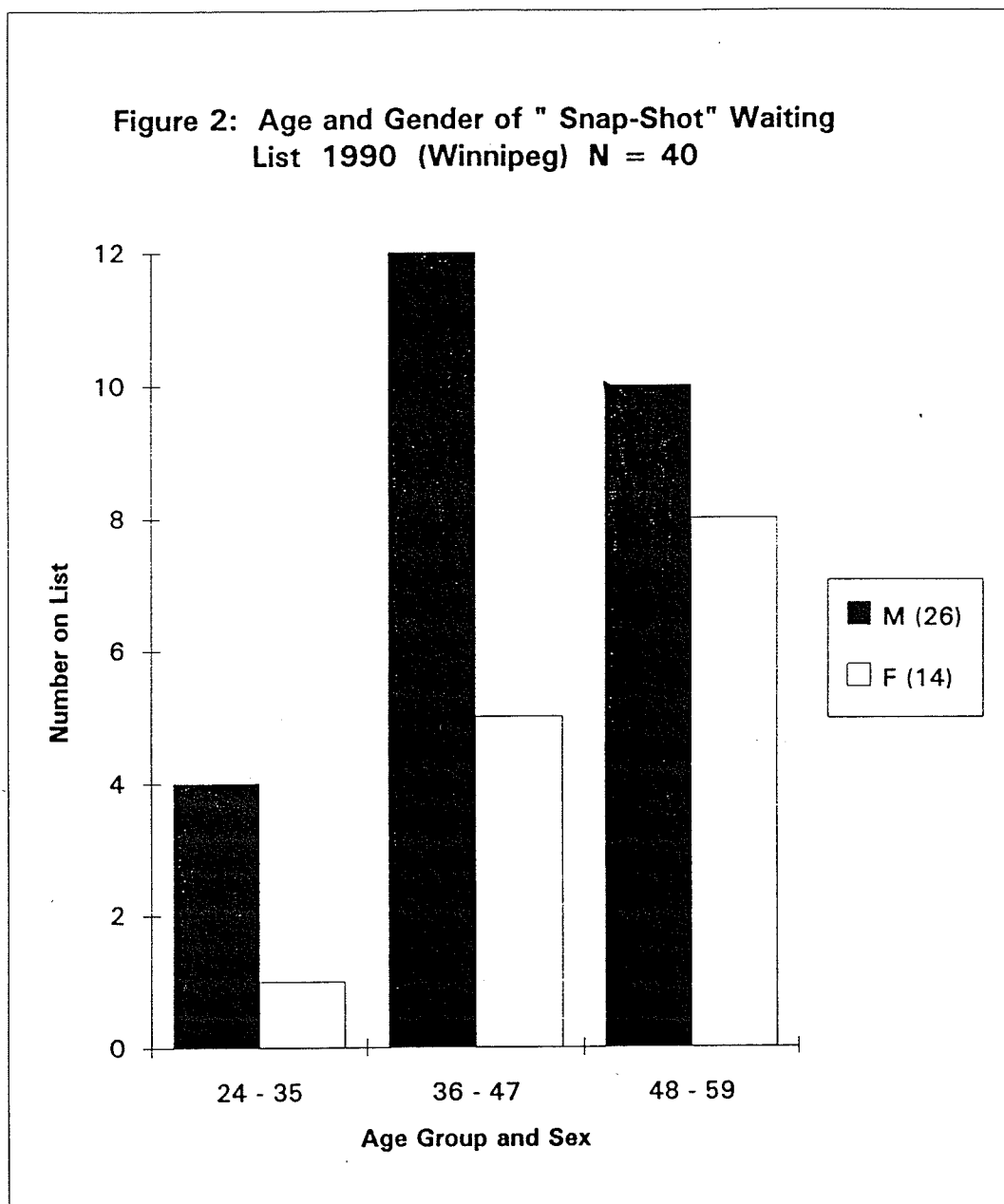
Of the 40 individuals on the waiting list, almost twice as many males as females are represented. There is a more equal distribution of individuals from the 36 year to the 59 year age group as compared to age group distributions of individuals who are already residents of nursing care facilities. It must be noted that waiting lists change rapidly, therefore, the 1990 statistics represent a "Snap-shot" view of the waiting list (Manitoba Health Services Commission, October, 1990). The age and gender distribution of the "snap-shot" waiting list is shown in Figure Two (see Figure 2).

Soltys also defined categories on the basis of primary and secondary diagnostic characteristics in the groups she examined. Category one included Central Nervous System dysfunction, disease, and damage or degeneration from organic causes with specific mention of physically disabling effect. More than twelve percent in category one had Multiple Sclerosis, the single largest diagnosis code in category one. Other



(Manitoba Health Services Commission, 1990)





(Manitoba Health Services Commission, 1990)

examples of medical diagnosis which were classified in Category one include, spinal cord injury, head injury, diplegia/hemiplegia, late effects of polio, and cerebral palsy. Within Sotlys' identified target group, the largest number were in Category one which was twice as high in occurrence as Category two, which was the next highest.

Category two included Central Nervous System dysfunction, disease, and damage or degeneration from organic causes without mention of physically disabling effects with low likelihood of physically disabling effects (Manitoba Health Services Commission, 1990).

Categories five and six fall under a description of mental illness, however, these groups represent disorders resulting from cerebral vascular damage and organic insult or injury -- 9% of target group. These categories cover what is described as brain injured individuals. Category seven also focuses on mental illness -- 5.4 % of target Group and Category eleven describes mental retardation -- 2.4% of target group (Manitoba Health Services Commission, 1990).

The levels of care required by young disabled adults varies from very high to moderate. Levels of dependency are assessed in six areas of care needs. These six areas include: bathing and dressing, assistance with meals, ambulation/ mobility/ transfers, elimination, professional intervention (treatment/medications), and behavioral management/support supervision. Each of these areas have four categories from minimal dependence, to partial dependence, to maximum dependence, to chronic care indicators. Levels of care are determined by the number of categories noted in each of the six areas of care needs. The greater the number of assessed needs in each

category, the higher the level of needed care. The Tache Nursing Centre does not accept individuals assessed as needing level one care.

Of the total target group, 75 % had been assessed as needing care level 3 (91), and care level 4 (85) for a total of 176. Level 1 had the lowest numbers (2), and 57 residents of the target group were assessed as needing level 2.

Solty's study also identified some of the differential needs of young disabled adults that separated their needs from the needs of the elderly population in long-term care. The different needs of young disabled adults that were identified included; higher privacy needs, education and information needs, needs around financial issues, higher family involvement needs, transportation needs, needs in the area of productivity and employment, higher and different socialization needs, and different needs in relationships with care-givers (Manitoba Health Services Commission, 1990).

Clearly, there is a significant number of young disabled adults in and/or awaiting entry into nursing home facilities in Manitoba. Nursing home facilities need to adjust their services to provide for the different needs of these individuals and their families. Solty's study made a number of recommendations. The primary recommendation was the development of a separate facility or area within a facility that was specifically designed to meet the needs of the young disabled adult population in long-term care (Manitoba Health Services Commission, 1990).

It is important to note that moving into a long-term care facility is a traumatic event under the best of circumstances. New residents are frequently leaving the comfort and familiarity of their homes, cherished possessions, and neighbourhoods to

enter an alien and often impersonal world. There is a frightening loss of individuality, power and independence for most of these individuals who were once valuable and contributing members of society with control over their environment . These effects can devalue a person and can lead to "institutionalized" behaviour (Manitoba Health Organizations, Inc., 1990).

The individual and families can fall into the routine and patterns of the institution. They neither challenge rules nor seek out information. This behaviour can result from the family's or the individual's fear of retribution, or the feeling of powerlessness within the institution's power structure, or even "don't make waves" or "they know what's best" belief system. "Institutionalized" behaviour makes the individual and frequently family members, compliant and cooperative. To increase resident compliance within the institution, staff may encourage rather than discourage "institutionalized" types of behaviour in residents and family members.

## **1.2 Rationale for This Practicum**

This practicum provided a supportive group intervention to families and young disabled adult residents of a nursing centre facility. The intervention was implemented in the newly developed young disabled adult residents unit at the Tache Nursing Centre in Winnipeg, Manitoba. Part of the impetus for the development of this unit came from Pearl Soltys's comprehensive study on the needs of young disabled adults

in Manitoba, which focused on long-term care programs (Manitoba Health Services Commission, October, 1990).

Given the information provided by the Worker's Compensation data, and the Soltys study on long-term care programs, it became clear that the needs of young disabled adults in nursing home facilities and their families were different from needs of the elderly residents in nursing home facilities and their families. Some of those different needs include education, information, greater independence, greater family involvement, and greater opportunities for socialization; for both the young disabled adults and their families. The opportunity to address some of these needs came in conjunction with the development of the young disabled adults unit at the Tache Nursing Centre.

The Tache Nursing Centre is a 316 bed nursing home facility. The Tache Nursing Centre has always made provision for disabled adults in need of long-term care. The Centre found that over recent years, between 20% and 25% of the population were consistently younger adults (59 years and under). Young disabled adults had been integrated within the general population of the Tache Nursing Centre. The different needs of the young adults became more and more apparent to the staff and professional departments of the Centre. The staff's growing awareness of younger residents' needs and the Soltys study prompted the staff to apply to the Government for a unit specifically designed to meet the different needs of young disabled adults (Manitoba Health Services Commission, 1990).

The young disabled adult unit was started six months (December, 1993) prior to this practicum and was still in developmental stages at the time of this practicum. Geriatric residents were gradually being relocated off the unit until the unit consisted only of young adult residents, fifty-nine years (59) and under. Construction to implement a more youth oriented, self-care focused environment for the residents and their families was ongoing at the time of the practicum.

It was important to examine the benefits of providing education and support, in a group setting, for young disabled adults in long-term institutionalized care, and their families. A supportive intervention that would enhance residents and families comfort and involvement in their environment could have positive health and life satisfaction benefits for both. This could become a very valuable part of the newly developed young disabled adults' unit.

### **1.3 Purpose of Practicum**

This practicum was designed to provide group intervention for young disabled adult residents of a long-term care facility, and their families. The objectives of the group intervention with the residents were in keeping with the objectives and goals of the newly developed young disabled adult unit in the Tache Nursing Centre. The objectives of the unit were firstly, to provide a separate physical environment that served the specific needs of young disabled adults, including increased privacy, increased opportunity for socialization, and more age appropriate daily activities.

Secondly, the unit was geared to provide counselling and treatment that would assist younger residents in reaching their maximum rehabilitation potential.

Finally, the young disabled adults unit was striving to provide individual programs/services which assist in the exploration of and involvement in specific recreational, educational, and vocational pursuits.

In keeping with the unit objectives, the goals included; providing a physical environment which assists young disabled adult residents in meeting social, emotional, and functional needs; encouraging and facilitating resident participation, self-expression, and self-direction in his/her daily life; and, to ensure the availability of recreational, vocational, educational, and rehabilitation facilities either within the Centre or in the community.

The purpose of the residents' groups in this study was focused on enhancing the individual's abilities to take advantage of the goals and objectives of the unit by providing a forum for the development of assertiveness and independence related skills that would empower them to become more directive and feel a greater sense of control and involvement in their environment. By providing information and support it was hoped that the residents on the unit could change their "institutionalized", behaviour patterns and develop greater independence and sense of control that would allow them to take advantage of what the unit had to offer.

The purpose of the family groups was somewhat different than that of the residents' groups. Family groups were based on an education and support format. The groups provided information through the different professional departments of the

Tache Nursing Centre. The purpose of the sharing of the information with family members was to enhance their feelings of community and involvement in their young disabled adult relative's environment, and to help them increase their knowledge about their relative's condition and care within the Centre. It was also believed that the family members would feel a greater sense of involvement with the Centre by reinforcing the open-door policy of the different professional departments. A further purpose for the education portion of the family groups was to reduce anxiety family members may feel when their dependant relative is in the care of an institution. Family member's sense of isolation and separation from the care of their loved one can evolve into "institutionalized" thinking and feelings of helplessness. Finally, the social support element in the family groups would help reduce feelings of isolation and anxiety, and increase feelings of empowerment within the institution through the medium of shared information and experience.

#### **1.4 Objectives of Practicum**

The objectives of this practicum were to develop, implement and evaluate support groups for young disabled adults in long-term care, and for families who have a young disabled adult member in long-term care. A further objective was to highlight the importance of developing a generic method of providing support and education to families who have a young disabled adult relative in long-term care. As facilities such as the Tache Nursing Centre provide more specific units for young adult disabled



residents, it is clear that the increased involvement of family members must be acknowledged and incorporated into the development. An important objective of this practicum was to generate a self help support group for the family members with a young disabled adult on the young disabled adult unit in Tache.

Finally, it is important to generate recommendations that would refine and enhance a generic education and support group format that is not dependent on specific disease process and or disabling injury for effective implementation with young disabled adults or their families.

Learning objectives were also an important part of this practicum. The learning objectives of this practicum include:

- (a) To develop an understanding and current knowledge base of the impact and effects of a long-term disability and/or chronic illness on individuals and their families through a review of literature and through practical experience.
- (b) To learn how to design and implement effective education and support groups within the parameters of a long-term care setting.
- (c) To learn how to assess, evaluate and present results and findings in a comprehensive proposal for further implementation.
- (d) To enhance knowledge and skill in group preparation and facilitation.

### 1.5 Summary

This Chapter has examined some of the data on incidence of disability and chronic illness. A brief overview of the characteristics of chronic illness and/or disability was discussed and will be expanded in the next chapter. Long-term care of young disabled adults in Manitoba was examined including a description of some of the diagnostic categories and levels of care for individuals in long-term care. In examining the Worker's Compensation Board data, and the Soltys study it became clear that some form of supportive intervention would be beneficial to young disabled adults and their families. These benefits will be examined more extensively in Chapter two.

This chapter looked at the rationale for this practicum. The rationale outlined the specialization of a young disabled adult unit in the Tache Nursing Centre. The rationale looked at the needs of the residents and their families for education, information, independence, socialization, and involvement, and the benefits of providing for these needs. It is important to note the development and characteristics of "institutionalized" behaviour patterns in looking at the purpose and the objectives of this practicum.

The purpose and objectives of the practicum were also outlined. These included providing support group intervention in a generic format, for young disabled adult residents and their families. Finally, the importance of developing recommendations was also highlighted. Chapter two will examine the impact of illness and/or disability in more detail.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1 Illness and/or Disability

Initially most people regard chronic illness and/or disability as an unanticipated event. Chronic illness begins as an internal event. Symptoms generally develop over time, sending people to doctors. Frequently the development of symptoms leads to diagnosis shopping, diagnosis limbo (waiting to find something) and/or distrust of diagnosis, especially if results are not what people want to hear. This is often a period of increased fear and anxiety (Corbin & Strauss, 1988). To relieve anxiety some seek a variety of medical opinions, rejecting those that do not confirm what they want to believe. Others deny the potential seriousness of symptoms, or make light of them (Corbin & Strauss, 1988). When severe chronic illness and/or disability crashes into someone's life, it separates the person of the present from the person of the past, ultimately, new conceptions of "Who and What I am", past, present, and future; must rise out of the remains. The individual and the family members must come to terms with the new reality and reconstruct identity and reintegrate the new identity. It is not too far fetched to assume that the integration of new identities would be especially difficult for individuals and families where nursing home placement is the only option left to them. Adapting to a new environment that is unfamiliar may require changes in role definitions, and demand the development of new skills for both the individual and

the family members. Without support or information, these major life change transitions can be awkward, difficult, and take greater time for the individuals and their family members. For some, these transitions can not take place without supportive intervention and information.

The enormity of illness and disability, however, is so pervasive, powerful, and all-encompassing that coping with, challenging, and overcoming the changes chronic illness and/or disability create for individuals and family members can not be left to chance. Dell Orate (1984) noted several generic characteristics regarding chronic illness or disability. These characteristics include:

- no one is completely prepared for illness or disability.
- illness changes a family and challenges its resources.
- the illness process brings out the best and worst in people.
- disability can deplete resources as well as create them.
- often the only support is family.
- all people do not have family they can rely on.
- not all families are capable of responding to the illness or disability of a family member.
- new skill are needed to meet the new challenges created by illness.
- coping with chronic illness/disability is an ongoing developmental process.

- existing health care resources can help as well as hinder adjustment.

In the midst of an illness, individuals and families may be so devastated that they are unable to cope with the hassles of identifying the very systems that are designed to help them. It is unfortunate when a person's pain and frustration is increased by the ignorance of resources and models rather than the lack of them (Dell Orto, 1984). Sharing of experiences may help provide individuals with information about resources that are available and also help identify resources that are needed. More frequently, individuals and families are isolated and so overburdened by immediate crises that there is little opportunity to find others to share experiences with. This can inhibit the capacity of the family to provide long-term care needs.

The family's capacity to provide long-term care and the consequences of caregiving to families is of great concern to those interested in maintaining and enhancing the well-being of families (Hafstrom & Schram, 1984). An appropriate time for assembling the family to deal with the chronic illness and/or disability is reached when it becomes apparent that the role changes would not be temporary (Schmidt, 1983; Williamson, 1985). The unfortunate reality is that these families seldom get the needed intervention. By the time nursing home placement becomes necessary, family members are often burnt out, frustrated and guilt ridden. Intervention following placement could be an asset to the disabled individual, the family members, and the facility.

Clearly, chronic illness and/or disability has serious negative repercussions for the individual and the family. Adjustment and adaptation can be impeded by a number of factors including; lack of coping skills, lack of information, lack of resources, the severity of the crisis, and the enormity of the changes required by both the individual and the family members. All of these factors can work against healthy adjustment and adaptation to a chronic illness and/or disability. Factors that interfere with health adjustment and adaptation can in turn, exacerbate health problems and dramatically decrease life satisfaction for the individual and the family members. These issues will be examined in more detail in the next sections.

## **2.2 Impact of Illness/Disability**

"I think something new is beginning to happen that makes me very sad.....I am a caregiver. He is no longer my friend, husband, lover.....And I guess, even though he is not responsible for what happened to him, that I feel angry with him." (pp.144-45) (Doernberg, 1986).

"I am faced with an unbearable decision. I may choose to take a step closer so that I can grab hold of him. This would bring me into the quagmire and I know that eventually I will be devoured unnecessarily with Ray. The second option is just as painful. Let go. Release the

almost imperceptible hold I have. Stand by the side and watch as he is drawn deeper and deeper into darkness." (pp. 104) (Doernberg, 1986).

The effects of a disabling chronic illness, such as Alzheimer's as referred to by Doernberg (1986), or a severely disabling injury, are felt by everyone who is involved, the individual and their family.

As early as 1905, it became apparent that due to many individual and family problems, patients were often unable to carry out medical treatment plans (Cabot, 1919). Joseph Pratt (1907) began educational lectures to enhance compliance among tuberculosis patients, whom, he noted, experienced feelings of demoralization as a result of their situation. The changes to physical status, functional capabilities, and appearance through illness and/or disability, frequently disrupts one's sense of well-being, and necessitates a revision of self-image (Rutchick, 1990).

Illness always represents an upset in physiological equilibrium and is often accompanied by psychological and social disequilibrium which represents a crisis for both the patient and the family. A crisis can be defined as an "upset in a steady state" of a magnitude that renders habitual problem solving techniques unable to effectively restore balance. This leads to states of disorganization, often accompanied by unpleasant feelings of guilt, fear, and anxiety (Rutchick, 1990).

The effects of a chronic illness and/or disability on the individual are numerous. Individuals can experience feelings of demoralization, changes in physical status, changes in functional capabilities, and changes in appearance. These changes can

disrupt the individual's sense of well-being and require revisions in the individual's self image. The individual's abilities to deal with these changes are further impeded by the disrupting effects of the onset of chronic illness and/or disability. The onset of a chronic illness and/or disability can lead to disorganized states and feelings of guilt, fear, and anxiety which make coping and adjusting very difficult, if not impossible for some. All of these factors also effect family member's abilities to cope and adjust.

### **2.3 Impact on Individual**

The combined effects of physical, emotional, or communicative impairments, social stigma, and isolation, are substantial obstacles to overcome on the path to self-determination (Safilios-Rothschild, 1970). Having experienced at least some degree of dependency upon others, adults who have disabling conditions may tend to perceive themselves as more subordinate than autonomous and therefore choose not to assert themselves. For individuals who develop a chronic illness and/or disability in early adulthood, the complexity of tasks of the normal development (ie. the development of mature interpersonal relationships) (Erikson, 1974), become greatly compounded. Reactions of family, friends, and associates certainly effect adjustment, but can also vary considerably (Glueckauf & Quittner, 1984). Kratz and Glass (1978) provide examples of exaggerated positive and negative displays towards the disabled individual, while Kleck, Ono, and Hastorf (1966) examine over-controlling and stereotypical behaviours of significant others towards the disabled young adult. Both



of these studies examined the negative effects of some typical reactions to the illness and/or disability by significant others.

The effects of exaggerated positive (overprotectiveness) or negative ("you're not even trying") displays, overcontrolling (not letting them do anything), and/or stereotypical (disability is often associated with mental problems: intelligence, smartness, hearing, unable to do anything) behaviours as reactions to a young adult's disability and/or illness, can lead the disabled individual to believe that the behaviour of others is unpredictable and their responses not genuine (Glueckauf & Quittner, 1984). This problem can become especially severe if the person perceives that the responses of significant others, particularly family and friends, are altered as a result of the illness and/or disability. Thus, newly handicapped individuals may choose to isolate themselves from social contact and from information which might help to reduce their uncertainty about the behaviour of others and about their own medical condition (Glueckauf & West, 1982).

Schag and Hienrich (1989) examined the anxiety associated with medical situations in adult cancer patients. They found that the amount and severity of anxiety was situation specific, in that, going to the hospital and awaiting test results showed the highest frequency of anxiety, while seeing other patients receive treatment was less significant. Furthermore, it was found that age, gender, communicating with the health team, and global adjustment to the illness all accounted for significant amounts of variance in the anxiety measures (Schag & Heinrich, 1989).

In the Schag and Heinrich (1989) study, good communication with the health team, and good overall adjustment to the illness helped reduce anxiety. Younger individuals global adjustment was lower, while older individuals frequently missed appointments and did not communicate openly with health teams. Women adjusted and communicated more effectively than men. All of these factors impacted on increasing and decreasing anxiety measures across age and gender.

Anxiety is a very important factor in the care and treatment of a chronic illness and/or disability. Untreated anxiety issues can lead to a variety of more serious problems including; decreased quality of life (Wellisch, 1984), impaired work performance, missed appointments and failure to complete curative therapies or treatments (Masur, 1981), and increased physiological morbidity (Gill, 1984). Severe anxiety responses can also interfere with immune functioning (Herberman & Ortaldo, 1981; Locke, Kraus, Lesserman, Hurst, Heisel, & Williams, 1984); and survival (Riley, 1981).

Individuals who develop a chronic, disabling condition as young adults are also faced with substantial alterations in their social environment (Safilios-Rothschild, 1970). These changes can be located in four major areas of interpersonal functioning, including:

- (1) differential behaviour patterns of the able-bodied toward the disabled,
- (2) public attitudes about physical disability,
- (3) embarrassing social situations related to specific medical disorders,
- (4) reinforcement of dependent behaviours by health care professionals.

Dependent behaviours can be reinforced by family and professionals involved with the individual. Typically, hospital rehabilitation does not teach newly disabled young adults the social skills for successful integration into the community (Cogswell, 1968). Rehabilitation therapies are usually delivered in highly structured, time-limited units in which the individual passively receives instruction from the professional staff. Formal therapies are likely to permit little behavioral independence and may not encourage the patient to develop problem solving skills (Harrison & Garfunkel, 1981). Further, most treatment services are delivered by hospital nursing personnel who have received little training in social interaction skills, although this is changing. In order to complete their assigned duties, they may inadvertently reward dependent responding in patients (Vineberg & Willems, 1971; Willems, 1972).

Overcoming the combined effects of physical, emotional, or communicative impairments, social stigma, and isolation can not be left to chance. For individuals struck with chronic illness and/or disability, there are a number of dramatic changes accompanied by severe negative emotions that impede coping skills. Available resources often act to reduce behavioral independence and create passive acceptance that reduces feelings of self-esteem and leave the individual feeling devalued. Anxiety is frequently increased, and this can have negative effects on adjustment, coping, and health. All of these issues point out the importance of an effective intervention that can empower the individual, reduce feelings of anxiety, and encourage less dependent behaviours. An appropriate and effective intervention can benefit both the individual and the family members.

## 2.4 Impact on Family

It is a well established fact that families maintain the primary responsibility for the care of chronically ill and/or disabled family members (Montgomery, Gonyea, & Hooyman, 1985). To those interested in maintaining and enhancing family well-being, the capacity of families, to provide long-term care and consequences to families providing long-term care is an area of great concern (Hafstrom & Schram, 1984). In a comprehensive examination and projection of American family demographics, Masnick and Bane (1980) and Wilkie (1981) predicted decreased family sizes and delayed parenthood in the 1990s. From this information, a number of authors outlined some of the demographics of the present day young disabled adult population:

1. Most of young adults who develop chronic illness and/or disability will have already left their family of origin.
2. Most will be unmarried.
3. For most individuals who do not live alone (unmarried or separated from spouses), the other household members will be dependents (ie. persons unable to assume burden of care).
4. Married young adults who develop a chronic illness and/or disability will be living in small families (ie. one to two children).

These four conclusions lead to a fifth:

5. If a chronically ill and/or disabled young adult is to live in a

family, the family environment will be either; a) the family of origin, including parents in their mid-forties or older, and siblings who remain in the family home; or b) the family of commitment including spouse and children.

In either case, the caregiving family will be a small one where family members who care for young disabled adults must assume these burdens knowing that there are few other family members who are able to help (Aadalen & Stroebel-Kahn, 1981; Caywood, 1977; Cohen, 1977; Hudson, 1976; Kane, 1981). These predictions have proved to be an all too accurate reflection of present times.

In looking at the stresses on caregivers of Alzheimer's Disease (AD) family members, Crook and Miller (1985), and Eisdorfer, Kennedy, Wisineiki, and Cohan (1983) found that these stresses leave caregivers at high risk for depression. There may also be progressive deterioration of caregivers' well-being related to the increased impairment of the AD family member over time. In a study where perceived decrements in health, decreased life satisfaction, decreased satisfaction with time for social participation, and increased levels of stress-related psychiatric symptoms were measured at one year intervals, substantial deterioration in caregivers' well-being were found (George & Gwyther, 1984).

Braham, Houser, and Cline (1975) evaluated the social needs, defined as needs for nonmedical support or action which can be met by the patient or family, of nonhospitalized Multiple Sclerosis (MS) patients. This study found that when the social needs were met, 80% were met by the individual or the family coping alone,

without outside help. It was also found that as the disability and dependency increased, the social needs increased in frequency (Braham, et. al., 1975). When Klien, Bogdonff, and Dean (1975) studied the effects of chronic illness on spouses, they found indications of reduced work activity, increased role tension, psychosomatic complaints, and emotional distress. Family roles often change when one member becomes chronically ill and/or disabled.

In 1983, Weinert described the role of social support in promoting family adjustment to long-term illness. A study of 149 families, where one spouse had MS, found that social support had a consistent and positive effect on family functioning. It was further found that emotional behaviour of the MS member had a strong influence on family system function, while physical limitations in self-care and mobility had little impact (Weinert, 1983). Foxall, Ekberg, and Griffith (1985) found that social contact was significantly related to higher adjustment for middle-aged chronically ill individuals and their spouses.

In a study of 49 families where one member had MS, it was found that the family's ability to cope with a chronic illness can be an important factor in the patient's own adaptation and possible rehabilitation. Power (1985) found that early intervention improved the family members to deal constructively with the illness by encouraging the proper use of information, encouraging outward-directed activities, and encouraging positive expectations for the patient, early intervention was found to be helpful to family members. It was found that these strategies in turn, facilitated the

patient's willingness to seek rehabilitative goals and their overall adjustment (Power, 1985).

As family members are primary caregivers, it is important to look at the effects of the chronic illness and/or disability of a family member on the family as a whole. The reactions and responses of family members impact directly upon the reactions and responses of the chronically ill and/or disabled individual. This section has pointed out a number of areas where family members may be negatively effected by a family member with chronic illness and/or disability. Family members can experience decrements in health, decreases in life satisfaction, decreased time for socialization, feelings of isolation, anxiety, and increases in general stress. Furthermore, these negative effects on family members also increase negative effects in the chronically ill and/or disabled individual.

This section began to examine the importance and the positive effects of providing social support group interventions for family members where a family member had a chronic illness and/or disability. The studies referred to in this section pointed out positive effects for family members which included, improvements in family members abilities to deal constructively with the illness, and a consistent and positive effect on family functioning. These studies also showed the positive impact of social support intervention for family members on the chronically ill and/or disabled individual. The impact of social support group intervention will be examined more closely in the next chapter.

## 2.5 Summary

This Chapter examined the impact of chronic illness and/or disability on its own, on the individual, and on the family. A number of factors were identified which effect individual as well as family members' health, adjustment, and coping with chronic illness and/or disability. The importance and benefits of group intervention with individuals and family members was also highlighted through a number of studies.

All of the issues discussed in this chapter have a strong bearing on the need for supportive interventions for both family members and the individual with the chronic illness and/or disability. The positive effects of supportive group intervention for family members and for the chronically ill and/or disabled individual have been well established in the literature, although only a few select studies have been reviewed in this chapter.

When developing a supportive intervention, it is important to evaluate the benefits that can occur as a result of a chosen intervention. For the purposes of this practicum, a supportive group intervention was clearly indicated. Chapter three will look at the types of groups, group models, and group process. The role of support groups in health care settings will also be examined. These are also important aspects to look at when determining an appropriate implementation of support group interventions.



## CHAPTER THREE

### GROUP WORK

Group work as a social work method has evolved and changed in the half-century since its origin. Social group work ranks among the earliest practical efforts to realize the potentials inherent in the small group experience to maximize the well-being of the individual and to improve the social condition (Alissi, 1980). A number of authors have outlined the historic development of groupwork from its inception to the present (Simmel, 1950; Kaiser, 1958; Coyle, 1959; Jones, 1967; Douglas, 1979; Alissi, 1980).

With the increased importance of group work it became clear that a search for consensus on the purposes of group work was important. Hartford (1964) was able to outline some major purposes which he had drawn from numerous references and materials. The five areas where agreement of group purpose were found included:

- (1) Corrective - a restorative or remedial experience where individual or social dysfunction or breakdown occur.
- (2) Preventative - prevent personal or social breakdown or deterioration.
- (3) Normal Growth and Development - facilitate growth and development especially during stressful life cycle periods.
- (4) Personal Enhancement - achieve greater self-fulfilment and/or personal enhancement through stimulating and meaningful relationships.

- (5) Citizen Responsibility and Participation - to promote group values to help involve individuals and group members as responsible and active societal participants.

It is important to note that as groups became more and more associated with agencies, so too did group work purpose become intertwined with agency purpose. Clearly, the most valuable view of agency-group relationship is described by Abe Vinik (1964) when he stated;

"The group is not a tool. There is integrity to its existence. It has a right to its own purposes and may expect help from the worker in seeking to realize its own purposes and work out its own problems.....  
The group is not the worker's or the agency's but the members." (pp. 103).

### **3.1 Types of Groups**

Groups fall into two global classifications, formed and natural groups. Formed groups generally come together through some outside influence or intervention and are dependent upon some affiliation or sponsorship. Natural groups come together spontaneously, through interpersonal attraction, mutually perceived needs, or naturally

occurring events, however, they frequently function without formal sponsorship (Toseland & Rivas, 1984). Groups can also be described as open or closed groups. Open groups have limited agendas and members join and leave on an ongoing basis. Self-help groups are frequently open groups. Closed groups are generally time-limited, follow an agenda, and once the sessions have started, new members are not introduced. Treatment groups and formed groups are generally closed groups.

Formed groups become defined by the purpose they were formed to serve. Group purpose identifies the reason for the group, the members who will be approached to join the group, and the way in which the group itself will function as a means to reach its purpose defined goals (Wilson, 1976; Klein, 1972). There are two general forms of formed groups, treatment groups and task groups.

The treatment group is defined by Toseland and Rivas (1984) as a group whose major purpose is to meet members' socioemotional needs, including education, personal growth, socialization, or behaviour change. Task groups, on the other hand, are groups where the needs of the members are neither intrinsically nor immediately linked to the groups' major purpose which is to accomplish a mandate and complete the work that the group was convened to produce (Toseland & Rivas, 1984).

As this practicum is using a form of treatment group, task groups will be examined first, followed by treatment groups. Organizations and agencies are the settings where task groups are most commonly found.

### 3.1.1 Task Groups

Task groups have two primary purposes; to serve organizational needs, and to serve the needs of clients; by generating new ideas, making decisions regarding a numerous variety of issues, and finding solutions to organizational problems (Toseland & Rivas, 1984).

The task groups that are geared towards meeting organizational needs include committees (most common), administrative groups, and delegate councils. The main purposes of most of these groups are system maintenance, policy making, or organizational change. Leadership of the task groups geared towards organizational needs tends to be legitimized authority normally a high executive of the organization or agency. These groups include groups like boards of directors which require diplomacy, organizational skills and patience of the members and are mostly focused on the agency or organization (Toseland & Rivas, 1984).

Task groups which focus on client need include teams, treatment conferences and social action groups. Teams provide a mutual involvement with the client system and are appointed by a sponsoring agency. Treatment conferences make decisions regarding treatment plans for clients by offering a diversity of speciality, function, and expertise that is overseen by a neutral facilitator or by someone who is seen as most responsible for the client. In an attempt to consider all points of view of the client system, the communication in treatment conferences is necessarily based on high disclosure of contacts regarding the client. Social action groups promote individual or

social change through an action oriented movements based on high client focus (Toseland & Rivas, 1984).

### 3.1.2 Treatment Groups

Treatment groups are based on four primary purposes, including; education, growth, remediation, and socialization; which are found in innumerable variations within practice settings. Educational treatment groups provide education and learning through didactic discussions, presentations, and experiences. The leader of education groups is viewed as a teacher and as a provider of structure for group discussion. A common interest in learning and skills development usually bring together members. Communication in educational groups is mostly member to leader and vice versa, with very low individual self-disclosure (Toseland & Rivas, 1984).

Growth groups attempt to develop member's potential of awareness, development, and insight through discussion and growth producing experiences. The leader can be seen as the expert or authority or simply as a facilitator. Communication in growth groups is highly interactive with members taking responsibility for group communication, and moderate to high self-disclosure (Toseland & Rivas, 1984).

The purpose of remediation groups is to use behaviour change interventions for rehabilitation, correction, coping, and problem solving with and expert or authority figure, or facilitator and a leader. Remediation groups may have separate member goals but relationship among members or common purpose keep them together with a

focus on individual concerns, problems, or goals. These groups can involve a diversity of individuals with commonality of concerns or problems making self-disclosure moderate to high in a member to member or leader to member format (Toseland & Rivas, 1984).

Finally, socialization groups increase communication and social skills, and improve interpersonal relationships through a number of mediums. For example, role play, program activities, or structured exercises can be used with the leader acting as director of group programs or actions. Group members can be homogeneous or diverse and communication is often represented in non-verbal behaviour or activities making communication frequently non-verbal with moderate to low self-disclosure (Toseland & Rivas, 1984).

### **3.2 Group Models**

It is important for group work to have a basis or theoretical model from which a method of implementation can be developed. A theoretical model is described as a map, or scheme for making sense of the portion of the real world in relation to which the worker seeks to act (Kogan, 1960). In other words, a model is a conceptual design to solve a problem that exists in reality. There are several group work models which will not be examined within this document. These models include; the Process Model, Klein's Eclectic Model, the Behavioral Model, the Task-Centred Model, the Group Centred Model, the Personal Growth Model, and the Maturation Model.

Definitive descriptions of these models can be found within a number of sources (Douglas, 1979; Alissi, 1980; Garvin, 1981).

Three important examples of social group work method include the Social Goals Model, the Remedial Model, and the Reciprocal Model. It is important to examine different theoretical models when looking for an appropriate framework for group intervention. Following are brief examinations of the three models mentioned above.

### 3.2.1 The Social Goals Model

The central problems which the social goals model attempts to deal with are those related to social value orientation and social order in small groups. This model assumes a unity between social action and individual psychological health with therapeutic implications of social participation which open its practical advantages to group work with groups of varying health and illness. The social goals model regards the individual as being in need of the assistance and opportunity in revitalizing their drive towards others in a common cause and in converting self-seeking into social contribution (Weiner, 1964). This model primarily envisions group work services at an agency and community level, where the setting is flexible and accessible in offering institutional auspices for a variety of collective efforts.

The social goals model has an eclectic theoretical base (Jones, 1967). The social goals model has not produced a theoretical design that can meet the problems of practitioners in all areas of practice adequately. This models' lack of attention to a

wide variety of individual needs, its' under-emphasis of individual dynamics, leave workers with no guidelines for interventions with client groups where individual problems take precedence over societal problems (Ryder, 1960; Weiner, 1960).

### 3.2.2 The Remedial Model

The remedial model historically facilitated the integration of group work method in the social work profession by offering a congenial base for the linkage of social group work method with social casework method. Adjustment problems in personal and social relations that can be treated through groups are considered to be within the special expertise of the social group worker. The concept of priority is introduced in the remedial model with its focus on individual adjustment problems by reasserting the profession's historic mission to provide service to those most in need (Vinter, 1959). The treatment group envisioned by this model is the formed group, where membership is pre-determined and diagnostically selected by the worker. Processes within the group which help members to help each other are recognized within this model (Sarri & Galinsky, 1964).

The remedial model assumes that group development can be controlled and influenced by the worker's action and in this way it draws heavily from theories of small group dynamics, which help to account for changes in the group and suggest opportunities for professional interventions in carrying out the change agent role (Sarri & Galinsky, 1964). Treatment goal is the central and most powerful concept in this



model. Emphasis on this concept can be seen throughout the remedial model's practice principles, which include the following (Vinter, 1959; Glasser & Costabile, 1963);

- (1) Specific treatment goals must be established for each member of the client group.
- (2) The worker attempts to define group purposes so that they are consistent with the several treatment goals established for individual members.
- (3) The worker helps the group develop that system of norms and values which is in accord with his/her treatment goals.
- (4) The worker prestructures the content for group sessions based on the worker's knowledge of individuals expressed through treatment goals as well as the workers knowledge of structural characteristics and processes which take place within the group.

The remedial model uses direct and indirect means, including extra-group means to influence its members who are deviants to some degree. The worker would require skills in intervention in group process to achieve specific goals. This model has a theoretical base which includes, sociobehavioral theory, ego psychology, role theory, and group dynamics (Jones, 1967).

The remedial model makes insufficient provision for a group to contribute to it's environment, and constrains the group leader from viewing the group as a system to be

sustained and utilized. The human group of the remedial model has little claim to existence except for what it can give to the individual (Vinter, 1959; Hasenfeld & Yeheskel, 1974). However, the remedial model has made several theoretical advances in that it has systematically set forth guidelines for diagnostic considerations of individual functioning in the group; criteria for group formation; foundations for clinical team participation; and diagnostic utilization of the group where other treatment modalities coexist, thereby facilitating the functioning of group work practitioners in clinical settings (Papell & Rothman, 1966).

### 3.2.3 The Reciprocal Model

The reciprocal model advances a helping process that is intended to serve both society and the individual. This model presupposes a systemic, organic, clearly symbiotic, relationship exists between society and the individual. The specific organization of the reciprocal model has been attributed to William Schwartz, however, its duality of focus and strong emphasis on enabling, process, and quality of engagement suggests the contributions of other influences ( Philips, 1957; Kaiser, 1958). Schwartz (1962) states that group members move to relate their own sense of need to the social demand implicit in the collective tasks of the group, common group goals with shared authority pursuing common decisions. The concept of shared authority is derived from the assumption that individuals create a number of helping

relationships in addition to and concurrent with the one they have formed with the worker (Schwartz, 1962; Tropp, 1965).

The reciprocal model views the individual primarily in terms of his/her motivation and capacity for reciprocity. The group purpose following the reciprocal model is to achieve a mutual aid system and initially there is no specific goal. The group leader acts as a resource person or mediator who facilitates the engagement of group members in the process of interpersonal relations through integrative, adaptive, and socialization services which would require worker skills in the area of dialogue and definition. Systems theory and field theory form the theoretical base of the reciprocal model (Jones, 1967).

Schwartz (1961) conceptualized five major tasks to be carried out by the social work practitioner, including briefly (Douglas, 1979);

- (1) The task of searching out the common ground between the client's perception of his own need and the aspects of social demand with which he is faced.
- (2) The task of detecting and challenging the obstacles which obscure the common ground.
- (3) The task of contributing data; ideas, facts, value concepts; which are not available to the client.
- (4) The task of lending a vision.
- (5) The task of defining the requirements and the limits of the situation in which the client-worker system is set.

Each of these generic tasks has been operationalized through a series of principles that specifically guides social group workers. The model suggests three primary principles, including; the worker helping the group to strengthen its goals through consideration of the common goal of the members; the worker acts to protect the focus of work against attempts to evade or subvert it; and the worker interprets his role through clarifying with the group what it is they wish from him/her that he/she has available to give from which a clear contractual agreement can be drawn (Papell & Rothman, 1966). This model provides intense individualizing and social focusing within the small group that provides a coherent footing for further theoretical development.

However, this reciprocal model does not make allowance for the latitude of human personality which may be necessary to explain the manner in which the individual coheres in any system in aid of others. Similarities or differences in the variety of group systems are not sufficiently taken into account by this model. While the reciprocal model provides a useful conception for beginning with the group, it does not offer a framework for dealing with the changes that may occur within the group over time. The reciprocal model also lacks any clarification or group program to guide workers in the group process (Papell & Rothman, 1966).

The three group models discussed above represent some of the variety in theoretical framework for group work. It is important to examine the theoretical outlines of several group models to determine which would provide the best fit to the

proposed needs and goals of the group and the intervention. This practicum will use the theoretical framework of the Reciprocal Model.

Schwartz's (1971) movement towards a mutual aid system is very appropriate for support group intervention for family members and residents within an institutional setting as the needs of the organization, the family members, and the young disabled adults are often compatible. Schwartz had refined this model into the Mediating Model which provides a clearer and more distinctive picture of the intervention process (Schwartz & Zalba, 1971). Schwartz's Mediating Model will be discussed more fully in Chapter four.

### **3.3 Group Process**

Group process involves the stages or changes that occur within the group as a whole, and the members, during the course of the meetings from the first through to the last. Durkin (1964), in an attempt to find a fundamental unity for the field of group dynamics, isolated three principles which were thought to do this;

- (1) That the group was always seen as a structure, which emerged from the constant dynamic interaction of individuals;
- (2) That the group continually restructured itself through a process of adaptation, setting up complex organizational patterns; and
- (3) That the group sets up a circularity of causal interactions which remains consistent.

Literature also addresses the mechanisms and processes involved with social support groups that promote change in people and facilitate adaptation to stress. Gottlieb (1985) stressed the health protective impact of support groups by their normalizing, supportive, and modelling functions. Leiberan (1979) and Dimock (1983) referred to similar functions and properties of small groups which are useful in facilitating supportive experiences. The normalizing function of the group comes from sharing thoughts and feelings in common and learning that members' problems are not unique. "Universality" is another word to describe a similar concept.

Some of the properties small groups possess, according to Leiberan (1979), which facilitate change, whether it is a self-help group, professionally facilitated support group, or therapy group are;

- (1) **COHESIVENESS:** The capacity to generate a sense of belonging, "wenness" amongst the participants. This can also be defined as the attractiveness to the group to its participant, which becomes the motivation to remain with the group. Unconditional acceptance and a supportive atmosphere for taking risks are factors that increase group cohesiveness.
- (2) **CONTROL:** The capacity of the group to control behaviour by influencing adherence to rules, control of group structure, and individual interactions. Consensual validation seems to be important to people.
- (3) **INDUCES AFFECTIVE STATES:** The capacity of the group to induce powerful emotional expressions such as those of pain, anger, and profound sadness.

- (4) **SOCIAL COMPARISON:** The group provides a context for individuals to compare their attitudes and feelings, which facilitates review and revision of individual identities, suggesting new possibilities for feeling, perceiving, and behaving; through techniques such as modelling.

Schulman (1984) and Gitterman (1986) identify nine elements that seem to capsulize the process that operate to promote mutual aid in groups, which are;

- (1) **SHARING DATA:** Group members share facts, ideas, beliefs, and resources that they have found helpful in coping with similar problems.
- (2) **DIALECTICAL PROCESS:** The group can act as a sounding board for ideas put forth by individual members.
- (3) **ENTERING TABOO AREAS:** This involves the encouragement of members to discuss a taboo subject where necessary.
- (4) **ALL-IN-THE-SAME-BOAT PHENOMENON:** As group members realize they share feelings, doubts, experiences, etc., it promotes the healing process.
- (5) **MUTUAL SUPPORT:** Group members can provide empathic support, in direct and indirect ways, towards members who are having a difficult time.
- (6) **MUTUAL DEMAND:** In order for the change process to proceed confrontation and demand must take place in order to move the group beyond avoidance behaviours.

- (7) **INDIVIDUAL PROBLEM SOLVING:** Group members can help each other with specific problems, and in doing so, help themselves with their own variation of the problem.
- (8) **REHEARSAL:** Through role play, individuals can practice difficult tasks with support and advice from group members.
- (9) **STRENGTH IN NUMBERS:** The strength for change is often found in a unified front, where individuals often feel powerless dealing with large tasks involving institutions and agencies.

These processes, according to Shulman (1984) and Glitterman (1986), promote a sense of commonality and integration which are necessary to building a mutual support system. Anderson and Robertson (1985) summarized similar change agents in groups;

"In summary, we believe that the change agents in groups are related to the opportunities to self-disclose feelings about self and others in the group, to give and receive feedback, to conceptually validate a variety of perceptions, and to practice new behaviours - all in an atmosphere of acceptance and psychological safety." (pp.142).

While the techniques for working with groups must be flexible and adaptable to the specific situations encountered, the worker must operate within certain frameworks. The work of Garland, Jones and Kolodny (1973) related to the stages of development



in social work groups and William Schwartz (1971) regarding workers tasks has provided a frame of reference from which interventive techniques may be developed. The former have identified five stages, problems levels which groups and members pass in their course of development, which are;

- (1) Pre-affiliation - approach and avoidance.
- (2) Power and control.
- (3) Intimacy.
- (4) Differentiation.
- (5) Termination.

The five stages noted above comprise a sequential process that may be referred to as one group process. These stages frequently overlap and are never really completed for all members of the group at the same time, especially in open groups where entry and termination occur on an ongoing basis. These stages are helpful to refer to as frames or references as one identifies what is transpiring for the group or any of its individual members at any given point in time;

- (1) TUNING-IN
- (2) BEGINNINGS
- (3) TRANSITIONS

Associated closely with this are the five major tasks of the social worker also defined by Schwartz and Zalba (1971) as;

- (1) Finding, through negotiation, the common ground between the requirements of the group members and those of the system they need to negotiate.

- (2) Detecting and challenging the obstacles to work as they arise.
- (3) Contributing ideas, facts, and values from their own perspective when they think that such data may be useful to the members in dealing with the problems under consideration.
- (4) Lending their own vision and projecting their own feelings about the struggles in which group members are engaged.
- (5) Defining the requirements and limits of the situation in which the client - worker - system is set.

It is these five tasks that represent the work for the social worker with groups. How these tasks are implemented are defined and shaped by the nature of the institutional setting in which the worker is located.

### **3.4 Support Groups in Health Care**

Research indicates that supportive group intervention can be an effective method of providing family members with help in coping with the stresses of caregiving (Toseland & Rossiter, 1989). In dealing with post-traumatic stress disorder in Vietnam Veterans, Brown (1984) found that separate support groups for the veterans and their spouses were very effective. Veteran group members were able to discuss situations which they had in common and to provide one another with feedback. They were able

to share techniques, such as reality orientation, which they were able to use during periods of disorientation and nightmares. This self-help group was able to provide support and reassurance by helping members reframe their experiences and examine the potential value of these experiences (Brown, 1984).

Brown (1984) noted that the veteran's spouses benefitted dramatically from the information the group provided about their partners war experiences. The veteran's partners were better able to cope with behaviours when they understood the reasons for the problems and were able to recognize the stimuli that provoked the veteran's outbursts of anger, rage, and depressive moods, such as smells, weather conditions, and sounds. Brown (1984) states that group members sought the comfort of others who share a common experience.

Family support interventions have been implemented in a number of varied settings. Group intervention has been a primary mode of implementing family support programs (Clark & Rakowski, 1983; Gallagher, 1985; Toseland & Rossiter, 1989). In a review of family support studies, seven major themes were identified, including: information about the care receiver's condition, the emotional impact of caregiving, support systems external to the group, home care skills, interpersonal relationships, caregiver self-care, and promotion of the group as a mutual support system (Toseland & Rossiter, 1989).

A recent study examined the comparative effectiveness of individual and group interventions in supporting the family caregivers of frail elderly relatives. It was found that while participants in both intervention methods showed significant

improvement, social support issues responded best within the group intervention while psychological issues responded best to individual therapy interventions (Toseland, Rossiter, Peak, & Smith, 1990).

Greene and Monahan (1989) found significant reductions in anxiety, depression, and sense of burden among family caregivers of frail elderly persons who attended professionally guided caregiver support group program. A follow-up several months later did show a reduction in positive effects (Greene & Monahan, 1989). Another study found that peer-led groups produced the greatest improvements in informal social networks, while professionally led group members showed dramatic improvements in psychological functioning (Toseland, Rossiter, & Labrecque, 1989).

Studies of social support have looked at health, general well-being, and its effects as a buffer during stressful times. The availability and receipt of emotional support are significant predictors of well-being (Isreal & Antoinucci, 1987). In a review of the literature examining the role of social support in pregnancy, childbirth, job loss, illness, and bereavement, the general findings showed improved reactions in patients, and their recovery from illness to be associated with social support (Cobb, 1976). Social support has also been shown to be associated with less depression in situations of loss, reduced general complaints, dampening of the effects of illness, positive health and morale effects, as well as a protective factor during times of stress (Gottlieb, 1986; 1987; 1988). In assessing the effectiveness of education and family support group programs, participants are usually asked to rate the helpfulness of the group and of the separate parts of the intervention. In a study where participants were asked to rate the

helpfulness of 17 aspects of the group intervention using a five point Likert Scale, the overall mean rating of helpfulness was 4.5 out of five (Glosser & Wexler, 1985).

While the authors concluded that family members did value the groups, no attempt was made to examine the relationship between group participation and caregiver well-being in this study (Glosser & Wexler, 1985).

Greene and Monahan (1989) found that intervention reduced anxiety and depression among caregivers, especially those who rated higher on pretest values of anxiety and depression. In comparing group participants with waiting list controls, Kahan, Kemp, Staples, and Brummel-Smith (1985), found that increased knowledge of group participants (through group information) was directly related to reduced burden. This study also found decreased depression and increased knowledge of dementia among group participants as compared to waiting list controls (Greene & Monahan, 1989).

Although evaluations of family support services to caregivers and/or caregiving families are not frequently reported in the literature, overall evaluations that have been done consistently document consumer and practitioner assessments of family support group usefulness (Haley, 1989; Zarit & Toseland, 1989; Haley, Brown, & Levine, 1987). It is clear that participants of family support group interventions do receive some benefit and that for the most part, these participants find these benefits to be positive and helpful to them.

### 3.5 Summary

A great deal of information has been dealt with in this chapter. This chapter looked at types of groups, group models, group process, and support groups in health care. Groups can be formed, through some affiliation or sponsorship, or natural, spontaneous. Groups can be open or closed. In any group work it is important to define the parameters of the group.

Two types of groups were described, task groups and treatment groups. It is important to look at the characteristics of the types of groups to determine which is best suited for the purposes of the intervention. This practicum used a treatment type of group. Knowing the purposes and the characteristics of treatment groups helps in the designing of appropriate aspects (i.e. educational and socializational input), that will give greater impetus to the group intervention.

There are a number of group models, or theoretical frameworks, from which to draw a group intervention design. In this chapter three examples of group model were described, the Social Goals Model, the Remedial Model, and the Reciprocal Model. Each model has a different theoretical basis, a different focus of problem areas, and a different way of defining the group and its goals.

The Reciprocal Model was important in its focus on the development of a mutual aid system between the individual (client), and the organization or institution. This model provided the theoretical framework for the support group intervention in this practicum. The connections between Schwartz's (1971) Mediating Model and the

Reciprocal Model were identified. Schwartz's Mediating Model will be discussed more fully in Chapter four.

Group process is an important part of group work. To assist the worker in group intervention, it is important to know what makes people stay in groups, how groups actually facilitate change, and what effects the interaction of group members from the start to the end of the group sessions. Some of the characteristics that facilitate change in groups include; cohesiveness, control, the ability to induce affective states, and social comparison. All of these characteristics are supported and promoted by a supportive atmosphere and unconditional acceptance within the group.

The processes that operate to promote mutual aid in groups were identified as; sharing of data, the dialectic process, the ability to enter taboo areas, the all-in-the-same-boat phenomena, mutual support and demand, the facilitation of individual problem solving, a safe environment for rehearsal, and the feeling of strength in numbers. Finally, some stages of the group process were identified. The first set of stages which the group members pass through over the course of the group development included, pre-affiliation, power and control, intimacy, differentiation, and termination. A second set of more global stages through which the group and group members may pass at any given point of time include, tuning-in, beginnings, and transitions.

All of the aspects of group process are important to know about and understand in providing a support group intervention. Understanding the process of groups helps the worker determine where certain topics should be approached. For example, it would

be important to wait until a stage of the group process where intimacy is higher to introduce issues which may be painful or feel threatening to group members (i.e. grief and loss issues). The understanding of group process and stages facilitated the setting up of presenters and issues within the group design of this practicum.

Finally, it was important to examine the benefits of support groups in health care settings. In this chapter a number of themes of family support groups were identified including, the emotional impact of caregiving, interpersonal relationships, information about the care receiver's condition, caregiver self-care, and the promotion of the group as a mutual aid system. The benefits of social support groups in health care have been found in areas of job loss, illness, bereavement, childbirth, and pregnancy.

When a support group intervention is to be implemented in a certain setting, it is important to determine that this will be the most effective intervention. This practicum provided support group intervention to young disabled adults and their family members. In looking at the positive effects of support group interventions in a number of health care situations, it was determined that support group intervention for young disabled adult residents and their family members was the best form of intervention to meet the goals and objectives of the intervention.



## CHAPTER 4

### METHODS PROCEDURES AND ASSESS TOOLS

#### 4.1 The Mediating Model

In implementing an intervention model for groups, the needs and resources of the nursing home facility, in this case, the Tache Nursing Centre, had to be taken into account. It was also important to evaluate the purpose of the group intervention within the parameters of the institutional setting to determine which group model most suited these goals. It was decided that the Mediating Model of group intervention would be the one most suited to this group intervention as it best defined the purpose of the group interventions as outlined in Section 1.3 of this document.

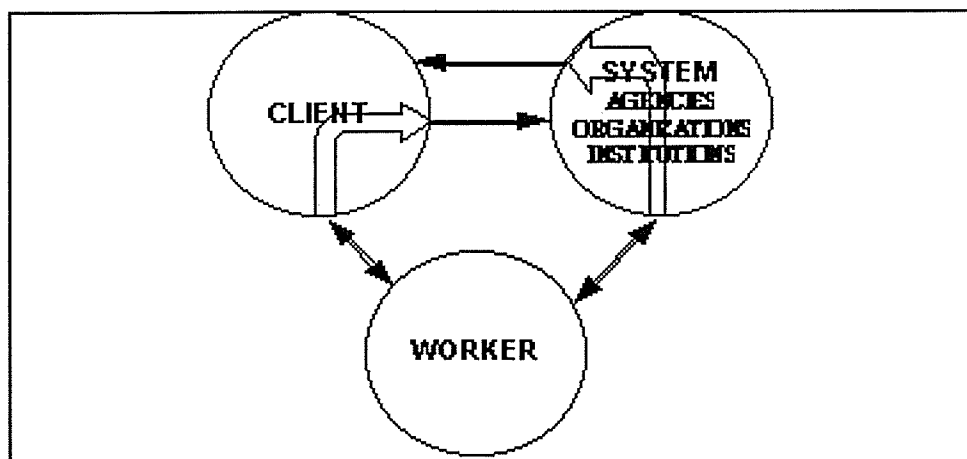
Generally, the family group purpose was to provide support and education (through the Centre's professional departments) to family members of young disabled adult residents: while the young disabled adult residents' groups proposed to enhance feelings of independence and self-determination through empowerment of the members. The Mediating Model provided the best vehicle for the groups' purposes (Schwartz & Zalba, 1971).

The major premise of Schwartz's Mediating Model is that the client (individual or group), interacts with the system (group, agency, or other), and while each may have similar goals, their means for achieving these goals may differ to the extent that it impedes the successful resolve of goals. In this sense, this model expounds a

reciprocal relationship between the client, and the system, agency, institution, or organization, where the worker acts as an unbiased mediator (Shulman, 1984).

The social worker in this Model acts as a mediator between the group members (clients) and the organization or institution to ensure that the goals of both are met with compromise and adaptation rather than conflict and misinterpretation. As both groups work on a common task, it is the worker's role to work towards fulfilment of these tasks in the best possible way for both parties, rather than acting on behalf of either groups' specific needs. In other words, the worker acts as a mediator rather than as a supporter or promoter for one side or the other (Schwartz & Zalba, 1971). Schwartz's Mediating Model is best described by this simple diagram which defines the client, the system, the worker, and how each interacts with the other (Roberts & Northen, 1976).

FIGURE 3: Schwartz's Mediating Model



The Mediating Model also promotes the idea of the group as a mutual aid system where the worker helps people to help each other. Schwartz (1961) defined the helping group as;

"The group is an enterprise in mutual aid, an alliance of individuals who need each other, in varying degrees, to work on certain common problems. The important fact is that this is a helping system in which the clients need each other as well as the worker. This need to use each other, to create not one but many helping relationships, is a vital ingredient of the group process and constitutes a common need over and above the specific tasks for which the group was formed." (pp.18).

#### **4.2 Identifying Group Members**

The focus of this intervention was on young disabled adult residents in long-term care at the Tache Nursing Centre, and families who have young disabled adult residents in long-term care on the unit or awaiting placement on the young disabled adults unit. At the time of this intervention the young disabled adult unit was six months into development at the Centre so most of the young disabled adults had already been placed on the unit. The young disabled adults unit only accepted residents who were 55 years or under, however, residents on the unit could stay there until they turned 60 years of age. The unit was designated for young disabled adult

residents 59 years and under. The intervention also incorporated all family members who had a young disabled adult on the unit or planning transfer to the unit.

The young disabled adult unit at the Tache Nursing Centre is a 36 bed unit. All of the rooms are individual occupancy to increase personal privacy of the residents. There were 16 level four care residents, 9 level three care residents, and 2 level two care residents on the unit. Higher levels of care means higher physical care requirements. There were two respite rooms on the unit which were usually held by level three or two care residents. The rest of the rooms were either still occupied by elderly residents, or waiting until construction was more complete before moving in the younger adult residents. Nineteen of the residents were male and seven of the residents were female.

Two resident groups were formed. All of the residents who were approached were asked to attend the groups on a voluntary basis, they were told they did not have to attend. Residents chosen to participate in the groups were chosen by the unit social worker. The choice to include a resident was based on the judgement that they were at a cognitive level to participate and could most benefit from the group interventions. Cognitive level of residents was informally assessed through the Centre.

Resident's group one included six residents. Nine residents were approached to participate in the group. All perspective participants were approached in person. They were asked if they would like to participate in the group. They were told that the group would be a way for them to attempt to develop skills to help them feel more in

control of their environment, more independent. All group participation was voluntary.

The reasons for not attending the group included, no time, they did not feel it was necessary for them, they already attended group meetings, or they did not feel that attending a group could change things.

Six residents agreed to attend the Young Disabled Group. Four men and two women. Four of the residents in this group were level 4 care, and two were level 3 care. The mean age of this group was 40 years, with the youngest being 25 years and the oldest included two residents who were both 51 years of age.

The second group was different from the first as the residents chosen to participate in this group were aphasiac. Aphasia can be defined as the pathological impairment or loss of the faculty of using or understanding spoken or written language. Lyon (1992) argued that disordered language and communication breeds disordered psychosocial well-being, which in turn breeds disordered language and communication. As psychosocial well-being diminishes, there is evidence that reluctance about and fear of participating in life, as well as communication, follow (Lyon, 1992).

Interactive and reactive group therapies have long been advocated for adults with aphasia and their primary caregivers as an effective means for minimizing the negative psychosocial aspects of aphasia (Kearns, 1986). For these reasons it was decided that group intervention focused on empowerment of aphasic residents would be beneficial to these residents.

Resident's group two included eight residents all of whom were unable to effectively communicate verbally. Ten aphasic young disabled adult residents in the Centre (most on the young disabled adults unit), who were felt to be at a cognitive level where they could benefit most from participation in the group, were approached in person. Again, cognitive levels were informally assessed through the centre.

The aphasic young disabled adult residents were asked if they would like to be involved in a group where they could help develop skills that would enhance their feelings of independence and control in their environment. They were told that the focus of this group would be to find ways to enhance communication skills, both verbal and non-verbal as a means to enhancing independence and control. Two of the residents approached refused to attend the groups. These residents gave no reason for their refusal to attend the groups.

Resident's group two included five males and three females. 5 residents in this group were at care level four, 2 were at care level three and 1 was at care level two. The mean age of this group was 43 years, with the youngest resident being 30 years of age, and the oldest included two residents who were both 50 years of age. The length of time that residents had been in care varied from ten months to over ten years. All residents who agreed to attend were told that there would be meetings (for each group), one day each week for ten weeks. All residents were also told that sessions would be videotaped, and verbal permission was obtained as none of the residents could write (see Appendix F).

The goals of both of these groups were the same. The major goal for these groups was to work towards empowerment of the residents. The majority of these residents had been institutionalized for many years. The policy of the new young disabled adults unit was to move from a medical model towards a social model thereby creating an atmosphere where residents can exercise more control over their daily lives.

The group intervention was intended to empower these residents by providing them with information about the unit policy, skills to help them in their interactions with staff and each other (negotiation skills), and self-care skills to enhance positive self-esteem. Empowerment for the aphasiac resident's group was achieved by enhancing present, or creating new means of communication with the residents. A speech therapist provided information and answered questions that arose for this researcher and the unit social worker during the group process with the aphasiac residents.

All family members who had a young disabled adult (59 years and under) on the unit or being moved to this unit in the Tache Nursing Centre were deemed eligible for attendance in the family groups. Contact with twenty four family members was attempted. Twenty one were actually contacted. Some were eliminated as the phone numbers were out of service, they did not answer after repeated attempts at various hours of the day and evening, or they did not want to be involved with the Centre. Of family members contacted, fifteen agreed to attend, however, one dropped out after one session, and two others attended only two sessions. Two supportive friends were also included as "family", however, neither ended up attending meetings. Both stated

that they were too busy. The family members contacted who refused the meetings, sighted a number of reasons, including; lack of time, too many other responsibilities, not wanting to be at the Centre outside of time spent visiting, and feeling that attending the groups would interfere with plans to remove their relative from the Centre.

Family members were contacted by phone and asked if they were interested in attending groups where information about the Centre would be provided through professionals within the Centre, and where they would have an opportunity to meet and talk to other families who shared similar experiences. Time was arranged for family members who wanted to meet in-person to discuss the groups. One couple and one father asked for an in-person meeting. The couple did attend the meetings, the father did not.

Family members were told that the meetings would be one day a week, two hours in length, and would run for ten weeks. Family members were also told that the sessions would be videotaped. Family members were told that an afternoon and an evening group were available and that they could attend whichever one was most suitable to them.

In all, twelve family members started and stayed with the groups until the end. Family group one was held in the afternoon and had eight members, two couples, one sibling pair, one wife, and a mother. There were two men in this group and six women. The mean age of this family group was 60.5 years, with the youngest member being 45 years of age, and the oldest being 75 years of age. One couple and



the sibling pair in this group also had elderly parents in the community to whom they provided assistance. These were the only family members in either group who had elderly parents as well as their young disabled adult relative.

Family group two was held in the evening and had four members, from four different family groups, who attended most or all of the sessions. There was one father, two mothers, and an ex-wife in this group. The mean age of this group was 64.5 years with the youngest member being 40 years of age, while the oldest member was 79 years of age. There was one male and three females in this group.

The length of time that family member's relatives had been in care in Tache Nursing Centre varied from about ten months to over ten years.

#### **4.3 Assessment Procedure**

Group interventions were assessed using pre- and post- measures from two types of evaluations, the General Well-Being Scale (refer to Appendices C), and the Sheltered Care Environment Scale (refer to Appendices D). A post intervention evaluation was also done using the Support Group Evaluation (refer to Appendices E), provided by the Alzheimer's Society of Manitoba. Some residents refused to respond to the evaluation forms. Family members completed the two scales at the beginning of the first (pre) and last (post) sessions. The Support Group Evaluation was given to family members at the last session where they either filled it out there or dropped it off later.

The facilitator went through each evaluation scale individually with each resident, following the first session (pre) and following the last session (post), as the residents could not write on their own. A social work student working for the Centre during the summer completed the Support Group Evaluation forms with each resident individually. This was done to ensure honesty, openness and confidentiality of responses.

#### **4.4 Assessment Tools**

##### **4.4.1 The General Well Being Scale**

The General Well-Being Scale has been shown to be a very good assessment of depressive mood and anxiety, so this scale was used as a pre- and post- measure for each participant in this intervention (U.S. Department of Health, Education, and Welfare, 1977). All group members completed the General Well-Being Scale (GWBS). Positive changes between pre and post test Scale measures show that group intervention enhanced positive emotions and in this way, group intervention would be shown to be supportive and empowering of group members. High scores on this scale represent low feelings of depression and anxiety, while lower scores show higher feelings of depression and anxiety.

The GWBS contains 33 items. The first 14 items each give six (6) response options. The next four (4) items provide 0-10 rating bars, and the last 15 items are

criterion-type behavioral and self-evaluation items. The GWBS provides six subscales which measure health worry, energy level, satisfying and interesting life, cheerful versus depressed mood, emotional-behavioral mood control, and relaxed versus tense-anxious. This scale also shows an overall total score. The GWBS is scored in a positive direction. Subscale correlations of the GWBS with the GWBS total scores should be ignored as each subscale forms a part of the total score.

Over a three month period the test-retest correlation for the total GWBS was .851. The mean values of 74.6 ( $s_D$  16.6) for the first test and 73.0 ( $s_D$  16.7) for the second test show high test-retest reliability of this Scale. When internal consistency coefficients of reliability were computed for the 18-item GWBS, and the 20-item Zung scale, the GWBS was found to have greater internal consistency (internal coefficient for males of .912 and .945 for females), ( $p < .01$ ) compared to the Zung scale (internal coefficient for males of .830 and .886 for females) in a comparative study (U.S. Department of Health, Education, and Welfare, 1977).

Product-moment correlations of several scales and subscales, which rate depression and/or anxiety compared with interviewer ratings of depression and/or anxiety showed the GWBS 18-item total scale ( $r = .96$ ) ( $p < .01$ ) and its two subscales of cheerful versus depressed mood (4 items) ( $r = .62$ ), and emotional-behavioral control (3 items) ( $r = .70$ ) had the second highest correlations for all subjects ( $N = 195$ ) (U.S. Department of Health, Education, and Welfare, 1977).

It is clear that the GWBS does measure depression and anxiety reliably and shows very good internal consistency. As this scale is scored in a positive direction, the

higher the score the lower the levels of depression and anxiety, while lower scores indicate higher levels of depression and anxiety. The highest possible scores on each variable are as follows; Total Score (147), Health Worry (15), Energy Level (20), Satisfying Interesting Life (10), Cheerful versus Depressed (25), Relaxed versus Tense (25), Emotional-Behavioral Control (15), Benignness of Life Situation (15), and Problem Indicator Behaviour (27). High scores are indicative of good or positive adjustment.

#### 4.4.2 The Sheltered Care Environment Scale

The Shelter Care Environmental Scale (SCES) was used to assess changes in feelings about the environment of residents in pre- and post group measures (Moos & Lemke, 1992). This Scale is a 63 question, true and false Scale which includes seven subscales that measure Cohesion, Conflict, Independence, Self-Disclosure, Organization, Resident Influence, and Physical Comfort. Differences between pre- and post- mean scores show changes in Relationship Dimensions (Cohesion and Conflict subscales), Personal Growth Dimensions (Independence and Self-Disclosure subscales), and System Maintenance and Change Dimensions (Resident Influence and Physical Comfort subscales). The highest score possible on each of the 7 variables was 9. A number of studies, although focused on the elderly in residential care, have shown this scale to be reliable and consistent (Moos & Lemke, 1984; Moos, Lemke, & David, 1987; Brenna, Moos, & Lemke, 1988; Moos & Lemke, 1989;).

Test-retest reliability (subscale and profile stability) was evaluated after an interval of nine to twelve months. The stability was found to be moderate to high for five of the seven subscale where correlations between pre- and post- scores ranged from  $r = .52$  to  $r = .93$  ( $N = 1901$ ), however, considerable variation over a years time was found in the self-disclosure and resident influence subscales. In computing profile stability for each of twelve (12) facilities tested, resulting correlations for residents ranged from  $r = .09$  to  $r = .96$  with a mean  $r = .57$  ( $N = 1,085$ ), and for staff the range was from  $r = .21$  to  $r = .85$  with a mean  $r = .60$  ( $N = 826$ ) (Moos & Lemke, 1992).

Internal consistency and split-half reliability score for residents ( $N = 1,041$ ) and staff ( $N = 792$ ) were calculated using Cronbach's alpha. Six of the seven Sheltered Care Environment Scale's (SCES) subscales showed acceptable to high internal consistency as can be seen in Table 1 (refer to Table 1).

The residence influence subscale showed only moderate consistency and the authors suggested that two related issues are being tapped by this dimension. One issue is how strict the staff are in enforcing regulations ("Would a resident be asked to leave if he or she broke a rule?") and the other is whether the facility is open to change in response to resident's input ("Do residents have any say in making the rules?") (Moos & Lempki, 1992). Moos and Lempke (1992) stated that in practice both issues appear to be only loosely related, although both issues concern residents' power in the facility. Percentage scores to a standard score conversion table based on residents value scores can be seen in Appendices F (Refer to Appendices F).

#### 4.4.3 The Support Group Evaluation

All group members completed a Support Group Evaluation during the final group meeting. This Evaluation assessed general consumer satisfaction with the intervention. The Support Group Evaluation includes twelve (12) items. Each item offers a variety of possible choices for responses. Items 7, 9, 10, and 11 provide opportunities for respondents to comment on different aspects of the group experience (i.e. Why you did or did not feel you contributed to the group, what did you like best and least about the group, and "How would you improve this support group?"). The questions on the Evaluation were very straightforward and it provided a good measure of consumer satisfaction based on actual responses.

Selected individuals were contacted following the final group meeting. These individuals were asked to expand on the Support Group Evaluation, and to provide comments and suggestions about the group. The Support Group Evaluation has been obtained from the Alzheimer Society of Manitoba (refer to Appendices E). Some alterations were made to adapt this evaluation to non-exclusive disease and/or condition statements instead of Alzheimer's Disease specific statements. Changes have been made with the permission of the Alzheimer's Society of Manitoba (refer to Appendix B).

Table 1 Internal Consistency and Split-Half Reliability on All Variables of SCES For Resident (N = 1,085) and Staff (N = 826)				
Subscale	Internal Consistency		Split-Half Reliability	
	Residents	Staff	Residents	Staff
Cohesion	.65	.73	.86	.67
Conflict	.76	.76	.80	.78
Independence	.60	.69	.80	.65
Self-Disclosure	.59	.68	.66	.59
Organization	.66	.74	.82	.69
Resident Influence	.44	.56	.69	.67
Physical Comfort	.76	.79	.90	.83

(Moos & Lempki, 1992)

#### 4.5 Summary

This chapter has presented the Schwartz's (1971) Mediating Model which provided the framework for the group intervention in this practicum. This Model was chosen because of its focus on meeting the needs of both the client and the organization through a process of negotiation rather than conflict, in which the worker acts as a mediator. The main purpose of this Model is to establish the group as a mutual aid system. The evolution of a mutual aid system would promote social support and help ensure the development of an ongoing support group, especially for the family group members.

The process of identifying and recruiting group members for the residents' groups and the family groups was outlined. Characteristics of the groups including, age,

gender, care levels, and size were presented. The procedure for using the measures for this intervention was outlined and the measuring tools were discussed.

The General well-Being Scale (GWBS) was chosen to measure changes in feelings of anxiety and depression within group members. This Scale is a reliable and consistent measure for feelings of depression and anxiety. The GWB Scale was chosen in the belief that support and empowerment would decrease feelings of depression and anxiety in respondents.

The Sheltered Care Environment Scale (SCES) measured respondent's impressions of different variables within the facility, including; cohesion conflict, independence, self-disclosure, organization, resident influence, and physical comfort. This scale showed good internal consistency and test-retest reliability. The SCES was used to determine if group intervention (i.e. information) changed respondent's impressions or assessments of the facility, positively or negatively. It was believed that information and a greater sense of involvement and/or independence would change respondent's impressions of the facility, or allow them to respond more honestly without fear of retribution.

Finally, it was important to evaluate group member's ratings of their group experiences. Support group evaluation provides valuable insight into the effectiveness of the group experience as a positive, informative, and supportive intervention. Information from the Support Group Evaluation was used to evaluate the successfulness of the intervention in reaching its goals of empowerment of residents, and providing information and support, in a positive and relevant manner to all group



members. Intervention evaluation tools provide a great deal of important and interesting information about the intervention.

## CHAPTER 5

### THE INTERVENTION

#### 5.1 Defining Empowerment

At this point it is important to define the concept of empowerment, and the reason for using it within this intervention. The concept of empowerment has been incorporated into the philosophy of the newly established young disabled adult unit at the Tache Nursing Centre. Part of the process for change included empowerment workshops for all the unit staff. The other part was to incorporate the empowerment philosophy into the resident group interventions. It was hoped that this philosophy would be developed throughout the Centre, in time.

"The empowerment process is an attempt at reform, to protect the dignity and self-worth of residents obliged to adapt to a new living environment within an institution. The object of empowerment is a redistribution of power among all groups in the facility. It is a process that seeks to invest not only residents and their families, but also staff with greater decision-making power." (pp. 1) (Manitoba Health Organizations, Inc., 1990).

Empowerment for residents would involve changing the hierarchical process of day-to-day interactions between the staff and the residents by encouraging residents to make their own decisions, good or bad, and encouraging the staff to respect resident decisions (where they are not a serious health concern), whether they agree with the decision or not. This process involves "deinstitutionalizing" the thinking and behaviour patterns of both staff and residents.

### 5.2 Group Procedure and Process

Supervision of the group work was provided by the Director of Social Work of the Tache Nursing Centre. All group sessions were video taped and the video tapes were viewed for supervision on a weekly basis. Feedback on the sessions was provided by the Director of Social Work during viewing. Only the Aphasic Group was co-facilitated by the unit social worker. All other groups were facilitated by this student.

All group sessions began with group members introducing themselves to each other (through facilitator if necessary) and a short review of the last session to provide opportunity for questions and comments. Resident's sessions ran for one hour and family sessions for two hours. Confidentiality issues were discussed in the first session of each group and intermittently throughout the sessions. Group sessions were held in a variety of rooms throughout the Tache Nursing Centre (i.e. classroom,

conference room, unit multi-purpose room, and unit common room), but all sessions were held in the Centre.

### 5.3 The Resident's Groups

Each of the resident groups was different in the way they acted, interacted, and reacted to the group experience. Both of these groups were extremely challenging. The fifth session for both of these groups was cancelled as none of the members wanted to come. There had been a death of a short-term resident on the young disabled adult unit where the majority of group members, from both groups, resided. When this was mentioned to staff, they did not feel it was significant. As death is a common feature in the normal functioning of a nursing care facility, staff did not see that it had an impact on this particular unit. Residents refused to talk about the incident and denied that it had any bearing on the cancelled meeting, however, there were no other incidents like this and the death was very close to the days of both of the group meetings. To an outsider, the behaviour of the residents that week showed a significant change from the norm.

#### 5.3.1 Young Disabled Group

Resident's group one ran for nine sessions. One scheduled session had to be cancelled and residents in this group became too busy to make this session up at the

end of the sessions due to an increase of summer activities with family and in the Centre.

In session one the purpose of the group was reviewed and residents were asked what kinds of things they felt they could control now and what kinds of things they would like to see changed so that they could feel more in control of their lives. Several suggestions were put forth at this session, including; having the staff take time to talk and to listen, more age appropriate activities (ie. shuffleboard, outings, and movies). The next few sessions seemed to involve much of the same things as the first session. Although residents began to interact together, this group still required a great deal of motivating for participation. By going to residents one by one for ideas or responses to ideas presented, the facilitator was able to generate some discussion, but this petered out quickly. The Director of Pharmacy for the Tache Nursing Centre attended the next meeting. Each resident asked for an individual follow-up with the pharmacist.

At this point it appeared that this group was going nowhere. As every time they had ideas they either said they could do nothing, rejecting all suggestions, or return the next week stating that the issue really was not a problem for them. After discussions with the Director of Social Work for the Centre, it was decided that perhaps this group required a more directive approach. It was felt that perhaps the cognitive skills of the group members made it difficult for them to follow through on their ideas or plans. The group facilitator took a more directive approach for the rest of this groups sessions.

A speech therapist from outside of the Centre attended the next meeting, describing what he does to improve or maintain verbal communication skills. The last two sessions were spent reviewing and working on ending the groups. By the last session, these group members did not want the meetings to end. They became more vocal in expressing their ideas of what they could change and how they planned to do this, but as individuals, not as a group.

This group appeared to follow the pattern of pre-affiliation, with approach-avoidance characteristics, into a stage of some power and control issues, however minimal, through to intimacy, and differentiation and termination, which seemed to be combined in the last session. This group only ran for nine sessions because of an unanticipated cancelation of one meeting.

### 5.3.2 Aphasic Group

As one resident in resident's group two was visually impaired, all sessions began with an introduction of residents, by name (this was done by the facilitator), and all who could respond, did. The location of each member, in proximity to the visually impaired resident, was also identified by the facilitator. All of the sessions were co-facilitated by the unit social worker. This was done to ensure that communication opportunities were maximized in this group.

The first two sessions with this group were spent in finding out what residents were able to do to communicate and how their current communication skills could be

enhanced. Some of the suggestions made by the Speech Therapist could not be used due to the severity of physical disability of most of this group's members.

By the third session it had become clear to the facilitator and co-facilitator that these individuals did not have trouble communicating, but others had trouble listening. For the rest of the sessions, part of the time was spent figuring out ways that individuals could make people stop and listen to them, including some assertiveness skills.

Session four was attended by the pharmacist. The pharmacist again agreed to follow-up with individual consultations with residents who requested them. The occupational therapist (OT) and an OT student, working in this department for the summer, both attended this meeting as well. The OT Department is a part of the Centre's facilities. Exchanges were animated with high interaction between the residents and between residents and guests.

During the next session residents brought the aides that they use for communicating. The OT student also attended this meeting. For example, one resident brought his Bliss Board which is a system of lights that can be moved with a chin button to particular symbols on the Board that represent words, or activities. Another resident brought a letter page with large letters and pictures of specific activities (ie. hair combing), that he could use to point out things he wanted.

Over the next two sessions residents showed an interest in finding out more about each others illness or injury. The speech therapist (ST) attended the eighth session. Residents responded to questions from the ST, some residents "answered" for others.

After his initial presentation and questions, the speech therapist (ST) spent individual time with each group member. One resident had to be removed from this session due to inappropriate behaviour, however, this did not seem to disrupt the session in any way.

The ninth session was spent going over some mouth and sound exercises recommended by the ST and preparing for the last session. The residents spent time practising the skills that had been worked on throughout the sessions. The tenth session was set up as a small party with refreshments and dainties provided by the Centre.

This group followed the pattern of group stages with early sessions showing clear pre-affiliation characteristics with little or no interaction between group members. The control and power stage was very apparent as each group member pushed to be heard over other members. From the third session on, group members frequently had to be reminded to wait for others to finish. By the last four sessions they were more respectful of each others time to communicate. It was very important for the facilitator and the co-facilitator to ensure that each group member had an opportunity to be heard and as residents became more assured of this, they allowed each other time to communicate. There was a great deal of intimacy in this group, and members attended to each other and their needs regularly. It is hard to determine whether any differentiation took place among the group members as communication and interacting levels remained high throughout the sessions. Termination for this group was difficult as they had found a forum where they were listened to with respect.



## 5.4 The Family Groups

There were twelve family members who attended meetings, eight in the afternoon meetings, and four in the evening meetings. The mean age of all family members was 62 years. The afternoon group will be presented first as Afternoon Family Group, followed by the evening group, Evening Family Group. Two meetings combined both groups. These sessions will be presented separately.

### 5.4.1 Afternoon Family Group

Session one started with the facilitator reviewing the reasons for the groups, and the goals of the groups, to provide information and support. Each member introduced themselves and told a little about their relative and their experiences. This was a very emotional experience in this group. Connections were made between family members immediately, based on the similarity of their experiences.

The head nurse (HN) from the young disabled adults unit attended session two and spoke about the mission and philosophy, and the physical care dynamics of the unit. The Head Nurse reinforced the open-door, open access policy of all areas of the Centre, and talked about the chain of command for problems and/or concerns family members had about their relatives care. Session three was spent expanding on individual experiences.

The pharmacist attended session four. Group members asked numerous questions and all asked for private consultations with the pharmacist. The young disabled adult unit's pastoral care worker (PC) attended the session five. Session six was one of the two combined sessions and will be discussed later.

Session seven was dominated by talk about how others (family and friends) reacted to family members situations. Members talked about lack of support and the need to educate the public. The common theme of messages, "you're so strong", "how can you throw your life away like that", and "I guess they're not a real person any more", were discussed as messages that told family members not to talk about their situation, "shut-up" messages. Family members shared feelings of isolation and aloneness in their situations. Session eight was the second combined session and will be discussed later. Session nine and ten were spent reviewing the past sessions, and planning for follow-up.

This group seemed to skip the pre-affiliation, and power and control stages, and go right into the intimacy stage. This did not seem to change for even at the last meeting they were planning independent, personal contacts, and the renewal of the family support group in September. This group was very powerful and highlighted with profound sharing on the part of all members. Termination did not seem to be there, only a short hiatus until the September meetings.

#### 5.4.2 Evening Family Group

The first session began with a brief review of the group's purpose, information and shared support. Although some members did become emotional, this group was generally reserved and withdrawn from each other. The HN attended the second session. Group members asked a lot of questions. The HN again reiterated the open-door policy of the staff and departments of the Centre.

During session three and four, these group members began talking about the similarity of their experiences in the reaction of other friends and family. They spent time discussing "shut-up" messages (as referred to in Afternoon Family Group) that they had all experienced. Session five was attended by the Pharmacist. The group members all had a number of questions and all asked for individual interviews with the Pharmacist. Session six was a combined session and will be discussed later. Session seven was attended by the PC worker. Session eight was a combined session that will be discussed later.

The ninth session was attended by only two members, due to work schedules of two of the members. Time was spent reviewing the past sessions and planning for the last session. All four members attended the last session.

This group followed the pattern of pre-affiliation, with minimal to no between member contact in the first few sessions. There did not appear to be a stage of power and control, and intimacy was slow and reserved within this group. This group

seemed to keep their differentiation throughout the sessions and the termination phase was business-like, although friendly.

#### 5.4.3 The Combined Family Groups

Session six and session eight combined both family groups. These sessions were held in the evening as the family members attending afternoon sessions were more flexible. Session six was attended by the speech therapist (from outside the Centre) and the physiotherapist (PT) and the occupational therapist (OT). All four of the evening group and four members of the afternoon group attended. All members were very interested in the presentations and asked lots of questions.

The unit doctor attended the eighth session. All four of the evening group members were there and four members of the afternoon group (two members of the afternoon group were on vacation) attended this session. Members were very interested in the presentation and again asked a number of questions.

#### 5.5 Summary of Group Process

Each of the four groups was different in many ways, and yet there were also a number of similarities. Family members were able to focus on experiential issues that they shared. Residents were very interested in learning about each other, "getting to

know one another". All group members were highly motivated to accept and enhance the feeling of community that allowed all of them to feel that they had some control over their environment.

A number of staff and other residents reported changes that were occurring over the course of the group sessions. Around the sixth and seventh family meetings, staff began approaching the facilitator and stating that family members were approaching them more frequently, to ask questions or make requests. Staff stated that this made them feel that they were more approachable, as they had felt that something they were doing kept family members from approaching them.

Family members were spending more time on the unit, and within a common area instead of in resident's rooms. Residents on the unit were becoming more vocal, and there was an increase in resident interaction. Residents, family members, and staff all reported feeling a stronger sense of community and connectedness.

## CHAPTER 6

### GROUP COMPOSITION PRESENTATION AND EVALUATION

In this chapter, a brief biography of each member of each group will be presented. Results of individual and group measures on the GWB Scale and the SCES will be presented for each group. The data collected from the Support Group Evaluation will also be discussed. As the data from the support group evaluation is confidential, the data has only been separated into family groups' data and resident's groups' data. Because of this, the support group evaluation data will be presented separately. Resident's responses on the Support Group Evaluation will follow the two resident's groups' data and family responses on these evaluations will follow the two family groups' data.

#### **6.1 Young Disabled Group**

Six residents attended the group sessions for resident's group one. Two of these resident's refused to do any of the evaluation forms so the data for this group was based on four residents. Resident A was a man in his late 30's who had Multiple Sclerosis (MS). He had been in the Centre for several years and was waiting for placement on the young disabled adults unit. Resident A had been a career blue collar worker prior to onset of the MS. The physical and cognitive deterioration caused by the MS had been very rapid in this case. Resident A had little emotional affect. He

had no community involvement and was only involved in Centre activities when the staff initiated his involvement. His wife and two pre-teenaged daughters visited him regularly. Resident A's parents and siblings seldom visit him. Resident A had been assessed as needing level four care.

Resident B was a woman in her early 40's who had MS. She had been a professional and was working on her post-graduate education when she was struck with MS. Resident B had moved into the Centre from another long-term care facility, a few years prior to this intervention. Resident B's parents visited her frequently and were very involved with her. Resident B had one sister who lived in another province. Resident B had no community involvement and only limited involvement on the unit. Resident B had been assessed as needing level four care.

Resident C was a 25 year old male who had suffered a severe head injury in the early 1990s. Resident C had been developing a blue collar career at the time of his injury. Resident C's parents visit him regularly and take him home most weekends. Resident C had been in the Centre, on the young disabled adults' unit for one year. Resident C had some community involvement and was involved on the unit. Resident C had been assessed as needing level three care.

Resident D was a man in his early 50s who had been born with Cerebral Palsy. Resident D had moved into the young disabled adult's unit eight months prior to the intervention, shortly after the death of his mother. Resident D's father, sister and aunts visited him regularly. Resident D was very involved in the activities and

programs of the Centre and of the community. Resident D was assessed as needing level three care.

Resident N was a man in his early 50s with MS. Resident N had been a professional in the social services field. Resident N had MS from early adulthood. Resident N had moved to the Centre from home, several months prior to the intervention and was moved to the young disabled adults' unit a short time before the end of the intervention. Resident N had a wife and two teenaged daughters, who visited regularly. Resident N had minimum contact with his parents and siblings. He had limited community involvement and was minimally involved with Centre or unit activities. Resident N was assessed as level four care. Resident N attended only five of the sessions as he became very tired in the early evenings and was often in bed when the sessions were held. Resident N refused to complete any of the surveys before or after the sessions.

Resident M was a woman in her early 30s who had been in the Centre for several years. Resident M was on the young disabled adults' unit. Resident M had been married when she suffered a closed head trauma (aneurism) Resident M did not like to be involved in community or unit activities and frequently suffered from disabling headaches that forced her to stay alone in her room. Resident M felt unable to attend the session although she was asked regularly. Resident M finally attended the last four sessions. Resident M had a mother and an aunt who visited regularly. Resident M is assessed as level four care. Resident M refused to complete surveys before or after the intervention.



The individual scores on the General Well-Being Scale (GWBS) for this group showed very little change (refer to Table 2). Resident A showed a positive change of only one point between pre- and post- measure Total Scores, however, on the

Name		A	B	C	D
Total	Pre	134	112	91	138
	Post	135	117	87	126
Health Concern Worry	Pre	15	15	15	15
	Post	15	15	12	4
Energy Level	Pre	20	10	2	15
	Post	17	11	10	20
Satisfying Interesting	Pre	8	4	0	9
	Post	8	5	0	4
Cheerful vs Depressed	Pre	24	11	12	24
	Post	22	13	10	22
Relaxed vs Tense	Pre	10	21	12	23
	Post	24	21	12	23
Emotional Behavioral Control	Pre	15	11	12	14
	Post	10	14	9	14
Benignness of Life Situation	Pre	15	13	11	11
	Post	13	11	8	13
Problem Indicator Behaviour	Pre	27	27	27	27
	Post	26	27	26	26

Emotional-Behavioral Control variable, the post- score (post = 10) did show a negative change from the pre- score (pre = 15). In other words, Resident A's feelings of control over emotions and behaviour went down between pre- and post- testing.

Resident A may have been more able to express his true affect following intervention.

Resident B showed a positive change between pre- (pre= 112) and post- (post= 117) Total Scores. This represented a reduction in depression and anxiety over the course of the intervention. The major change occurred in the Emotional-Behavioral Control variable where the pre- score (pre= 11) was three points lower than the post- score (post= 14). This showed that Resident B felt a greater sense of Emotional-Behaviour Control by the end of the intervention.

Resident C showed a decrease between pre- scores (pre= 91) and post- scores (post= 87) on the Total Scores of the GWBS. The greatest changes were in the Emotional-Behavioral Control variable (pre= 12, post= 9) and the Benignness of Life Situation variable (pre= 11, post= 8), however, a positive change in the Energy Level variable (pre= 2, post= 10) was also evident. Resident C had become more active in his rehabilitation, and over the course of the intervention, he was able to be more realistic about his situation which could account for the reductions in the other two variables.

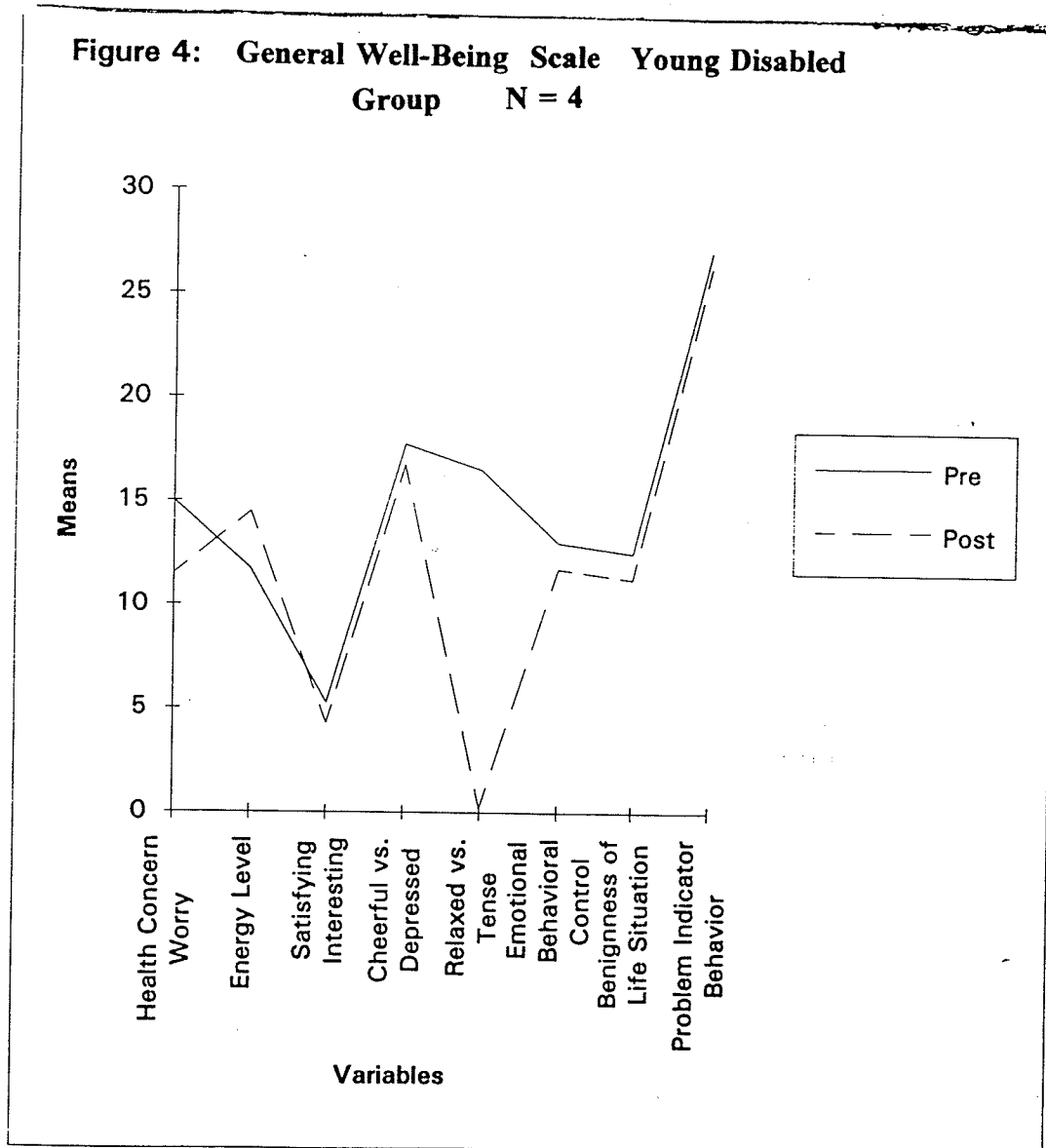
Resident D showed the greatest changes on the GWBS compared to other group members. There was a reduction in positive affect (pre= 138, post= 126) on the Total Scores variable. The greatest reductions were found in the Health Concern Worry variable (pre= 15, post= 4), and the Satisfying Interesting Life variable (pre= 9, post=

4). There was a positive change in the Energy Level variable (pre= 15, post= 20). Resident D did have some health concerns over the course of the intervention. However, considering this resident's involvement in the Centre, the reduction in the Satisfying Interesting Life variable is very interesting. Resident D frequently argued that nothing could be changed at the Centre, however, he did make some significant positive changes in his independence over the course of the intervention (these will be discussed later). Perhaps with his growing ability to change his own circumstances he became more dissatisfied with the resources available at the Centre.

The mean scores on the variable in the GWBS for Young Disabled Group show little variation between pre- and post- scores on group means (refer to Figure 4).

There was a negative change in pre and post in Group Means on Health Concern Worry (pre= 15, post= 11.50) which represents an increase in negative affect on this variable. Positive changes between pre- and post- group means were seen in the Energy Level variable (pre= 11.75, post= 14.50) and the Relaxed versus Tense variable (pre= 16.50, post= 20). This indicated that residents were feeling more energy and more relaxed in their environment, while the health concerns of Resident D clearly impacted on the group means on this variable. These results also showed a reduction in overall feelings of tension for this group. This group reported feeling more comfortable and showed stronger feelings of community within the unit following the group interventions.

The individual scores on the Sheltered Care Environment Scale (SCES) can be seen in Table 3 (refer to Table 3). Residents B and D showed no significant changes on any of the variables between pre and post scores on the SCES. Resident A



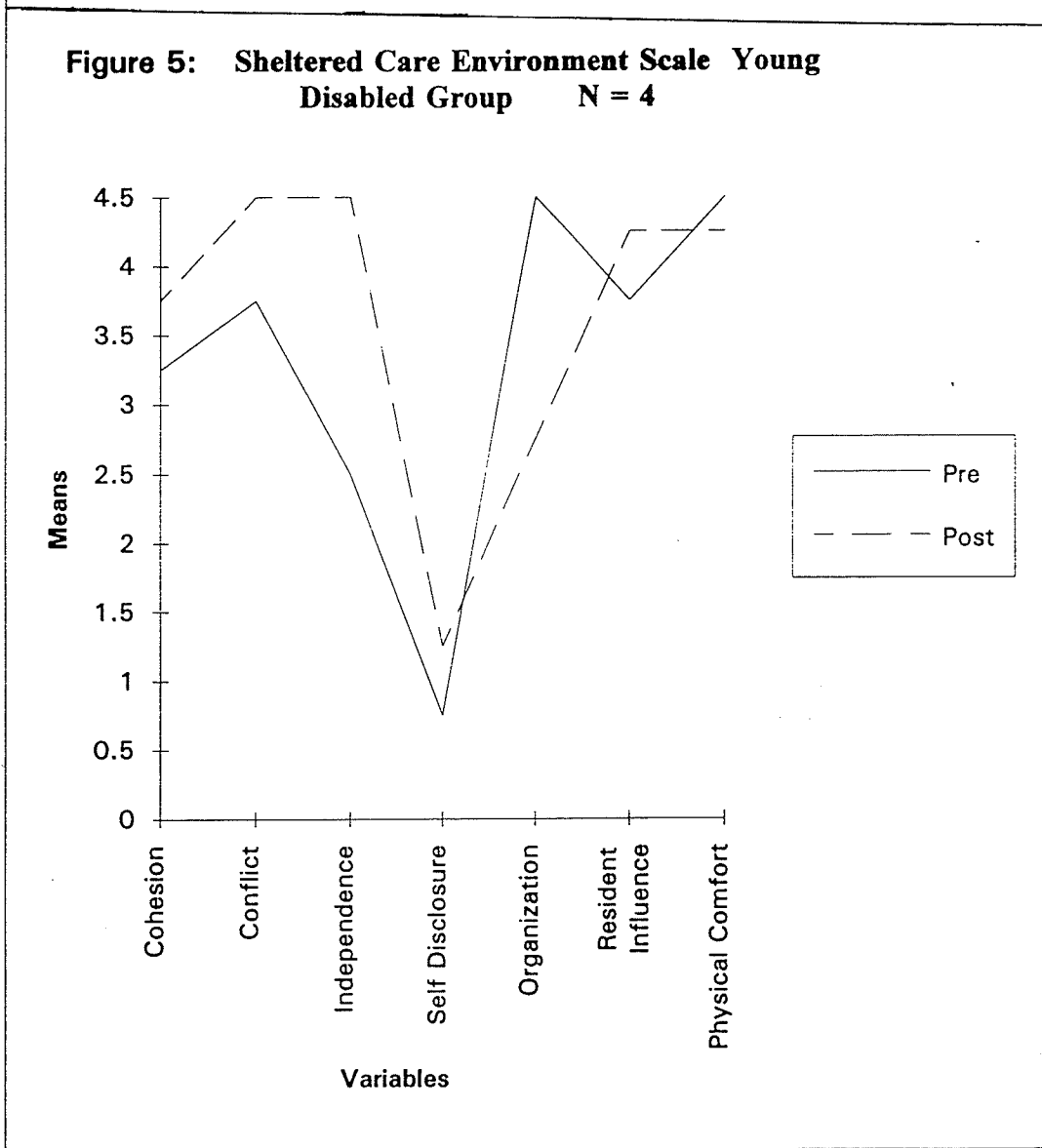
showed increases in perceived Conflict (pre= 0, post= 5) and Resident Influence (pre= 3, post= 6), and a decrease in perceived Organization (pre= 7, post= 2). Resident A may have been attending more to his environment and through the group experience, may have been able to express himself more openly on the Conflict variable. He did feel that there was an increase in Resident Influence. The

information and interacting within the groups did benefit this resident. Resident C showed a dramatic increase in his perceptions of Independence (pre= 2, post= 6). As he became more involved in his own rehabilitation, he felt more positive about his abilities to increase his own independence in the Centre.

Name		A	B	C	D
Cohesion	Pre	4	3	3	5
	Post	2	3	4	4
Conflict	Pre	0	3	7	5
	Post	5	4	6	3
Independence	Pre	1	1	2	6
	Post	3	2	6	7
Self Disclosure	Pre	0	1	1	1
	Post	2	0	1	2
Organization	Pre	7	4	4	3
	Post	2	4	3	2
Resident Influence	Pre	3	4	2	6
	Post	6	4	1	6
Physical Comfort	Pre	8	4	4	2
	Post	6	5	5	1

The mean scores on the variable of the SCES showed only two interesting variations (refer to Figure 5). The perception of Independence (pre= 2.50, post= 4.50) increased (difference of the means score = -2, df=3) while the perception of Organization (pre= 4.50, post= 2.75) decreased. These variations can be attributed to

changes in perceptions of Residents A and C on these variables. The higher the score on the variable in this scale, the greater the perception of this variable being present in the environment. In looking at these score it would appear that the



residents in Resident Group One did feel a significant increase in feelings of independence related to their environment.

## 6.2 Aphasic Group

The Aphasic Group included only aphasiac residents. There were eight residents in this group and only one refused to complete pre and post surveys. Resident K was a woman in her mid 40s, and a stroke survivor. Over the course of the group sessions, Resident K frequently approached the facilitator with concerns about different residents on the floor. Resident K had been in the Centre for many years. When the unit she was on was changed to a young disabled adults unit she was initially reluctant to stay, however this changed as the unit developed. Resident K had sisters and adult children but there was little contact. Resident K had not seen her adult children for three years. Resident K could verbally agree and disagree, and she was dyslexic as a result of her stroke. She had little community involvement, but was very active in the Centre and on unit. Resident K was assessed as needing level two care.

Resident E was a man in his early 40s who had Cerebral Palsy. Resident E had been prepared by his parents to move into the Centre for many years. Resident E's parents were very involved in the Centre, and visited frequently. His sister also visited frequently. Resident E had been in the Centre for several years. He was on the young disabled adults' unit at the time of the intervention. Resident E attended a program outside of the Centre every day where he used a Bliss Board to communicate as he was extremely difficult to understand when he tried to speak. He was involved with activities in the Centre and on the unit. Resident E was assessed as needing a level four care.

Resident F was a woman in her mid 40s who sustained severe head injuries from an auto accident in early adulthood. Resident F had been in a coma for some time. Resident F was unable to speak and communicated by lifting her arm up for agreement and down for disagreement. Resident F had been developing an administrative career at the time of her accident. Resident F had been in the Centre for several years and was awaiting placement on the young disabled adult's unit at the time of the intervention. Resident F's mother visits regularly and she has a sister who lives outside of the country. She had no community involvement and was only involved in staff initiated activities in the Centre. Resident F was assessed as needing a level four care.

Resident G was a man in his early 50s who suffered severe whiplash and brain damage in an auto accident at college as a young adult. Resident G's speech was very garbled and difficult to understand. Resident G had been in the Centre for many years and was on the young disabled adult's unit at the time of the intervention. Resident G read daily newspapers from cover to cover. Resident G had an elderly mother who was ill and saw him only twice a year. He had little community involvement, but was involved in a number of Centre activities. Resident G was assessed as needing a care level four.

Resident H was a man in his early 30s who had sustained brain stem damage in a skiing accident in the early 1990s. Resident H was attending two courses for his pre-masters at the time of the intervention. Resident H had been a professional prior to his accident. He was bilingual. Resident H was visually impaired and could speak



clearly, but only with great difficulty. Resident H needed a great deal of time to communicate verbally. Resident H had been in the Centre for a few years, and was undecided about moving from his present unit to the young disabled adult's unit. Resident H's father visited him regularly, and numerous other relatives and friends who also visited regularly. He was very active and involved in the Community and the Centre. Resident H was assessed as needing a level two care.

Resident I was a woman in her mid 40s who suffered from a rare degenerative disease. This resident communicated with a typing board, however, she continued to attempt to communicate verbally although she was often impossible to understand. Resident I had been at the Centre for many years and was on the young disabled adult's unit at the time of the intervention. Resident I had a friend who visited frequently and her adult children also visited somewhat regularly. Resident I had lost two brothers and one sister to the same disease. Resident I had done accountant work prior to the onset of her illness. She had minimal community involvement, but was involved in Centre and unit activities. Resident I was assessed as a level four care.

Resident J was a man in his early 30s who had suffered severe brain injury in a car accident in early adulthood. Resident J was not spontaneous and often unresponsive when directly spoken to. Resident J frequently mouthed words with no vocal volume, however, he had been heard speaking out loud. Resident J was normally unresponsive to his environment. Resident J had a brother who visited regularly, but none of his other family visited him much. He had some community

involvement and was involved in staff initiated activities in the Centre and unit.

Resident J was assessed as needing a level four care.

Resident L was a man in his early 50s who was mentally retarded and suffered from epilepsy. Resident L had been in the Centre for many years and was on the young disabled adult's unit at the time of the intervention. Resident L could not communicate verbally and he was illiterate. Resident L had been in foster homes prior to placement in the Centre and he had no family. He had no community involvement, but was involved in the Centre's activities. Resident L refused to complete any of the pre or post surveys. Resident L was assessed as needing a level three care.

For this group the changes in the individual scores on the GWBS were mostly negative as can be seen Table 4 (refer to Table 4). Resident E showed a decrease from pre- to post- Total Score measures (pre= 135, post= 93). These decreases showed in the Energy Level measures (pre= 15, post= 1), the Relaxed versus Tense variable (pre= 23, post= 13), and the Emotional-Behavioral Control variable (pre= 15, post= 9). This resident had personal issues going on during the time of the post- test that were very upsetting to him. His post test scores showed a significant increase in feelings of depression and anxiety that seem to be in keeping with the personal issues he was dealing with at the time of the post measures.

Resident G also showed a decrease between pre and post Total Scores measures (pre= 136, post= 121). The major decreases were seen in the Health Concern Worry variable (pre= 15, post= 9) and the Relaxed versus Tense variable (pre= 25, post= 8), both of which showed increases in worry over health and in tension/anxiety.

Name		E	F	G	H	I	J	K
Total	Pre	135	145	136	145	116	131	135
	Post	93	145	121	147	112	128	112
Health Concern Worry	Pre	15	15	15	15	11	15	15
	Post	11	15	9	15	15	15	15
Energy Level	Pre	15	20	15	20	14	18	19
	Post	1	20	17	20	19	15	18
Satisfying Interesting	Pre	6	10	9	9	6	6	5
	Post	5	8	7	8	3	7	4
Cheerful vs Depressed	Pre	21	24	21	24	17	18	22
	Post	17	25	23	24	16	21	13
Relaxed vs Tense	Pre	23	25	25	23	15	25	21
	Post	13	25	8	24	8	25	17
Emotional Behavioral Control	Pre	15	13	15	15	15	15	13
	Post	9	15	15	15	12	15	11
Benignness of Life Situation	Pre	13	15	9	14	13	8	13
	Post	10	15	15	14	13	6	9
Problem Indicator Behaviour	Pre	27	27	27	25	25	26	27
	Post	27	27	27	27	26	24	25

There was a positive change in the scores on the Benignness of Life Situation variable (pre= 9, post= 15). Resident G did get quite ill over the course of the intervention and he found this very distressing. The positive change on the Benignness of Life Situation variable indicates a reduction in the negative feelings about his life situation

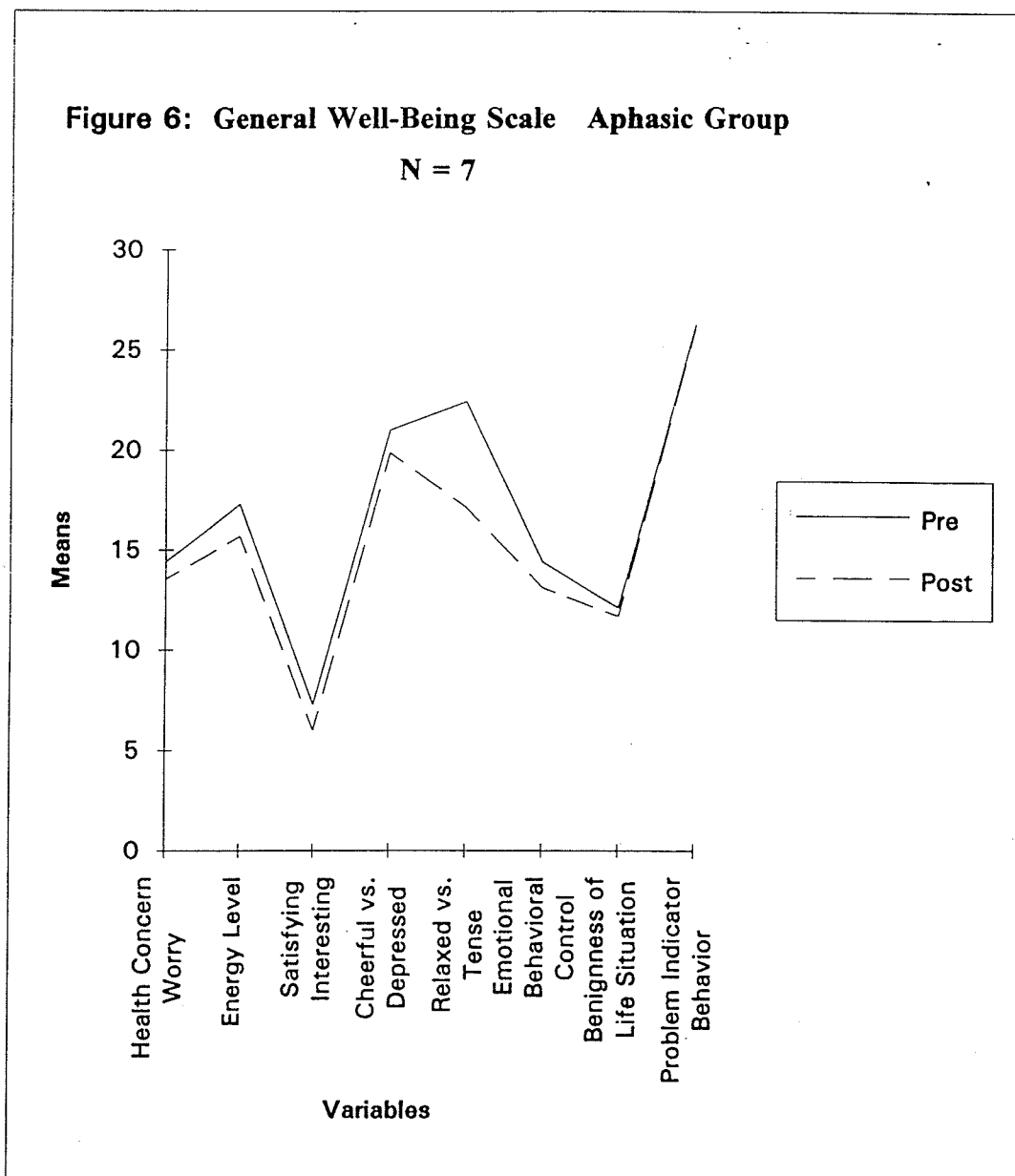
in general. It is possible that Resident G was feeling more positive and accepting of his environment following the group intervention.

Resident K also showed a significant negative change between her pre- and post-test Total Scores (pre= 135, post= 112). Resident K's greatest differences showed up on the Cheerful versus Depressed Mood variable (pre= 22, post= 13) and the Benignness of Life Situation variable (pre= 13, post= 9). Resident K was also dealing with some personal issues that would account for an increase in feelings of anxiety and depression. In this case, Resident K was actively pursuing some solutions to her personal problems. She sought out assistance, something she has seldom done in the past, in dealing with her personal issues. Perhaps she felt more able to approach staff to assist with her personal issues, rather than deal with them on her own.

The Relaxed versus Tense (anxious) variable of the General Well Being Scale, showed the only significant differences between pre- and post- mean scores (refer to Figure 6). Aphasic Group pre- test mean of pre= 22.43, post- mean of post= 17.14 (N=7), with a mean difference of the means score of 5.29. This score represents an increase in feelings of tension (anxiety). Again, this could have been a variable where residents felt more comfortable and safe about being able to express themselves more freely and openly.

The individual scores for the SCES of resident's group two can be seen in Table 5 (refer to Table 5). Resident E showed decreases in perceptions of Organization (pre= 7, post= 2), Resident Influence (pre= 7, post= 4), and Physical Comfort (pre= 6, post=

3), and an increase in perceived Conflict (pre= 1, post= 4) at the Centre. Resident F showed decreases in perceptions of Conflict (pre= 6, post= 3) and Self Disclosure (pre= 5, post= 0), and increased in perceived Resident Influence (pre= 1, post= 4). Resident J showed increases in perceptions of Independence (pre= 3, post= 7) and Physical Comfort (pre= 6, post= 9).



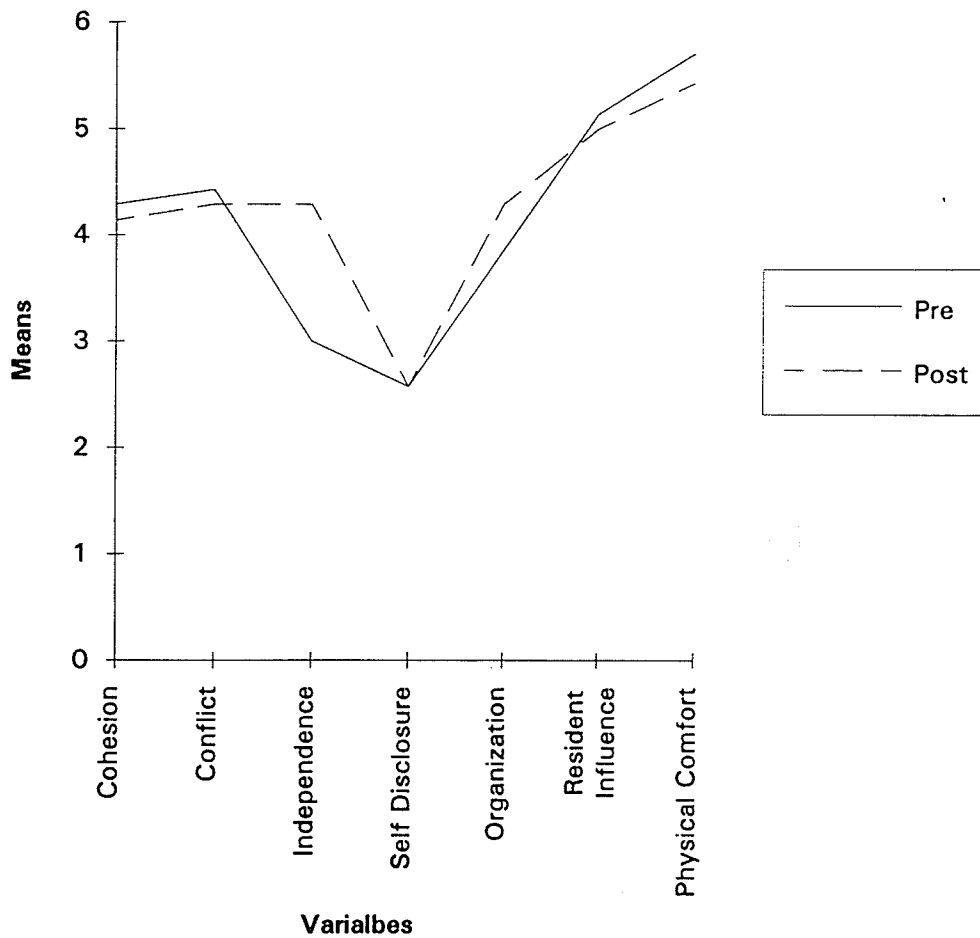
Construction was ongoing on the unit during group sessions which could account for a number of changes on the Organization and Physical Comfort Variables.

Residents appeared less reluctant to voice complaints about the Centre as group sessions proceeded. Clearly, for some residents, the group experience increased their feelings of independence and their feelings about resident's influence in the Centre.

The only real variation on the mean group scores of the SCES for the Aphasic Group was on the Independence variable (pre= 3.0, post= 4.29) (refer to Figure 7).

Name		E	F	G	H	I	J	K
Cohesion	Pre	4	5	4	5	6	4	2
	Post	2	3	5	7	4	4	4
Conflict	Pre	1	6	4	2	8	3	7
	Post	4	3	5	0	7	3	8
Independence	Pre	4	3	2	5	2	3	2
	Post	3	5	1	7	4	7	3
Self Disclosure	Pre	1	5	1	1	6	3	1
	Post	1	0	2	1	6	4	4
Organization	Pre	7	5	5	7	1	4	4
	Post	2	7	5	7	1	6	2
Resident Influence	Pre	7	1	4	7	5	7	5
	Post	4	4	3	8	4	8	4
Physical Comfort	Pre	6	6	7	8	4	6	3
	Post	3	5	5	9	4	9	3

**Figure 7: Sheltered Care Environment Scale**  
**Aphasic Group N = 7**



Most of the changes on the Independence variables were positive changes of one or two points. Only Resident E and Resident G went down one point each on this variable.

The Support Group Evaluations for the two resident's groups were very interesting. Eleven residents completed these evaluations (refer to Appendix G). These responses will be discussed and compared to family responses on the Support Group Evaluation in section 6.5.

### **6.3 Afternoon Family Group**

Eight family members attended the Afternoon Family Group. Mrs. O was a woman in her early 70s, whose daughter was awaiting placement on the young disabled adults unit. Mrs. O had one other daughter who lived outside of the country. Mrs. O was no longer married and saw little of her extended family. Mrs. O visited her daughter regularly.

Mr. P1 was a man in his mid 70s, and his wife Mrs. P2 was a woman in her late 60s. They had been very active in the Cerebral Palsy Society since its inception. They had one daughter who visited regularly. They had been very involved in the Centre for a number of years prior to their son's placement and continued their involvement following his placement. Mr. P1 and Mrs. P2 visit their son several times a week.



Mr. Q1 was in his late 60s and Mrs. Q2, his wife, was in her mid 60s. Both are retired professionals. Mr. Q1 and Mrs. Q2 had some very negative experiences with the health care system dealing with their daughter prior to her placement in the Centre. At one point they had been told to place their daughter in the long-term care facilities to die, however, this proved very difficult for Mrs. Q2 and after her daughter's begging, they ended up taking her home and caring for her on their own for several years. Mrs. Q2's elderly parents continue to live in the community and require a great deal of family support to do this. Mr. Q1 and Mrs. Q2 did not perceive other family members as supportive, however this changed over the course of the intervention.

Mrs. S and Mrs. T are sisters, both in their late 40s. Both immigrated to Canada over ten years ago. Mrs. S and Mrs. T's elderly parents still live in their country of origin where friends watch them and notify Mrs. S and Mrs. T of crisis and emergencies which they try to take care of from Canada. This was very stressful for both of them. Mrs. S was no longer married and Mrs. T was married.

Mrs. T was a woman in her mid 40s who's husband had recently moved into the Centre from home. They had prepared for his placement in long-term care for a number of years. She cares for her two teenaged daughters and works to see that family and friends continue to visit with her husband.

The individual scores on the GWBS for Afternoon Family Group show some significant individual changes (refer to Table 6).

Table 6 Individual Scores For All Variables of The General Well-Being Scale Afternoon Family Group (N = 8)									
Name		O	P1	P2	Q1	Q2	R	S	T
Total	Pre	128	136	143	144	131	95	82	105
	Post	130	147	147	115	144	93	101	147
Health Concern Worry	Pre	14	14	15	14	14	8	13	3
	Post	15	14	15	10	14	8	14	15
Energy Level	Pre	14	12	17	19	17	8	5	15
	Post	18	20	20	16	19	6	10	19
Satisfying Interesting	Pre	6	9	10	8	7	4	3	7
	Post	8	9	8	7	9	4	4	10
Cheerful vs Depressed	Pre	19	23	24	24	21	15	10	20
	Post	20	25	24	19	24	13	12	24
Relaxed vs Tense	Pre	22	22	23	23	20	13	11	16
	Post	20	24	25	18	23	14	14	25
Emotional Behavioral Control	Pre	15	15	15	15	15	9	10	13
	Post	10	15	15	11	15	10	12	15
Benignness of Life Situation	Pre	11	14	13	14	11	11	7	8
	Post	12	14	13	10	13	12	10	15
Problem Indicator Behaviour	Pre	27	27	26	27	27	27	23	23
	Post	27	26	27	24	27	27	25	27

Mrs. T's individual score on the Total Score pre test of pre= 105 and went to post= 147 in the post test. The increases occurred mostly in the Freedom from Health Concern or Worry variable (pre= 3, post= 15), the Relaxed/Tense (anxious) variable (pre= 16, post= 25), and the Benignness of Life Situation variable (pre= 8, post= 15). These results represent major reductions in feelings of anxiety and depression,

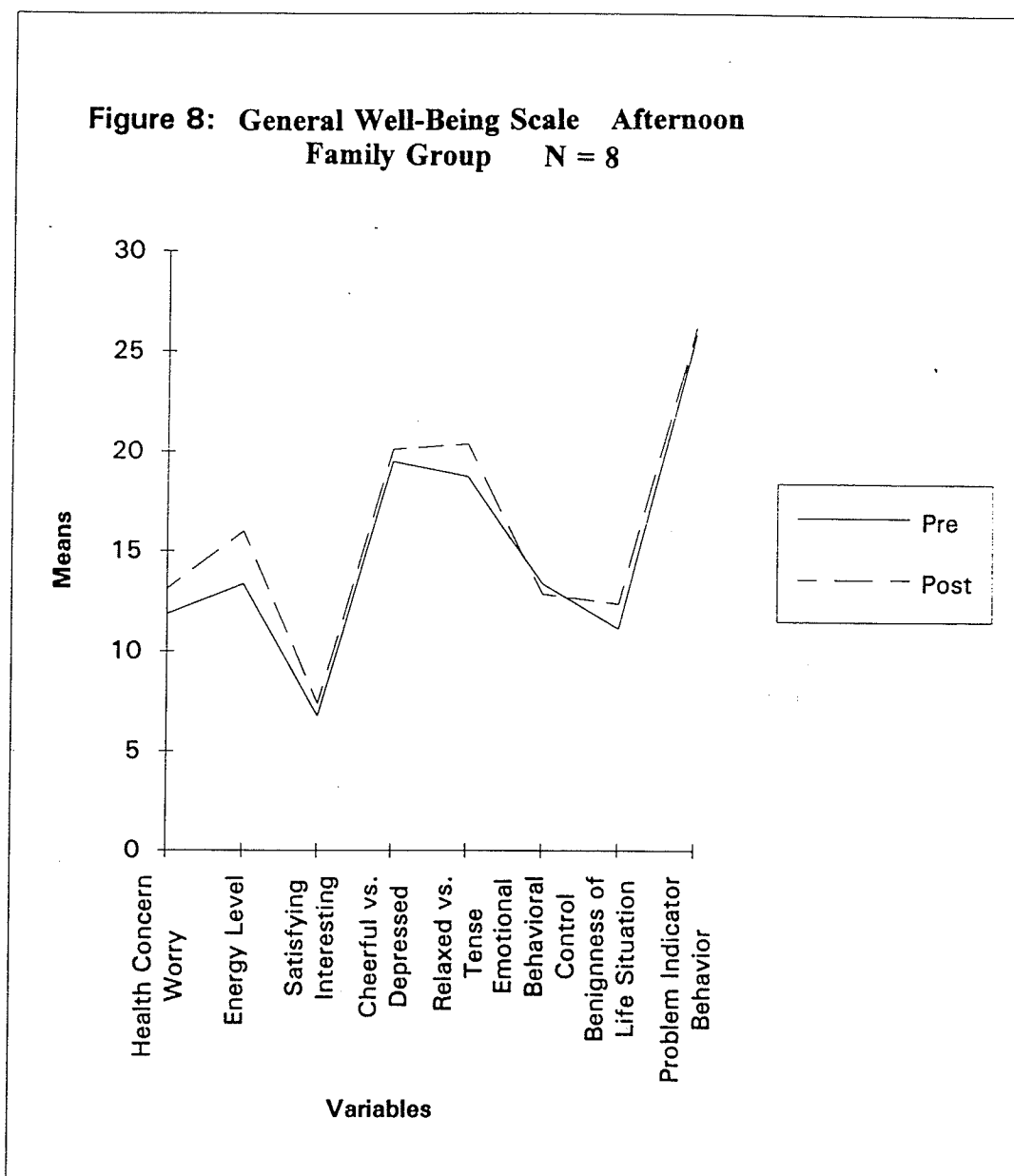
especially in the areas noted above. Mrs. T found the support and information of the group intervention very beneficial.

Mr. P1 showed a positive change on the Total Score (pre= 136, post= 147), with the greatest change on the Energy Level variable (pre= 12, post= 20). Mrs. S also showed some positive changes on the Total Score of the GWBS (pre= 82, post= 101), with the greatest change again occurring in the Energy Level Variable (pre= 5, post= 10). From conversations with family members, the facilitator found that reductions in feelings of depression and anxiety were directly related to group experiences. Family members found the information and the sharing of experiences to be very positive and this resulted in participants feeling more relaxed and positive about the Centre, and their own situations.

The most significant negative changes occurred for Mr. Q1 whose Total Score went from pre= 144 to post= 115. The variables where the greatest negative changes occurred included Health Concern worry variable (pre= 14, post= 10), the Cheerful versus Depressed variable (pre= 24, post= 19), the Relaxed versus Tense variable (pre= 23, post= 18), and the Benignness of Life Situation variable (pre= 14, post= 10). Interestingly, Mr. Q1 had been very supportive of his wife over the course of their daughter's MS. Perhaps, given the opportunity for positive outside support for his wife and an outlet for his own frustration and pain at his daughter's situation, Mr. Q1 was able to allow some of his own painful emotions to surface.

The two variables on the group mean scores of the GWBS that showed changes were the Energy Level variable (pre= 13.38, post= 16), and the Relaxed versus Tense

variable (pre= 18.75, post= 20.38) (refer to Figure 8). The changes in these variables can be directly related to changes in individual scores within this group.

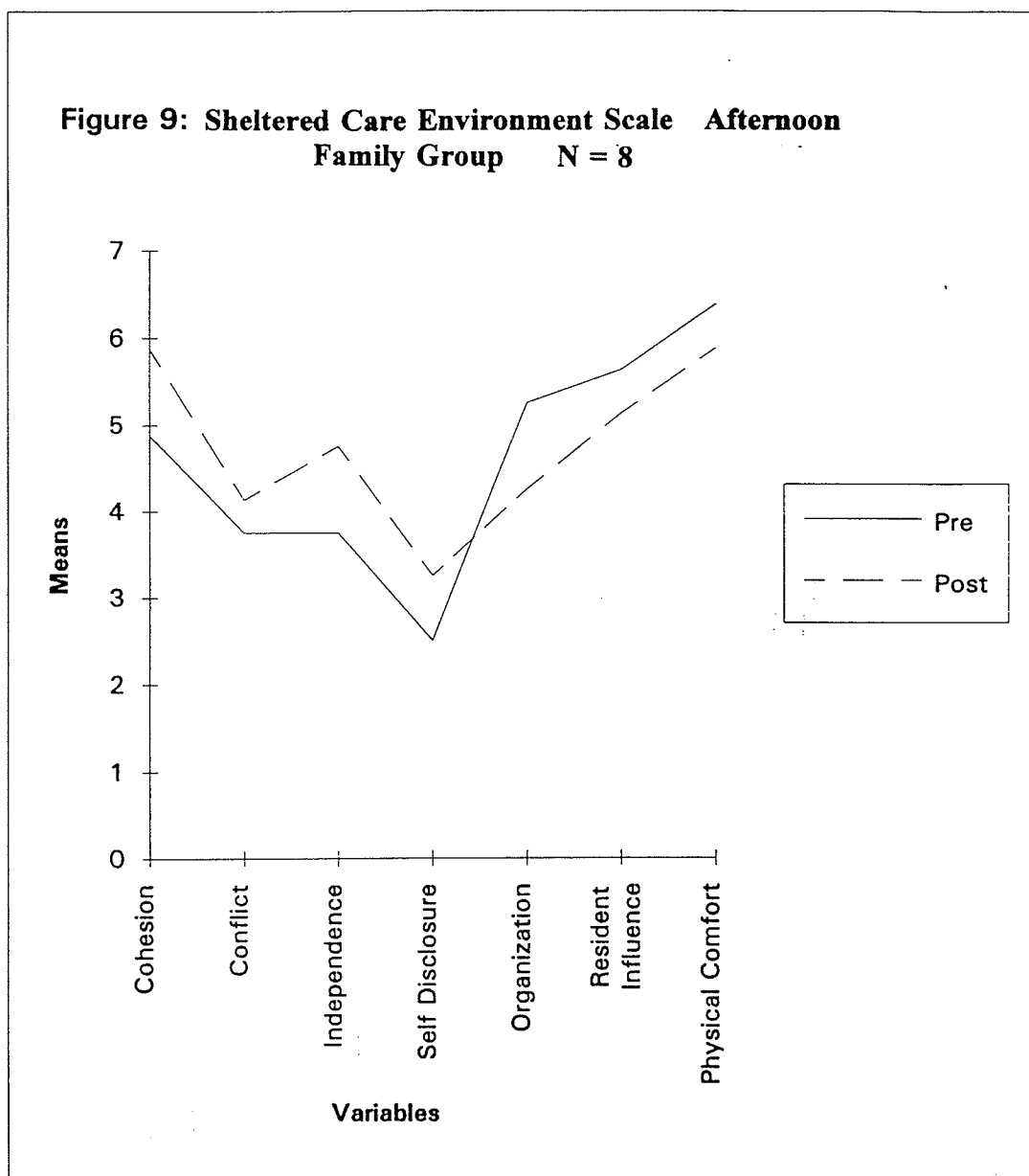


The individual scores on the SCES for family group one showed only one change over three points (refer to Table 7).

Name		O	P1	P2	Q1	Q2	R	S	T
Cohesion	Pre	6	8	7	2	2	3	3	8
	Post	8	8	7	1	5	4	7	7
Conflict	Pre	1	1	3	4	5	4	6	6
	Post	3	4	4	4	5	3	5	5
Independence	Pre	4	7	2	3	3	2	3	6
	Post	6	7	4	2	5	4	5	5
Self Disclosure	Pre	2	5	2	1	4	2	2	2
	Post	4	6	2	3	4	1	3	3
Organization	Pre	6	7	5	5	8	3	3	5
	Post	7	4	5	2	7	4	3	2
Resident Influence	Pre	4	6	4	7	4	6	7	7
	Post	3	5	4	4	6	6	6	7
Physical Comfort	Pre	9	9	9	6	6	4	3	5
	Post	8	8	6	7	7	5	3	3

Mrs. S showed a significant increase in her perception of Cohesion in the Centre (pre= 3, post= 7). Previously, Mrs. S had felt that she was not as entitled to approach staff about concerns about her daughter. As the staff presenters at the group sessions focussed on an open-door policy, Mrs. S reported feeling more comfortable with the unit staff.

In looking at the group mean scores on the SCES for Afternoon Family Group, only three variables show a full one point difference (refer to Figure 9).



The group's mean on the Cohesion variable increased (pre= 4.88, post= 5.88), as did the Independence variable (pre= 3.75, post=4.75), while the Organization variable decreased (pre= 5.25, post= 4.25). Family members attributed changes to the information and support within the group and to spending more time on the unit.

#### **6.4 Evening Family Group**

There were four group members in Evening Family Group. Two other family members attended only one or two of the sessions and were not included in any of the data. Mrs. U was a woman in her late 60s whose only son had been brain damaged in a biking accident in the late 1980s. She had no other family and visited her son daily. Mrs. U worked full time.

Mr. V was a man in his late 70s. Mr. V had been widowed in mid 1993, and his son, who had lived in the home for his whole life, had moved into the Centre shortly after. Mr. V had been a career blue collar worker who had travelled extensively. Mr. V's daughter and sisters visited frequently. Mr. V was very involved with the Cerebral Palsy Association of Manitoba, and had worked extensively in this area throughout his life.

Ms. W was a woman in her early 40s who was the ex-wife of one of the residents on the young disabled adults unit. She now worked as a professional in the health field. Ms. W remains in contact with her ex-spouse. They have two sons in their late teens.

Mrs. X was a woman in her early 70s whose daughter was a resident on the young disabled adult's unit. Mrs. X had been widowed in the early 1990s. Both of Mrs. X's daughters suffered from a rare degenerative disease. Mrs. X's younger daughter was already awaiting placement in the Centre but was in an independent living facility at the time of the intervention. Mrs. X and her family were farmers and she continues to live in a small community outside of the city. Mrs. X commutes daily and visits both her daughters, doing laundry and other household chores for them. Mrs. X has infrequent contact with her extended family.

The individual scores on the GWBS for Family group Two showed positive and negative changes (refer to Table 8). Mrs. U and Mr. V both showed decreases in feelings of depression and anxiety between pre- and post- test scores. On the Total Score variable, Mrs. U went from pre= 94 to post= 112, with positive changes on the Cheerful versus Depressed variable (pre= 12, post= 19), the Relaxed versus Tense variable (pre= 12, post= 16), and the Benignness of Life Situation (pre= 8, post= 12). The Total Scores for Mr. V were pre= 114 to post= 138, with increases on the Energy Level variable (pre= 10, post= 14), the Emotional-Behavioral Control variable (pre= 10, post= 15) and the Benignness of Life Situation variable (pre= 8, post= 14). Both of these group members attributed decreases in depression and anxiety feelings to their group participation. They felt that the information and the sharing of experiences helped them feel more positive about the Centre, and their own situations.



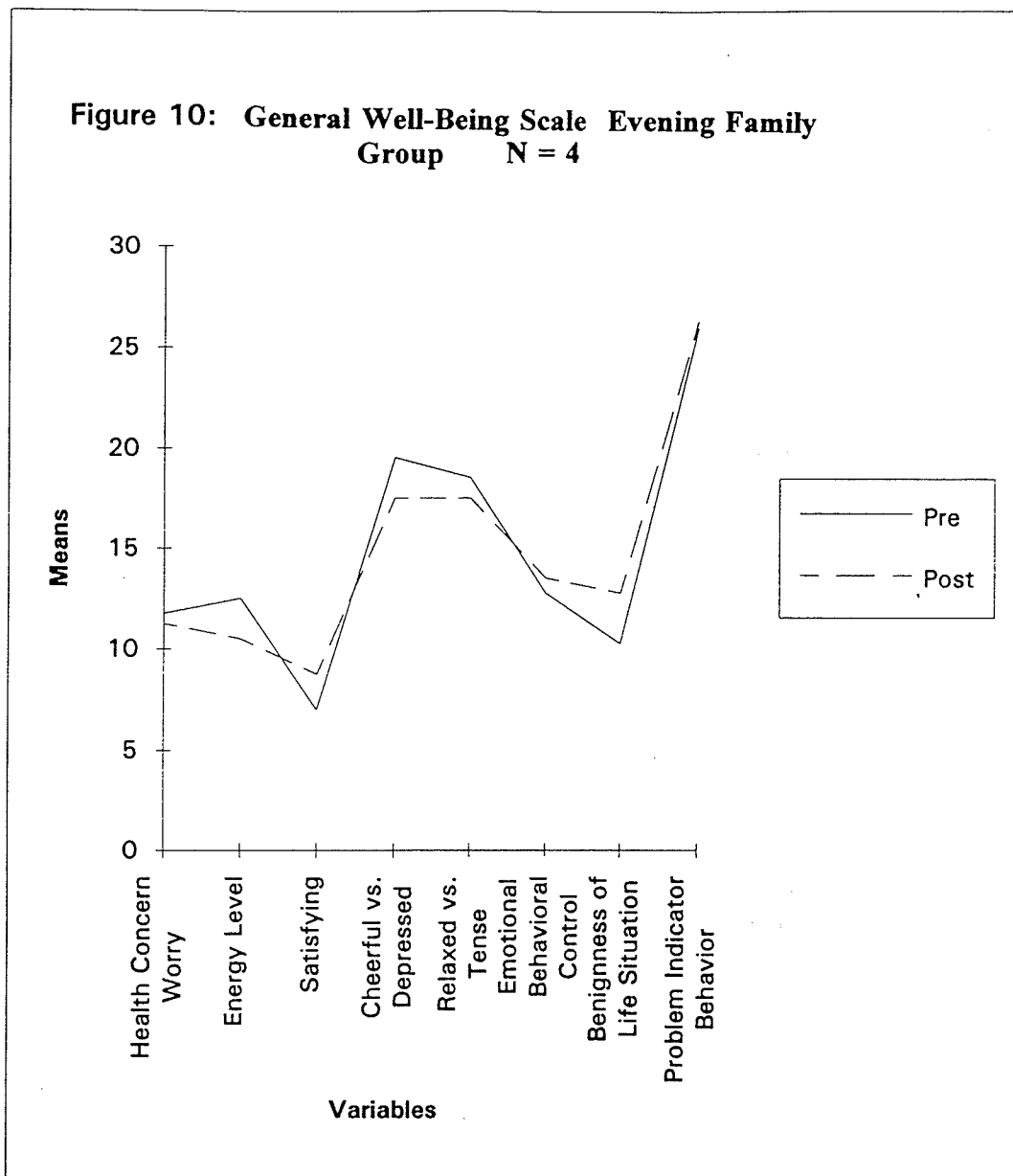
Name		U	V	W	X
Total	Pre	94	114	129	135
	Post	112	138	122	93
Health Concern Worry	Pre	10	9	15	13
	Post	12	12	15	6
Energy Level	Pre	9	10	14	17
	Post	7	14	11	10
Satisfying Interesting	Pre	6	12	8	9
	Post	5	10	5	8
Cheerful vs Depressed	Pre	12	20	17	20
	Post	19	23	20	8
Relaxed vs Tense	Pre	12	18	22	22
	Post	16	24	20	10
Emotional Behavioral Control	Pre	11	10	15	15
	Post	14	15	12	13
Benignness of Life Situation	Pre	8	8	13	12
	Post	12	14	12	13
Problem Indicator Behaviour	Pre	26	27	25	27
	Post	27	26	27	25

Mrs. X showed a negative change in her individual scores. Her pre Total Score was pre=135, while her post Total Score was post= 93. The greatest decreases showed in the Health Concern Worry variable (pre= 13, post= 6), the Energy Level variable (pre= 17, post= 10), Cheerful versus Depressed variable (pre= 20, post= 8), and the

Relaxed/Tense variable (pre= 22, post= 10). These scores show significant increases in feelings of depression and anxiety. Mrs. X was normally a very reserved person and she reported in the group that she had dealt with her relative's disability alone since the death of her husband. She spent a lot of time sharing these issues and her grief during the group sessions, so perhaps her scores represent a more accurate assessment of her feelings in her situation.

The group mean scores on the GWBS for Evening Family Group can be seen in Figure 10 (refer to figure 10). Three variables show a two point or greater difference in group mean scores between pre and post scores. The Group Mean Scores on the Energy Level variable (pre= 12.50, post= 10.50) shows a general decrease in energy, and the Cheerful versus Depressed variable (pre= 19.50, post= 17.50) showed an increase in depressed feeling for this group. There was a positive change in the Benignness of Life Situation variable (pre= 10.25, post= 12.75) which showed an general increase in positive feelings about their life situation.

The individual score on the SCES for Evening Family Group showed little variation between pre- and post- test scores (refer to Table 9). Mrs. U showed a decrease on individual scores in her perception of Physical Comfort in the Centre (pre= 7, post= 2). Mr. V showed a perception of increased Cohesion (pre= 6, post= 9), Physical Comfort (pre= 6, post= 9), and a decrease in perceived Conflict (pre= 4, post= 1). Ms. W showed increases in perceptions of Conflict (pre= 2, post= 8) and Self Disclosure (pre= 5, post= 9); and decreases in perceptions of Cohesion (pre= 8, post= 4) and Physical Comfort (pre= 9, post= 5), in the Centre. Mrs. X showed a



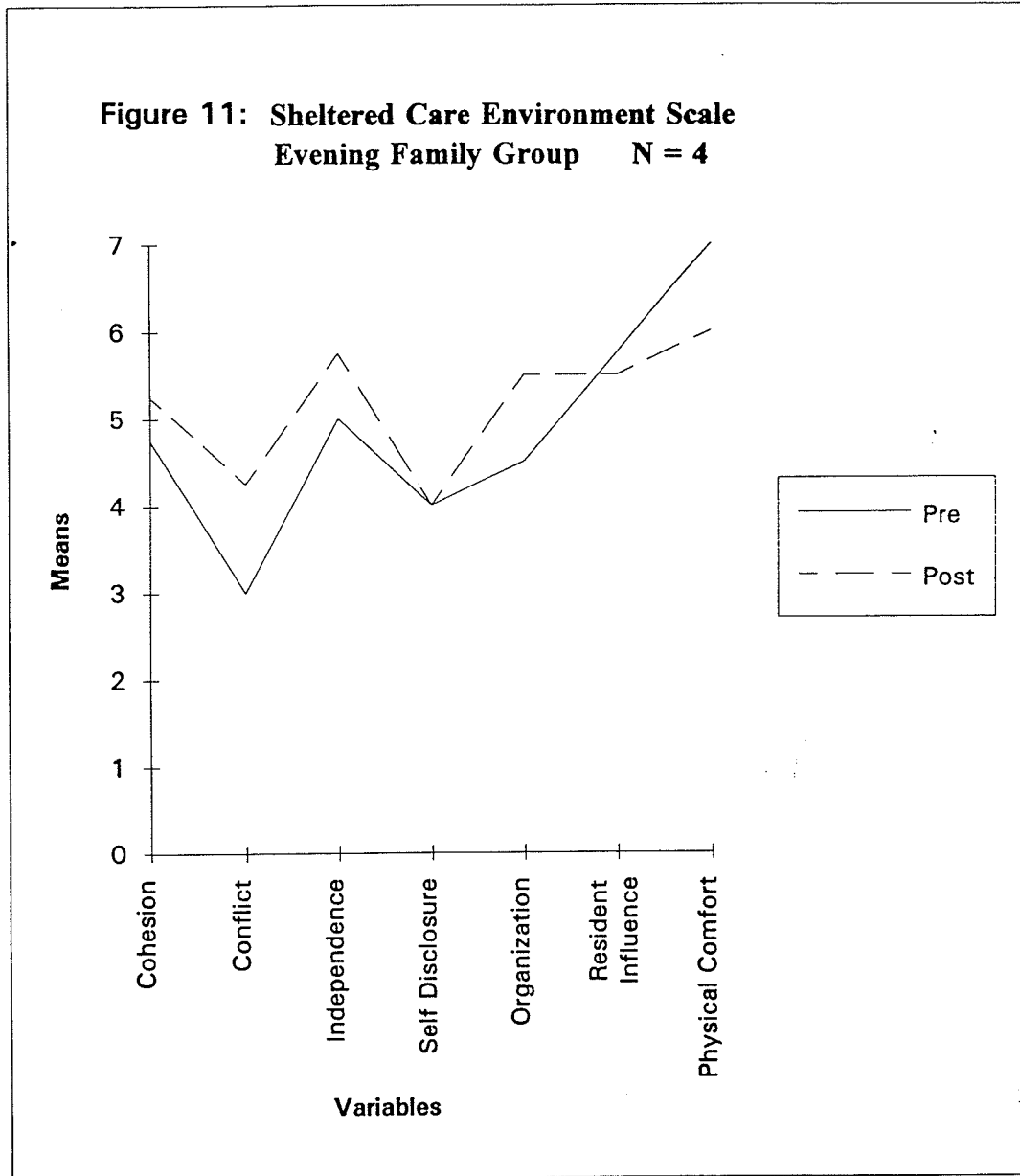
perception of increased Organization (pre= 1, post= 5) in the Centre. In examining these results it would appear that increased information about the Centre, and increased time spent on the unit had positive effects on perceptions of Cohesion, Conflict, and Self Disclosure. The Organization and Physical Comfort variables were certainly effected by the ongoing construction on the young disabled adult's unit.

Name		U	V	W	X
Cohesion	Pre	2	6	8	3
	Post	4	9	4	4
Conflict	Pre	5	4	2	1
	Post	6	1	8	2
Independence	Pre	5	5	7	3
	Post	6	6	6	5
Self Disclosure	Pre	3	2	5	2
	Post	5	0	9	2
Organization	Pre	1	8	8	1
	Post	2	7	8	5
Resident Influence	Pre	7	8	8	0
	Post	6	6	9	1
Physical Comfort	Pre	7	6	9	6
	Post	2	9	5	8

Three of the group mean scores showed changes of one point or more between pre- and post- test group means (refer to Figure 11). The group mean scores for Conflict (pre=3.0, post= 4.25) and Organization (pre= 4.50, post= 5.50) increased, while the group mean scores for Physical Comfort (pre= 7.0, post= 6.0). Again, increased time spent on the unit and ongoing construction can account for these changes.

Ten family members completed the Support Group Evaluation forms. These responses will be discussed and compared to resident responses on the Support Group Evaluation in section 6.5.

**Figure 11: Sheltered Care Environment Scale  
Evening Family Group N = 4**

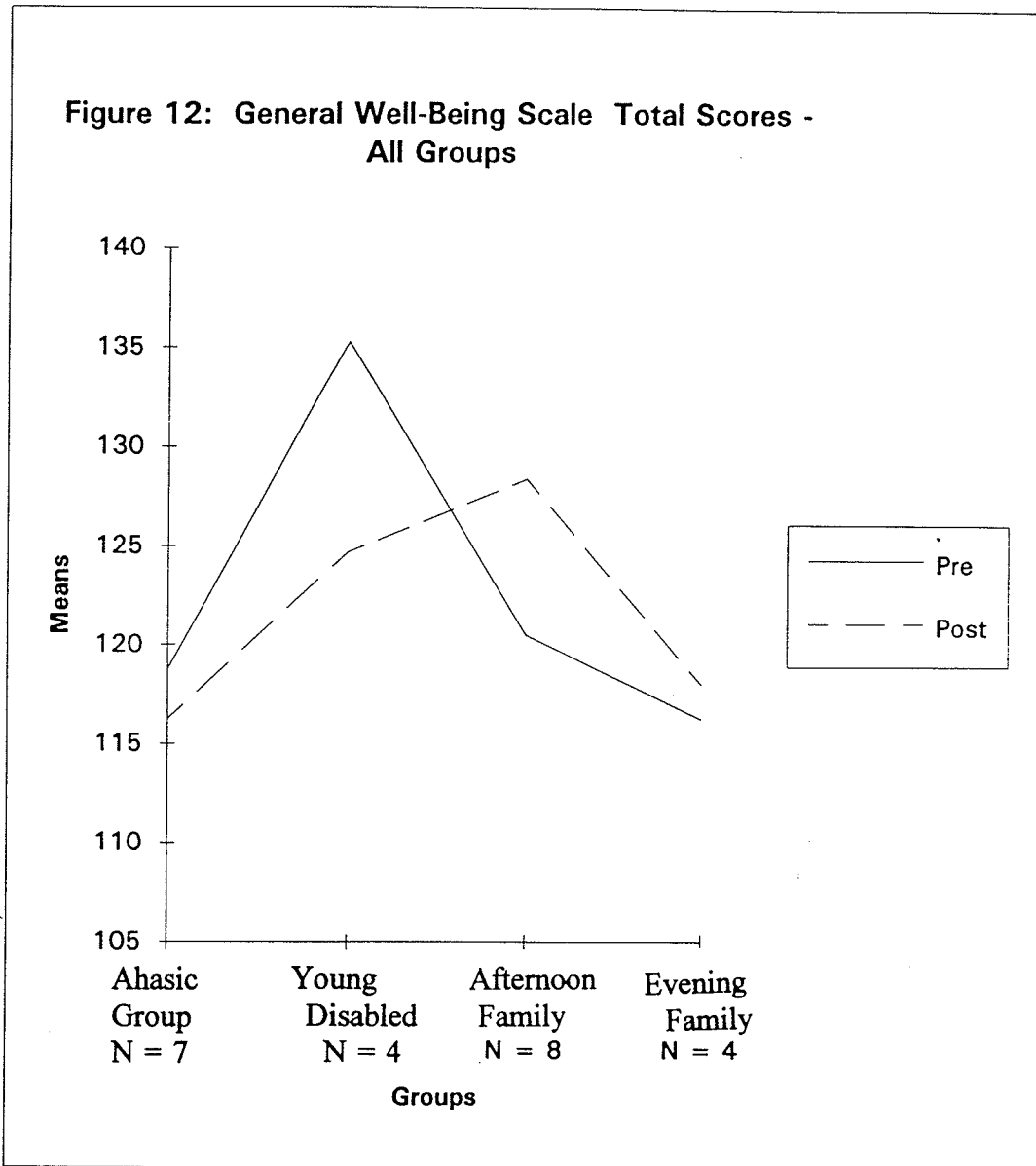


## 6.5 Discussion of Data

The only comparison data for the GWBS are the total possible scores for each variable as noted in section 4.4.1. The lowest scoring respondents on the GWBS showed only moderate depression and anxiety. The pre- and post- group mean scores on the Total Score variable of the General Well-Being Scale showed little between group differences (refer to Figure 12). Comparison of the individual scores on the GWBS for the resident's groups shows that most of the largest changes were negative. It is interesting that the group intervention provided one of the few experiences that allowed residents the opportunity to share their experiences and feelings. This kind of sharing could understandably increase feelings of depression and anxiety. Changes in the Aphasic group were more dramatic than those in the Young Disabled group. In this case, group size appeared to be a mitigating factor. The larger group had more interacting between members and greater intimacy than the smaller group.

The group means for resident groups were very similar except for opposite direction changes on the relaxed versus tense (anxious ) variable. The Young Disabled group showed a positive change in means on this variable (pre = 16.50, post = 20), while the Aphasic group showed a negative change (pre = 22.43, post = 17.14). Some of these changes did result from individual concerns within each group at the time of the pre- and post- testing. However, the impact of intimate sharing in the Aphasiac group did increase negative affect and this could also have

**Figure 12: General Well-Being Scale Total Scores - All Groups**



effected the relaxed versus tense variable. The Young Disabled group did not experience the high intimacy and sharing as the Aphasiac group and as a result, positive changes in the relaxed versus tense variable could be accounted for in increases in feelings of comfort within the group setting.

In looking at individual scores for the family groups on the total score variable of the GWBS it is noteworthy that most of the large changes were in a positive direction, with only one large negative change in each group. Group members, in both family groups, reported feeling very positive about their group experiences and the opportunity to meet other family members in similar situations. The sharing of experiences appeared to be the most impotent factor for family members, followed by the information the groups provided.

The pre and post group means on the GWBS for the family groups are very similar in their patterns, with very small within group pre- and post- changes on most of the variables. The greatest differences are seen in the cheerful versus depressed variable and the relaxed versus tense variable which each showed opposite direction changes on pre- and post- test scores between the Afternoon and the Evening group. The Afternoon group showed increases on the cheerful versus depressed variable (pre = 19.50, post = 20.13) and the relaxed versus tense variable (pre = 18.75, post = 20.38). The Evening group showed decreases on the cheerful versus depressed variable (pre = 19.50, post = 17.50) and the relaxed versus tense variable (pre = 18.50, post = 17.50). The afternoon group was the larger of the two groups and did experience a greater degree of interacting and intimacy between the members than was



achieved by the Evening group. There were also much larger positive individual changes in the Afternoon group than in the Evening group.

The highest pre test group mean score was seen in Aphasic Group (aphasiac) at pre= 135.29 (N=7), and the lowest pre- test mean score was in the Family Group Two at pre= 118 (N=4). Tables of the pre and post group means, standard deviations, difference of the means scores, and standard deviations of difference of the mean scores for all groups on all variables GWBS are presented in Table 10 (refer to Table 10).

In comparing Total Score pre and post test of the groups, Family Group One showed the most improvements, pre test mean was pre= 120.5 (N=8), while the post test Total Score mean for this group was post= 128.38, with a mean difference of the mean score of  $D = -7.88$ . This change showed a reduction of feelings of anxiety and depression for Family Group One.

Aphasic Group showed the largest negative change in scores with a Total Score pre- test group mean of pre= 135.29 and a post- test group mean of post= 124.17 (N=7), which represented a mean difference of the mean scores of  $D = 10.57$ . This actually represented an increase in feelings of anxiety and depression. This can possible be explained as the residents feeling more able to identify and express their feelings, and being given an opportunity to express these feelings. Both of these groups were the larger of the four groups. Both groups shared greater interaction and intimacy than the two smaller groups. This indicates that group size is an important factor in intervention outcomes.

Table 10 Pre and Post Group Means, Standard Deviations, Mean Difference of The Means Scores, and Standard Deviations of Standards of The Means Scores of The General Well-Being Scale								
Variable	Group	N	Pre	S <sub>D</sub>	Post	S <sub>D</sub>	Diff	S <sub>D</sub>
Total Score	Fam. 1	8	120.5	21.9	128.4	21.2	-7.88	7.38
	Fam. 2	4	118	15.8	116.3	16.3	1.75	15
	Res. 1	4	118.8	18.8	116.3	18.1	2.5	3.66
	Res. 2	7	135.3	9.8	124.7	20.8	10.57	8.74
Health Concern Worry	Fam. 1	8	11.9	3.92	13.1	2.47	-1.25	1.64
	Fam. 2	4	11.8	2.39	11.2	3.27	.50	2.26
	Res. 1	4	15	0	11.5	4.5	3.5	2.6
	Res. 2	7	14.4	1.4	13.6	2.32	.86	1.22
Energy Level	Fam. 1	8	13.4	4.5	16	4.9	-2.63	1.29
	Fam. 2	4	12.5	3.2	10.5	2.5	2	2.27
	Res. 1	4	11.8	6.65	14.5	4.15	2.75	2.39
	Res. 2	7	17.3	2.37	15.7	6.23	1.57	2.28
Satisfying Interesting	Fam. 1	8	6.8	2.22	7.4	2.12	-.63	.65
	Fam. 2	4	8.8	2.17	7	2.12	1.75	.23
	Res. 1	4	5.3	3.56	4.3	2.86	1	1.35
	Res. 2	7	7.3	1.83	6	1.85	1.29	.47
Cheerful Depressed	Fam. 1	8	19.5	4.56	20.13	4.83	.625	1.03
	Fam. 2	4	17.3	3.27	17.5	5.68	-.25	4.19
	Res. 1	4	17.8	6.26	16.8	5.36	1	2.65
	Res. 2	7	21	2.51	19.9	4.23	1.14	1.56

Table 10 Pre and Post Group Means, Standard Deviations, Mean Difference of The Means Scores, and Standard Deviations of Standards of The Means Scores of The General Well-Being Scale								
Variable	Group	N	Pre	S <sub>D</sub>	Post	S <sub>D</sub>	Diff	S <sub>D</sub>
Relaxed Tense	Fam. 1	8	18.8	4.47	20.4	4.33	-1.63	1.44
	Fam. 2	4	18.5	4.09	17.5	5.17	1	4.04
	Res. 1	4	16.5	5.59	20	4.74	-3.5	3.5
	Res. 2	7	22.4	3.33	17.14	7.12	5.29	2.49
Emotional Behavioral Control	Fam. 1	8	13.4	2.34	12.9	2.21	.5	.93
	Fam. 2	4	12.8	2.28	12.5	1.12	-.75	1.93
	Res. 1	4	13	1.58	11.8	2.28	1.25	1.75
	Res. 2	7	14.4	.9	13.14	2.3	1.29	.99
Benignness of Life Situation	Fam. 1	8	11.13	2.42	12.4	1.65	-1.25	1.09
	Fam. 2	4	10.3	2.28	12.8	.83	2.50	1.56
	Res. 1	4	12.5	1.66	11.3	2.05	1.25	1.10
	Res. 2	7	12.14	2.42	11.7	3.19	.43	1.26
Problem Indicator Behaviour	Fam. 1	8	25.9	1.67	26.3	1.09	-.375	.73
	Fam. 2	4	26.3	.83	26.3	.83	0	.913
	Res. 1	4	27	0	26.3	.43	.75	.25
	Res. 2	7	26.3	.88	26.14	1.13	.15	.55

The only important change that occurred on the SCES was in the Independence variable. A table of the pre- and post- group means, standard deviations, difference of the means scores, and standard deviations of difference of the means scores for all groups on all variables of the SCES can be seen in Table 11 (refer to Table 11). Both of the resident's groups showed the largest improvements on group means on the

independence variable of the SCES. The young Disabled group had the greatest changes (pre = 2.50, post = 4.50) with a mean difference of the means score of  $D = -2$ , while the Aphasiac group's means (pre = 3.0, post = 4.29) showed a smaller but still important mean difference of the means score ( $D = 1.29$ ). Both resident group's members did feel a major positive direction change in perceptions of independence within the Centre.

The individual scores on the SCES for both family groups showed very few noteworthy changes. In the Afternoon group, only one member had a change of over three points and this was a positive change on the cohesion variable. In the Evening group, three points or more direction changes were seen on the physical comfort variable, with two negative and one positive change, the cohesion variable, with one positive change, conflict and self disclosure variables, each with a positive

Variable	Group	N	Pre	S <sub>D</sub>	Post	S <sub>D</sub>	Diff	S <sub>D</sub>
Cohesion	Fam. 1	8	4.88	2.47	5.88	2.26	-1	.627
	Fam. 2	4	4.75	2.39	5.25	2.16	-.50	1.56
	Res. 1	4	3.75	.83	3.25	.83	-.75	.56
	Res. 2	7	4.29	1.16	4.14	1.46	.143	.71

Table 11  
Pre and Post Group Means, Standard Deviations, Mean Difference of The  
Means Scores, and Standard Deviations of Standards of The Means Scores  
of The Sheltered Care Environment Scale  
df = N-1

Variable	Group	N	Pre	S <sub>D</sub>	Post	S <sub>D</sub>	Diff	S <sub>D</sub>
Conflict	Fam. 1	8	3.75	1.76	4.13	.80	-.375	.532
	Fam. 2	4	3	1.58	4.25	2.86	-1.25	1.84
	Res. 1	4	3.75	2.59	4.5	1.15	-.75	1.55
	Res. 2	7	4.43	2.44	4.29	2.48	.143	.77
Independ- dant	Fam. 1	8	3.75	1.71	4.75	1.39	-1	.5
	Fam. 2	4	5	1.41	5.75	2.45	-.75	.629
	Res. 1	4	2.5	2.06	4.5	2.06	-2	.65
	Res. 2	7	3	1.07	4.29	2.05	-1.29	.68
Self Disclosure	Fam. 1	8	2.5	1.23	3.25	1.39	-.75	.366
	Fam. 2	4	3	1.23	4	3.39	-1	1.29
	Res. 1	4	4.5	1.5	2.75	.83	-.5	.65
	Res. 2	7	2.57	1.99	2.57	1.99	.14	.924
Organi- zation	Fam. 1	8	5.25	1.64	4.25	1.85	1	.627
	Fam. 2	4	4.5	3.5	5.5	2.29	-1	1.08
	Res. 1	4	4.5	1.5	2.75	.83	1.75	1.10
	Res. 2	7	3.86	2.03	4.29	2.37	.43	.922
Resident Influence	Fam. 1	8	5.63	1.32	5.13	1.27	.25	.50
	Fam. 2	4	5.75	3.35	5.50	2.88	.25	.75
	Res. 1	4	3.75	1.48	4.25	2.04	-.50	.87
	Res. 2	7	5.14	2.03	5.0	1.93	.14	.74

Variable	Group	N	Pre	S <sub>D</sub>	Post	S <sub>D</sub>	Diff	S <sub>D</sub>
Physical Comfort	Fam. 1	8	6.38	2.23	5.88	1.90	.25	.54
	Fam. 2	4	7.0	1.23	6.0	2.74	1.0	2.04
	Res. 1	4	4.50	2.18	4.25	1.92	.25	.75
	Res. 2	7	5.71	1.58	5.43	2.38	.29	.75

change, and the conflict variable which showed one negative change. These findings indicate that for the Afternoon group, the general perceptions of the Centre changed very little from pre- to post- testing, while the perceptions of the Evening group members did change on a number of variables. Positive direction changes on the self disclosure and organization variables, negative change on the conflict variable, and both on the physical comfort variable (two positive and one negative) and the cohesion variable (one positive and one negative) do show dramatic changes in perceptions of the Centre among these group members. Members of the Evening group may not have been able to spend as much time at the Centre prior to the intervention. In attending the groups, and spending more time in the Centre and among the residents, the Evening group members did have more dramatic changes in perceptions of the Centre on the SCES.

The changes on group means on the SCES for family group members did show positive direction changes on the cohesion and independence variables for the Afternoon group, and on the conflict and organization variables for the Evening group. The Afternoon group showed a negative change in mean scores on the organization

variable and the Evening group showed a negative change on the physical comfort variable. Validation and support of feelings within the group setting, greater time spent in the Centre and among residents, and stronger feelings of involvement may have allowed family members the opportunity to express their perceptions of the Centre more openly on the SCES post- test. Construction on the unit can also be a factor in changes on the organization and physical comfort variables for all family members.

Family members who completed the SCES found it difficult. Most did not feel they knew enough about the environment to answer the questions, however for all of the forms completed, very few questions were actually unanswered. The group mean scores showed no outstanding differences between pre and post scores for family groups on any variable. In comparing the individual scores of residents on the SCES it can be noted that the scores of the Young Disabled group were generally lower (overall) than the scores of the Aphasiac group members. The residents in the Young Disabled group were generally more active and involved in the Centre than the residents of the Aphasic group, most of whom were more dependent on staff for involvement in the Centre's activities. This could account for the higher positive assessment of the Centre on the SCES scores of Aphasic group members. Having greater dependency on staff and less involvement within the Centre may promote more positive assessments of the Centre.

In the Young Disabled group, each variable that did change (conflict, resident influence, organization and independence) only occurred once and all major changes

were accounted for by the scores of two of the group members. All of the changes were positive except on the organization variable which could be accounted for by the ongoing construction on the unit. In the Aphasic group, change on several variables were accounted for by the responses of three residents. Physical comfort, resident influence and conflict variables changed for two residents while independence, organization, and self disclosure variables changed for one resident each. Positive changes occurred on physical comfort and independence variables, negative changes on self disclosure and organization variables, and both positive and negative changes (one of each) occurred on the resident influence and conflict variables. Changes can be accounted for by increased involvement in the Centre and by feeling more free to express ones self in the safety of the group environment. Knowing that others shared their feelings may have validated individuals perceptions, and offered them the courage to express their feelings more openly.

The total possible scores for each variable on the SCES was nine (9). The percentage scores on the group means for each variable can be seen in Table 12 (refer to Table 12).

Table 12 Percentage of All Group Means and Groups Means on All Variables of The Sheltered Care Environment Scale					
Group	N	Pre	%	Post	%
Cohesion					
Fam. 1	8	4.88	54.2	5.88	65.3
Fam. 2	4	4.75	52.7	5.25	58.3
Res. 1	4	3.75	41.7	3.25	36.1



Table 12 Percentage of All Group Means and Groups Means on All Variables of The Sheltered Care Environment Scale					
Group	N	Pre	%	Post	%
Res. 2	7	4.29	47.7	4.14	46.0
Conflict					
Fam. 1	8	3.75	41.7	4.13	45.9
Fam. 2	4	3.0	33.3	4.25	47.2
Res. 1	4	3.75	41.7	4.5	50.0
Res. 2	7	4.43	49.2	4.29	47.7
Independence					
Fam. 1	8	3.75	41.7	4.75	52.8
Fam. 2	4	5.0	55.6	5.75	63.9
Res. 1	4	2.5	27.8	4.5	50.
Res. 2	7	3.0	33.3	4.29	47.7
Self Disclosure					
Fam. 1	8	2.5	27.8	3.25	36.1
Fam. 2	4	3.0	33.3	4.0	44.4
Res. 1	4	.75	08.3	1.25	13.9
Res. 2	7	2.57	28.6	2.57	28.6
Organization					
Fam. 1	8	5.25	58.3	4.25	47.2
Fam. 2	4	4.5	50.0	5.5	61.1
Res. 1	4	4.5	50.0	2.75	30.6
Res. 2	7	3.86	42.9	4.29	47.7
Resident Influence					
Fam. 1	8	5.63	62.5	5.13	56.9
Fam. 2	4	5.75	63.9	5.5	61.1
Res. 1	4	3.75	41.7	4.25	47.2
Res. 2	7	5.14	57.1	5.0	55.6

Table 12 Percentage of All Group Means and Groups Means on All Variables of The Sheltered Care Environment Scale					
Group	N	Pre	%	Post	%
Physical Comfort					
Fam. 1	8	6.38	70.8	5.88	65.3
Fam. 2	4	7	77.8	6.0	66.7
Res. 1	4	4.5	50.0	4.25	47.2
Res. 2	7	5.71	63.4	5.43	60.3

A percentage score to Standard Score Conversion Table based on nursing home resident responses can be seen in Appendices F (refer to Appendices F) (Moos & Lempke, 1992). Although only a few of the Standard Score Conversion percentages have small N, the percentage scores on the variables in the SCES scores of the groups in this intervention are generally higher than those in the Standard Score Conversions. It would appear that overall, both resident and family groups have very high positive perceptions on the different variables of the SCES when comparing percentage scores to the Standard Score Conversion Table (see Appendix I). Overall, in the perception of all group members, the Tache Nursing Centre gave very strong positive perceptions of cohesion, independence, self disclosure, organization, resident influence, and physical comfort. The high percentage scores on perceived conflict may also be positive, for an environment where individual expression (right or wrong) is not strongly discouraged can be a very positive environment, even though conflict may be uncomfortable to some individuals.

Family members saw changes in the Centre's environment over the course of the sessions. Negative perceptions on the Scale could be attributed to increased time spent in the Centre and among residents. Family members may have felt "safer" to express themselves at the time of the post test, without fear of repercussions against their relative although all were told that the SCES was in no way an evaluation of the Centre. Positive changes could also have occurred as a result of more time spent in the Centre and among the residents. Family members got to know about the Centre, each other, and spent more time among residents and staff of the Centre as a result of intervention.

In looking at the data from the Family Support Evaluation Forms, a number of differences can be seen between family and residents responses. Six residents felt they always felt welcome in the meetings while five residents usually felt welcome. Eight residents reported the primary reason for attending the groups was to learn to cope with their own condition, and secondly, to learn to cope with relatives reactions to their condition. The third most frequent reason cited was to resolve specific problems. Four residents found the groups very relevant, two found the groups relevant and five found them to be somewhat relevant. Most of the residents found the groups very helpful and felt better able to cope, however, a number of respondents felt their coping skills were the same as before, even though they found the groups very helpful.

The primary reason noted by family members for attending the meetings was to learn to cope with their relative's behaviour related to their condition. The second most cited reason was to have contact with others in similar situations, followed by

learning about the condition, learning about community resources, and finally, to resolve specific problems. Six family members reported that they found the meetings very relevant, three said they found them relevant, and one stated the meetings were somewhat relevant. It would appear that for the most part, all group members did find the groups relevant, although there were differences in reasons for attending between the residents and the family members. Most of the residents wanted to learn to cope with their own conditions and with relative's reactions to their conditions. Family members wanted to learn to cope with the behaviour of the ill and/or disabled relative and to meet others who shared their experiences. It would appear that all group members wanted some kind of forum to provide them with information and skills to cope with their situations.

Ten residents reported that they did feel they contributed to the groups, by talking about how they felt, and sharing their experiences. The two most frequently noted benefits these respondents identified were gaining new understanding of others behaviours, and feeling like they get along better with others. Two residents rated their group experience as excellent, seven as good, and two as fair. Residents felt very positive about meeting others like them, learning about everything, having people listen, and the coffee and socializing. Some residents had trouble hearing others, had personality conflicts with group members, and found altercations between people to be very sad.

Eight family members found the sessions somewhat helpful, while three found them helpful. Nine family members reported feeling more able and confident about

their ability to cope with caring for their relative, while one felt there had been no change in this. Eight family members felt they had been contributing members of the groups, citing reasons such as participation, sharing, sharing experiences, and empathy. Two family members put question marks by this question. The most important benefit members reported about their group experience was sharing with others who had similar concerns. Six family members were evenly divided between evaluating and confirming, and evaluating and changing, beliefs and attitudes as the second most important benefits.

Six family members rated the general group experience as good while four rated it as excellent. There were a number of positive comments including, meeting with the different disciplines at the Centre, sharing ideas and problems, mutual respect for similar problems, meeting with others who "have walked in my shoes". A few family members found the ten weeks too long and the time of the meetings inconvenient. Many wanted to have the groups continue, to have more casual contact outside of the group structure, or to have a social time arranged outside of the group. It is interesting that the resident and family group members all found that meeting others in similar situations and sharing experiences were very important parts of their group experiences. This kind of response highlights the importance of education and support groups for residents in long-term care settings, and their family member. Considering that residents live together, most on the same unit, it is very telling that some found meeting others like themselves to be very important and helpful. Other residents reported that learning to understand their own behaviour and the behaviour of others

was an important part of the group intervention for them.

As the Tache Nursing Centre moves away from a medical model towards a social model, it is clear that many residents have maintained the separation and isolation inherent in the medical hierarchy. Part of the problem for staff is the need to protect the privacy of residents which is a very important part of any long-term care setting. However, protecting individual privacy in a medical setting often leads to separation and isolation of the individuals as they are treated like "patients" rather than residents of a small and dynamic community. To move to a more social model, more sharing must be encouraged in a voluntary group setting so that residents are given the opportunity and encouragement to get to know and interact with the members of their community. This is certainly possible without infringing on individual's privacy. This kind of interaction can also help empower residents as it will reduce their feelings of isolation and strengthen community bonding to support changes that residents would like to make. Us against them is certainly more powerful than me against them.

Part of the evolution towards a social model on the young disabled adult's unit in the Tache Nursing Centre included increased family involvement. Again, meeting others in similar situations and the opportunity to share experiences was important for the family members who attended the groups. As a result of the group participation family members felt more valued by the Centre and more important in the unit's community. Previously, family members had very little interaction with staff, residents, and other family members on the unit. Time on the unit was spent specifically visiting with their relative. Family members now felt that they too were

an important part of the unit as a whole and were interacting much more with staff, other residents, and each other.

## CHAPTER SEVEN

## DISCUSSION, IMPLICATIONS, AND CONCLUSIONS

7.1 Discussion

Did the group experience actually empower residents? On the face of it, it appeared that Resident Group One group was unsuccessful. A number of changes were made by individual group members over the course of the sessions. Resident B had been reluctant to see her parents take a vacation as she felt very afraid when they were not close to her. Just after the middle of the sessions her parents took a vacation overseas. They had not gone away like this before. Resident B would beg them to stay even while she agreed they needed a vacation. In this case however, Resident B did not stop her parents, and she used the available resources of the unit and the Centre to help her deal with her fears during their absence. Resident B also began to refuse to be put to bed on staff schedule, telling them to wait, even if it was for short periods of time. This began to occur closer to the end of the sessions. Staff frequently approached her stating that they needed to put her to bed or their schedule would be disrupted.

Resident C had frequently voiced his concern that his physiotherapy sessions had been reduced and that he could do nothing about this. During the last two meetings, Resident C began to discuss ways he could increase his therapy sessions and do some of the work on his own, rather than focusing on things he could not do or change was



empowered this way. With this change of attitude, it would appear that Resident C had been empowered by his participation in the groups. It appeared that he no longer felt that he could not change things. Resident C was empowered to become a more active participant in his life course rather than a helpless recipient.

The most dramatic event occurred with Resident D. Resident D attended the sessions even though he said they were of no use and would not change anything. Prior to the session with the pharmacist, this group talked about having to wait for things too much and too long. Resident D specifically focused on medications that he required prior to meals. When these medications were delayed, Resident D had to delay his meal. The Pharmacist had discussed the issue of some residents having medications (where they were physically and cognitively able to self-monitor) in their rooms. Resident D had adamantly refused this option from the first time it was suggested in early session discussions. However, following his private meeting with the Pharmacist, after the group session the pharmacist attended, and a tour of the Centre's Pharmacy, Resident D did get part of his medication so he could self administer for one meal per day. After further discussion, including getting a more accessible pill dispenser from the Pharmacist (on his own initiative), resident D got his second daily dose in his room for self administration. He no longer has to wait for staff, he has more control over his life and his environment. The Pharmacist has since informed the facilitator that a number of other residents have also used the option of having medications in their rooms. Resident D also began to go to another unit to get one of the group members (from the fourth session on). Outside of the group, resident

D made efforts to find this resident and make sure he was being included in Centre activities.

Resident D, although active within the Centre's community, did not feel that residents had any power to change things within the Centre or on the unit. However, over the course of the groups, he did become aware that residents, as a group, could change things. The groups empowered Resident C to take his knowledge a step further and change things in his own life situation, as an individual. As he began to feel more powerful in his environment, with more control over his own life, he also began to involve another resident in Centre activities. The other resident was dependent on staff for activity involvement. The involvement with each other in the groups did in fact, break down the separation barriers, allowing Resident C to become more personally involved in the empowerment of the other resident by reducing his dependency on staff.

Resident Group Two also had a number of events occur that showed the group interventions to be effective. Group members had a number of interesting experiences during the session where they were able to examine the different communication devices that some group members used. Resident L was able to clearly communicate that although he could spell his name on the sheet, this was all he knew how to spell. Residents each examined the different means of communication that were brought in. Resident H examined the devices by touch. One of the devices was a keyboard on which Resident I was able to type out what she wanted to say. This device also speaks. While Resident H examined it, the device said "Hello" to him, causing a

started response which generated a great deal of laughter from the rest of the group members. Resident K, through pantomime, informed the facilitator and co-facilitator that she was dyslexic.

Resident K appeared to take a "mothering" role within the group. She frequently drew attention to less aggressive residents who wanted to be "heard", and attended to residents to ensure that they were involved in the sessions. Resident L appeared to take a "fatherly" role in the group, tapping less attentive residents to ensure that they paid attention to what was going on.

Resident J, who could speak, but only mouthed words with no vocal volume, was encouraged to speak up as the visually impaired resident could not see him speaking. Staff also began to encourage this resident to speak louder. Resident J also slumped in his wheelchair and appeared inattentive to the environment around him. He did not speak spontaneously, and responded only sometimes, when spoken to. Over the course of the sessions, this resident sat up and became more and more attentive to what was going on around him, both in the sessions and on the unit. During the last session, resident J moved himself towards the facilitator and spoke directly to the facilitator. Resident J told the facilitator, in a normal speaking voice, that he had a music tape, he said the name, and that he really liked it. This was spontaneous communication and very dramatic. Staff report that this resident continues to be more attentive to his environment and to speak up more frequently.

Resident Group Two members were asked if they saw an improvement in people taking time to listen to them and most agreed that there had been some improvement

in this area. In general, residents stated that they felt very positive about the group experience. Resident Group Two's experience appeared to successfully empower its members. Members became more aggressive in their efforts to get people to stop and listen to them. Interaction between these group members was spontaneous, loud, and frequently filled with laughter. Staff reported that they were spending more time interacting with aphasic residents. During one of the later meetings, as Resident I was commenting that "men are always" (in very slow laboured speech), Resident G jumped in with "punctual" which got everyone laughing as the conversation was about the tardiness of the co-facilitator (a male). The Aphasic Group did feel more involved and more powerful within their environment. The fact that they were interacting more as a group, as had been noted by staff in later conversations, showed that the separation and isolation barriers had been effected by the group intervention. These residents were now interacting at a community level rather than individually. The changes in interacting and approaching of staff indicated that empowerment did succeed with these group members.

In the second family sessions, the head nurse had coined the phrase "Pioneers" for what the unit, the staff, and the families were trying to accomplish. The family members hung on to this idea and a focus on creating a sense of community. Family members now felt that a sense of community did exist, and that they wanted to involve all families who had a young disabled adult in the Centre. Family members reported the meeting where the HN presented to be a very positive experience for them.

Family members reported being surprised and pleased when told of their relative's Spiritual interest and involvement by the unit pastoral care worker. Ms. W reported that her ex-spouse had tried to tell her about the "Church Lady", but she kept telling him he was mistaken. Ms. W was very surprised to find that it was she that was wrong, not him. Ms. W's ex-spouse communicated by writing, however, his writing was very small and often difficult to read as a result. Staff were asked to encourage him to write larger and Ms. W involved as many staff and family members as she could to reinforce the larger writing. This resident began to and continues to write larger.

Ms. W also began to spend more time on the unit than she had for many years. Although her ex-spouse did not always visit with her, she stated that she liked to come and visit with other residents as getting to know them through their family members had made her feel more comfortable with them.

Mr. P1 and Mrs. P2, found that they were more able to approach staff to provide services to their son, Resident E. The P's had a long time involvement with the Centre and were surprised at what they didn't know about the Centre. The P's reported feeling much more comfortable about "interrupting" staff, where previously they would not have bothered as they perceived staff as being too busy.

Mr. Q1 and Mrs. Q2 had not taken a vacation for many years as Resident B made them feel too guilty for leaving, and they did not feel they could approach relatives, who would not understand, for help. Mr. Q1 and Mrs. Q2 spoke frequently about this problem through the early sessions. Other group members encouraged them to try,

focusing on the importance of self-care. In the middle of the sessions, the Q's went on a two-week vacation and did find relatives to help out with visits to their relative while they were gone. To their surprise, the relatives elected to continue regular visits even after they had returned. Group members were encouraging them to go away again during the last session.

During one session, as Mrs. X was describing an incident of inappropriate behaviour by a resident. She had been in the elevator and the resident had bitten her. At hearing this Mrs U turned to her in shock (and somewhat embarrassed) and stated, "Your the lady!!", as this resident was her son. Family members now felt able to support other family members and to provide understanding and advice, rather than focus solely on their own issues. The groups provided a compassionate and understanding environment for all family members to discuss their situations, concerns and frustrations. This in turn, led to sharing of solutions that each had found successful in their own situations. Family members in the Afternoon group felt close enough to advise and cajole other group members into self care needs and concerns. Many shared their own experiences and the learning process for them in being able to take more time for their own self care needs without carrying the guilt of neglecting a young disabled son, daughter, or spouse. Family members also stated that they did feel more comfortable about the Centre after hearing the information provided by the different Centre professionals and staff. Family members also were able to provide support to each other by arranging to visit with residents while their family members did go away for self care breaks. A strong sense of community developed among

family members who attended the groups.

Family group members were asked if they found the groups helpful and in what ways. All members felt that the group was a very positive experience and all felt more comfortable in the Centre because of the candour and openness of presentations by Centre staff and professionals. Members were looking forward to the September meeting. The only complaint was that one member would have liked to have seen more men in the group and he felt kind of overwhelmed. A family phone list was generated and plans were made for family members to meet again in early September to start a family support group on the young disabled adults unit

The focus of the Mediating Model on the development of a mutual aid society was fulfilled in the group interventions for the families and the residents. The fact that family group members were planning ahead to the development of a supportive and educational self-help group is indicative of the aims of the Mediating Model. Residents continued to interaction with each other and increased active involvement with each other and the unit also demonstrated the development of a mutual aid society for these group members.

Within this intervention, the system (Tache Nursing Centre), the clients, and the worker were able to work together to fulfil the needs of the system and the clients. The Centre wanted to promote empowerment of residents and increased family involvement. Families wanted more acceptance and involvement within the Centre. Residents needed to learn new skills that would empower them within their environment. The use of the Mediating Model proved very successful in achieving the

goals of residents, families, and the system in this intervention.

Most family members felt that this type of group experience should have been offered to them long ago. It was important to be aware that there is more than one person involved in an illness and/or disability. As one writer points out, "Disease is an integral part of the continuous process of living. The family is the unit of illness, because the family is the unit of living." (Hunter, 1985, pp. 341). All members felt that they had learned a great deal and felt better about their relatives being in the Centre, as well as feeling more comfortable in, and more a part of the Centre. All family members felt the group experience was a positive one. Most expressed very good feelings about meeting others who they knew and understood what they had and were going through.

Problems were expected to occur, due to the newness of this unit and its philosophy, for the staff, the residents, and the families. Construction was ongoing on the unit and this was expected to interfere somewhat with the resident's groups. Space became a major problem as groups were shuffled through a number of different locations over the course of the ten weeks. Group members were very understanding about this.

In examining the overall data, it would appear that the two larger groups (Aphasic resident and Afternoon family) were the most successful. Group size was an important factor in the success of these two groups. The Afternoon family group appeared to have the greatest positive changes among individual members compared to all of the other groups. This group was very motivated to participate with all of the



presenters and the positive affirmation among the group members appeared to be strongest in this group. The motivation and positive affirmation factors in the Afternoon family group were very beneficial to individual members. The strength of the cohesion and intimacy in this group enhanced positive affirmation and motivation in a non-judgemental setting.

The Aphasic group also achieved higher levels of cohesion than did the two smaller groups. This group, unlike the Young Disabled group, were very motivated to participate and attend group sessions. The motivation, cohesion and intimacy factors were very important to the success of this group. The Young Disabled group and the Evening family group were also successful, but not to the degree of the two larger groups. The Young disabled group lacked motivation to attend the groups. Most of the Young Disabled group members felt that the group would not be helpful or important, but agreed to attend because it was being offered. By the end of group sessions, these group members had come to value their attendance at the group and the importance of the group. However, this was very slow in coming for the group members.

Cohesion and intimacy were slow to develop in the Young Disabled group and the Evening family group. Each of these groups did see important changes among some individual group members. The members of the Evening family group were much more reserved with each other than the members of the Afternoon family group. This reserve hindered the development of intimacy and cohesion among these group members. Members of the Young Disabled group were difficult to motivate to

participate and interaction between group members was often sporadic and short. Again, these factors interfered with the development of intimacy and cohesion among these group members. If there had been more members in each of these groups, the intimacy and cohesion may have evolved more rapidly and these groups may have been more successful. As it was, positive affirmation and motivation appeared much later in the two smaller groups and this could have undermined the supportive and information gathering elements in these groups. The results for these two groups (Young Disabled and Evening family) make a strong case for successful groups containing between six and twelve members and not five or less members.

It would appear, when looking at the data and the reports from staff and group members that this intervention had shown itself to be successful. Family members were planning to go on and form a self-help group, and residents are asking for more meetings along the same lines. Part of the problem with this intervention was that it became focused too much on the young disabled adult unit. Presenters consistently referred to the unit and family members focused on continuing within the unit. In spite of this, the generic premise is still very successful. This format can be adapted to a very diverse group of both family members and residents.

Residents appeared to benefit from the groups. It is very interesting to hear that they attended the groups to meet others in similar situations. It was also very telling that they reported that the two primary benefits they got from the groups was learning more about other's behaviours and that they felt they got along better with others now. These points could be very important in looking at the social needs of young disabled

adult residents in long-term care. The residents wanted the staff to come so that they could ask questions and hear about their environment in the group format. As the pharmacist discovered, the residents were very interested. Most residents did not know that there was a pharmacy in the Tache Nursing Centre and several did go for a tour when they found out they could do this.

The family members included parents, wives, ex-wives, and aunts who were all able to find common ground in which to interact effectively. The age differences of the family members did not seem to be an issue in this intervention either. Two of the families were able to talk about the problems they had with elderly parents who refused to go into care, and how this compounded the issues they had to deal with in the illness of their daughters. Family members felt more comfortable approaching other family members who had not attended the meetings. People seemed to be very surprised that they did have so much in common.

## **7.2 Implications and Recommendations**

What are the implications that can be drawn from this intervention and its results? One of the most important facts that surfaced as a result of the Resident Groups was the benefit to the residents of attending such groups. As mentioned in Section 7.1, a number of individual residents benefitted dramatically as a direct result of their attending the groups. Clearly, this type of intervention was able to provide information and independence related skills that were not being provided to the

residents in the normal functioning of the Centre.

Residents were very disappointed that more Centre staff did not present at their sessions. When approached about presenting at resident group sessions, most staff felt it was unnecessary as they saw and met with residents frequently. Staff who need to be involved in the physical care aspects of their job often lose sight of the social and emotional needs of residents in long-term care.

In future implementation of this intervention, it would be important to ensure that staff do make the effort to participate in the group sessions. For residents to achieve greater independence, it is imperative for them to become more than "patients", and to be more involved with the Centre as a whole and the different departments within the Centre. This became very clear in the response of the residents to the session which the Pharmacist attended.

It was surprising that residents, even those who had been at the Centre a long time, were aware that there was a full pharmacy on the premises, or that it was their right to see the pharmacy and talk to the pharmacist about their medications. Residents were surprised and happy about the pharmacist attending the groups. All resident group members asked the pharmacist lots of questions and most of the resident members of both resident groups did follow through with the pharmacist at a later, personal session.

However, although the present policy is to encourage resident and family involvement in as many aspects of the Centre as possible, this may have some negative ramifications now and in the future. Having an "open door policy" can be a

double-edged sword for the Centre and its' staff. Not all staff may appreciate numerous interruptions from family members and residents. Staff are still required to perform their medical care duties and numerous interruptions and/or demands from family and residents can certainly interfere with a job that already has time pressures. This could evolve into feelings frustration and being overwhelmed among the staff. These types of feelings are frequently associated with staff "burn-out" and should be taken into consideration when asking staff to provide the extra services.

In this intervention, the two larger groups (Aphasic Group and Family Group One) appeared to get the greatest benefits from the group interventions. This would indicate that group size is a strong factor in this type of supportive intervention. The larger groups had a greater amount and more intimate interactions between group members than the smaller groups did. In the future it would be important to attempt to have at least six to eight group members, especially in verbal resident groups. Increasing group membership to six or eight would help to initiate greater between group member interactions and exchanges. Aphasic Group, the aphasic residents, appeared to be a very good size provided two facilitators are available to ensure equal communication for all residents attending.

Both the family members and the residents expressed very positive reactions to the supportive group interventions, frequently asking why something similar had not been offered earlier. Clearly there is a large gap in the social services net. Family members who had dealt with their situations for many years frequently reported feeling isolated and not understood or helped by friends and extended family. Most of

the family members did not know of or did not have access to appropriate support groups in the community. Mrs. T did attend spouse support groups through the MS Society which she found very helpful. She was the only family member who reported attending any other support group intervention.

As noted earlier in this document, the impact of chronic illness and/or disability can be so overwhelming that families are frequently too exhausted and/or overburdened to seek out the community supports that are available, or are unable to find time to use these supports (Dell Orto, 1984; Corbin & Strauss, 1988). Most of the family group members stated that they were unaware of groups that could help them or that they did not have time in their lives for such help through the crisis period. For some, this crisis period lasted for many years. Clearly, more generic educational support groups need to be made available to families with a young disabled adult member. Public awareness of the groups available needs to be enhanced, especially within the medical setting so appropriate supportive referrals can be made.

Residents also appreciated meeting others like themselves, and learning about the Centre. Within the Centre there are issues around privacy and confidentiality that may be isolating residents from each other, and encouraging them not to be involved with other residents. Perhaps this can be seen most clearly in the response of staff when approached about residents' reactions to the death of a short-term resident on the young disabled adult's unit. Although staff are regularly given the opportunity to share their experiences and grief in scheduled Post-Death Conferences, no such provision is made for or even considered for the residents. Clearly, the needs of residents following a

death on the unit need to be re-examined and re-evaluated. Some provision needs to be made in the future to encourage the sharing of experiences and grief about a resident who has died on the unit, among the unit residents as a community. Perhaps a scheduled "wake" for the resident who has died would open a non-threatening arena for sharing among the unit residents. Dealing with grief and loss issues for residents is important. Care must be taken not to create an atmosphere where these issues are focused on a great deal, as this may prove more harmful than helpful. Although short grief and loss group intervention may have some value for some residents, for others, this kind of intervention could lead to serious psychological concerns (ie. depression and/or anxiety).

The provision of Post Death Conferences for residents may provide a safe outlet for their own fears and pain of grief and loss by allowing residents a third party to discuss these issues around. Residents would also learn, through the sharing of feelings, that they are not alone in their fears and this may increase their abilities to share their own grief and loss issues in a non-threatening forum. This could prove to be a very empowering experience which would further break down the barriers of isolation which separate residents in a long-term care community from patients in a medical setting.

Finally, follow-up of the residents and family members who attended these groups would generate valuable information of the effectiveness of this process over time. It is important for all long-term care facilities to attend to family needs as well as the residents needs. Families who feel a greater sense of belonging and involvement, and

who have access to information are more comfortable, and this is passed on to the relative in care. The positive effects for both family members and the resident are beneficial to the institution.

### 7.3 Conclusions

This practicum has generated a great deal of data and information. The purpose of the practicum was to provide a group intervention that would empower residents of the newly developed young disabled adult's unit at the Tache Nursing Centre. Another purpose was to provide a supportive and educational group intervention to family members who had a relative on or awaiting placement on the young disabled adult unit. Did the group intervention fulfil these purposes?

In parallel with the goals and objectives of the young disabled adult's unit, this intervention was able to empower most of the residents who attended the groups, and even provide positive impact for some residents who did not attend the groups. Furthermore, family members who attended the groups reported feeling more involved and more accepted on the unit. Family members felt that meeting staff and learning about the Centre and each other was responsible for their stronger sense of acceptance and community on the young disabled adult's unit.

In running the groups at the Tache Nursing Centre, this facilitator was frequently on the unit after social worker staff had left for the day. As a result, this facilitator was frequently approached by staff and residents to provide intervention in crisis



situations where the nursing staff felt their skills were not appropriate. Individual intervention was provided to a number of resident on the young disabled adults unit over the course of the group sessions. Most of the residents seen individually were not attending either of the resident groups. It was very clear that there was a very strong need for social worker services on this unit in the evenings, for residents and staff. Several staff also availed themselves of the services of this facilitator over the course of my presence on the unit. New policies and adjustment to new living conditions would be much more successful for staff and residents if social work services could be provided to them in a more immediate and accessible manner.

The objectives of this practicum to design, develop, implement and evaluate support groups for young disabled adults in long-term care, and their family members have been fulfilled by this practicum. The learning experiences provided through this practicum were excellent. As all of the groups were different, a variety of facilitating skills were learned and used. The experience of working within a large institutional setting was extremely enlightening.

The learning objectives for this practicum included; developing and understanding and current knowledge base of the impact of illness and/or disability on individuals and families, to learn to design and implement and effective educational support group, to learn to assess and evaluate data, to learn to present data and draw valuable implications from the data, and to enhance knowledge and skills in group preparation and facilitation. All of these objectives were met in completing this practicum.

The development of a current knowledge base and understanding of the impact of

chronic illness and/or disability has evolved through research and, on a practical level, through interactions with residents, family members, and staff at the Tache Nursing Centre. Effective educational support groups were designed and implemented successfully. The assessment, evaluation and presentation of data was successful in showing the process and outcomes of the interventions. Important implications evolved from the data and were also presented. Knowledge and skill in group preparation and facilitation were increased and honed through practical experience and supportive supervision of the process.

Supportive supervision is a very important part of the learning experience. Learning to present concerns and issues in a positive light as a mediating skill was a very valuable part of this intervention. Supervision helped to enhance mediating skills a great deal for this facilitator. Working with groups was a very rewarding experience. Learning coping and surviving skills from group members was enlightening and interesting. Getting to know the group participants and the challenges that they have faced and overcome was a very positive experience.

Learning more about the impact and effects of long-term chronic illness and/or disability only served to increase the facilitator's interest in this area of social services. Learning about group work and group process helped to provide a successful supportive group intervention for the group members and the facilitator. Ongoing individual follow-up during and after the sessions was a part of this experience. Even staff, at times, needed some help in adjusting to the changes that were going on. Evaluating the data was interesting and sometimes surprising. Learning to present the

data and to draw rational and valuable implications from the data is an arduous task.

The greatest concern this practicum has brought forth is the desperate need for a generic supportive group intervention to empower group members through information and sharing of experiences, whether they are young disabled adults, or family members who care for a young disabled adult. It is hoped that this project will be of help to others who see a need and feel that they too can provide assistance in that area.

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## APPENDIX A

LETTER OF PERMISSION FOR USE OF THE SHELTERED CARE  
ENVIRONMENT SCALE (Moos, R. H. & Lempke, S., 1992).





STANFORD UNIVERSITY MEDICAL CENTER

STANFORD, CALIFORNIA 94305 • (415) 858-3996 • FAX (415) 852-3420

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STANFORD UNIVERSITY SCHOOL OF MEDICINE  
Department of Psychiatry TD-114  
Rudolf H. Moos, Ph.D., Professor  
Director, Center for Health Care Evaluation

July 1992

Dear Colleague:

As part of our work at the Center for Health Care Evaluation, we have developed the Multiphasic Environmental Assessment Procedure (MEAP) for characterizing the physical and social environments of group residential facilities for older adults, such as nursing homes, residential care facilities, and congregate apartments. The new materials available for the MEAP consist of a User's Guide and manuals for each of the five Inventories that comprise the MEAP.

The *MEAP User's Guide* explains the multiphasic approach, introduces the five instruments, suggests how to organize data collection, describes the conceptual background and development of the MEAP, and discusses both practical and research applications of the Procedure.

The five Manuals describe the development, norms, and psychometric characteristics of each of the five MEAP Inventories. Each Manual includes directions for administering and scoring the relevant Inventory, and covers applications for practitioners and program evaluators and research applications and validity. Each Manual also includes a copy of the relevant Inventory (on perforated pages that can be removed for easy reproduction) and directions for obtaining standard scores and plotting profiles.

The five Inventories are:

- (1) The *Resident and Staff Information Form (RESIF)*, which assesses characteristics of the residents' and staff in a facility.
- (2) The *Physical and Architectural Features Checklist (PAF)*, which measures the physical and architectural resources of facilities in terms of eight dimensions; there is also an Ideal Form of the PAF, which assesses people's preferences for physical and architectural features.
- (3) The *Policy and Program Information Form (POLIF)*, which assesses nine dimensions of the policies and services available in facilities; there is also an Ideal Form of the POLIF, which assesses people's preferences for policies and services.

MEAP.LTR  
4D; 7/6/92

- (4) The *Sheltered Care Environment Scale (SCES)*, which assesses residents' and staff's perceptions of the social climate of facilities on seven dimensions; the Ideal Form of the SCES assesses people's social climate preferences on the same seven dimensions.
- (5) The *Rating Scale*, which assesses two aspects of the physical features in a facility and two aspects of resident and staff functioning.

To order these materials, complete the enclosed request form and send it with a check for the appropriate amount to the address above.

You are welcome to use the MEAP or parts of it in your research and to make copies of it for this purpose. Please be sure to include the copyright notice on all reprinted copies of the MEAP forms. We like to maintain information on work using the MEAP. If you find applications for it, we would like to hear from you concerning your experiences and receive a copy of any relevant manuscript.

Good luck with your work,

Rudolf H. Moos, and Sonne Lemke

APPENDIX B

LETTER OF PERMISSION FOR USE OF THE SUPPORT GROUP EVALUATION  
FORM

(Alzheimer's Society of Manitoba).

# Alzheimer

Provincial Office  
Alzheimer Society of Manitoba  
205 Edmonton Street  
Winnipeg, MB R3C 1R4  
Bus. (204) 943-6622  
Fax. (204) 942-5408

Regional Office  
**Westman**  
First Street Plaza  
42 McTavish Avenue E.  
Brandon, MB R7A 2B2  
Bus. (204) 729-8320  
Fax. (204) 726-1082

Regional Office  
**South Central**  
Box 653  
394 - 6th Street  
Winkler, MB R6W 4A8  
Bus. (204) 325-5634

August 23, 1994

Ms Cheryl Nuytten

To Whoever It May Concern,

Cheryl Nuytten was given permission to use the Alzheimer Caregiver Support Group Evaluation and to make changes to it as was appropriate for her program.

Sincerely,

Wendy Schettler  
Support Group Coordinator

Charitable Registration  
#0666420-11

# MANITOBA

APPENDIX C

GENERAL WELL BEING SCALE

(U. S. Department of Health Education and Welfare, 1977)

# GENERAL WELL-BEING SCHEDULE (GWB)

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(U.S. Department of Health, Education and Welfare)

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE  
PUBLIC HEALTH SERVICE  
HEALTH SERVICES AND MENTAL HEALTH ADMINISTRATION  
NATIONAL CENTER FOR HEALTH STATISTICS  
HEALTH AND NUTRITION EXAMINATION SURVEY

## GENERAL WELL-BEING

a. Name (Last, first, middle)	b. Deck No. <p style="text-align: center;">171</p>	c. Sample No. <p style="text-align: center;">_ _ _ _ _</p>	d. Sex 1 <input type="checkbox"/> Male 2 <input type="checkbox"/> Female	e. Age <p style="text-align: center;">_ _</p>
-------------------------------	---	---	--	--

**READ** - This section of the examination contains questions about how you feel and how things have been going with you. For each question, mark (X) the answer which best applies to you.

<p>1. How have you been feeling in general? (DURING THE PAST MONTH)</p>	1.	(001)	<p>1 <input type="checkbox"/> In excellent spirits</p> <p>2 <input type="checkbox"/> In very good spirits</p> <p>3 <input type="checkbox"/> In good spirits mostly</p> <p>4 <input type="checkbox"/> I have been up and down in spirits a lot</p> <p>5 <input type="checkbox"/> In low spirits mostly</p> <p>6 <input type="checkbox"/> In very low spirits</p>
<p>2. Have you been bothered by nervousness or your "nerves"? (DURING THE PAST MONTH)</p>	2.	(002)	<p>1 <input type="checkbox"/> Extremely so -- to the point where I could not work or take care of things</p> <p>2 <input type="checkbox"/> Very much so</p> <p>3 <input type="checkbox"/> Quite a bit</p> <p>4 <input type="checkbox"/> Some -- enough to bother me</p> <p>5 <input type="checkbox"/> A little</p> <p>6 <input type="checkbox"/> Not at all</p>
<p>3. Have you been in firm control of your behavior, thoughts, emotions OR feelings? (DURING THE PAST MONTH)</p>	3.	(003)	<p>1 <input type="checkbox"/> Yes, definitely so</p> <p>2 <input type="checkbox"/> Yes, for the most part</p> <p>3 <input type="checkbox"/> Generally so</p> <p>4 <input type="checkbox"/> Not too well</p> <p>5 <input type="checkbox"/> No, and I am somewhat disturbed</p> <p>6 <input type="checkbox"/> No, and I am very disturbed</p>
<p>4. Have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile? (DURING THE PAST MONTH)</p>	4.	(004)	<p>1 <input type="checkbox"/> Extremely so -- to the point that I have just about given up</p> <p>2 <input type="checkbox"/> Very much so</p> <p>3 <input type="checkbox"/> Quite a bit</p> <p>4 <input type="checkbox"/> Some -- enough to bother me</p> <p>5 <input type="checkbox"/> A little bit</p> <p>6 <input type="checkbox"/> Not at all</p>
<p>5. Have you been under or felt you were under any strain, stress, or pressure? (DURING THE PAST MONTH)</p>	5.	(005)	<p>1 <input type="checkbox"/> Yes -- almost more than I could bear or stand</p> <p>2 <input type="checkbox"/> Yes -- quite a bit of pressure</p> <p>3 <input type="checkbox"/> Yes -- some - more than usual</p> <p>4 <input type="checkbox"/> Yes -- some - but about usual</p> <p>5 <input type="checkbox"/> Yes - a little</p> <p>6 <input type="checkbox"/> Not at all</p>

6. How happy, satisfied, or pleased have you been with your personal life? (DURING THE PAST MONTH)	6. (006) 1 <input type="checkbox"/> Extremely happy -- could not have been more satisfied or pleased 2 <input type="checkbox"/> Very happy 3 <input type="checkbox"/> Fairly happy 4 <input type="checkbox"/> Satisfied -- pleased 5 <input type="checkbox"/> Somewhat dissatisfied 6 <input type="checkbox"/> Very dissatisfied
7. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory? (DURING THE PAST MONTH)	7. (007) 1 <input type="checkbox"/> Not at all 2 <input type="checkbox"/> Only a little 3 <input type="checkbox"/> Some -- but not enough to be concerned or worried about 4 <input type="checkbox"/> Some and I have been a little concerned 5 <input type="checkbox"/> Some and I am quite concerned 6 <input type="checkbox"/> Yes, very much so and I am very concerned
8. Have you been anxious, worried, or upset? (DURING THE PAST MONTH)	8. (008) 1 <input type="checkbox"/> Extremely so -- to the point of being sick or almost sick 2 <input type="checkbox"/> Very much so 3 <input type="checkbox"/> Quite a bit 4 <input type="checkbox"/> Some -- enough to bother me 5 <input type="checkbox"/> A little bit 6 <input type="checkbox"/> Not at all
9. Have you been waking up fresh and rested? (DURING THE PAST MONTH)	9. (009) 1 <input type="checkbox"/> Every day 2 <input type="checkbox"/> Most every day 3 <input type="checkbox"/> Fairly often 4 <input type="checkbox"/> Less than half the time 5 <input type="checkbox"/> Rarely 6 <input type="checkbox"/> None of the time
10. Have you been bothered by any illness, bodily disorder, pains, or fears about your health? (DURING THE PAST MONTH)	10. (010) 1 <input type="checkbox"/> All the time 2 <input type="checkbox"/> Most of the time 3 <input type="checkbox"/> A good bit of the time 4 <input type="checkbox"/> Some of the time 5 <input type="checkbox"/> A little of the time 6 <input type="checkbox"/> None of the time
11. Has your daily life been full of things that were interesting to you? (DURING THE PAST MONTH)	11. (011) 1 <input type="checkbox"/> All the time 2 <input type="checkbox"/> Most of the time 3 <input type="checkbox"/> A good bit of the time 4 <input type="checkbox"/> Some of the time 5 <input type="checkbox"/> A little of the time 6 <input type="checkbox"/> None of the time
12. Have you felt down-hearted and blue? (DURING THE PAST MONTH)	12. (012) 1 <input type="checkbox"/> All of the time 2 <input type="checkbox"/> Most of the time 3 <input type="checkbox"/> A good bit of the time 4 <input type="checkbox"/> Some of the time 5 <input type="checkbox"/> A little of the time 6 <input type="checkbox"/> None of the time

<p>13. Have you been feeling emotionally stable and sure of yourself? (DURING THE PAST MONTH)</p>	<p>13. (013) 1 <input type="checkbox"/> All of the time          2 <input type="checkbox"/> Most of the time          3 <input type="checkbox"/> A good bit of the time          4 <input type="checkbox"/> Some of the time          5 <input type="checkbox"/> A little of the time          6 <input type="checkbox"/> None of the time</p>																							
<p>14. Have you felt tired, worn out, used-up, or exhausted? (DURING THE PAST MONTH)</p>	<p>14. (014) 1 <input type="checkbox"/> All of the time          2 <input type="checkbox"/> Most of the time          3 <input type="checkbox"/> A good bit of the time          4 <input type="checkbox"/> Some of the time          5 <input type="checkbox"/> A little of the time          6 <input type="checkbox"/> None of the time</p>																							
<p>15. How concerned or worried about your HEALTH have you been? (DURING THE PAST MONTH)</p>	<p>For each of the four scales below, note that the words at each end of the 0 to 10 scale describe opposite feelings. Circle any number along the bar which seems closest to how you have generally felt DURING THE PAST MONTH.</p> <p>15. (015)</p> <table border="1"> <tr> <td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>8</td><td>9</td><td>10</td> </tr> <tr> <td colspan="5">Not concerned at all</td> <td colspan="6"></td> <td>Very concerned</td> </tr> </table>	0	1	2	3	4	5	6	7	8	9	10	Not concerned at all											Very concerned
0	1	2	3	4	5	6	7	8	9	10														
Not concerned at all											Very concerned													
<p>16. How RELAXED or TENSE have you been? (DURING THE PAST MONTH)</p>	<p>16. (016)</p> <table border="1"> <tr> <td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>8</td><td>9</td><td>10</td> </tr> <tr> <td colspan="5">Very relaxed</td> <td colspan="6"></td> <td>Very tense</td> </tr> </table>	0	1	2	3	4	5	6	7	8	9	10	Very relaxed											Very tense
0	1	2	3	4	5	6	7	8	9	10														
Very relaxed											Very tense													
<p>17. How much ENERGY, PEP, VITALITY have you felt? (DURING THE PAST MONTH)</p>	<p>17. (017)</p> <table border="1"> <tr> <td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>8</td><td>9</td><td>10</td> </tr> <tr> <td colspan="5">No energy AT ALL, listless</td> <td colspan="6"></td> <td>Very ENERGETIC, dynamic</td> </tr> </table>	0	1	2	3	4	5	6	7	8	9	10	No energy AT ALL, listless											Very ENERGETIC, dynamic
0	1	2	3	4	5	6	7	8	9	10														
No energy AT ALL, listless											Very ENERGETIC, dynamic													
<p>18. How DEPRESSED or CHEERFUL have you been? (DURING THE PAST MONTH)</p>	<p>18. (018)</p> <table border="1"> <tr> <td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>8</td><td>9</td><td>10</td> </tr> <tr> <td colspan="5">Very depressed</td> <td colspan="6"></td> <td>Very cheerful</td> </tr> </table>	0	1	2	3	4	5	6	7	8	9	10	Very depressed											Very cheerful
0	1	2	3	4	5	6	7	8	9	10														
Very depressed											Very cheerful													
<p>19. Have you had severe enough personal, emotional, behavior, or mental problems that you felt you needed help DURING THE PAST YEAR?</p>	<p>19. (019) 1 <input type="checkbox"/> Yes, and I did seek professional help          2 <input type="checkbox"/> Yes, but I did not seek professional help          3 <input type="checkbox"/> I have had (or have now) severe personal problems, but have not felt I needed professional help          4 <input type="checkbox"/> I have had very few personal problems of any serious concern          5 <input type="checkbox"/> I have not been bothered at all by personal problems during the past year</p>																							



<p>20. Have you ever felt that you were going to have, or were close to having, a nervous breakdown?</p>	<p>20. (020) 1 <input type="checkbox"/> Yes -- during the past year  2 <input type="checkbox"/> Yes -- more than a year ago  3 <input type="checkbox"/> No</p>
<p>21. Have you ever had a nervous breakdown?</p>	<p>21. (021) 1 <input type="checkbox"/> Yes -- during the past year  2 <input type="checkbox"/> Yes -- more than a year ago  3 <input type="checkbox"/> No</p>
<p>22. Have you ever been a patient (or outpatient) at a mental hospital, a mental health ward of a hospital, or a mental health clinic, for any personal, emotional, behavior, or mental problem?</p>	<p>22. (022) 1 <input type="checkbox"/> Yes -- during the past year  2 <input type="checkbox"/> Yes -- more than a year ago  3 <input type="checkbox"/> No</p>
<p>23. Have you ever seen a psychiatrist, psychologist, or psychoanalyst about any personal, emotional, behavior, or mental problem concerning yourself?</p>	<p>23. (023) 1 <input type="checkbox"/> Yes -- during the past year  2 <input type="checkbox"/> Yes -- more than a year ago  3 <input type="checkbox"/> No</p>
<p>24. Have you talked with or had any connection with any of the following about some personal, emotional, behavior, mental problem, worries, or "nerves" CONCERNING YOURSELF DURING THE PAST YEAR?</p> <p>a. Regular medical doctor (except for definite physical conditions or routine check-ups) . . . . .</p> <p>b. Brain or nerve specialist . . . . .</p> <p>c. Nurse (except for routine medical conditions) . . . . .</p> <p>d. Lawyer (except for routine legal services) . . . . .</p> <p>e. Police (except for simple traffic violations) . . . . .</p> <p>f. Clergyman, minister, priest, rabbi, etc. . . . .</p> <p>g. Marriage Counselor . . . . .</p> <p>h. Social Worker . . . . .</p> <p>i. Other formal assistance: . . . . .</p>	<p>24a. (024) 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p> <p>b. (025) 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p> <p>c. (026) 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p> <p>d. (027) 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p> <p>e. (028) 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p> <p>f. (029) 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p> <p>g. (030) 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p> <p>h. (031) 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p> <p>i. (032) 1 <input type="checkbox"/> Yes - What kind? _____  _____</p> <p>2 <input type="checkbox"/> No</p>
<p>25. Do you discuss your problems with any members of your family or friends?</p>	<p>25. (033) 1 <input type="checkbox"/> Yes - and it helps a lot  2 <input type="checkbox"/> Yes - and it helps some  3 <input type="checkbox"/> Yes - but it does not help at all  4 <input type="checkbox"/> No - I do not have anyone I can talk with about my problems  5 <input type="checkbox"/> No - no one cares to hear about my problems  6 <input type="checkbox"/> No - I do not care to talk about my problems with anyone  7 <input type="checkbox"/> No - I do not have any problems</p>

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APPENDIX D- Sheltered Care Environment Scale (pgs. 183-187)

APPENDIX E

SUPPORT GROUP EVALUATION

(used with permission of the Alzheimer's Society of Manitoba)

## SUPPORT GROUP EVALUATION

(used with permission of the Alzheimer's Society of Manitoba)

The purpose of this questionnaire is to help us evaluate our meetings so we can better meet the needs of those attending.

We would greatly appreciate your responses to the following questions.

Please answer frankly so we can obtain an accurate impression of how our support group is currently doing.

1. Do you feel welcome at the meetings (circle one)?  
a) always   b) usually   c) sometimes   d) rarely
2. Check up to three main reasons for attending this group.
  - a) \_\_\_\_\_ to learn to cope with the behaviour of my relative's disease or condition.
  - b) \_\_\_\_\_ to learn how to cope with the way the condition/disease has affected my life.
  - c) \_\_\_\_\_ to understand myself better.
  - d) \_\_\_\_\_ to resolve specific problems.
  - e) \_\_\_\_\_ to gain new knowledge and information about the condition/disease.
  - f) \_\_\_\_\_ to learn about available community resources.
  - g) \_\_\_\_\_ to have contact with people in similar situations.
  - H) \_\_\_\_\_ other (please specify). \_\_\_\_\_
3. The group has talked about these concerns (circle one).  
a) not at all   b) somewhat   c) quite thoroughly
4. Do you feel the information shared in the group is relevant to the kinds of problems you encounter?  
a) very relevant   b) relevant   c) somewhat relevant   d) not relevant
5. How helpful is the support group in presenting ways to ease the problems you might encounter with your relatives disease/condition?  
a) very helpful   b) helpful   c) somewhat helpful   d) not helpful
6. After attending the meetings, how do you feel about your ability to cope with caring for an individual with a disease/condition?  
a) more able and confident   b) less able and confident  
c) same as before
7. Do you feel like you are a contributing member of the group?  
a) yes \_\_\_\_\_   b) no \_\_\_\_\_  
Why or why not? \_\_\_\_\_
8. The following are some of the benefits that people may get out of being in a family support group. Choose the three that best describe you gained from this experience. Number

them one to three with one equalling the greatest benefit.

- a) \_\_\_\_\_ I had a chance to get out and be with other people.
- b) \_\_\_\_\_ I was able to share with people who had concerns similar to mine.
- c) \_\_\_\_\_ I was able to help others.
- d) \_\_\_\_\_ I learned new facts and information about community resources.
- e) \_\_\_\_\_ I was able to evaluate and confirm some of my own attitudes and beliefs.
- f) \_\_\_\_\_ I was able to evaluate and change some of my own attitudes and beliefs.
- g) \_\_\_\_\_ I learned and actually tried out some new behaviours and ways of handling situations.
- h) \_\_\_\_\_ I feel better about who I am.
- i) \_\_\_\_\_ I gained new understanding of others' behaviours.
- j) \_\_\_\_\_ I seem to be getting along better with others.
- k) \_\_\_\_\_ I feel more accepting about my family member's illness.
- l) \_\_\_\_\_ I learned more about the condition/disease and its effects on my family member.
- m) \_\_\_\_\_ Other (please specify) \_\_\_\_\_

9. What do you like best about the support group?

\_\_\_\_\_

10. What do you like least? \_\_\_\_\_

\_\_\_\_\_

11. How would you improve this support group?

\_\_\_\_\_

12. In general, how would you rate this group experience?

- a) not very good   b) fair   c) good   d) excellent

## APPENDIX F

PERCENTAGE SCORES TO STANDARD SCORE CONVERSION TABLE  
BASED ON NURSING HOME RESIDENT SCORES  
THE SHELTERED CARE ENVIRONMENT SCALE

(Moos, R. H. & Lempke, S., 1992)

Nursing Homes (NH)  
Residential Care (RC)  
Independent Living Apartments (APT)

Percentage Score to Standard Score Conversion Table  
(Based on Resident Samples)

Percent- age Score	<u>Cohesion</u>				<u>Conflict</u>				<u>Independence</u>			
	Total Sample	NH	RC	APT	Total Sample	NH	RC	APT	Total Sample	NH	RC	APT
100	81	82	78	78	-	98	-	-	92	-	91	90
95	77	78	74	74	98	95	97	100	88	98	87	85
90	73	73	70	70	94	91	94	96	83	93	83	80
85	68	69	66	66	90	87	90	92	79	88	79	75
80	64	65	62	62	86	83	86	88	75	83	75	70
75	60	61	58	58	82	79	83	85	71	78	72	65
70	56	57	55	55	78	75	79	81	67	73	68	60
65	52	53	51	51	75	72	76	77	63	68	64	55
60	48	48	47	47	71	68	72	73	58	63	60	50
55	43	44	43	43	67	64	69	69	54	58	56	45
50	39	40	39	39	63	60	65	65	50	53	52	40
45	35	36	35	35	59	56	61	62	46	48	48	35
40	31	32	32	32	55	52	58	58	42	43	45	30
35	27	28	28	28	52	48	54	54	38	38	41	25
30	23	23	24	24	48	45	51	50	33	33	37	20
25	18	19	20	20	44	41	47	46	29	28	33	15
20	14	15	16	16	40	37	44	42	25	23	29	10
15	10	11	12	12	36	33	40	38	21	18	25	5
10	6	7	8	8	32	29	36	35	17	13	22	0
5	2	3	5	5	28	25	33	31	13	8	18	-
0	-	-	1	1	25	22	29	27	8	3	14	-

(Moos & Lempke, 1992)

(Continued)

Percent- age Score	<u>Self-Disclosure</u>				<u>Organization</u>				<u>Resident Influence</u>			
	Total Sample	NH	RC	APT	Total Sample	NH	RC	APT	Total Sample	NH	RC	APT
100	-	-	-	-	79	86	76	75	-	-	-	-
95	-	-	-	-	75	81	72	70	-	-	96	-
90	-	-	-	-	70	76	67	65	97	97	92	-
85	100	-	96	-	65	71	63	61	92	92	87	-
80	95	96	92	-	61	66	58	56	87	87	83	-
75	90	91	87	95	56	61	54	52	82	82	78	94
70	85	86	83	89	52	56	49	47	77	77	74	87
65	80	81	78	83	47	51	45	43	72	72	69	80
60	75	76	74	76	43	46	40	38	67	67	65	73
55	70	71	69	70	38	41	35	34	62	62	60	66
50	65	66	65	64	34	36	31	29	57	57	55	59
45	60	61	60	58	29	31	26	25	52	52	51	51
40	55	56	55	51	25	26	22	20	47	47	46	44
35	50	51	51	45	20	21	17	15	42	42	42	37
30	45	46	46	39	15	16	13	11	37	37	37	30
25	40	41	42	33	11	11	8	6	32	32	33	23
20	35	36	37	26	6	6	4	2	27	27	28	16
15	30	31	33	20	2	1	-	-	22	22	24	9
10	25	26	28	14	-	-	-	-	17	17	19	1
5	20	21	24	8	-	-	-	-	12	12	15	-
0	15	16	19	1	-	-	-	-	7	7	10	-

(Continued)



Percent- age Score	<u>Physical Comfort</u>			
	Total Sample	NH	RC	APT
100	68	75	64	64
95	64	70	59	59
90	59	65	55	53
85	55	60	50	48
80	50	55	45	42
75	45	50	41	37
70	41	45	36	31
65	36	40	32	26
60	32	35	27	20
55	27	30	23	14
50	23	25	18	9
45	18	20	14	3
40	14	15	9	-
35	9	10	5	-
30	5	5	0	-
25	0	0	-	-
20	-	-	-	-
15	-	-	-	-
10	-	-	-	-
5	-	-	-	-
0	-	-	-	-

## APPENDIX G

## SUPPORT EVALUATION RESULTS FROM THE RESIDENTS' GROUPS

Each Question will be covered and the number of responses to each will be noted. Eleven residents completed the evaluations and this was their responses:

1. Do you feel welcome at the meetings?
  - a) Always **6** b) Usually **4** c) sometimes **1** d) rarely **0**
  
2. Check up to three main reasons for attending.
  - a) **4** - to learn to cope with the behaviour of my relative with respect to my disease/condition.
  - b) **8** - to learn how to cope with the way the disease/condition has affected my life.
  - c) **5** - to understand myself better.
  - d) **4** - to resolve specific problems.
  - e) **4** - to gain new knowledge and information about the disease/condition.
  - f) **3** - to learn about available community resources.  
Means of All Variables of SCES For Resident Group 2
  - g) **3** - to have contact with people in similar situations.
  - h) **0** - other.
  
3. The group has talked about these concerns.
  - a) not at all **4** b) somewhat **5** c) quite thoroughly **2**
  
4. Do you feel the information shared in the group is relevant to the kinds of problems you encounter?
  - a) very relevant **4** b) relevant **2** c) somewhat relevant **5**
  
5. How helpful is the support group in presenting ways to ease the problems you might encounter with your condition/disease?
  - a) very helpful **4** b) helpful **1** c) somewhat helpful **6**
  
6. After attending the meetings, how do you feel about your ability to cope with your disease/condition?
  - a) more confident and able **5** c) same as before **6**

7. Do you feel you are a contributing member of the group?

a) yes **10** b) no **1** Why or Why not comments:

- we didn't have very many groups.
- contributing to the discussion about uniforms.
- talked about how I felt.
- because I have MS and feel I can share some of my experiences.

8. Choose three of the benefits which best describe what you gained from this experience.

- a) **6** - I had a chance to get out and be with other people.
- b) **4** - I was able to share with people who had concerns similar to mine.
- c) **1** - I was able to help others.
- d) **1** - I learned new facts and information about community resources.
- e) **0** - I was able to evaluate and confirm some of my own attitudes and beliefs.
- f) **1** - I was able to evaluate and change some of my own attitudes and beliefs.
- g) **3** - I learned and actually tried out some new behaviours and ways of handling situations.
- h) **2** - I feel better about who I am.
- i) **3** - I gained new understanding about others' behaviours.
- k) **1** - I feel more accepting of my disease/condition.
- l) **2** - I learned more about the disease/condition and its effects on my family members.
- m) **2** - other: Comments
  - learned about Speech Therapy.
  - I get to keep my own pills in my room.

9. What do you like best about the support group? Comments:

- Being around other people
- Going out with people.
- Liked the speech therapist.
- Someone actually listened to me.
- Learning about everything.
- Meeting people like me.
- A chance to meet other people with MS.
- Chance to get together and be a group member.
- Different opinions and opportunities to talk about them.
- Coffee
- Social gathering.
- Helpful ideas.
- Someone listened.
- Very supportive.

10. What did you like least? Comments:

- Timing was bad.
- Personality conflicts with some of the people there.
- Couldn't hear some people.
- Residents popping in that had nothing to do with the group.
- altercations people get into sometimes - very sad.

11. How would you improve this support group? Comments:

- Have speech therapist more often.
- Change the time and the day.
- More speakers and topics.
- More structured.
- Having everyone say how they feel before startup.

12. In general, how would you rate this group experience?

a) not very good 0 b) fair 2 c) good 7 d) excellent 2

## APPENDIX H

## SUPPORT GROUP EVALUATION FORM RESULTS FOR THE FAMILY

## GROUPS

Each question will be covered and the number of responses to each variable will be noted.

1. Do you feel welcome at the meetings?

a) always **10**

2. Check up to three main reasons for attending this group.

a) **6** - to learn to cope with the behaviour of my relative with his/her disease/condition.

b) **3** - to learn how to cope with the way the disease/condition has affected my life.

c) **1** - to understand myself better.

d) **2** - to resolve specific problems.

e) **4** - to gain new knowledge and information about the disease/condition.

f) **5** - to learn about community resources.

g) **8** - to have contact with people in similar situations.

h) **1** - other. Comments:

- to learn about Tache and Tache people.

3. The group talked about these concerns.

b) somewhat **1** c) quite thoroughly **9**

4. Do you feel the information shared in the group is relevant to the kinds of problems you encounter?

a) very relevant **6** b) relevant **3** c) somewhat relevant **1**

5. How helpful is the support group in presenting ways to ease the problems you might encounter with your relative's disease/condition.

a) very helpful **3** b) helpful **0** c) somewhat helpful **8**

d) not at all helpful **0**

6. After attending the meetings, how do you feel about your ability to cope with caring for an individual with the disease/condition.

a) more able and confident **9** c) same as before **1**

7. Do you feel like you are a contributing member of the group?

a) yes **10** b) no **0** Why or Why not? Comments:

- encouraged to meet and share with others in my situation.
- felt understood.
- hoped other members sensed my empathy for their situations.
- participation.
- sharing.
- sharing experiences.

8. Choose the three that best describe what you gained from this experience.

- a) **2** - I had a chance to get out and be with people.
- b) **8** - I was able to share with people who had concerns similar to mine.
- c) **2** - I was able to help others.
- d) **2** - I learned new facts and information about community resources.
- e) **3** - I was able to evaluate and confirm some of my own attitudes and beliefs.
- f) **4** - I was able to evaluate and change some of my own attitudes and beliefs.
- i) **3** - I gained new understanding of others' behaviour.
- k) **4** - I feel more accepting of my family member's illness.
- l) **1** - I learned more about the disease/condition and its effects on my family members.
- m) **1** - other. Comments:
  - got to know about other residents and their families.

9. What do you like best about the support group? Comments:

- meeting with people who have "walked in my shoes".
- session with Marilyn (HN) - could ask specific and practical questions.
- getting to meet various disciplines (Pharmacy, OT, PT, MD & clergy).

- mutual respect for similar problems with relatives in care of Tache.
- sharing ideas.
- everyone was sharing and expressing their feelings openly.

10. What did you like least? Comments:

- very positive experience.
- ten weeks - too long.
- time meetings started - rush after work.

11. How would you improve this support group? Comments:

- good idea to communicate more freely in or out of this context; may lead to more casual interactions.
- six weeks with written agenda - later follow-up session.
- prior notification to families by mail.
- social meetings away from institution.
- by continuing the group.
- learning how others handle some of the situations.

12. In general, how would you rate this group experience?

c) good 6 d) excellent 4

APPENDIX I

CONSENT FORM FOR VIDEO TAPING AND SUPERVISION OF GROUP  
SESSIONS



## CONSENT FORM

I, \_\_\_\_\_, have been informed that the group meetings will be video taped. I have been told that these video tapes will be used by the Tache Nursing Centre, Department of Social Work. The video tapes will be used exclusively for teaching and training purposes within the Department of Social Work. I understand that the video tapes will not be used outside of the Tache Nursing Centre. I agree to video taping of the group meetings I attend. I understand that the video tapes will be erased within one year from the last group meeting.

SIGNED \_\_\_\_\_

DATE \_\_\_\_\_