

EARLY STAGE ALZHEIMER'S DISEASE SUPPORT AND
SELF-ADVOCACY GROUPS: EMPOWERMENT WITHIN A
DISEMPOWERING DISEASE PROCESS?

by

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ABSTRACT

Historically, individuals with cognitive problems such as Alzheimer's disease (AD), and other forms of dementia, have had little say in determining the course of their own lives. Assumptions have been made by professional caregivers, family, friends, and government agencies (such as those responsible for social and health services), that people with AD, even in the early stages, are incapable of enunciating their own concerns and speaking on their own behalf. But times are changing and a growing number of people with dementia are developing organizational forums that will allow their voices to be heard. This project examines the development process of one such forum - support and self-help groups. The project is set within an emancipatory framework and is undertaken in the hopes that it will contribute to the empowerment and self-determination of persons with AD. The development process of a new support and self-advocacy group for people with early stage AD, established in Prince George in September 1999, is examined utilizing a case study format. A review of the literature relating to the formation of support and self-help groups for persons with cognitive problems both in Canada and internationally is presented, along with a case description of the formative months of the Prince George group (for which the author is a co-facilitator). A critical, retrospective case analysis of the group's development process is undertaken. Major themes, including new ageism, empowerment, group theory, practice challenges and policy issues, are identified and examined. A comparative analysis of the Prince George group and other early stage support groups (as presented in the literature review) suggests that early stage supports groups can play a positive role in facilitating the empowerment of persons with Alzheimer's disease and related dementias.

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Acknowledgment

This Master of Social Work Project, examining the process of development of a new support group for persons with early stage Alzheimer's disease, arises from many years of volunteering and working with older adults, and particularly those with cognitive difficulties. It is my firm conviction that the older generation, which has sacrificed in so many ways to create the society we live in today, deserves not only our respect and thanks but also the means to enjoy the best quality of life possible. I believe that support groups for persons developing memory issues are one small part of providing that quality of life. I hope that this report on the recent development of a group in Prince George will prove helpful to others who are beginning such groups and, thus, will assist people with Alzheimer's disease (and related dementias) to live happier and healthier lives.

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CHAPTER ONE

Setting the Stage

Introduction

The Canadian population is aging. In 1991, there were 3.2 million Canadians aged 65 years and over; that is, 11.6% of the total population. This figure is expected to reach more than 4 million, or 13%, by 2001 (Canadian Study of Health and Aging, 1994). An increasing number of people in this older population group have been diagnosed with dementia; that is, an acquired, persistent impairment in mental functioning affecting memory, language, and visuospatial skills along with emotion, personality, and judgement (Cummings, Benson & LoVerme, 1980). Numbers projected from the Canadian Study of Health and Aging (1994) suggest that, as of 1999, 316,500 Canadians (most over 65 years of age) are living with a form of dementia (Wickens, 2000). The number of older adults faced with dementia is expected to triple by 2030 (Canadian Study of Health and Aging, 1994). More than 60% of those experiencing dementia are diagnosed with Alzheimer's disease (AD), a progressive, irreversible and, currently, incurable form of dementia (Alzheimer Society of British Columbia, 1998).

As the babyboomers reach retirement age, federal and provincial governments and policy makers are increasingly being forced to acknowledge the need to address the psychosocial and health concerns of older citizens (Rock, 2000). However, it remains to be seen whether appropriate health care dollars will be allocated to provide needed services, particularly in a historical period when cost-cutting (particularly in the sphere of social spending) is on the agenda of all levels of government. Many seniors' organizations (e.g., the Council of Senior Citizens Organizations of British Columbia, the Old Age Pensioners

Organization of British Columbia and the national organization, the Association for the Fifty-Plus) lobby federal and provincial governments on behalf of older adults.

Unfortunately, the voices of seniors with cognitive problems often go unheard.

Assumptions are made that individuals diagnosed with dementia, even at early stages, are incapable of enunciating their own concerns and speaking on their own behalf. Perhaps not surprisingly, there is a paucity of research available that directly asks people with dementia about their concerns and whether their needs are being met (Cohen, 1991; Cotrell & Schulz, 1993).

But times are changing and a growing number of people with dementia are developing organizational forums that are allowing their voices to be heard. This project highlights one such forum; specifically, it examines the development process of a new support and self-advocacy group currently being organized with, and by, people with early stage Alzheimer's disease in the Prince George area. Although focused on individuals with early AD, it is hoped that this project will aid in developing a better understanding of the potential of similar support groups for individuals with other types of cognitive difficulties. The project is of particular relevance to, and in keeping with, the values and ethics of social work practice. The development of such support groups relates to the responsibility of social workers to facilitate the empowerment of all service users, including individuals with cognitive impairments, and to ensure that persons with dementia are afforded every opportunity possible to exert maximum control over their lives (Canadian Association of Social Workers, 1994; Congress & Lynn, 1997).

My Standpoint

Undertaking this project fits well with my own life, work history, and philosophical perspective. I was born into a family of social activists and, thus, was raised with a concern for social justice issues. That concern grew into my own activism at an early age. My grandfather, who had also grown up in an activist environment, was a big influence on my life. For me, he was a living example of the capacities of his generation. With my grandfather as a model of the wisdom and strength of older adults, I had a real shock, when as a 14-year-old junior high school student, I began working in the kitchen of a local nursing home. I can still remember pushing the food cart outside the kitchen door so that the care staff could deliver trays to the residents. What I observed outside that door was disturbing. Three wheelchairs were lined up, tied to the railing, and the three occupants were tied to their chairs. They seemed uncommunicative. There was an unmistakable smell of urine. I wondered how such a reality could exist in Canada in the 1960s. Contrary to everything I believed about the right of people to control their lives, these elders seemed to have lost any independence, self-determination and dignity. Out of that experience came the first research I ever conducted (but, of course, I did not know it was research). A friend and I decided to each “adopt” a person in one of those wheelchairs. We started to visit them after work. We talked and went for “walks” and brought our newfound friends presents on special occasions. The results were incredible. These residents, who had previously appeared to be in a zombie-like state, came alive. They began to smile, carry on conversations and reach for our hands when we came to visit. We were told by the care staff that these residents were even eating better. Since that time, I have been involved, in one way or another, with older adults, and particularly those with cognitive problems.

In addition to the fact that my own history and beliefs seem to naturally send me in the direction of this project, the biggest single impetus compelling me to do this work is the people who have AD. Time and time again people have said to me: “I want to keep my independence; I want control over the things that are happening to me”; “I’m still a person. Talk to me. Listen to me.” Similar themes are reflected in newsletters and books that carry interviews with people who have early stage AD (e.g., Alderton, 1998a, 1998b; Alzheimer’s Society of BC, 1999; Snyder, 1999). One of the most poignant quotes is from Henry, a member of the Kelowna support group, who recently spoke out in an interview with the Vancouver Sun (Wigod, 1999). In commenting on the need for early stage people to get organized, he said: “The person with Alzheimer’s disease is not unable to think...They treat us like idiots, like has-beens, and that’s not right. There are a lot of reasons for getting together and educating the public, starting with the family. We have to stop people from demeaning the likes of myself” (p.B11).

My Theoretical Lens: A Critical, Structural Social Work Perspective

This section will provide a brief overview of critical, structural social work (an in-depth analysis would require, at a minimum, a report unto itself) in order to clarify my general perspective and outlook. As its name suggests, a structural social work perspective identifies societal structures as being at the root of problems faced by oppressed peoples in our society. Rather than emphasizing individual pathology and the need for the person to change (as is often the case in conventional social work), a structural approach focuses (although not exclusively) on the need to change society as a means of alleviating individual problems. As part of the larger radical social work movement, structural social work (Carniol, 1992; Middleman & Goldberg, 1974; Moreau, 1979, 1989) was initially presented

as a variation on the ecological model (which examines the fit between the person and their environment). In Canada, it was Maurice Moreau who first formulated a structural approach to social work practice. Grounded in a contemporary Marxist analysis, heavily influenced by feminism, Moreau (1989) highlighted the need to recognize not only class divisions in society but also oppression based on gender, race, age, ability and sexuality. Further, Moreau attempted to present a structural perspective in relation to empowerment and progressive social work practice (Carniol, 1992).

Structural social work has now developed into an approach that encompasses aspects of both Marxism and social democracy as well as components of feminism, anti-racist practice and even postmodernism (Mullaly, 1997). Although these philosophical perspectives may seem incompatible, structural social work theory is designed to incorporate “the best” that each approach has to offer. Thus, a structural viewpoint can (and does) incorporate aspects of seemingly divergent philosophies. For example, at one end of the continuum of postmodernism are those who would argue that everyone’s reality is different and that it may not be possible for ‘unique’ individuals to unite in common cause to solve a societal problem, such as the oppression of older adults with dementia (Quicke, 1992). On the other hand, a structural approach advocates the unity of differing groups of marginalized peoples around common interests as a basis for social change, but it also embraces and promotes the aspect of postmodernism that highlights diversity and recognizes many voices (Leonard, 1994, 1995; Mullaly, 1997).

Fundamental to structural social work is critical theory that criticizes and provides alternatives to existing social, political and economic institutions, with a view to building a more equitable, egalitarian society. At the foundation of structural social work is a conflict

perspective (associated with Karl Marx) that portrays society as comprised of groups with opposing values and interests and which compete with one another for power and resources. The dominant group (capitalists) imposes its ideology, culture, practice and economic system on the subordinate group (workers and other oppressed/marginalized peoples). Thus, social problems do not originate with the individual but rather from the inequitable and oppressive structures and practices of the ruling elite. Central to the Marxist component of structural social work is its economic theory. This theory holds that, in a modern capitalist society such as exists in Canada today, making profits for a small but powerful minority of citizens takes precedence over meeting the basic day-to-day needs of the vast majority of people. As a result, there is a tendency to value people on the basis of their economic productivity. Within such a framework, older adults (and particularly those with disabilities) are devalued because they are viewed as less productive (read: less profitable) than younger, healthier members of society.

Whereas most traditional social science theory describes and attempts to explain social processes within the framework of purely positivist scientific inquiry, critical theory strives to change the world through the empowerment of oppressed individuals and groups, including recognizing the knowledge and insights of those living on the margins of society. According to Leonard (1990), three elements must be addressed when implementing critical theory and, thereby, enhancing the opportunity for empowerment of oppressed groups: (1) the source of oppression must be located in actual social practices; (2) an alternative vision free from oppression should be presented; and (3) the means to achieve the new vision must be understood and embraced by those who are oppressed. In this instance, the oppression of people developing dementia (and particularly early stage Alzheimer's disease) is located

within the dominant societal view that labels them “incapable” and dismisses or undermines any efforts toward empowerment; that is, control over their destiny. The alternative vision is one that recognizes the capacities of people who are developing cognitive problems and seeks out the ways to facilitate the maximum utilization of those capacities. This is not to deny that there is a disease process underway and that the condition of a person with AD will inevitably deteriorate, but rather to recognize that there is the possibility for empowerment, even within a deteriorating disease process. Although there are many aspects of the lives and experiences of persons with dementia that could be addressed within a critical, structural framework, the primary focus of this report is on the early stage AD support and self-advocacy group as one possible means of creating or enhancing conditions for empowerment.

In its most basic form, empowerment is usually characterized as a process through which oppressed persons reduce their powerlessness and gain more control over their lives (Mullaly, 1997). Simon (1990) suggests that empowerment (including the aspect of self-determination) is multifaceted and encompasses a personal, psychological component alongside a systemic, economic and political component. The individually-based dimension involves creating the conditions whereby people can be assisted to understand and overcome their oppression; for example, an older adult who has developed Alzheimer’s disease comes to understand not only the ageism inherent in the dominant culture but also the marginalizing and devaluing of persons with dementia. At a personal level, the consciousness of this oppression and its unjust character provides a framework within which older adults, facing a progressive dementia, can begin to exert control over their own lives. The systemic dimension of empowerment involves the coming together of persons with dementia (and

their supporters) to make the structural, societal level changes necessary to end the oppression and discrimination they are currently facing. Focusing on the development of the Prince George group as an example, this project will examine the impact of early stage support groups on both the individual and systemic dimensions of empowerment.

CHAPTER TWO

A Review of the Literature

Alzheimer's Disease: A Definition

Alzheimer's disease is an acquired, progressive and degenerative brain disorder that results in loss of memory, changes in behaviour, thinking and reasoning, and a significant decrease in overall functioning (Snyder, 1999). Unlike reversible dementias that sometimes accompany thyroid problems, infections, depression, and inappropriate medication use, AD is an irreversible dementia with no known cause or cure (Cummings & Benson, 1992). The course of AD is not the same with every individual but there is a tendency for the disease process to develop gradually over a period of years. Further, with diagnostic procedures improving, the disease is being identified much earlier on in the degenerative process than was possible in previous years. Thus, people are living with the disease for longer periods of time post diagnosis. Currently, individuals live an average of 8 years after diagnosis, but can live as long as 20 years or more (Snyder, 1999).

Many of these individuals are finding themselves diagnosed at a stage in life when they are still working and functioning fully in society. Such persons are often characterized as being at the early stage of the disease; that is, at a stage in which they are experiencing only mild impairments. Early stage is neither connected to age nor to the recency of diagnosis, but simply to level of impairment. Unlike people at the later stages of the disease process, who have limited capacity for introspection and comprehension, those at the early stage of AD are often aware and concerned about the cognitive changes they are experiencing (Yale, 1995). One method of coping with dementia is for people who have

been diagnosed to come together in a group to share feelings, information, and gain support from others in similar situations.

Group Work: What is it and How Does it Relate to the Early Stage Support Group?

According to Gladding (1996), a group involves a minimum of two people who have come together for a specific purpose that requires the interaction of group members. This coming together can take many different organizational forms. For example, a group may be leader-directed or participant-directed (that is, in the hands of the members or a professional facilitator), formal or informal (following a structured or more flexible format), open-ended or closed (accepting new members at any time or requiring a screening process with entry into the group only allowed at specific times), of fixed duration (for example, 10 sessions) or of indefinite duration (that is, members may participate for as long as they choose) (Jacobs, Masson & Harvill, 1998). Within a social work framework, groups afford an opportunity for practitioners to be creative in designing interventions that involve collective interaction, that focus on strengths and capacities and that promote social well-being through self-help and mutual-aid (Mesbur, 1999). More specifically, according to Shulman (1996), "group work has emerged as an important tool for service for many oppressed and vulnerable populations" (p. 17).

Although there are a wide variety of groups, seven major types can be identified. These include education groups, in which professionals provide clients with information on different topics; discussion groups, in which the focus is on discussing a particular topic rather than on a member's individual concern; and task-oriented groups, designed to accomplish a specific task. There are also growth and experiential groups for people who want to experience being in a group setting in which they can learn more about themselves

without necessarily having a particular problem or issue in mind as well as counselling and therapy groups which members join in order to address specific problems in their lives.

Finally, there are support groups, composed of members who share something in common and who want to share their feelings with each other, usually under the direction of a professional and self-help groups, similar to support groups except that the leadership comes from non-professionals who share the same interest, concern or problem as other group members (Jacobs, Masson & Harvill, 1998).

For the purposes of this project report, the focus will be on support and self-help groups, terms that are often used interchangeably. In general, a support group is described as a voluntary organization established to help members cope with life stresses (for example, life transitions and chronic conditions) through strengthening coping skills in a group setting (Toseland & Rivas, 1995). Oftentimes, support groups are facilitated by professionals but there is also an increasing number facilitated by volunteers. Self-help groups are often presented as distinct from support groups because in self-help groups organizational leadership is provided by group members rather than by a paid professional. However, in practice, clear lines of distinction are often absent and groups often share aspects of both support and self-help (Toseland & Rivas, 1995). For example, a professionally run support group may have a component that is facilitated by a group member or group members may pair up in a "buddy" system to provide support outside group meetings. In the examples of early AD support groups provided in the literature review, there are a range of practice techniques and objectives represented, including some groups which are making specific efforts to exert their right to self-determination through both education and self-advocacy and others focusing primarily on education and support. In terms of the Prince George

group, it would seem that it is a hybrid formation with components of both support and self-help. Whether or not a group explicitly adopts a goal of empowerment, a major goal of all early stage groups is to put more control into the hands of the person with dementia (Synder, 1999). Having increased control creates the conditions for increased self-determination, including self-advocacy.

Self-determination and Self-advocacy

Within the context of social work, self-determination is an element of empowerment, of taking control of one's own life. Specifically, self-determination is defined as "the practical recognition of the right and need of clients to freedom in making their own choices and decisions" (Biestek, 1957, p. 103 cited in Hepworth, Rooney & Larsen, 1997). Advocacy is defined as "the process of working with and/or on behalf of clients to obtain services or resources that would not otherwise be provided; to modify existing policies, procedures, or practices that adversely affect clients, or to promote new legislation or policies that will result in the provision of needed resources or services" (Hepworth, Rooney & Larsen, 1997). There are two types of advocacy: case advocacy (directed at the needs of a particular individual or family) and class advocacy (directed at changes in policy, practice or laws that affect an entire group of people). Class advocacy could be characterized as a form of social action. Although these two types of advocacy have distinct definitions, the fact of the matter is that, in practice, they are often connected (Hepworth, Rooney & Larsen, 1997). For example, fighting for the right of an individual with AD to receive particular home support services may not only impact on that individual but may also play a role in changing the policy for others. Self-advocacy involves the same concepts and definitions as advocacy except that service users advocate on behalf of themselves (for

example, in an early stage support group) rather than others advocating for them (or at least the service users play a major role in partnership with other advocates). Of course, any efforts to enhance self-determination or to self-advocate take place within, and are affected by, a definite societal context.

The Societal Context

Within the social service and health care fields, empowerment and self-determination for service users has increasingly become a hallmark of practice. In contrast to the paternalism of years past, the preservation of autonomy for people who are ill and/or dependent has become a principle of modern ethics over the past 20 years or so (Rice, Beck, & Stevenson, 1997). The proclamation of the right to self-determination purports to place the service user at the centre of the decision-making process. However, application of this principle has not always been fully implemented with older adults and particularly those with cognitive difficulties (Rosin & Sonnenblick, 1998). In fact, an examination of the literature suggests that, while there are many advocates for the rights of those with cognitive problems, there are few occasions on which those with AD are asked to become involved in directing their own lives (Cohen, 1991; Cotrell & Schulz, 1993). Assumptions have been and continue to be made that people with a dementia no longer have the capacity or the right to make decisions that affect them (Snyder, 1999). Social workers and other caregivers tend to respond to the individual's increasing cognitive difficulties by consciously (or unconsciously) making more and more choices and decisions for that person. This, in turn, can have a snowball effect, with the individual becoming even more dependent on the caregiver (Chapman, 1993).

Until recently, even large advocacy organizations, such as the Alzheimer's Society, have not directly involved those with AD in the fight for change. Support group activity and advocacy work has primarily been undertaken with caregivers and not with individuals who have AD. At first glance, organizing in this way may seem logical and necessary. After all, people with AD do have impaired cognitive abilities. However, it is important to recognize that there is a continuum of cognitive impairment in those with dementia. For example, in the case of AD, an individual can be at an early stage of the disease, with measurable cognitive deficits, but still be able to continue to work and live independently (Selbie, 2000; Snyder, 1999). Unfortunately, once the diagnosis is made and the "dementia" label given (even if it is early on in the disease process), caregivers and friends often overlook the person's significant skills and abilities that are still intact (Harding & Palfrey, 1997). Of course, as the disease progresses, cognitive functioning will deteriorate further and independent functioning will become more difficult. But adopting a view that emphasizes *incapability* rather than *capability* denies the right of persons with dementia to maintain control of their own lives for as long, and in as many ways, as possible.

In line with the *capability* view, there is a small but growing number of people with early stage dementia (in particular, early stage AD) who are organizing to take control of their own lives. Support and self-advocacy groups are springing up in Canada and internationally (Selbie, 2000; Snyder, 1999; Yale, 1991, 1995). However, these groups face a daunting task because their development flies in the face of the dominant political, economic, social and cultural outlook of modern capitalism which views older adults (and certainly those with cognitive deficits) from a perspective of loss, degeneration, incapability and, generally, as non-contributors to, and a burden on, society at large. Cohen (1990)

suggests that one impediment to empowerment for older adults is the dominant societal view that regards older adults as being in a state of irreversible physical and mental decline and, thus, increasingly in need of outside assistance. This dominant view undermines efforts by older adults to fully develop and maintain their own empowerment and self-determination. Rosenfelt (1965) characterized this societal attitude toward older adults as the "elderly mystique". Today, it is more commonly referred to as "ageism". In recent years, some advances over this mystique have been made, especially among older adults who remain healthy later in life. It is elderly persons with disabilities (such as dementia) that are increasingly becoming the main targets of new ageism (Cohen, 1990).

Facilitating the empowerment of a person with dementia, and safeguarding their right to self-determination, is a complex but necessary process, if the individual is to be afforded the same rights as all other citizens. Groups, particularly those based on the self-help, mutual aid model (Hoehne, 1988; McKnight, 1995), seem to provide a mechanism through which people with cognitive problems can support one another in a safe environment as well as initiate self-advocacy work. Establishing groups specifically for early stage people is still relatively new. In 1992, Robyn Yale, a clinical social worker and pioneer in the area of early stage AD support groups, undertook a pilot study at the University of California to assess benefits of such groups. She found that there was an overwhelming sentiment amongst study participants (and their caregivers) that sharing feelings and concerns with others in the same predicament was helpful (Yale, 1995). However, since that time, there have been few published studies specifically examining early stage support groups (Trabert, 1996). Yale's (1995) California-based work focuses on support groups that are run by professionals and "provide a therapeutic environment for the participants in which changes in lifestyle may be

openly discussed, information and reassurance about symptoms offered, and community resources to assist with problem solving identified” (p.7). Trabert’s model (1996) (also California-based) takes on a club format that includes social activities as well as a support component over 10 weekly sessions.

More recently Canadian support groups, such as those in Thunder Bay, Kelowna, Vernon, Salmon Arm and Prince George, are developing frameworks that are more participant-directed. These groups consciously work toward empowerment and incorporate elements of community education and self-advocacy in relation to absent or inadequate government policies and services for persons with dementia.

Early Stage AD Support Groups

The following is a brief survey examining a variety of early stage groups in Canada and internationally. In reviewing this material, it is important to keep in mind that the work of early stage groups is recent and, therefore, literature about developments to date is somewhat scarce. Further, there are inherent difficulties in objectively evaluating the success of support groups in a population that is in the midst of a degenerative cognitive process. Thus, the information about these groups tends to be somewhat informal and located primarily in organizational minutes/notes, Alzheimer-related newsletters or passed on by word of mouth between activists in different Alzheimer organizations. As a result, the same level of information is not available on all groups. Further, although all the groups presented are characterized as support groups for people with early stage AD, there are substantial differences between these groups.

Memory Discussion Group in South Australia

The South Australia group is a six-week educational support group for people just diagnosed with AD and for their family members. As described by Philip Alderton (1998a, 1998b - who has early stage AD himself), the six weeks of "classes" cover such things as early symptoms, assessment and diagnosis; adapting to life changes that result from memory loss (including practical strategies for coping); planning for the future; and, finally, stress management and relaxation. Philip went on to say that the discussion group provided a safe place to talk with others in a similar situation and was a good source of information for all.

Younger person's group in Grampian, North East Scotland

In 1996, Alzheimer Scotland-Action on Dementia staff identified five relatively young people (under 60 years of age) with dementia who seemed to have a lot in common with each other and yet had needs and interests that were different from the older cohort (Younger person's group in Grampian, North East Scotland, 1998). After talking with these people (all of whom were men) and their partners, it was decided that there were two primary concerns that everyone wanted to address. First, there was a need for an opportunity to talk with others in a similar situation both about the disease and its early onset. Second, there was a desire to keep doing "normal" things such as outdoor activities, movies, visiting a pub and generally enjoying activities in which people in mid-life participate. There was also a desire on the part of both the partners and those with AD to be able to socialize in a safe environment where small, disease-related faux pas would go unnoticed or be accepted. Thus, it was decided to begin an informal mutual support group that also included a lot of outings in its activities. Facilitators from Alzheimer Scotland take care of the technical details but group members decide what kinds of activities they want to

undertake. Perhaps the success of the group to date is best summed up by the comments of one of its members: "Having this illness is a lonely experience, even when you have a close family who gives you a lot of love. There is part of me that they can't reach or understand, but when I'm with my buddies I don't have that lonely feeling because they can understand me" (Younger person's group in Grampian, North East Scotland, 1998, p.5). It should be noted that this group receives no government funding and, as a result, members must pay to attend. The amount varies depending on the activities undertaken, but the fact that there is a charge limits the types of activities that can be undertaken as well as excludes some potential members who are unable to afford the cost.

The CARE Club, Granada Hills, California, USA

The CARE Club is a program designed by the Center for Aging Research and Evaluation at the Granada Hills Community Hospital specifically for people at the early stages of AD (Santa Barbara Alzheimer's Association, 1998). The Club is designed to provide an opportunity for newly diagnosed people to work through their feelings of loss, anger and frustration and provide them a chance to engage in positive social activities and develop new friendships. The focus is on the interests, assets, skills and abilities of the participant, not on their losses. In addition to community outings such as to museums and theaters, the Club also provides physical and speech therapy as well as two weekly counselling/therapy groups. Individual therapy is also available, if needed. Intake is limited to 15 people and each potential participant must go through an initial screening and cognitive assessment to ensure that they are still at the early stage of the disease and, thus, appropriate Club members. Although the hospital provides space for the group to meet, there is a charge of approximately fifty dollars per day. Thus, once again, the cost is

prohibitive for many potential Club members. One other difficulty specified by Club staff is that of telling a member, and his or her family, that the person no longer fits into the program (i.e., the disease has progressed too far). This has been proven to be a stress for staff, Club members and family caregivers (Santa Barbara Alzheimer's Association, 1998).

Diablo Respite Center Club (DRC Club), Walnut Creek, California, USA

The DRC Club is a support group that was initiated by a social worker at a respite center who observed that people at the early stages of AD were not being well served by existing adult day health or social programs. For example, unlike people at a more advanced stage of the degenerative process, the early stage people tended to be younger and functioning at a relatively high level, in many cases, still being employed (Trabert, 1996). There appeared to be a real need for them to have an opportunity to get together with others in a similar situation. Club activities include members providing support to each other and participating in a variety of outings. The Club, which began in 1994, is made up of seven women. The all female composition came about simply because all the initial applicants were women and it seemed to work well. (A separate men's Club was also established once enough men had applied.) Limiting the group to seven participants came about due to staffing issues and technical matters such as only two cars being available for field trips. The Club operates in 10-week sessions with a 3-week break in between to allow for recruitment of new members and to allow staff a break from the intensity of working daily with people experiencing the trauma of newly diagnosed AD. There is a screening process. Participants must acknowledge that they have memory loss or impaired thinking and must be willing and able to take part in support group discussions and field trips. Members can (and do) rejoin after a 10-week session (if they still meet the criteria) and the group has an open-ended

structure so that new members can also join in the course of a 10-week session should an opening occur. Fees are paid on a sliding scale so as not to exclude those who are less able to pay.

Long Island Alzheimer's Foundation, New York, USA

An innovative group was launched in Long Island in the summer of 1998; specifically, an on-line chat group for people with early stage AD was begun (Snyder & Yale, August – October 1998). The chat room is private and potential participants have to go through a screening process in order to receive the password that allows entry. Although a relatively new means of support, the initial response has been positive. One particularly helpful feature of the chat room is the links it provides to up-to-date, on-line information about Alzheimer's disease; that is, its educational aspect. The chat room also makes it possible to engage in completely confidential discussion with others at the early stage of the disease. Total anonymity is something that traditional, face-to-face support groups cannot provide. However, it would seem that one downside of the on-line chat group would be the lack of direct human contact. Another would be the cost of acquiring a computer and Internet access. As well, since AD tends to attack older adults, there are those who have never had the opportunity to learn about or work with computers. Learning such skills late in life, while at the same time trying to deal with declining cognitive functioning, may be an insurmountable obstacle for some. Nonetheless, for someone living in a remote area of northern British Columbia, it might be a welcome opportunity.

Penticton Early Stage Support Group, Penticton, BC, Canada

The Penticton group was formed in 1997 and utilizes a closed-group, fixed time period format. Each session lasts 10 weeks with intake of new participants at the beginning

of each session. Each participant must acknowledge that she or he has been diagnosed with Alzheimer's disease and be willing and able to participate in support group discussions. The group meetings are structured so that both the person with AD and her or his caregiver participate but are in different rooms. Both groups come together for a coffee break and social time at the mid-point of each session. The sessions have a structured educational component followed by a time to share experiences and feelings with each other (Penticton Early Stage Support Group, May 1998).

Thunder Bay Early Stage Support Group, Thunder Bay, Ontario, Canada

The early AD support group in Thunder Bay, Ontario is an example of a group that has chosen not only to provide support through sharing experiences and being there for each other, but also to raise awareness in the community as a whole and to self-advocate for change. For example, in 1997, group members compiled a document, entitled "Words of Advice", in which they shared insights into some of their own experiences and how they have coped and lived with AD. In order to make their information available to other people with AD and to the general public, the group published the list of advice in the form of a bookmark. Bookstores throughout the region made it available to the public during Alzheimer Awareness month in January 1997 (Puurunen, 1998). Another action of the support group was to write a letter to local physicians outlining some of the frustrations that people with AD feel when being assessed by their doctors. The letter also served as a reminder that, despite the cognitive difficulties they might be having, there is a living, caring person behind the AD symptoms. Some of the suggestions made to the physicians included that they should listen more carefully when the person with AD is talking as well as be more sensitive when explaining about the disease to the patient. Also key was "[not treating]

elderly people as if they are stupid” and “allow[ing]...time to explain...problems” (Thunder Bay Early Stage AD Support Group, 1998, p. 7).

Early Stages Support Group (ESSG), Kelowna, B.C., Canada

The Alzheimer’s Society in Kelowna initiated the ESSG in March 1999 with four participants and two staff/volunteers. With a large seniors population in the area, and an increasing number of people with early stage AD approaching the Alzheimer’s Society for support, a need was identified. From the outset, the group not only had the issue of support, but also education and self-advocacy, on its agenda (Phylliss Dyck, Regional Representative, North/Central Okanagan, Alzheimer Society of B.C., personal communication, August 17, 1999). Point seven of its initial statement of unity is particularly revealing, especially in reference to the group members’ desire to influence public policy and to advocate for themselves.

“7. How will we protect the integrity of the group?

- * By ensuring that we help each individual with their specific challenges; to provide advocacy and group support to individual issues;
- * By becoming “pioneers” for the cause; by recognizing that we have a cause to live and work for;
- * By respecting each other’s most personal feelings;
- * By looking for opportunities, as a group, to influence law makers and government;
- * By finding advocates to help the group state its cause and purposes;
- * By educating the public at large to remove the stigma associated with the various dementia diseases” (Kelowna Early Stages Support Group, 1999).

These guidelines are reflected in the activities undertaken by group participants. For example, two members, Norma (a former teacher) and Henry (a former physician) have been speaking out publicly about their condition and about the need for more public education and services. In addition to being interviewed on television and through the print media, Norma and Henry, along with other support group members, have also initiated a series of

panel discussions to inform physicians, and other health and human service workers, about the situation faced by people with early stage dementia (see Appendix A). The group is currently considering videotaping these discussions and making them available to other early stage support groups throughout BC and the rest of Canada.

In addition, Kelowna hosted an Early Stage Dementia Conference in May 1999, the first of its kind in Canada. Themes arising from the morning brainstorming session included the need for more education (both for families and for the public), to “gather our own to have clout” (connecting with others who understand and support); and also to change the “picture” of Alzheimer’s disease (Alzheimer’s Society of BC - North Central Okanagan Region, 1999). Specific ideas included beginning an early support group newsletter; contributing to the provincial Alzheimer Society newsletter; speaking to service clubs and health and human services workers in order to educate and raise funds; and building a bigger network of people with early stage AD. In addition, the conference participants decided to go for maximum participation at the Provincial Alzheimer Society Conference in May 2000, including having early stage people make conference presentations. The work of the Kelowna group has had its impact throughout the region with new groups of similar character recently being established in both Vernon and Salmon Arm. It is particularly exciting and encouraging to note that the new groups were organized by Norma and Henry, members of the original Kelowna group.

With this background information in mind, the next chapter addresses the method utilized in developing the current project report.

CHAPTER THREE

Method

The current project examines the process of development of the Prince George early stage AD support and self-advocacy group from September 1999 to June 2000 as seen through my own eyes and experience. It takes the form of a case study, but a modified case study, as prescribed by the UNBC Social Work Program Handbook (Tang, 2000). The principle component of the modified case study approach is the researcher's critical reflections and analysis of a specific practice experience. However, before examining the application of this modified method in more detail, a description of traditional case study research is provided along with an explanation of why a case study approach is appropriate for the current research.

The Traditional Case Study

Defining case study research is not an easy task. There are many and varied definitions available. However, I will attempt to highlight key features that are common to most definitions. According to Moon and Trepper (1996), case study methodology restricts the researcher's attention to a small number of purposively selected cases (or a single case) that are (is) studied in depth. Cases can be tightly bounded systems such as that of an individual client or more loosely bounded as in the study of events or time periods. According to Merriam (1988), although case study design can be utilized by researchers engaging in both qualitative and quantitative work (and from a variety of disciplinary and philosophical perspectives), there is a tendency for case study research to be qualitative (or descriptive) research in which the objective is to describe and explain rather than to predict or identify cause and effect (a quantitative approach). Within the qualitative framework, it is

more likely that the direct voice of the research participants will be heard, either exclusively or filtered through the lens of the researcher. Data collection methods are varied and can include case notes, journals, audio-visual materials, interviews, observations, field notes, memories, reflections and other documentary materials (Merriam, 1988; Moon & Trepper, 1996; Stake, 1994).

Furthermore, in the field of research, there is considerable pressure to verify the scientific validity of findings; that is, to establish a high level of rigor. In case study research, rigor can be measured in terms of: truth value (internal validity) -- that is, the extent to which findings match reality; transferability (external validity) -- that is, the extent to which findings can be generalized beyond the case; and consistency (reliability) -- that is, the extent to which the findings can be replicated (Lincoln & Guba, 1985). In order to increase the truth value of case study research, Merriam (1988) suggests triangulation (use of multiple sources of data or multiple methods), participant review of data, long-term observation, peer examination, participatory research and acknowledgment of the researcher's own standpoint. Two techniques that increase generalizability include providing rich, thick description (so that adequate information is present to allow for the possibility of transferability) and choosing to describe the 'typical' case (so as to allow others to make comparisons with their own situation) (Merriam, 1988). Finally, in terms of reliability, Merriam (1988) suggests that the researchers should explain their bias and the logic for selecting the particular case, use multiple methods of data collection and analysis (triangulation) and keep a detailed record of the case and research methods (an 'audit trail') that other researchers can review and potentially reproduce.

According to Yin (1994), the case study method is particularly appropriate when examining contemporary and/or unique events (for example, new AD support and self-advocacy groups) in which behaviours can neither be manipulated nor controlled. Merriam (1988) suggests that a case study approach is often preferable when addressing problems “in which understanding is sought in order to improve practice” (p. xiii) as is the case with these support groups. Thus, the general framework of a case study appears to be appropriate for the current research.

A Modified Case Study Approach

At the heart of the modified case study is the student’s critical reflection and analysis of a bounded case (Tang, 2000). The case may be an individual, a group, a process or a policy, but it must have identified boundaries. Usually, the case selected is one with which the researcher has had intimate experience, either in her student practicum or in her own professional practice. Unlike traditional case study research, the social work project option usually does not involve structured data collection, such as in-depth interviews with study participants, but rather consists of a critical (and, most often, retrospective) reflection on a specific practice experience through the eyes of the practitioner. Thus, data sources tend to be based on the researcher’s direct experience, either in the form of personal observations, reflections and recollections or documentary records. These data are analyzed in the context of a review of the related literature and filtered through the lens of the researcher’s epistemological framework.

Similar to traditional case study research, the modified social work case study is not wed to a particular philosophical outlook. Thus, it allows students of different epistemological stances to undertake projects that reflect their own perspectives. Yet, I

would argue that the seemingly "neutral" philosophical stance of the modified case study is not really "neutral". For example, because the social work case study is usually a retrospective seen primarily through the eyes of the student, it does not directly highlight the voice of study participants. Thus, for a researcher (such as myself) who adopts a critical structural stance, although the modified case study approach is workable, it is not a perfect fit. The modified design allows for a critical structural analysis to be presented but, unfortunately, does not accommodate hearing the direct, unfiltered voices of the research participants.

In this report, the case examined is the Prince George early stage AD support and self-advocacy group; in particular, the first nine months of its operation. I am a co-facilitator of the group, along with the regional representative of the Alzheimer Society. Group members are supportive of the research being undertaken with the proviso that group members will not be identified. At the outset, it is important to highlight the fact that, although a modified case study can be conducted from a variety of philosophical perspectives, I place my research in an overall emancipatory framework; that is, I undertake the study with the hope of contributing to the empowerment of people with AD. In applying the modified case study approach, the unit of analysis for the research is the group. However, the particular focus is on studying and providing a critical analysis of the process of group development.

The project is grounded in a search of the literature relating to the establishment of support and self-help groups for people with cognitive difficulties (within a framework of empowerment) including any documentary records and newsletters available from the groups across Canada and internationally as well as from the Prince George group. Based

on my direct practice experience and the related literature, a critical, retrospective reflection and analysis is undertaken, including the development of key themes and related practice and policy recommendations. On the one hand, because of the modified nature of the case study conducted and the 'newness' of early stage AD support groups (particularly those with an emphasis on self-direction by group participants rather than by professionals), there are limitations to the generalizability of the research. In other words, my analysis of the Prince George experience may not reflect the experiences of, nor be applicable to, other groups. On the other hand, precisely because early stage groups are relatively new, literature regarding their development is scarce. Thus, although the story is told by the researcher (rather than directly by the group participants), it is expected that this modified case study will have both academic and clinical utility. Specifically, it is hoped that this report will contribute to the development of literature about early stage groups as well as provide some insight and practical assistance for the future group-building.

Ethical Considerations

Because the research method utilized in this project is a critical reflection on a case as seen through the eyes of the researcher, it might seem that ethical considerations or concerns would be relatively minor (particularly given the fact that the reflection is focused on group process and does not identify individual participants). However, given that support group members have been diagnosed with an irreversible dementia a cautious approach is proposed. In addition to obtaining ethical approval from the UNBC Ethics Review Committee, support group members (and their legal representative, where applicable) received an information sheet that outlined the nature and scope of the research project and were asked to sign a consent agreeing to participate (see Appendix B). Steps

were taken to make information about the project as accessible as possible (Ebersole & Hess, 1998). Specifically, both the information sheet and consent form were written in non-jargonistic language and printed in a large size font. Further, as much time as necessary was taken in order to ensure that the participant and/or legal representative understood what the proposed project would entail. For example, participants were encouraged to take the information home to study and review prior to consenting. The researcher also verbally explained the project to participants and fielded any questions. Finally, in order to evaluate whether the scope of the project and the nature of participation required are understood, the researcher posed key questions to the participants and/or legal representatives before the consent form was completed. The other co-facilitator of the support group (who is also a local Alzheimer Society representative) was also asked to give her consent to participate in the project. Finally, it should be noted that the Board of Directors of the local Alzheimer's Society, under whose auspices the support group operates, has lent its support to the project.

CHAPTER FOUR

The Case: A Memory Issues Group in Northern British Columbia

Preparatory Phase

Discussion regarding the possibility of a support group for people with early stage AD in the Prince George area began in 1998, primarily among volunteers and members of the local Alzheimer's Society. There was a growing sense amongst local members of the need to provide a forum for people diagnosed with AD. Up to that time, the primary local focus had been supporting families and caregivers, who in turn helped the person with AD. But there was no organized forum for the people with AD themselves. A growing familiarity with groups that had been organized in California (Trabert, 1996; Yale, 1995) and more recent news of a group beginning in Penticton, BC (Penticton Early Stage Support Group, May 1998), prompted a conscious effort on the part of the Prince George Alzheimer's Society to find volunteers willing to take on the responsibility of helping establish a support group for people with AD. However, it was not until 1999, when the spouses of two people with AD approached the local society to ask if such a group existed, that the first organizational steps were taken to begin the group.

The first task undertaken was to determine who would be the group facilitators. One facilitator was to be the Alzheimer Society Regional Representative (based in Prince George), but there was also an effort to find a volunteer to become co-facilitator. In this instance, it was myself, a Master of Social Work student, an active member and volunteer with the society for several years and, at that time, the coordinator of a research project at the University of Northern British Columbia that focused on persons in the early stages of memory loss and, specifically, those with Alzheimer's disease.

Both myself and the other facilitator had been involved in discussions about the growing movement of early stage AD support groups and had some familiarity with the variety of group models being adopted in other centres; that is, models ranging from structured, facilitator-directed, closed groups (e.g., Yale, 1995) to relatively more informal, participant-directed, open groups (eg., Selbie, 2000). Initial one-on-one discussions between both facilitators confirmed that there was unity of thinking regarding the model to be adopted; specifically, a participant-directed group such as those that were successfully underway in Kelowna, Vernon and Salmon Arm (Selbie, 2000). This approach was not only in line with the self-help model guiding the Alzheimer Society's caregiver support groups, but also with my own philosophical perspective. However, although both facilitators were familiar with, and had copies of, the mission statement and goals of the Kelowna group, a conscious decision was made not to take a pre-existing format or set of goals (such as those available from Kelowna) to the Prince George group for approval but rather to take the time necessary for a participant-directed local format and character to emerge.

However, other (albeit tentative) decisions were made by the facilitators prior to the first group meeting. For example, unlike some groups in which family members and individuals with memory loss meet simultaneously and come together during a designated break time, it was decided that, in order to put ownership of the group firmly in the hands of those who joined, family members or caregivers would not be part of the Prince George group (at least, initially). Our thinking was that, if the group was to belong to its members, it would be important for members to have a time to themselves, including an informal coffee time. However, once the group was underway, members would be able to change the format if they chose to do so. In addition, other tentative logistical decisions, such as

meeting location (Alzheimer's Society office) and frequency (once a month) and length of meetings (one hour), were also made by the facilitators. Although gatherings were to be located at the office, it was decided to hold group meetings after office hours (at 2 PM) for the privacy and comfort of participants. No budget was required because neither facilitator was to be paid for assisting with the group (although, the Alzheimer's Society representative was an employee and would include group facilitation in her working hours), the meeting space was free of charge and the Society agreed to cover the cost of any other expenses such as advertising and refreshments.

The next step was to recruit people interested in participating in the group. Four main methods were employed. These included contacting the people associated with the local Alzheimer's Society who had inquired about having such a group, placing announcements in local media, providing information to local health care professionals working specifically with older adults, and, finally, letting participants in the UNBC Memory Project (coordinated by the author) know about the launching of this new group. From the outset, although advertised as a group for people with early stage Alzheimer's disease, a decision was made to open the door to anyone developing memory problems. Thus, there was no formal screening or admission process adopted that would require participants to have a probable Alzheimer's disease diagnosis or to provide medical documentation. To start, this decision was designed to make the group accessible to people who had not yet contacted a physician about memory concerns, but who had noticed substantial changes. As well, it recognized the fact that there is often variation in the type and amount of information provided by physicians to their patients who are experiencing memory problems. Some patients may be given a diagnosis of dementia or probable AD. Others may be told they

have short-term memory loss or memory changes. In fact, often a diagnosis of AD is not given while the person is still in the early stage of the disease. Our intent was to make the support group as inclusive as possible and to reach people at the earliest stage of memory loss possible.

Start-up Phase

Initial group meetings (beginning in September 1999) were attended regularly by two people with connections to the Alzheimer's Society and one person who had been part of the UNBC Memory Project. A fourth person, a friend of one of the other participants, attended irregularly. All had been diagnosed with AD. Both facilitators also attended the meetings. Group members agreed that anything said in group sessions would stay in the group, unless the group unanimously decided otherwise (e.g., publicizing a decision to have a public forum or circulate a petition). Early activities had three primary components: getting to know each other (members talking about themselves both historically and currently), talking about what the group should be and do (included discussion about supporting each other, sharing coping ideas, having educational sessions and doing self-advocacy work) and, finally, having presentations on and discussion of educational material about Alzheimer's disease. Facilitators also introduced the idea of discussing what name the group should be given, responding to a suggestion that more advertising should be undertaken in order to get more people involved.

Until December 1999 (that is, for the first four group meetings), elements of all the above-listed activities were incorporated into the agenda of the group; for example, discussion of personal experiences took place, coping strategies were shared, newspaper clippings and articles about the latest Alzheimer's research were copied for members and

discussed, a video of persons at the early stage of AD was shown, and plans for a petition demanding that the provincial government cover the cost of Aricept were discussed.

(Aricept is a drug intended to treat symptoms in individuals with mild to moderate AD. In clinical trials, individuals who took Aricept showed improvement or no further decline in cognition and function. However, the results cannot be maintained indefinitely because Aricept is not a cure for AD and does not affect the underlying degenerative disease process [Alzheimer Canada, 1997]). Although on the agenda for discussion, the names and goals of the group were not finalized. It was decided that these decisions might be better made as the group grew. Decisions about what to do each month were discussed in group meetings but further preparation and additions to these plans also took place at the debriefing and planning meetings of the co-facilitators. However, even with the facilitators coming back to the subsequent meeting with an agenda, oftentimes the group decided to opt for talking about their own recent experiences or sharing tips learned over the intervening month rather than following through with the planned agenda. The key point is that the course of each meeting remained flexible and, in fact, was adjusted and directed, as much as possible by group participants.

There was general agreement among participants of the need to let more people know about the group. Facilitators assumed the task of developing strategies and tactics for reaching others, including media announcements, articles in the Alzheimer's Society newsletter, putting up posters/information sheets and contacting professionals working with older adults. In the course of this work, it became clear that gerontologically-oriented professionals tend not to see people with AD until the disease process has advanced beyond

the mild stage; that is, until the individual or her family approaches the health care or social services system for assistance.

One thing that was immediately noticeable in this start-up phase was the variation in the participation level and expectations of group members. At one end of the spectrum, there were participants who tended to focus primarily (or exclusively) on talking about past life experiences and current personal concerns. At the other end, there were people who tended to address broader issues about how families and society in general viewed Alzheimer's disease. This included speaking about self-advocacy work (although not using that terminology); specifically, starting a petition to make the drug, Aricept, free and accessible to all who need it. The range of input was also reflected in the amount each group member spoke. Again there was a continuum of participation with one member rarely speaking and another who was willing to jump in at any point. However, we discovered after the first two sessions that the person who rarely spoke was just slow getting started. We were having a discussion about past working experience and, once given the time to collect thoughts and begin speaking, this individual had many work-related stories to tell.

Another important feature of the group that quickly made itself apparent was the impact that one person could have on the atmosphere and direction of the group. The most active and vocal person in the group, who also appeared to be at the earliest stage of the disease, left the group for personal reasons after attending several meetings. With this person gone, another group member stepped up to take a more active role but the element of self-advocacy was no longer as central to the agenda. In fact, a proposed media release regarding the Aricept petition was postponed. No one else felt comfortable speaking about it to the press. In addition, going from a regular attendance of three people to only two,

seemed to undermine or, at least, decrease the sense of group to the point where a discussion about attracting more members spontaneously erupted once again. There was a sense expressed that although three people are a group, two people really are not.

When an opportunity arose to have a representative of the Kelowna support group speak in Prince George, the group facilitators took the initiative to organize the meeting. It was thought that this would be an opportunity not only for current support group members to hear about another more established group but also a means of advertising the existence of the Prince George group. A meeting location was selected that was near a variety of seniors' services. These included a senior's centre, an apartment complex, a group of assisted-living apartments, an adult day centre and a care facility. The meeting was advertised widely in the media, in seniors' centres and other housing and service locations. With a turnout of more than 50 people (including many older adults with memory issues), it was decided, on the spot, that the next early stage AD support group would be held at the same location (rather than in the Alzheimer's Society office). Therefore, after the guest speaker, Norma Selbie, completed a presentation about her experiences as a person with AD and as a support group member, an announcement was made inviting anyone interested to attend the next Prince George support group meeting. The invitation emphasized that group members were not required to have an AD diagnosis but rather that the group was for anyone developing memory issues. In fact, the guest speaker had previously stated in her address that, although she personally had been diagnosed with AD and was in the early stages of dementia, many others in the Kelowna group preferred to characterize their own situation as one of having memory issues.

Building Phase

The public forum described above ushered in what constituted the current stage of the local support group; that is, the building phase. As a result of hearing about and attending the public meeting, four new people joined the Prince George group: three new members were from assisted seniors' housing and a fourth was still living completely independently in the community. The entry of four new people into a group that, at the time, had only two regularly attending members had a major impact on the May and June 2000 meetings. In the first instance, the "old" members were tremendously pleased about the growth of the group. It meant new blood, new ideas and much improved possibilities for sharing information and experiences. At the same time, such a large influx of new people required that time be allotted for members to talk about themselves and their experiences and generally get to know and become comfortable with each other - similar to the initial group meetings. Going back to the "getting to know you" stage might seem like a potential reason for instituting a closed format; that is, only letting new people join at definite intervals. However, because of the impact of the disease process, repetition, reminders and recapping are an integral part of the regular group process. A member may be functioning at a high level at one meeting but have serious memory and language difficulties the next time the support group gets together. As a result, the structured stages of a more traditional group development process may not necessarily be a good fit, particularly if the group prefers an open format and is participant-directed.

At the time of preparation of this report, the group remains in the building phase, with old and new members continuing to develop a level of comfort with each other. Discussion about group goals and direction has restarted as well as discussion about the best

way to attract even more members and possibly starting a second group. Sentiment expressed by current members indicates that they are finding the group process helpful and look forward to each session together. This sentiment is exemplified in the “overturning” of a decision made by the co-facilitators to cancel one group meeting because it was scheduled one day after the speaker from Kelowna was scheduled to come. Facilitators (erroneously) thought that meetings held two days in a row would be “too much” for people. However, at the overwhelming request of members, the support group went on as scheduled. One other issue arising at this time is the dilemma about what to do when a group member moves beyond the early stage of the disease process and is no longer an appropriate group participant. Currently, there is one member whose condition has deteriorated to such an extent that she appears to be neither benefiting from the group nor contributing to it. Although no steps to end this person’s group membership have been taken as yet, it is an issue that will soon have to be tackled.

Case Analysis: A Critical, Retrospective Reflection

This critical review of the Prince George support group is conducted with the acknowledgment that the group is still in the midst of a development process. Therefore, no final lessons can be drawn. Nonetheless, several major themes have been identified and examined. These include: new ageism, empowerment, group theory, practice challenges and policy issues.

New Ageism. The stereotypical view of later life as a time of decline and incapacity has a profound impact on societal views of older adults with dementia. These individuals face what Cohen (1990) characterized as “new ageism”; that is, ageism directed at those with disabilities. Although the case example under examination is still very much in the

building stage, it provides concrete examples of “new ageism” in action as well as glimpses of the role that support and self-advocacy groups can play in combating the discrimination and oppression of persons with dementia. One important feature of ageism is the impact that it has on how older adults view themselves; that is, the internalization of a negative view of oneself and one’s capabilities. Such a view is compounded in older persons with disabilities and was reflected in the reluctance of all but one group member to speak publicly about their situation.

The profound stigma still attached to acknowledging a diagnosis of dementia would also seem to have influenced the size of the group membership. Deciding to attend a support group not only requires admitting to oneself that there is a problem, but, in many cases, it also entails making a more public admission to family and friends. Therefore, individuals may hesitate about coming forward to join. Further, the stigma that exists also serves to undermine the confidence of the those with dementia to the point that they are reluctant to fully take control of the group, fearing their own incapability. Another sign of “new ageism”, and the stigma attached to having dementia, is reflected in the decision to advertise the support group as a group for people with “memory issues” rather than as an early stage AD support and self-advocacy group. One reason for this decision was to make the group open to all people with memory problems and not only those with AD; but another factor influencing the decision was the fact that many people, wishing to avoid the “dementia” or “Alzheimer’s” label, choose not to acknowledge that they have a disease. Living in a culture and social system that tends to devalue older adults, and particularly anyone who is less than a perfect physical and mental specimen, there is an incredible pressure on people to keep their diagnoses private. Further, because individuals developing dementia are also

influenced by societal attitudes, they often do not want to accept the diagnosis themselves. It was felt that these individuals might be more inclined to join a "memory issues" group than an Alzheimer's group or a dementia group. As well, it seems more important to include people than to require acknowledgment of a diagnosis.

Failure to cover Aricept under the provincial medical plan (mentioned previously) was raised by one group member as an example of the economic discrimination against persons with dementia, reflecting the oppression of both older adults and persons with disabilities. Similarly, the fact that there is little funding for preventative, home-based health care for older adults means that many people at the early stage of dementia, who are living independently in the community, are never provided with information about programs such as a memory issues support group. The limited support for, and contact with, people at the early stages of AD was highlighted in a local example. Specifically, when local professionals, working in the area of geriatrics, were asked to pass on information about the new support group to anyone who might be interested, we found out that their work is focused almost entirely on people at the more advanced stages of dementia. Thus, in terms of recruitment, it is necessary to find other means of reaching those in the community who are just beginning to experience problems. One idea that is currently being implemented is the preparation of an information sheet for local family physicians as well as small information cards that physicians can pass onto their patients. This approach is being tried because it seems that family doctors may be among the first people, other than family members and close friends, who notice changes that might warrant a person attending a memory issues support group. The information cards are being designed as an invitation to anyone who is noticing memory changes to call the local Alzheimer's Society office or drop in at one of the support group.

meetings. Another idea being considered is having the facilitators make community presentations about early stage dementia and the memory issues group. In the longer term, the objective would be to have group members who are willing to take over this responsibility or, at least, join with the facilitators in making presentations.

Facilitating the Process of Empowerment. Activities of the group to date have also provided glimpses of how support and self-advocacy groups might play a role in combating ageism and facilitating empowerment. In contrast to the potentially immobilizing impact of ageism and discrimination, empowerment is a process through which people can begin to exert more control over their lives. To date, the local group has played a role, and I believe has the potential for playing an even greater role, in enhancing both the individual (psychological) and systemic (societal) components of empowerment.

At the personal level, perhaps the most obvious element of the empowering process is that members like to come to the group and have become increasingly more vocal about "their group" and more supportive of each other. There is also an increased level of confidence displayed in terms of expressing views and raising questions. Greetings at the beginning of each meeting are more animated and genuine concern is expressed about how others have been doing since the last gathering. Having the opportunity to speak about their strengths (for example, trades, skills or profession) appears to have had a positive impact on individual self-efficacy. For example, one member, relatively quiet to start, spoke to the group about work life, including some very unique skills. The group responded with interest and questions. Since that occasion, this particular member has become more vocal and more willing to contribute to group process.

Another interesting development has been the role taken on by those who appear to be functioning at the highest level. Specifically, they are beginning to play a leadership role in group discussion and activities. For example, during group meetings, they are conscious of lulls in discussion and often take the initiative to keep a conversation going. On other occasions, they might try to draw out the feelings or views of another member who has been particularly quiet. In terms of meeting logistics, these individuals have also taken some initiatives such as coming early to help set up the room or volunteering to bring and serve refreshments.

In terms of broader societal issues, one of the group members was quite vocal about the need to make the new symptom-alleviating Alzheimer drug, Aricept, available to everyone at the early stage AD. As a result, the previously-mentioned petition campaign was initiated (for a copy of the petition, see Appendix C). Members also provided feedback to another support group about a pamphlet being prepared describing experiences of people at the early stages of the disease process. The pamphlet is designed as a tool for those recently diagnosed with dementia and is to be made available to support groups throughout the province. However, there was one important stipulation regarding editing. Just as the pamphlet had been written by people with dementia, so, too, all reviewers of the leaflet were to be persons experiencing memory problems.

Also, on the systemic level, organizing the forum at which the representative from the Kelowna group spoke was an important part of beginning to educate families, health care professionals and the general public in the Prince George area about the nature of early stage dementia. It was an opportunity not only to hear someone with dementia speak about the disease process but also for the audience to see first hand the obvious and varied

capabilities of the speaker. In stark contrast to the stereotypical view of someone with AD (for example, the elderly disheveled, non-communicative woman staring into space from a wheelchair in a care facility, no longer competent to look after her financial affairs or health care needs), the speaker was animated, well-dressed, gracious and coherent. Breaking down this stereotype is an important step toward acknowledging not only in words, but also in deeds, that individuals with memory problems are human beings who, particularly at the early stages of their illness, are able to continue to make contributions to society and direct their own lives. Hearing the speaker was also a validating experience for many support group members, one that instilled increased confidence in their own potentialities and capabilities. In fact, in the June 2000 group meeting, time was spent viewing segments of the videotape of the forum and other segments are scheduled to be seen at future meetings over the next several months. The response among group members has been extremely positive.

Finally, although this project has focused on the positive impact that empowerment (as facilitated by participation in early stage support groups) can have on the lives of those with dementia, it is important to acknowledge that there is the potential for conflict between enacting the desires of a person with AD and upholding the rights of individuals in the wider society. For example, if a person with dementia insists on self-determination in relation to retaining a driver's license, even though it is no longer safe to drive, the rights of the wider societal collective are undermined. The lives of innocent citizens, as well as the person with dementia, may be put in jeopardy. Thus, in the same way that all citizens face limitations on their right to self-determination (insofar as their actions infringe on the rights of others), persons with dementia face similar restrictions in their struggle to gain control over their

lives. The potential conflict between individual and collective rights has not yet arisen in the Prince George group. However, it may in the future. It is, therefore, important to acknowledge that there are limits to any citizen's right to self-determination. At the same time, it is also necessary to acknowledge that the main characteristic of the lives of persons with dementia is not one of exerting their self-determination to the detriment of other citizens, but rather one of profound lack of control over their own destiny.

Group Theory: Where Does this Case Fit? Although the Prince George group has yet to formally select a name, it has come to be known as a support group. However, as the case description reveals, it is not a support group in the technical sense but rather a hybrid with elements of support and self-help. There are no paid professional staff providing leadership and direction to the group, nor are there group members who have taken on the task of facilitating, although it is hoped that such a leadership may eventually develop. Further, there has been no planned, structured group development process whereby certain tasks are completed within a specified period of time. On the contrary, the group has remained informal and open to new members. Similarly, the group process has been flexible and responsive to the requests and expressed needs of group participants. Although this process may seem chaotic and without needed direction, there is a definite plan and goal in mind and that is to find the ways to put as much control as possible in the hands of group participants. So, for example, it would have been very easy to go ahead with the press conference about the Aricept petition campaign even though there was no group member willing to be interviewed. Both facilitators are accustomed to dealing with the media and are familiar with the issues surrounding Aricept. Taking over would not have been a problem. However, our sense was that it would be better to create the conditions in which a

group member would come forward to take on that task, even if it meant delaying the campaign. Otherwise, the campaign would not really belong to the group, but rather to the facilitators.

The group's informality and flexibility can also be helpful in responding to the variations and individuality in the Alzheimer's disease process. For example, within the group there are people with a range of abilities and incapacities. There are some members at a very early stage of the disease process and other members who are approaching the moderate stage of the disease. To further complicate matters, most participants are experiencing a gradual, but unrelenting, decline in functioning. Thus, abilities that are present one month may begin to wane the next. Finally, people with AD have good days and bad days; therefore, there is no certainty about anyone's abilities from one meeting to the next. Given this situation, sticking to a pre-determined program that cannot take into account the ups and downs inherent in AD, may not be the best way to meet the needs of group members. That is not to suggest that there should be no plan. On the contrary, the Prince George group has a plan in mind for each meeting, but it is a plan with many options and much flexibility. On most weeks, at least the general gist of the planned program has been maintained, but there have been other occasions when the particularities of peoples' conditions and needs warranted a more substantial shift in programming. It would seem that such flexibility is a necessary component of any group that strives to empower members and respond to their specific needs.

Working within a framework that attempts to maximize the control of group members over the group's direction and activities also has its shortcomings. For example, in the case under examination, neither a group mission statement nor written goals have been

completed. Nor has an official name been adopted. The group continues to be at a building stage. In fact, there has been a much slower process of group development than either of the facilitators had anticipated. Nonetheless, the empowerment perspective, first initiated by the group facilitators, seems critical to group development. It was arrived at by examining the direction of the early stage movement and the sentiment expressed by its emerging leadership; specifically, that people in the early stages of dementia already have enough professionals and experts in their lives and that support groups should remain informal, participant-directed and belong to the those with memory issues (Selbie, 2000).

Given this framework, is the flexibility and fluidity of the current responsive group model undermining or aiding group development? The enthusiasm of participants for the group, the increasingly lively atmosphere at group gatherings, the members' desire to advertise and recruit new members, and positive comments from family members all seem to be indicators that, although professional or paraprofessional facilitators may feel somewhat uncomfortable with the lack of a quantifiable, linear group development, group members are responding favorably and are increasingly, at least in a psychological sense, taking ownership of the group.

Challenges to be Addressed.

1. Facilitator versus Participant Leadership

Perhaps the biggest challenge, particularly during the building phase of the group, is finding the balance between facilitator and participant leadership. For example, currently, the facilitators are playing a more active and directive role than is desirable in the longer term. It is, therefore, critical that each aspect of group work and activity is viewed through the lens of empowerment and how to create the conditions for empowerment among members.

The other important feature of this challenge is to recognize that empowerment of group members means that they play the major role in reaching decisions about the group. From the perspective of the facilitators, we hope that a leadership emerges that will provide ideopolitical and organizational direction to the group. However, in the end, the role that group members play is up to them. Because of the nature of dementia (even at the early stages), it would seem that it will always be necessary to have resource people available (who do not have dementia) to deal with logistical issues such as booking meeting rooms, purchasing refreshments, providing clerical assistance as well as fulfilling research and information-gathering functions. Although group members may be able to fulfill the above functions, having facilitators or resource people take over these technical responsibilities, frees up the group leadership to concentrate their time and energy on more substantive group issues and concerns.

2. Variation in Functional Level of Group Participants

The variation in the functional level of group participants poses some challenges as well. For example, in the case being considered in this report, one of the highest functioning participants has expressed concern about whether or not he belongs in the group. He has noticed that several other members seem to have more obvious and numerous difficulties than him or that they describe experiences not yet familiar to him. While expressing uncertainty about his place in the group, this participant did begin to assume a leadership role, particularly around practical, logistical concerns but also, for example, in seeking to involve quieter members in discussion. As facilitators, we are conscious that there is a continuum of capability within the early stage of dementia and that the local group includes people at both extremes of that continuum. In this regard, the videotape of the public forum

in Prince George has been helpful. In it, the Kelowna group representative speaks about how their group has developed to include people with a very broad range of skills and abilities. Having the opportunity to view this tape seems to have afforded Prince George group members a level of comfort as well as facilitated some discussion on the matter. At the same time, in an effort to create a positive atmosphere for all group members, regardless of current capacity, facilitators have made every effort to highlight the strengths of all participants as well as to cultivate the leadership skills displayed (albeit in rudimentary form) by some of the higher functioning members.

3. What to do About Group Membership as the Disease Process Progresses?

Because Alzheimer's disease is a progressive, irreversible degeneration of the brain, inevitably, group members will move beyond the "early" stage and may no longer be appropriate participants in an early stage memory issue group. Although this has not yet become a major issue in the Prince George group (because the group is relatively new), the issue is now looming with one person approaching a moderate stage of the disease (as mentioned in the case description). When considering how to facilitate group leaving, there are two principal aspects that may need to be addressed. First, there are the concerns and expectations of the group member and, second, the concerns and expectations of caregivers (if they are involved). In terms of group participants themselves, one suggestion currently being considered is adopting a transition process that would allow continued relations between current and past members. This transition process would involve inviting current and past group members to quarterly social functions organized by the Alzheimer's Society. Such occasions would provide an opportunity for ongoing contact between all those who have ever participated in the support group. It is hoped that this would offer a method of

leaving the group that does not completely sever relations between members and, thus, should make leaving less traumatic. Although these social occasions would primarily be for group members (past and present), caregivers, family members or friends would also be welcome (presence of a caregiver will be a necessity for many past members who have progressed to a moderate or advanced stage of the disease process).

In addition to addressing the needs of group members, facilitating the leaving process with family members may also be necessary. Having a loved one leave the early stage group is a concrete manifestation of the progressive (and ultimately, terminal) nature of Alzheimer's disease, a progression toward death that family members often have difficulty accepting. Nonetheless, the issue must be addressed. One proposal to assist family members cope with this difficult transition is to ask the local caregiver support groups (i.e., groups for families and friends of persons with dementia) to inaugurate a session for families that specifically addresses the transition of their loved ones from the early stage support group to the quarterly social functions. An invitation would be extended to all caregivers or partners of early stage support group participants. The session would be offered on a regular basis and, rather than focusing on the situation faced by any one particular individual, would serve as a general orientation on transitioning from the support group to the quarterly socials. It is hoped that this type of forum would assist in preparing families for the time when their relative is no longer able to participate in the early stage group. There may be occasions when the group member or caregiver is resistant to the idea of leaving the group, despite the quarterly socials and the caregiver orientation. Such cases would have to be dealt with individually. It would seem that there are no easy answers that would apply in all situations.

Policy Issues. Although the main focus of this report is on group process and its relationship to empowerment, there are related public policy concerns that also arise and which will be briefly presented. The international backdrop for Canadian public policy as relates to persons with AD can be found in the Charter of the United Nations (1945) which enshrines the rights of all human beings, including those with cognitive disabilities. Coupled with the Charter is the Universal Declaration of Human Rights (1948) that entitles those with disabilities to exercise all civil, political, economic, social and cultural rights contained in UN Conventions (Despouy, 1993). Within Canada, the rights of all citizens are outlined in the Canadian Charter of Rights and Freedoms, Constitution Act, 1982; specifically Section 15(1), which states that "Every individual is equal...without discrimination based on race, national or ethnic origin, colour, religion, sex, ages or mental or physical disability" (p. 3). At a provincial level, some provinces, such as British Columbia, have enacted human rights codes that should provide a further level of protection for the rights of those with dementia. In BC, the Human Rights Code [RSBC 1996] Chapter 210 states in Section 3(a) that one of its purposes is "to foster a society in British Columbia in which there are no impediments to full and free participation in the economic, social, political and cultural life of British Columbia" (p.4). Therefore, if a person with dementia experiences "impediments to full and free participation", a complaint can be laid under the provisions of the Code. There is also a range of federal and provincial legislation (e.g., social welfare and health legislation) that is supposed to live up to these human rights requirements. However, in practice, legislation, and policies flowing from it, do not always fully recognize and adhere to human rights standards in relation to persons with AD. In fact, Ontario is the only province in

Canada that, in the mid-1980s, adopted a specific program to tackle AD (McClelland, 2000).

An atmosphere has been created which suggests that there is not enough money for health and social programs; further, that these programs are “draining” the economy. Therefore, taxpayers are told, through politicians and in the media, that “tough decisions” need to be made about how to divide the few health care and social services dollars that are available. Given the ideopolitical outlook inherent in a profit-based economy, it is not surprising that it is the most vulnerable who are also considered most expendable. In such an atmosphere, suggestions are made about the futility of spending valuable resources on persons with physical or cognitive disabilities; after all, their quality of life is lacking anyway. It is within this framework that organizations like the Alzheimer Society (including support groups of both persons with the disease and their families) are working to change the overall approach of governments and to win the support of the Canadian population.

In addition to working towards changing attitudes and the overall orientation of governments, there are specific policy issues for which advocates (such as the Alzheimer's Society) and self-advocates (such as some early stage support groups) are fighting. Some of these include improving access to medical services, and particularly to diagnostic testing equipment; increased availability of home care services so that persons with dementia can stay in a home environment for as long as possible (including funding for family members who are currently providing most of the care); providing more assisted living arrangements for people without families or for those whose families are unable to provide care; free access to new drugs such as Aricept; and, perhaps most importantly, a recognition of the

importance of empowerment for people with dementia, including funding to assist with educational programs, support groups and self-advocacy work.

Conclusion

Despite the fact that the support group in Prince George is still in a formative stage, there are several lessons that can be drawn from the experience to date. One important lesson for the facilitators has been the acknowledgment that, although we may adhere to a perspective of empowerment, the extent to which participants embrace the same perspective is, in large part, in the hands of the participants. In other words, an atmosphere that facilitates self-determination can be created, but it is up to group members to embrace, reject, ignore or further advance our efforts. Further, the degree to which the empowerment perspective is developed is, at least in part, dependent on which individuals are members of the group. For example, the departure of one person from the group had a negative impact on a public launching of the Aricept petition campaign. In terms of an overall perspective, the experience to date has shown the need for flexibility in all aspects of the group work. This flexibility is necessary in order to take into account the highs and lows, the good days and bad days that are characteristic of Alzheimer's disease. Thus, although an agenda should be prepared for each gathering, the facilitators must be willing to adjust or abandon plans according to the concrete conditions of the particular day. Another important feature of the work to date has been confirmation of the profound strengths and capacities of people with early stage AD as well as direct experience with, and observation of, how the support group appears to enhance and highlight those strengths and capacities still further. In the same vein, participating in this work has provided an opportunity to see, in practice, the positive impact that group participation has had on the self-confidence and general

demeanor of the members. This experience alone, although not a formally conducted evaluation of the success of the group, is concrete feedback indicating that early stage support groups can play a positive role in facilitating the empowerment and self-determination of persons with memory problems.

CHAPTER FIVE

Do Early Stage Support Groups Facilitate Empowerment? A Comparative Assessment

The following section examines the role of early stage support groups in the empowerment process in relation to the Prince George case study and to the other examples of early stage support groups described in the literature review. There are a number of ways in which the question can be addressed. In the broadest sense, there can be an evaluation of the declared goals and practice of early stage groups. At this level, it is possible to discern real differences between the support groups described earlier. For example, there are groups such as those in Thunder Bay and Kelowna whose practice explicitly includes self-advocacy; that is, people with early stage AD speaking out for themselves and about themselves. Here, I am referring to such things as the letter the Thunder Bay group wrote to local physicians making known their concerns about the way doctors treat people with AD and making some suggestions including, "Don't treat elderly people as if they are stupid" (Thunder Bay Early Stage AD Support Group, 1998, p. 7). Similarly, the activities of the Kelowna group, including organizing the spring 1999 retreat for people at the early stage of AD, organizing panel discussions to present their views to health and social service professionals, speaking to the media, and starting a newsletter, all reflect the desire of persons with AD to take more direct control over their own lives. There is also the example of the Prince George group which, although still in its building phase, has both an empowerment perspective and some related practice as exemplified by the initiating the Aricept petition (although it has not been widely distributed as yet) and organizing a public meeting on the development of early stage support groups. On the other hand, there are groups, such as the one in South Australia, which are focusing primarily on education of

group members and providing an opportunity to talk with others in a similar situation.

Others, such as the group in Scotland, in addition to providing support, are focused on facilitating continued social activities for its members. Similarly, the CARE Club and DRC Clubs, both located in California, have large components devoted to recreational and social outings.

On the surface, at least, it would seem that those groups with more explicit self-advocating activities might be more successful in enhancing the empowerment and self-determination of those with dementia. Not only are they providing support to each other within their group setting, but they are also taking their message outside the group and declaring to the world that 'we are still capable and here's what we have to say'. Standing up for themselves, and doing so in a public way, appears to be bringing a new strength to individuals who are emerging as leaders, as well as to the movement as a whole. Respect for the work of those with AD is growing and the more public interviews, panel discussions and conference participation that take place, the more it becomes clear that people with early stage AD continue to have a great deal to offer society and are capable of representing themselves and their own interests in a credible way.

However, a strong argument can also be made that the work of those early stage groups that do not have an explicit self-advocacy component and do not have visible leaders emerging from amongst their membership is still an integral part of developing the empowerment and self-determination of people with early stage AD. Remaining active, being in a supportive atmosphere, and becoming more educated about the disease process are all building blocks that can assist in the process of taking more control over one's own life. These activities may not be as overtly empowering as being interviewed by the media or

starting a petition, but without these building blocks, it would be difficult to take the next step. Comments made by participants at the Kelowna retreat about where their strength comes from also highlight this point. For example, these included, "...meeting [another person with AD] was like walking into a sunlit room", "I feel free to share my experience because I won't be put down" and "It's so nice to have a friend who has AD" (Alzheimer Society of B.C., 1999).

Another factor impacting on the success of support groups in enhancing empowerment and self-determination relates to the dynamics within the organization itself. It is clear from the support groups described previously that most of the professional and/or volunteer group facilitators do not have Alzheimer's disease. The degree to which these facilitators direct group activities appears to vary from group to group. For example, it was a member of the Kelowna support group (with AD) who organized the new group in Salmon Arm (although the local AD Society representative remained a co-facilitator) (Phyliss Dyck, North/Central Okanagan Representative, Alzheimer Society of B.C., personal communication, August 17, 1999). On the other hand, the American, Scottish, and Australian groups, as well as the ones in Prince George and Penticton, B.C., all have facilitators who do not have dementia. Whether in a group with more non-AD leadership or in a group where members with AD play a more directive role, the fact remains that there is a constant dynamic between professional and participant control. In my view, being aware of this dynamic is a starting point to ensuring that self-determination for group members remains paramount. But being aware also does not mean that non-AD leadership has no role to play. On the contrary, when dealing with a degenerative disease such as AD, a professional presence is often necessary at some level.

In fact, assistance from professionals has the potential to aid in the development of self-determination. Similar to the continuum of impairment experienced by people with AD (Brechling & Schneider, 1993), there is a continuum of assistance needed, even within groups designated as "early stage". At one end, there may be a need for peripheral assistance such as providing material and moral support (for example, preparing minutes, doing the background research for a letter to the government or arranging press interviews). At the other end, there may be more direct assistance required, not only doing the research but also writing a letter to the Ministry of Health or playing a central role in a press conference. If someone with early AD is in need of assistance in order to further develop an idea or put it into practice, does it mean that her or his self-determination has been usurped? I believe the answer is "no". The key is to create an organizational forum that maximizes the empowerment of those with AD, but which also recognizes and provides the assistance necessary to facilitate that empowerment. Surely, a non-AD facilitator who refuses to do background research for a letter to physicians undermines self-determination more than would be the case if assistance was provided. The key is to acknowledge the ongoing dynamic between the role of the support group members and the role of the professionals or non-AD facilitators. Always keeping this issue on the agenda (incorporating it organizationally) and addressing it in relation to each decision made, is the best way to ensure empowerment of group participants. This is no less the case in a group with prominent AD leadership than it is in a group in which staff provide a larger component of the leadership.

Empowerment and self-determination for those with AD also involves educating the broader public about the disease and its impact on those suffering from it. In this vein, one

of the major issues raised at the spring 1999 retreat in Kelowna was the need to "change the face of Alzheimer's Disease"; that is, to make the families, caregivers, the government and the general public realize that people in the early stages of AD are still people, that behind the muddled speech can be a clear-thinking person simply having a difficult time verbalizing her or his thought processes. Organizing support groups, and particularly those with the self-advocacy and political action components, is playing an important role in showing, through example, the capabilities and humanness of those with AD. Interviews in the *Globe and Mail* (Alzheimer Canada, June 28, 1999) and in the *Vancouver Sun* (Wigod, June 7, 1999), with members of early AD support groups, reached people right across the country, as have radio and television interviews. The work of the Kelowna group in organizing panel discussions about what it is like to be at the early stages of AD and the public forum organized by the Prince George group also play an important role in creating an atmosphere in which myths about AD can be dispelled. These myths, often projected in literature and the media, imply that people with AD are without capability and are essentially non-functional and non-communicative. By dispelling such myths, conditions are created for the further development of self-determination.

In my view, the very existence of the early stage support groups objectively changes the situation of those with AD as well as their place in society. First of all, there is strength acquired by individual members when they are able to share and work with others facing similar problems. Secondly, being organized affords the group more power and influence in relation to health and human service professionals, agencies and government ministries. It is much more difficult to ignore the voice of a hundred people than it is the voice of one person phoning Pharmacare to find out why Aricept is not covered. The presence of early

stage support groups is also a living proof that the “elderly mystique” is indeed a myth. These groups are in action. Their members are speaking out. Through their actions, early stage support and self-advocacy groups are objectively part of the movement toward fundamental change in the society, change that would put an end to oppression (whether it is based on age, ability, gender, class, race, or lifestyle) and would afford true self-determination to those with AD. Being organized also means that groups of people with early stage dementia can team up with other organizations (that is, with other oppressed groups) in order to build a broad coalition for change. Another empowering aspect of early stage support groups is the fact that, similar to the role of non-governmental organizations (NGOs), support and self-advocacy groups have the potential to expose the inequities of the current system while, at the same time, exemplifying an empowering organizational form that could be developed further in a new society.

CHAPTER SIX

Limitations and Proposals for Future Research

Perhaps the most obvious limitation of this project is the fact that the main case being examined is of a group still in its formative period. The experience to date provides information about practice issues in the preparatory and building stages as well as hints of the future features of the Prince George group. However, it is much too soon for definitive conclusions. In order to overcome this limitation, I hope to conduct another case study in about one year. With more time past and experience gained, it is hoped that it will be possible to present specific practice recommendations for other practitioners and researchers to consider and evaluate within their own working environments.

Another shortcoming of the current work is that the story of the group is told only through the eyes, and from the experience, of the author. Thus, it provides only one point of view with regard to the group development process. Neither the direct voice of the group participants, nor of family members is heard unfiltered. One aspect of the critical, structural approach to social work is to ensure that there is a forum to present the unfiltered voices of those who are oppressed and marginalized in the society. Thus, future research should include a mechanism, such as unstructured, open-ended interviews, to get as much information as possible about the experience of participants. Other possible sources of data could include the design of a support group evaluation form to be completed by all direct and indirect group participants; that is, group members, facilitators as well as family members. Family members could also be included in the interviewing process. It would also be interesting to include direct input from the other co-facilitator.

In this report, a brief comparative analysis was presented looking at the practice of a variety of early stage support groups. This analysis relied in large part on group newsletters, information meetings and personal communications. Future research could involve undertaking a more in-depth comparison of two or more groups, including direct interviews with group members and facilitators. Further, it would be helpful if an evaluative method or instrument (or both) could be designed to assess the impact of early stage support groups. The difficulty in this regard is developing an outcomes measure or evaluative method that could take into account the degenerative disease process that group members are experiencing. Designing an instrument to be administered over time, for example, prior to participation in the group and also one year later, may not provide an appropriate evaluation method if the individual whose opinions are being sought has experienced a significant advance in the disease process between the two evaluation times.

One final proposal for future research that I plan to pursue is the possibility that members of the Prince George support group might be interested in becoming part of a process of participatory action research. According to Fals-Borda and Rahman (1991), "the basic ideology of participatory action research is that a self-conscious people, those who are currently poor and oppressed, will progressively transform their environment by their own praxis. In this process, others [academic researchers] may play a catalytic and supportive role but will not dominate" (p.13). Flowing from this perspective is the notion that the domination of oppressed groups is rooted not only in the economic and political control exerted by the rich and powerful, but also by their control over the production and dissemination of knowledge (for example, stereotypes of people with Alzheimer's disease). Participatory action research embodies the notion that the most legitimate form of

knowledge development is that which is validated by the full participation of those being researched. Such emancipatory, philosophical underpinnings would seem to be compatible with a critical, structural approach.

Whatever the form, there is a critical need for practice-based research to assist the process of group development, particularly at a time when the number of people with Alzheimer's disease is increasing and the demand for empowerment is becoming more widespread.

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Appendix A

Alzheimer Society

BRITISH COLUMBIA

Provincial Office
Alzheimer Society of B.C.
#20 - 601 West Cordova Street
Vancouver, B.C. V6B 1G1
Bus. (604) 681-6530
Toll Free: 1-800-667-3742
Fax. (604) 689-6907
www.alzheimerbc.org

Regional Office
North/Central Okanagan
1763 Abbott Street
Kelowna, B.C. V1Y 1B2
Bus. (250) 860-0305
Toll Free: 1-800-634-3399
Fax. (250) 860-0418

June 15, 1999

Have you ever wondered what it is like to have Alzheimer Disease?

The members of the Early Stage Support Group in Kelowna and Vernon invite you to a **panel discussion** to hear our stories. We would like you to know what it is like to be a person diagnosed with Alzheimer Disease. Please join us.

Date: July 7, 1999
Place: Education Rooms,
Vernon Jubilee Hospital
Time: 1:30pm to 3:00pm

Alzheimer Disease profoundly affects us but does not wholly define us!

Maria Gode Donna Selkie
Rena Herbst B. Ferworn
Sharon Breuer
Gerhard Benedict
Grace Sebring
He. Schreier



Appendix B

MASTER OF SOCIAL WORK PROJECT INFORMATION SHEET AND CONSENT FORM

The purpose of this information sheet and consent form is, first, to let you know about the project I am working on for my Master of Social Work Degree at the University of Northern British Columbia and, second, to outline your possible role in this project and to see if you want to participate.

Researcher: Dawn Hemingway, Master of Social Work student
161 Pioneer Avenue
Prince George, B.C. V2M 4L9
(250) 563-3892
e-mail: hemingway@uniserve.com

Supervisor: Glen Schmidt, Social Work Professor
University of Northern British Columbia
(250) 960-6519

Project Title: Early Stage Alzheimer's Disease Support and
Self-Advocacy Groups: Empowerment Within a
A Disempowering Disease Process?

PART 1: INFORMATION ABOUT THE PROJECT

Purpose: The purpose of this project is to study the development of support and self-advocacy groups for people with early stage Alzheimer's Disease, especially the Prince George experience. Based on the experience of our local group, a report will be written and recommendations made about the development of our group and of similar groups in the future. The project report will examine the Prince George group from September 1999 to June 2000.

Anonymity and Confidentiality: The project will focus on the process of the group's development and not on individual group members. No interviews with individual group participants will be undertaken and the project notes and final report will not include the identity of any group

member. In this way, the anonymity and confidentiality of group members is protected.

Voluntary participation: Participation in this project is completely voluntary and you may withdraw consent at anytime. Non-participation will in no way affect your right to be a member of the support group.

Risks and Benefits: There are no known risks connected with participation in this project because the entire focus is on a retrospective look at group process and not on individual group members. In terms of benefits, I hope that the project report will provide information and analysis that may help the future development of the Prince George support group and groups in other places. Improvement in the work of the support groups may, in turn, increase the level of empowerment experienced by group participants and, thus, improve their quality of life.

Getting a copy of the project results: By contacting the researcher at the address or phone number listed above, a one-page summary of the project report will be made available to anyone who is interested. As well, each support group participant will receive a copy of the summary either in person or by mail (if he or she is no longer attending the group meetings). In addition, a copy of the complete project report will be available at the resource library of the Prince George Alzheimer's Society as well as in the UNBC library.

How to get in touch: If you have any questions about the project, please feel free to contact the researcher or her supervisor at the numbers provided above. If you have any concerns about this project, please contact the Office of Research and Graduate Studies at the University of Northern British Columbia ((250) 960-5820).

PART 2: INFORMED CONSENT

I understand that this project involves an examination of
and written report about the development of the Prince
George early stage Alzheimer's Disease support group..... **yes** **no**

I have read and received a copy of the attached information sheet **yes no**

I understand the benefits and risks involved in participation in this project..... **yes no**

I have had the opportunity to ask questions and discuss this project..... **yes no**

I understand that I am free to refuse to participate in this project. No reason has to be given if I choose not to participate and non-participation will not affect my right to participate in the support group..... **yes no**

I have had confidentiality and anonymity explained to me and I understand that no individual group members will either be interviewed or identified in this project..... **yes no**

This project was explained to me by: _____

I agree to participate in this project as explained above.

(participant signature) (date) (witness)

(legal representative or family member, if applicable) (date) (witness)

I believe that the person signing this form understands what is involved in the project and voluntarily agrees to participate.

(researcher) (date)

**THANK YOU FOR YOUR CONTRIBUTION TO THIS PROJECT.
Copy to participant.**

Appendix C

**BRITISH COLUMBIA'S PHARMACARE PLAN SHOULD COVER THE COST OF
ARICEPT**

(the first drug available in Canada to treat symptoms of Alzheimer's Disease)

WHEREAS Aricept is the first drug approved in Canada for the treatment of symptoms in the early stages of Alzheimer's Disease (AD);

AND, WHEREAS clinical drug trials have shown that, compared to people who did not take Aricept, some individuals taking Aricept showed improvement or no further decline in cognition (including memory, orientation and language) and function (including performance of daily activities);

AND, WHEREAS such improvement or stabilization (although not a cure) may lead to a better quality of life for people with AD and, by extension, their family and friends;

AND, WHEREAS the positive impact of Aricept on the well-being of some individuals with AD may also save health care dollars by delaying or decreasing the level of medical intervention needed;

THEREFORE, WE THE UNDERSIGNED ask that the provincial government immediately take the necessary steps to cover the cost of Aricept under the Pharmacare plan so that this important drug is available to all individuals at the early stage of AD and not just those who can afford it.

NAME (please print)	ADDRESS	SIGNATURE

**When complete, please return petition to: Prince George Alzheimer's Society
P.O. Box 2864, Station B
Prince George, B.C. V2N 4T7
(250) 564-7533**