CONNECTING CAREGIVERS:

SUPPORT GROUPS AND TODAY'S OLDER FAMILY

BY

Janet L. Cooper

A Practicum
Submitted to the University of Manitoba
In Partial Fulfillment of the Requirements
for the Degree of Master of Social Work

University of Manitoba
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Winnipeg, Manitoba
Canada

July, 1987

ISBN 0-315-37381-4

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CONTENTS

INTRODUCTION

To care one must offer one's own vulnerable self to others as a source of healing. To care for the aging, therefore, means first of all to enter into close contact with your own aging self, to sense your own time, and to experience the movements of your own life cycle. From this aging self, healing can come forth and others can be invited to cast off the paralyzing fear for their future.

As long as we think that caring means only being nice and friendly to old people, paying them a visit bringing them a flower, or offering them a ride, we are apt to forget how much more important it is for us to be willing and able to be present to those we care for. And how can we be fully present to the elderly when we are hiding from our own aging?

How can we listen to their pains when their stories open wounds in us that we are trying to cover up? ... when speaking about caring in the context of aging, we want to speak first about caring as the way to the self before we speak about caring as the way to others

From: Burnside, Ebersole, & Monea (Eds.); Psychosocial Caring Throughout The Life Span.

PREFACE

For the past several years, I have found myself moving, both personally and professionally, into the complex and often perplexing world of the older family.

Early in my search for a meaningful and challenging "piece of work" for study, Joe Kuypers, my primary advisor, suggested that I begin to "follow my heart". In following my heart, I have experienced the movement inward and outward between the objective and subjective perspectives called reality. This blend of observing, feelings, and growing in understanding has become the most meaningful part of my work, quite apart from any "educational benefits" of a didactic learning nature.

Experiential and reflective learning has been stressed in my work with family caregivers in declaring and defining that true"expertise" arises from all of these interwoven learning styles.

The following report is meant to make a conscious effort to separate out, for purposes of discussion and knowledge building, how we have come together to share and develop our "expertise" to better serve ourselves and our elders in our capacity as caregivers, now and in our future roles as older adults - "the new pioneers".

DEDICATION

For all those beloved older folks who have gone
before me.

For those, family and friends, who remain to guide
me and enrich my life with their presence.

For my husband and sons who stand beside me and
warm me with their understanding and
compassion.

And for all the newcomers in my life whose shared
interest in my work has allowed me to continue
for the sake of us all - past, present, and
future givers of care.

OBJECTIVES

Aims of the Intervention

The overarching purpose of intervening with adult children acting as caregivers to their parents is to recognize and normalize the nature of this emerging societal and familial transition. Specifically:

1. To promote awareness of the impact of assuming a caregiving role upon the older family through information and discussion at the community level as a preventative and normalizing strategy.
2. To explore possible strategies to further link formal and informal services for the elderly community in a complementary manner at the agency level.
3. To recognize, support and enhance the caregiving efforts of adult children with increasing dependent parents through the creation of an agency sponsored support group.
4. To further examine the support group form of intervention with older families in appropriate alternative settings.

Expected Educational Benefits

Central to any expectation of possible or probable benefits to be gained by "studying" the older family, caregiving adult children specifically, was the opportunity to expand upon and assimilate past knowledge bases and practical experience in working with people in a variety of situations. Specific anticipated benefits included the opportunity:

1. To synthesize and begin to utilize general theories in developing new ways of working and creating specific strategies.
2. To increase and modify counseling and group work skills, specifically in groups defined as support groups.
3. To increase self-supervision abilities in becoming more accountable to agencies and client populations involved.
4. To validate my own life experience as a member of today's older family.

LITERATURE REVIEW

Introduction

Any review of the literature describing the complex problems faced by caregiving adult children must be broad enough in scope to include material:

1. defining today's older family;
2. illustrating the dilemmas <u>and</u> rewards of adult children struggling to balance the needs of increasingly dependent parents with their own;
3. establishing a theoretical and practice framework for intervention; and finally
4. outlining the intervention methods currently being used to educate and support older family caregivers coping with loss and change in later life.

Each of these topics will be examined more completely and interwoven with other relevant literature in the following sections of this report.

Practice Issues And Target Population

> "My thoughts are: 1. No matter how much you do, to you it seems too little". (L., a daughter, 1986)

Twenty-one years ago, Margaret Blenkner (1965) wrote the following statement: "Social Work is not prepared, either theoretically or experimentally, to assist a growing group of persons in our society, namely, the middle-aged children of aging parents". Today the issue remains unresolved despite research examining all aspects of caregiving by adult children. Called the 'mirthless generation' "... sandwiched between their aging parents and their own maturing children ... the major resource and support for the elderly, this group has a need for services that is only beginning to be met by the helping professions" (Miller, 1981, p. 419)

Adult children, who find themselves in caregiving roles as their parents become increasingly dependent, are often scapegoated by social policy which dictates social service planning and implementation (Brody, 1985). Family focused services, including daycare and respite care, are limited and often implemented only when the overburdened caregiver is deemed "overextended" or "unwilling" to "do more".

These "practice issues" are also personal issues as members of the helping professions face their own aging as well as that of their client population. Meeting the needs of the disadvantaged and institutionalized elderly will still be vital as the population ages. Increasingly, though, the focus of service to the older adult population will include self-enhancement and social relatedness both at a preventative and restorative level. In this regard "... attention to informal social supports that are crucial to the well-being of the aged in their everyday lives, tends to be overlooked" (Getzel, 1982, p. 92).

Challenged by shrinking or re-allocated economic resources, increasing numbers of older adults who remain within the community, and the growing awareness of the importance of social networks as a means of supporting the aging population, human services professionals must begin to identify, create, understand and utilize these networks in complementary ways with professional interventions.

In introducing the concepts defining social support networks, James Garbarino poses this challenge to members of the helping professions, "How do we respond? ... The key to this puzzle lies in the paradox upon which many religions are built: only by losing ourselves can we find ourselves. We must lose ourselves in the social landscape, blend in with the human terrain, become part of the natural ecology of human social life" (Whittaker and Garbarino, 1983, p. 28). No matter what our areas of interest are at a professional level, we all have a personal stake in the creative usage of formal and informal supports for the elderly, because we <u>are</u> part of the "social landscape". We <u>are</u> part of the "aging population", we <u>are</u> the adult children of aging parents, we <u>are</u>, personally and professionally, part of the new frontier of the relatively unexplored "human terrain" - the land of the older and, increasingly, very old adult.

Today's Older Family

> "My thoughts are ... 2. My biggest guilt feeling is that it would be impossible for either of my parents to live with us - Municipals and a "home" may soon be in the future." (L., a wife and mother, 1986)

Most of the "new pioneers" (Shanas, 1980) in today's four generation modified extended family never knew all of their grandparents, let alone their great-grandparents. Captured in time, family portraits from the past 100 years illustrate two, sometimes three, generations gathered together to celebrate or to mourn changes in the family structure.

The realities of the widely reported demographic transition into an aging society by the marker year 2001, are becoming, for many members of the older family, self evident. Older chronologically than the "elderly" at the turn of the century, the middle-aged "supporting cast" in the changing family portrait, has often been taken unaware by the increasing care needs of the old and very old within the individual family at a time when their own resources are limited by other responsibilities (Shanas, 1980).

The emergence of the modified extended family, defined by Litwack are "a coalition of nuclear families in a state of partial dependence", (Litwack, 1965, p. 291 in Miller, 1981, p. 419) is illustrative of the complexity of today's older family. As the stability of the family is altered in temporal terms, so does the structure, composition,and availability of resources "fluxuate". The supportive function of the family therefore changes over time as well. Within the constellation of the older family, change, then, becomes the norm and, perhaps, the only constant factor.

During the past twenty years, the supportive function of the family in relationship to the elderly has been clearly recognized and examined in careful detail despite the continual rebirth of the "hydra-headed monster" (Shanas, 1979) - the myth of abandonment of elders in late life by the family.

Prior to 1970, much of the research which centered upon the family in late life and inter-generational relationships between parent and adult child overlooked the viewpoint of the middle generation (Robinson & Thurnher, 1979). Consequently, this earlier material on the older family is limited in its "... utility in understanding the family and aging in a changing, complex bureaucratic society" (Streib & Beck, 1980, p. 937).

Research on the older family expanded greatly in the decade between 1970 - 1980 and began to clarify the frequency and extent to which older family members interacted across generational lines and extended established patterns of assistance as increasing dependencies of the oldest family members precipitated change in family involvement (Blenkner, 1965; Brody, 1981; Johnson & Bursk, 1977).

"The Family As A Social Support System In Old Age", is described by Ethel Shanas (1979) as:

1. the key to supporting the eldest family members in times of illness; and
2. in linking the elderly to community supports as dependency in old age increases.

While spouses remain the primary source of help for increasingly dependent elderly person, adult children are the next main source of assistance. Even though the majority of older adults remain in independent living accommodations separate from their adult children, the family continues to interact frequently and informally - exchanging help and a variety of supports when needed (Shanas, 1979).

In adjusting to and accommodating for the changing needs and dependencies of the parental generation, the tasks faced by the adult children within the older family are complex, varied and unique to each family constellation as it "pioneers" unknown "territory".

Lillian Troll writes that this "... diversity of intergenerational relations ..." is "... a consequence of diversity in family boundaries and family themes" (Troll, 1980, p. 76). In gaining an understanding of the unique aspects of the older family as a system she asks that both

"... person-to-person bonds ... as well as person-to-group bonds be considered". A seven point framework for considering intergenerational relations in later life includes:

1. Content of Interaction;
2. Diversity of Interaction;
3. Quality of Interaction;
4. Patterning of Interaction;
5. Reciprocity v.s. Complementarity;
6. Intimacy; and
7. Interpersonal Perception (Troll, 1980, p. 85-87)

This framework affords a way of looking at the shift in family interaction and function occurring when physical and mental health factors within the parental generation change in relationship to the normal aging process. Troll relates that "... families will react to the aging of their relatives in terms of their shared family theme or value system. All generations in a family share perceptions of how aging should go based upon models presented by earlier family members who grow old" (Troll, 1980, p. 89).

The shared familial perception of "... how aging should go" is closely tied to the variable of health in the elder generation. Health "... becomes the catalyst in relation to a number of aspects of family life: residential patterns, economic support, kin interaction, and, on occasion, legal implications" (Streib & Beck, 1981, p. 942).

The caregiving capacity of the older family in attempting to meet the needs of older relatives as health care concerns emerge in later life often brings the family into contact with formal systems of care. In negotiating with a bureaucratic system, the older family often finds itself in an adversarial position because of the pervasive nature of the myth of family alienation and abandonment of the elderly. According to Elaine Brody (1981), these destructive beliefs based upon the alienation myth "... impede the utilization of knowledge in the interests of older people and their families" (Brody, 1981, p. 471). These beliefs are as follows:

1. "the formal support system (composed of government and community services) gives the bulk of care received by the dependent elderly";
2. "the provision of services by the formal system undermines family responsibility and encourages the family to shirk"; and
3. "families repay the devotion of elderly parents by abandoning them - even dumping them into institutions" (Brody, 1981, p. 471).

In order for the older family as a whole to meet this perspective with the goal of working as an equal member of the caregiving "team", Sussman argues that families "... must have a knowledge of their options and the skills to use them, in order to cope with and constrain the powers of bureaucracies" (Sussman in Streib & Beck, 1981, p. 947).

Before reviewing the literature pertaining to today's older family in a caregiving role, a statement about the future direction of research relating to the older family is worth considering in its entirety. It was written as follows:

"Earlier research has concentrated on the microenvironment - the activities, emotions, and interactions in the individual family. However, researchers in the 1980's will find it fruitful to study the macroenvironment and how it impacts on older families microenvironment i.e., the effects of bureaucracy, pension provisions, service programs, and changes in medical care provisions. In our opinion, the area of family - bureaucratic linkages will provide some of the most challenging research opportunities in the next decade" (Streib & Beck, 1981, p. 952).

In 1987, the older family is increasingly challenged in coping not only with caregiving responsibilities to elder family members, but with the impact of the macroenvironment upon family life (Brody, 1985).

Problem Definition - Adult Children Coping With Aging Parents

> "My thoughts are ... 3. Having to leave them and they won't stop crying gets to me.: (L., an only child, 1986)

Adult children coping with their own aging as well as the increased dependencies of older relatives is paradoxical in nature; all caregiving efforts will not prevent the eventual decline and death of the older generation and our becoming that generation in turn. Society has no clear role definition for the adult child caregiver. Old roles and expectations often block creative adaptation as each individual in the older family negotiates change (Kuypers & Trute, 1978). The adult child seeks meaning in the caregiving role (misunderstood, denied or unappreciated in society) while often overwhelmed by his/her own life-span developmental tasks. Fear of one's own aging and death, fear of dependence and loss of independence, lack of preparation in taking care of parents, interference of caregiving tasks with anticipated freedom, sibling rivalry over sharing caregiving, and the need to help parents through their own grief and losses are issues specific to the situation in which the adult children of aging parents must interact in uniquely diverse ways (Miller, 1981, p. 422).

Additionally, the continued <u>independence</u> of the parental generation often becomes an issue of concern and anxiety for the middle generation as anticipation of disaster and decline based upon society's ageist definition of late life <u>fails</u> to appear in family elders according to the chronological "clock" (Bumagin & Hirn, 1979, p. 127). As both the "expected" and "unexpected" become woven into the complex fabric of older family living, it is no wonder that denial of change within the individual and within the family emerges as a primary coping style for adults of all generations (Kuypers & Trute, 1978).

Whether the necessity of assuming a caretaking role becomes apparent over time or whether it is suddenly thrust upon the adult child at a time of crisis, it is laden with emotional overtones. The reality of assuming the multiplicity of tasks that this role implies emerges only as caregivers "take on" the role out of love, duty, past experience or proximity (Robinson & Thurnher, 1979).

Initial work defining and presenting the supportive nature of the older family did not attempt to delineate the role of women as caregivers but focused upon adult children in general (Blenkner, 1965; Shanas, 1979). The idea of "filial maturity" (Blenkner, 1965) was early proposed as a way (at least philosophically) to overcome the inability of adult children to accept and accommodate to the demands placed upon them by the increasing dependency needs of the older adults within the family. For many mid-life women traditional gender-appropriate roles have been "added to" by entry into the work place, the return of young adult children to the "empty nest", and the expansion of the caregiving needs of older relatives (Brody, 1981).

"Adequate role performance" and the promised relief of achieving "filial maturity" may be overridden by continuous and increasing pressure on the caregiver to adjust family and work schedules in an attempt to cope with all that filial responsibility may demand (Brody, Johnson & Fulcomer, 1984).

Recent studies focused upon inter-generational caregiving by women reveal that "women in the middle" (Brody, 1981) are increasingly embarking upon a "caregiving career" (Brody, 1985) of assisting several aging relatives at the same time or one after another over time. This need for "extended care" at the familial level perhaps reflects the known demographic increase in the number of the very old, those over 80 years, who are (and will remain) disproportionately female (Neysmith, 1981, p. 55). The need to provide care for this proportion of the growing aged population and the response of "women in the middle:" in meeting this need is described by Elaine Brody in the following manner:

> "Belatedly, 'alternatives' to institutional care are now being advocated, the 'natural or informal support system' has been discovered, and the 'family' is being cheered on in its caregiving role.... It has become clear that such words and phrases are only euphemisms for adult daughters (and daughters-in-law) who are the true alternatives" (Brody, 1981, p. 474).

Interestingly, little has been studied about mother-daughter relationships in later life when the mother is not dependent or frail and the daughter is a mature adult. One study of 171 women between the ages of 35 - 55 contradicted the "image of mother-daughter relationships as normatively and permanently a conflicted anxiety-producing one" (Baruch & Barnett, 1983, p. 605). However, distressful periods when the rewards of the mother-daughter relationship were often overshadowed were discovered:

1. during the daughter's struggle for identity and autonomy in early adulthood; and
2. when the mother was found to be in poor health Baruch & Barnett 1983).

The "linked lives" (Fischer, 1986) of adult daughters and their mothers often remain positively perceived when the parent continues to lead an active, independent life but becomes defined in predominately negative terms if symptoms of erratic behavior and mental deterioration are present in the older family member resulting in an increasingly stressful caregiving relationship (Robinson and Thurnher, 1979, p. 590). Mutual aid and positive regard can characterize the mother-daughter relationship in later life (Bromberg, 1983) if the tasks associated with caregiving do not become overwhelming to the caregiver.

In an attempt to clarify the relationship between age, marital status, work/non-work status, living arrangements and the amount of help provided to aged mothers by mid-life daughters, Lang and Brody (1983) discovered that:

1. age factors illustrated parallel aging by both generations with some indication of the changes in helping patterns as ages increased;
2. marital status and work/non-work status both signified the possibility of time and energy limitations due to competing demands; and
3. living arrangements were indicative of the type and amount of care required by the elder family member (related to the known relationship of poor health and sharing a household).

Again, these mid-life caregivers were revealed to be a very heterogeneous group with changing, varied lifestyles whose caregiving capacities were often overextended by their situations (Lang & Brody, 1983).

Defined as a "normative stress" (Brody, 1985) caregiving to the elderly may lead to burnout, (Freudenberger & North, 1985) self neglect (Marcus & Jaeger, 1984) and most serious of all, abuse of the elderly (Giordano & Giordano, 1984).

The literature discussing physical abuse of the elderly, self-neglect in the elderly, financial exploitation, negligence, psychological abuse,and violation of elders' human rights shows the extent of family caregivers' involvement in this crisis. The most frequently cited U.S. statistics show that from 500,000 to 2.5 million cases of elder abuse occur in one year (Pedricks-Cornell & Gelles, 1981). One in ten older adults living with a family member are estimated by Law and Kasberg (1979) to be victims of abuse (Giordano & Giordano, 1984, p. 232-233).

O'Rourke (1981) believes that elder abuse is triggered by the interplay of multiple factors that are hypothesized to lead to abusive situations. The theories proposed include the following dimensions:

1. family dynamics;
2. dependence brought on by impairments;
3. personality traits of the abuser;
4. filial crisis;
5. internal stress;
6. external stress; and
7. negative societal attitude toward the elderly (Giordano & Giordano, 1984, p. 234).

The complexity of crisis elements impacting upon a perhaps already vulnerable caregiver can lead to decreased competence, frustration, exhaustion and immobilization, which, in combination with a negative viewpoint can culminate in abuse.

"Patterns of elder abuse and neglect may be reinforced by negative stereotypes toward elderly people and their roles in society ... the resulting misperceptions may be a major force in the creation of situations that are conducive to abuse because these negative attitudes tend to dehumanize elderly persons and make it easier for an abuser to victimize them without feeling remorse" (Giordano & Giordano, 1984, p. 235). Little research has been done on the extent, nature and causes of elder abuse but there is some conjecture (Maddox, 1975) as to future increases in abusive situations due to reduced services to the elderly, caused by budget cuts in the U.S. (and in Canada). Already overextended families (specifically larger numbers of women) will find it necessary to care directly for dependent older relatives in often highly vulnerable situations (Giordano & Giordano, 1984, p. 236).

In summary, virtually all of the recent literature which examines the caregiving role of the mid-generation of women in today's older family recommends in concluding their findings that the stressful nature of caring for a dependent elder must continue to be addressed by the formal system of care. As the spectre of increased incidents of elder abuse has entered the social consciousness, the real danger may lie in the continued mythology that giving "too much" to the older person in way of support services will "cause" caregivers to "shirk their duty" (Brody, 1981). The adversarial nature (or merely rhetorical acknowledgement of family support) of the formal system has led Elaine Brody (1985) to state that increasingly overburdened "women-in-the-middle" will become the scapegoat of social policy dictates involving care of the elderly. Current programs of home care services are established to meet the needs of increasing dependency, but a recent study in Manitoba illustrates that users of the services are provided care by <u>both</u> formal and informal care providers and are in poorer health than non-users (Chappell, 1985). The idea that, under stress, a family will "opt-out" if formal service is introduced seems to be unfounded. What is known, however, is that a variety of ways to assist adult children acting as older family caregivers to remain in balance with the formal system continues to need to be defined, implemented and examined both at a preventive and restorative level.

Framework For Intervention

> "My thoughts are ... 4. I get too much in my head, trying to accomplish too much and I miss little things that just don't occur to me." (L., a caregiver, 1986)

Intervention with an individual coping with meeting the needs of an increasingly dependent older family member must include enough flexibility to "fit" the often changing situation and perception of the client in a pro-active and supportive manner. "One of the important ingredients is adaptation of a basic stance towards working with normal people with normal troubles during critical times in their life span" (Golan, 1981, p. 261). Golan goes on to say that the use of relationship between the client and worker in transitional situations goes beyond the "degree of involvement" in intervening in acute crisis situations to one in which "... a professional can inject into a treatment experience ... the quality of a warm, empathic, concerned, and genuine relationship that really accepts the person as he is, with all of his 'bumps and warts' ... this type of bonding can have both educational and therapeutic implications quite over and beyond the nature and content of the intervention itself" (Golan, 1981, p. 270-271). In addition to this basic stance, the worker should have experience with older adults and current knowledge about normal age-related change, the older family, ego and developmental psychology, chronic illness, and availability of both formal and informal services in the community.

In planning an intervention, it is vital to begin with the basic premise and value orientation which assumes that "... Individuals are inherently problem solving and desire the resources and skills to act in a problem solving manner, also, within undefined limits, as wanting an expansion of connectivities and clusters, and thus new information, resources and the possibility of support" (Erickson, 1984, p. 15). Building upon this orientation is the concept of competence within the older family. "Competence is a useful description of the behavioral goal or ideal in negotiating the transitions of aging" (Kuypers & Bengtson, 1983, p. 11). In their discussion of ecological issues within the older family, Kuypers and Bengtson (1983) go on to delineate three equally important facets of competence:

1. "adequate role performance";
2. "capacity to adapt"; and
3. "experienced mastery".

It is when these interworking aspects of competence become reduced or inadequate for a variety of reasons and at critical times in the older family caregiver's negotiation of transitions within her/his own life that help is needed in altering behavior, thinking and feeling in adapting to change.

Recognizing that the older family in its entirety is often viewed as a "... poor unit for work" in crisis situations (Kuypers & Trute, 1978), the utilization of the concept of "network coaching" in reference to working with one motivated family member in order to produce beneficial change in the entire family offers a modified approach (Kliman & Trimble, 1983). Linking the idea of "network coaching" with that of "network construction" through the "... establishment of psychotherapeutic mutual support groups" (Kliman & Trimble, 1983, p. 293) may afford a new "net" for concerned, caregiving members of the older family.

The "possibility of support" from the "expansion of connectivities and clusters" (Erickson, 1984) offered by a created or "constructed" network may function in a similar manner as other social support networks in later life. "... They can buffer individuals from the effects of stress or illness, serve as a protective shield, provide exposure to new ideas and attitudes, meet emotional and affection needs, and provide material resources and instrumental aid" (Saulnier, 1982, p. 19). All of these functions that support the elder family member in meeting the challenges of aging may apply equally as well to the generation of adult children acting as caregivers. Construction of a "buffer" for the informal "net" of care of the elderly remains central to the concept of supporting the elder population in society today.

Various treatment approaches in intervening with life transitions can be unified under a problem-solving and task/action continuum with a flexible time frame. Golan (1981) offers a three phase hierarchy of intervention that is appropriate in helping the adult child cope with the increasing dependency of older family members. Phase one is closely linked with crisis intervention as the caregiver often initiates contact during a crisis event involving the parent or as the caregiver approaches a state of exhaustion. Phase two involves working out material-arrangemental tasks for each problem area identified. Phase three focuses upon the psychosocial tasks faced by the caregiver. It is at the level of Phase three that the individual often becomes "stuck" in coping with transition. These psychosocial tasks run concurrent with, compound or block the ability of the caregiver to carry out necessary or appropriate material-arrangemental tasks and are those areas or issues most helped by professional intervention (Golan, 1981, p. 266-267).

Searching the limited conceptual tools available in the literature pertaining to intervention with the older family in its caregiving role has resulted in an attempt to link aspects of Naomi Golan's Crisis Intervention Framework (1978) with a Three Phase Hierarchy for intervention in life transitions offered by Golan (1981) blended with Inputs from the Family Support Cycle developed by Kuypers and Bengtson (1983) as part of their heuristic model of ecological issues and the older family.

The following integrative practice model may serve to specify intervention "steps" in assisting adult children experiencing the "pushes and pulls" of acting as caregiver to older family members.

Phase 1

Beginning (Formulation)

1. Contact.
2. Clarify nature of crisis event:
    a. physical/health components;
    b. mental health/impairment components;
    c. components of physical environment (living conditions); and
    d. financial components.

3. What is current crisis status?:
    a. acute state; and
    b. chronic state (on-going hazardous events, elements of burnout).
4. Allow for ventilation of feelings/hazard enumeration:
    a. anxiety/fear;
    b. anger/rage;
    c. guilt/concern;
    d. disbelief/denial; and
    e. sadness/sorrow.
5. Examine caregiver resources, expectations, conflicts:
    a. examine what has been done by caregiver to meet demand; and
    b. focus on demand vs capacity to meet demand.
6. Describe and mobilize external supports:
    a. medical support;
    b. formal home-care services;
    c. respite care; and
    d. informal help - friends, neighbors, other family member, volunteers.
7. Future working contract:
    a. Suggest limited roles of short term involvement;

1. show family caregiver that limited roles are acceptable;
2. avoid over-extension of caregiver's resources;
3. recognize competing intergenerational demands;
4. recognize time/energy constraints - reduce stress; and
5. mediate the "hostile elements" of over-involvement (the "martyr" caregiver).

Phase 2 & 3

Middle (Implementation)

1. Program quick success:
    a. demonstrate and re-affirm experience of mastery.
2. Delineate reasonable involvement with solving specific, current problems.
3. Identify and carry out material-arrangemental tasks:
    a. recognize lack of supports/services;
    b. explore available/potential solutions, resources, changing roles; look at choices and options; weigh advantages and disadvantages;
    c. made a choice and "try it out" (may be series of 'trial and error' attempts or

period of 'waiting' for formal services);

d. begin use of new solution/resource: explore expectations, limitations of functioning in new rule; and

e. go through adaptation period; developing increasing competence; stress decreases to more manageable state.

4. Explore cognitive and affective impact of changes (<u>psychosocial tasks</u>):

a. examine threat to past security, sense of competence;

b. deal with fears, sense of helplessness, frustrations in dealing with changes in role; acknowledge stress, panic, ambivalences;

c. pin-point and work out active coping for meeting stress and frustration in implementing solutions, resources;

d. examine moralisms and guilt:

   1. explore external, inappropriate labels;
   2. explore feelings of failure, implied criticism from others; lack of satisfaction and appreciation from others; and

e. assist in recognizing and accepting

reality of losses caregiver is/will experience in order to accept limits.

5. Achieve limited, feasible goals:
   a. reward approximation; and
   b. agree to lessened gratification of needs for short term.
6. Mobilize strengths:
   a. learn new coping patterns;
   b. look for new sources of gratification/enjoyment; and
   c. focus on what <u>can</u> be done, reduce crisis "panic"/pressure.

<u>Termination</u>

1. Review the intervention from start to finish:
   a. emphasis on tasks accomplished and new ways of coping.
2. Outline new ties with persons and resources.
3. Foster realistic view of future:
   a. all caregiving efforts will not prevent eventual loss of older family member; and
   b. begin to face own aging.
4. Follow-up with/develop on-going supports:
   a. support groups for family caregiver for on-going problems resolution/expansion of knowledge about aging, communication, ways of coping; and

b. disease specific support/education groups (i.e. Alzheimer's, Parkinson's, Stroke, etc.)

Each of these tasks or interim goals can be further specified/modified as the worker and client move through the phases of intervention. Emphasis throughout should be placed on separating facts from feelings, myths and stereotypes about old age from individual parent who is aging, and normal aging from age-related or other disease. Becoming "educated" helps to normalize the stress experienced in coping with increased parental dependency and allows the client to enhance her/his coping skills and decision making powers (or to share decisions with parents).

Within the "constructed" network of the support group all of the above tasks both arrangemental and psychosocial can be addressed in a parallel manner. "Many of these tasks, both arrangemental and psychosocial, are engaged in without conscious pressure or ambivalence; others may require considerable support, learning and 'girding of the loins'. But they lie at the heart of the bridging process and can offer an appropriate guide by which the practitioner can help the client first examine and then cope with the complex process" (Golan, 1986, p. 31). By building upon competence, reducing stress and offering new learning at both a experiential and didactic level, the support groups method of intervention seems to "match up" with the process of coping with transitions within the older family and reflected in the surrounding "growing older" social world.

Method of Intervention

> "My thoughts are ... 5. I feel guilty my mother needed Home Care." (L., a woman, 1986)

Informal small group work is based upon the restorative and preventative functions of naturally occurring support systems defined as:

> "An enduring pattern of continuous or intermittent ties that play a significant part in maintaining the psychic and physical integrity of the individual overtime ... [they] are attachments among individuals or between individuals and groups that serve to improve adaptive competence in dealing with short term crisis and life transitions as well as long-term challenges, stresses, and privations" (Caplan & Killilew, 1976, p. 41 in Rosenberg, 1984, p. 174)

Recent literature reporting the effectiveness of small group work with family caregivers reflects the importance of these functions. While little has been emphasized in regard to theory or process in this body of work and well defined evaluation methods have not been established, the small group remains the intervention of choice in assisting family caregivers to cope with meeting the needs of dependent parents. The full potential for this group work is just beginning to be recognized (Silverman, Kahn & Anderson, 1977,; Hausman, 1979; Getzel, 1982; Clark & Rakowski, 1983; Hartford & Parson, 1983; Cohen, 1983).

Support Group Definition and Characteristics

Similar in some ways to therapy and self-help groups, the support group is set apart by Pearl Rosenberg (1984) as a special "therapeutic entity". She states that, "The core of the most common definition of the support group - that is, sharing one's problems with others suffering from the same stress - has always been recognized as a powerful weapon for ameliorating that stress" (Rosenberg, 1984, p. 173).

She goes on to specify the characteristics, goals, dynamics of change and leadership strategy of a support group and differentiates the support group from therapy groups and self-help groups. "Constructed" along horizontal rather than hierarchical lines, members consist of "normal people with normal troubles" looking for answers and help in a problem-solving way. Closer to social network concepts and descriptions of reality than systems concepts of interaction, the actual complexity of social phenomena is paralleled rather than simplified (Abels & Abels, 1980) within the group, stressing enhanced coping and interpersonal rather than generic insights. "Soft" therapy dynamics within the group reinforces rather than reconstructs and concrete guidance is offered by group members who control its focus. While leadership transparency is high (in contrast with group therapy), the support group leader shares feelings, acts as a positive role model emphasizing trust, support and communication among group members and provides information, guidance, and advice along with the group members. As facilitator, the group leader seeks to "make easy" the cohesion of the group by pointing out similarities and differences in situations as revealed in the discussion-stepping back when group members are successful in working on their own (Rosenberg, 1984, p. 175-183).

The therapeutic significance of the support group evolves from the following elements:

1. Installation of hope;
2. Universality;
3. Imparting of information;
4. Development of socializing techniques;
5. Initiative behavior;
6. Intrapersonal learning; and
7. Catharsis (Yalom, 1970, in Rosenberg, 1984, p. 179).

The development of a program that uses the support group as a means of assisting the family caregivers in their service to their elders is a realistic service approach to both generations. "While this approach cannot be a

Caregiver Groups

The literature that addresses the issues and methodology that currently comprises work with groups of adult children (and/or relatives of an aging family member) is generally descriptive in nature. Slightly varying emphasis, format, size, time-frame and leadership of these groups are delineated but, in general, they are seen to provide:

1. "Information about the aging process (biological, psychological and social) as they impact on loved ones;
2. Aid in obtaining resources, entitlements, and benefits to aid their own efforts;
3. Assistance with interpersonal problems among the caregiver, the elderly and other relatives;
4. Support for the caregiver who is under pressure and frequently lacks recognition; and
5. Assistance in planning for the elderly in light of their changing condition" (Getzel, 1982, p. 96).

This growing body of gerontological literature illustrates the need to develop a knowledge base about the stages of caregiving, the nature of the stress and the demands upon the caregiver, the kinds of coping skills needed, and the possibility of long-term benefits from support group participation. Current information is composed of program reports, case studies, and observations noted by practitioners and group members. To date, the greatest benefits reported are in the realm of psychosocial tasks related to caregiving. Material-arrangemental tasks seem not to cause as much stress for caregivers who have participated in these programs, but the results are limited in their generalizability and evaluation methods - development of empirical approaches will continue to need study and demonstration in future group programs (Clark & Rakowski, 1983).

The development of programs using the small group intervention started about ten years ago with plans to offer educational programs to caregivers of elderly parents. Originating through Child and Family Services of Washtenaw County in Ann Arbor, Michigan, this program offered didactic and therapeutic learning about aging by using a lecture/discussion format presented by family therapists and resource persons (Silverman, Kahn & Anderson, 1977).

Emphasis on counseling groups was the approach taken by the Community Psychiatric Clinic of Montgomery County, Maryland, for its work with Adult Children coping with aging parents. This eight week program focused upon relationship and dependency issues and is often cited in the bibliographies of more recent work (Hausman, 1979).

Hartford and Parsons (1983) also used a time-limited, closed small group for caregivers, but began to move toward the cohesion needed in a support group by allowing potential participants to assist in defining the goals of the group. Emphasis on process and pre-group planning is more evident in this report and the themes focused upon in the sessions included:

1. Actions taken with relatives;
2. Feelings related to caregiving;
3. Relationships; and
4. Increased knowledge (both didactic and experiential)(Hartford & Parsons, 1983).

An expansion of Hausman's (1979) and Hartford & Parsons' (1983) work is outlined in the literature by Cohen (1983). This group used additional reading as an adjunct to group work. Goals specified for this group included:

1. Offering support;
2. Information and assistance to those needing to make specific decisions; and
3. Teaching self-care skills in assertiveness, stress management and communication.

No evaluation other than subjective reports and behavioral evidence demonstrated by group participants was included in this project report (Cohen, 1983).

The group work program which is part of the Natural Support Program of the Community Service Society of New York is described by George Getzel (1982) as offering "... counseling, educational content and social action opportunities to persons who generally are unaware of available options to enhance their caring activities"

(Getzel, 1982, p. 91). This report sets out guidelines to handle what he calls "phase specific situations" in these groups which are located throughout the community. Six phases offer a pattern of intervention to the practitioner and are the closest to the dynamics and leadership strategies examined in Rosenberg's (1984) discussion of support group characteristics and dynamics. By "... setting the conditions by which members are given maximum autonomy in setting group priorities and consolidating their caregiver roles" these neighborhood support groups have a high cohesion factor which has allowed them to form both self-help and caregiver advocacy groups (Getzel, 1982, p. 94-96). Described as the "most helpful" of supports offered by the project, this small group "network" has remained available for on-going concerns and new "work" long after the project (itself time limited) could offer assistance to growing numbers of caregivers.

One major focus of support group work with family caregivers has been for those whose relatives are struggling with cognitive impairment and dementias resulting primarily from Alzheimer's Disease. Utilizing information gained from the educational/support group literature, these groups address the specific stressors of caring for a person with cognitive impairments. Participants report that, again, these groups offer both necessary information and emotional support for difficult and demanding situations (Safford, 1980; Lazarus, Stafford, Cooper, Cohler & Dysken, 1981; Stever & Clark, 1982).

Taking all of the above into consideration, one program was chosen to serve as a "platform" for beginning work with adult children acting as caregivers to parents in the Winnipeg area. The "As Parents Grow Older" Program will be explained in detail in the next section of the literature review and referred to in the sections of the report examining implementation of the intervention as an agency sponsored offering to family caregivers coping with change in elder family members.

"As Parents Grow Older" Program

Putting theory and practice together is always the goal of the Social Work practitioner. Practice and practicality often are linked realistically at the agency level and "re-inventing the wheel" often slows or negates the process of planning and implementing a new program.

Because it was believed that the need for a supportive program for family caregivers (specifically adult children) would become more evident in our community over time, the search for something "hands on" that had been developed and utilized with good results in other communities to "leave behind" at the agency was undertaken. Readily available at minimal cost, a manual for replication of the "As Parents Grow Older" program served such a purpose. The Development and Evaluation of Educational and Support Groups For Families of the Aged, a co-operative project of The Institute of Gerontology in Ann Arbor and Child and Family Services of Michigan, Inc. was planned and field tested in several Michigan communities beginning in 1978. The program manual reflects the results of this project in careful detail. Contents of the manual includes:

1. Introduction and Program Description;
2. Facilitating The Group Process;
3. Preparation;
4. The Sessions (6);
5. Appendix A - examples of publicity;
   Appendix B - handouts for duplication
   - other recommended material;
   Appendix C - bibliography for each subject area offered in the sessions.

(Silverman, Brahce, & Zielinski, 1981)

Depending upon the goals of each group, emphasis can be placed upon the educational format presented in six sessions or upon the supportive (experiential) focus also addressed in the program. Variation in groups, individual needs and situations are easily accommodated for by modifying and expanding upon the common issues and practical suggestions offered.

If the program is presented as primarily educational with secondary supportive purposes, each of the six sessions is given as a complete lesson plan. Detailed session by session plans include topic, objectives, concepts (both content and process), materials, handouts and charts, recommended references, preparations and session instructions for group leaders to follow. The sessional topics covered by this program include:

1. Understanding the Psychological Aspects of Aging;
2. Chronic Illnesses and Behavioral Changes With Age;
3. Sensory Deprivation and Improving Communication;
4. Living Arrangements and Shared Decision Making;
5. The Availability and utilization of Community Resources; and
6. Dealing With Our Feelings.

(Silverman, Brahce, Zielinski, 1981)

Plans for developing a support group with educational adjuncts stresses the use of the session by session plan from the perspectives of the group members. In this regard, topics would be dealt with as they arose from group discussions with consideration of situational variations specific to each group member. Order of discussion and "weight" of each topic would vary with group members' needs. For example, the topic "Chronic Illnesses and Behavioral Changes With Age" can be addressed in the group by first discovering what illnesses are specific to group members' elders, what factual information have they learned and can share (along with reading materials), what changes in parental behaviors have they observed and how they have coped with these changes and, secondly, what more do they need or would like to know about the subject. New information can be presented informally by the facilitator or by a mini-lecture. Group members' shared knowledge building, validation of experience, and movement toward group cohesion is promoted by this approach utilizing the "As Parents Grow Older" program as a "platform" for work and information.

As increasing numbers of competent, caring adult children continue to "hunt down" available resources and learn to cope with scarcity, waiting lists, and the limitations of the formal system to meet increasing dependencies in our "growing older" population, this model will continue to serve as a basis for planning, implementation and practical guidance necessary for future and on-going support groups in the community. Deleting old information and adding current information will help keep both practitioner and clients "on top of things" as changes in service provision takes place and research on aging and age-related disease continues. The successful aging of the support generation may well be assisted by such a program being offered "as is" or modified according to changing needs as caregivers experience societal, familial and person transition - "pioneering" on the new "frontier" of life experiences.

Conclusion

The complexity and scope of issues, concerns and problems and beginnings of ways to assist caregivers of the elderly within the older family constellation today is reflected in the literature currently available. As new information and ways of evaluating work with caregivers is added to this growing body of knowledge, it will be the responsibility of agencies and practitioners to respond by utilizing this new information in their work with people of all generations in the older family in a pro-active, preventative and practical manner.

INTERVENTION

Introduction

Intervention based upon educational/support group models previously outlined was developed and implemented under the sponsorship of two community based agencies in Winnipeg - The Age and Opportunity Centre Inc. and The Fort Garry Family Life Information Centre Inc.

Both of these agencies, funded in part by the United Way, have similar objectives mandated to meet the needs of residents within the Fort Garry area and residents of greater Winnipeg with educational programs and personal services. Both agencies have well developed volunteer programs, focus on prevention and knowledge building in their educational programs, and are regarded in a positive way by the community in general.

The role of each agency will be elaborated upon in the following discussion specific to planning, implementation, content, process, client progress and outcome in the support groups as they evolved within the two settings.

Concurrent Groups

Beginning in April of 1985 and continuing into January of 1987, three separate groups of adult children caring for aging parents came together seeking information and mutual support for their continuing involvement in attempting to meet the increasing needs of the older adults in their families. Although planning and initial stages of program implementation had been initiated at The Age and Opportunity Centre, Inc. for six weeks prior to contact with The Fort Garry Family Life Information Centre Inc., work with small groups of family caregivers began with an inquiry and invitation from the project coordinator at the Fort Garry Centre to participate in the development of a group in that setting.

The ongoing group that has developed under the sponsorship of the Fort Garry Family Life Information Centre will be described first. Similarities and differences, advantages and disadvantages of the various groups will be discussed in detail in the evaluation section of this report.

Agency - The Fort Garry Family Life Information Centre Inc.

As previously stated, The Fort Garry Family Life Information Centre Inc. is a volunteer agency offering educational programs and services to the residents of the Fort Garry area. The central goal of the agency is to enhance the quality of family life. Three specific objectives in the agency's mandate are closely tied to the purposes of the small group intervention to enhance and support the efforts of informal caregivers to older adults within the community. These objectives are:

1. "To provide learning experiences for parents

and other family members related to their individual needs and roles within the family;

2. To assist the community in obtaining social and family-related services, by working in consultation with existing social service agencies and institutions; and
3. To provide residents in the community with information on family -related resources." (Brochure for Ft. Garry)

Originally established to meet the needs and interests of younger families, Fort Garry began in April of 1985 to offer information to mid-life and older families through a presentation entitled "The Sandwich Generation".

Origin

This meeting was attended by approximately 25 persons, many of whom were of the "generation caught in the middle" (Miller, 1981). Based upon information gathered in a study conducted by the Faculty of Human Ecology at the University of Manitoba, the presentation revealed to the audience what it already knew through everyday experience:

1. That families continued to care for elderly members as they negotiated the sea of loss and change in later adulthood; and
2. That the members of the middle generation who did the caregiving were women.

While interesting, informative, and based upon research done in Mennonite communities in Manitoba, this presentation left the audience with the unanswered questions bringing them to the meeting in the first place, "What do we do about all of these responsibilities to our kids and to our folks - when it is my turn?"

Following some discussion of a support group for "sandwich" people at this meeting, I was contacted by the project coordinator for suggestions and materials that would help her in planning a group for caregivers.

Pre-Group Planning

Following several meetings with the project coordinator at the agency, it was decided that an open, informal meeting would serve to establish need and interest in forming such a group in the Fort Garry area.

In addition to letters sent to those attending "The Sandwich Generation" meeting, posters were distributed to local stores and doctors offices, flyers were sent home with school children in the Fort Garry Area, radio spots for public service announcements utilized, and notification of the open meeting was announced in church bulletins in the Fort Garry area. All of these means of publicity are frequently used by the agency and were easily put into place by the office staff.

Materials from the 'As Parents Grow Older' program were freely shared with the project coordinator and available pamphlets from community services and agencies supporting the elderly community were obtained for distribution. Readings about the older family, support groups for caregivers and a bibliography compiled by the St. James Branch of the Winnipeg Library System with additional useful books available in local bookstores gave the coordinator some necessary background materials to use. Suggestions and ideas that had come out of the pre-group planning at Age and Opportunity were offered and discussed, as were possible barriers to the eventual development and continuation of a 'sandwich generation' support group.

Decisions were made about proposed membership and general purposes of this group to be emphasized in the publicity offered. From its inception, the support group in Fort Garry was open to anyone caring for a parent, elderly relative or friend. The older person could be sharing a household with the caregiver, living independently in their own home or apartment, or residing in a Personal Care Home. Members could also be involved in caring for elder family members who are residing outside of the Winnipeg area as well as within its boundaries.

The original purposes proposed for the Fort Garry Support Group paralleled the guidelines characterizing support groups in general (Rosenberg, 1985), specifically:

1. to gain mutual recognition for caregiving efforts;
2. to provide a supportive environment in which to share the difficulties and rewards of caring for an older family member;
3. to obtain new information about normal aging;
4. to explore with others experiencing the stress and uncertainty of caring for an older relative the feelings, attitudes, and ideas needed to cope with increasing demands; and
5. to discover the availability and utilization of formal services and community resources in balancing the care needs of the older relative.

Place, frequency, length and time of meetings would be decided upon at the "town house" meeting if enough interest was shown in forming a caregivers support group. It was decided that this open meeting would be facilitated by the project coordinator with possible input from myself regarding discussion related to information about aging and the older family in a caregiving role. The possibility of co-facilitating and aiding in the formation of any group that might evolve from interest demonstrated at the first meeting was discussed but not finalized when the meeting was held on the evening of May 15th, 1985 at Pembina Crest School in Fort Garry. Links between Fort Garry Family Life Information Centre and local schools and churches made the availability of space at a certain time and place relatively easy to investigate and obtain - again, this detail was attended to by the project coordinator at the agency.

Beginning

The five participants who attended the "town house" open meeting were welcomed by the project coordinator as representative of the sponsoring agency. Her introduction included the purpose of the meeting as one of exploring the possibility of forming a caregivers support group and the role of Fort Garry Family Life Information Centre as sponsor for such a group. While referral to another agency was appropriate, no individual counseling could be provided and the educational/informational components of the group's purpose would be stressed in this setting. As possible adjuncts to this information gathering process, ideas about bringing in speakers, films, and other resources were explored as future possibilities. Group interaction was begun with self-introduction including information about what had brought each person to the meeting, what they hoped to gain from group participation and what were they currently struggling with related to parental care.

All participants were actively looking for information and support. Only the couple who attended wanted to be "told" what to do about their situation; the three women who participated had had past experience and were currently involved with on-going "endurance contests". All of these people were in their 50's with parents and in-laws in their 80's. One participant had heard about the meeting on the radio, the couple had read about it in their church bulletin and two friends, who had attended "The Sandwich Generation" presentation, received letters informing them of the meeting. Everyone present worked, with the exception of one woman who had left her job to assist both her parents and her in-laws cope with increasing dependencies. The three women were married and had young adult children; the couple had no children.

Physical and mental impairments of the older family members included: loss of mobility and motivation following a stroke, recent surgery, heart disease, memory loss and confusion, and incontinence. Sensory changes in vision and hearing were common factors as well as were other aspects of normal aging. Home Care was involved in three situations, two parents were currently hospitalized and one father had recently been evaluated for Alzheimer's Disease.

One set of parents and one set of in-laws lived outside of the city necessitating frequent trips to assist them - especially on weekends when formal services were not available. All of the parents were still living in their own homes which meant that the time and energy constraints of caring for several homes at the same time had become issues of concern for this group of people. Other material-arrangemental tasks attended to by group participants included shopping, laundry, cooking, yard and housework, banking, transportation to and from appointments and some physical care related to personal hygiene on the weekends. Most of the participants had long-standing, on-going concerns and had given up vacation time and other activities in order to help their elders (and, often, their children).

In contrast with the on-going concerns expressed by the women at the meeting, the couple had come during a crisis period. Recent hospitalization of the husband's mother had revealed the extent to which his father has become cognitively impaired. Without the stability and patterning of daily living established by his wife's presence, he became very agitated, confused and demanding, began to wander the neighborhood and, in general, was unable to care for himself. In response to this dilemma, the son had stayed with his father, taken him to another doctor who arranged for a complete geriatric assessment (only carried out two days before the meeting) and felt that it was his responsibility to continue to assist his father and his mother in making plans when she was able to return home. Frustrated and angered by the amount of time and attention demanded by "... that nasty old man", the daughter-in-law was certain that her spouse "... should be 'counseled' to stop all of this worry and unnecessary attention". Concerned that "a marriage could suffer at the expense of caring for a parent", she felt that, because her own parents had "died early", she had no role in caring for "other old people".

Other participants expressed understanding of her point of view because of their involvement with the care of their in-laws, but were clearly more supportive of the action taken by her husband on behalf of his parents as the only realistic short-term alternative given the circumstances. Hearing from others that their own vacation and "couple time" had also been eroded under the demands of parental care only served to add to her dismay. Stating that she had come only for "a lecture" and found discussing others' situations "only made things worse:", she felt that a support group wouldn't be "good for her" if it was decided to continue. A suggestion to contact the Alzheimer's Family Resource Centre was made to this couple as an alternative source of information - especially for the son to pursue if he found group discussion helpful.

In concluding this "town house" meeting, participants were asked if they wished to continue as a group and under what specific format. The five original participants felt that the group should be left open, with two hour monthly meetings held at Pembina Crest School from 7:30 to 9:30 p.m. Themes and topics for discussion were to be decided at the close of each session with the facilitators leading discussions, providing handouts and didactic learning opportunities as well as building upon the experience of individual group members. It was also decided to keep the group small (10 - 12 members) and informal. All evaluation would be participant observer and recorded on the basis of group interaction (See Appendix A-1 for form used). This process of evaluation was seen as sufficient by the agency sponsoring the group and the project coordinator whose background was in Sociology.

A second meeting was held on the evening of June 11, 1985, to further explore the possibility of group formation. Notices of this meeting (now called a support group) were placed in the public announcement sections of the paper and on radio, following the procedures commonly used by the agency.

Following the initial meeting, an offer to co-facilitate the group was accepted. Differing perspectives of leadership or facilitator styles were discussed and the need to "balance" the often sterotypical view of aging with "reframing" from the perspective of the older generation, thus normalizing certain aspects of growing older apart from age-related illness and frailty. The "Message" of successful aging had, somehow, to be maintained or re-introduced as new participants entered the group and the possibility of "coming and going" of people as their needs changed dealt with. The project coordinator would continue to speak to interested people contacting the agency as a form of "intake" - no other interview of prospective group members was deemed necessary if the primary purpose of the group was to gather and share information involving caring for an elderly relative or friend.

Still in a contract stage of development, the second meeting in June, 1985 was attended by five people (two returning). Pamphlets, handouts from the "As Parents Grow Older" program, and books on caregiving to parents available through the public library system were displayed at this meeting. "Help yourself" coffee, tea and juice was provided. While the classroom setting was recognized to be less than ideal (the chairs were not "two hour chairs"), the neutral territory it offered was made more welcoming by using the space and available tables and chairs in as informal a way as possible.

Group discussion was again introduced by outlining the purpose, open format, and hoped for goals of forming an educational/support group for family caregivers sponsored by Fort Garry Family Life Information Centre. Issues of confidentiality, mutual trust and non-judgmental participation were presented as the only "rules". The informal nature of the meetings was emphasized and the role of facilitator of such a group clarified as one of mutual exploration and network formation. The theme for discussion was "Responsibility for Parental Care" as had been planned. Open-ended questions about who was responsible, to what extent, for how long, and could (or should) that responsibility be shared were put to the group participants.

Issues arising from this discussion included having to "take responsibility" for parents who had never taken responsibility for their own actions and the failure of the "system" to respond. Struggling with hospitals, doctors, and homecare whose responsibility was limited in providing assistance was stressed as problematic for several group participants. The lack of "offered" assistance from other siblings, especially those from "out of town", was an issue common to all and the possibility of sharing some responsibility for parental care with other family members viewed as unrealistic in most cases. The need to be given recognition as a "responsible partner" in planning and implementing realistic care for parents following hospitalization was discussed as an underlying issue of concern. Frustration and anger were expressed by group members who had been "told" what to do for their parents rather than being "asked" by physicians and other formal caregivers. Responsibilities to themselves, to spouses, to work, to children, and to parents were brought into the discussion as was responsibility about property and finances in the case of cognitive impairments in the parental generation.

Parental health care concerns described at this meeting included clinical depression, alcohol abuse coupled with over medication, hypoglycemia, stroke, heart disease and Parkinson's disease.

Questions about responsibility remained for the most part unanswered other than the verbalized consensus of the group that they all **were** responsible, like it or not, and would remain so despite the great desire to be free of that responsibility.

Discussion about "freedom and getting away" led to a question about vacation time and the possibility of meeting over the summer months. All those present decided to meet again in September to "face together" the winter months ahead with the idea of sharing more of their experiences. More information on normal aging was requested by the group as a starting place for discussion in the fall meetings. The one man present at this meeting stated that he never thought he could laugh over the difficulties he was having with his parents but found out that he could in this setting because "everyone else" understood how ridiculous things got at times - he planned to "relax" a little more over the summer and was looking forward to seeing everyone in the fall.

As a beginning for future group development, this meeting was promising with regard to the ease of interchange between group participants. Contributions were relevant, needed little clarification and were often linked to the comments made by others. Group members demonstrated listening ability as well, and allowed each other the time needed to "think out loud" about their own feelings and situations. At this stage, group members were still looking for answers and directing questions to the group leaders alone. These questions were re-directed to the group members for ideas based on their own experience in similar situations in an attempt to foster group interaction and cohesion. The risk of having to start all over in the fall was acknowledged as a possible outcome of this break in group formation. The reality of seasonal variation in group attendance was also recognized as "the norm" for most people and accepted as such by the co-facilitators. Plans for meeting in September using the same manner of publicity for the first meeting were confirmed. Letters would be sent from the agency to those already interested in the support group and newcomers welcomed by the "veterans" of the two beginning meetings.

Viewed as another beginning step in group formation, plans for the September meeting included bringing in materials from a variety of sources on normal aging, especially sensory changes. Information from the "As Parents Grow Older" program was used as the basis for this planning process. Helpful books that had been shared with the project coordinator for her own information were made available for the group members to borrow. Copies of You And your Aging Parent (Silverstone & Hyman, 1976), Aging Is A Family Affair (Bumagin & Hirn, 1979) and I Love You But You Drive Me Crazy (Watt & Calder, 1981) had been purchased for the resource library at Fort Garry Family Life Information Centre as a result of this sharing and served as both a guide for group leaders and as a source for group members' knowledge building.

Made available through McNally Robinson's Booksellers at Grant and Kenaston, I Love You But you Drive Me Crazy was eventually purchased by most group members as the most practical source book available.

Returning to the group after a "break" were four "veterans", including the couple who had been at the last meeting, and three newcomers - all women in their 50's. All of the new people had read about the group in the notices placed in the Free Press.

This meeting began on an upbeat when introductory rounds revealed that the returning members had some successful "adventures" to report, not only about finding but also about taking time for themselves over the summer months. Anticipating future demands, several members said they needed to "... grab a holiday" while they had a chance. Vacation time for two newcomers, whose mother and mother-in-law respectively lived with them, was difficult to arrange because "someone" had to stay with the elder family members - usually a grand-child who offered a short term respite to her parents. Another new member, who had given up her job to assist her parents, hadn't "risked" a vacation for several years and was being pressured by her husband to do so.

Group members were interested in finding out how the two parents who shared houses with their children had decided on this option or if sharing just "happened". One newcomer,whose mother-in-law lived with her husband and herself, had been "trapped" into the arrangement when a temporary stay two years previously had become a permanent "invitation". Offers of help from her husband's five brothers and sisters had been withdrawn when they had been approached to "spell" the couple as the needs of their mother changed over time.

The discovery of parallels and variety in situations, responses and personal "quirks" facilitated the flow of interaction and mutual interest between group members at this meeting.

Spontaneous laughter was generated as people recognized the changes in themselves related to normal aging. Connecting their own responses to greying, balding, wrinkles, hearing and visual changes to those of the parental generation added better understanding of both generation's response to loss and change. The effects of age related, work related and role related changes upon self-image, self-esteem and self-determination were pointed out by one group member discussing changes in her own life. Coping with lack of motivation and depression in parents following loss was defined by all as an on-going concern. Ways of coping with these problems and coming to some understanding of their pervasive nature was chosen as a topic for the following meeting in three weeks time. The decision to meet more frequently than once a month was established at this meeting and has been the pattern for the on-going group that evolved from the early meetings..

A final "light note" ended the meeting when someone asked, "Do your mothers know where you are and what you are doing?" Laughingly, everyone revealed that they had avoided mentioning going out to "a meeting" even in general terms. "Sneaking out of the house" to 'visit the neighbors' was the ploy of both women sharing a household with a parent! This "bond of conspiracy" served to unite everyone at a very human level, but also raised the question about feelings of disloyalty and guilt. Meeting to discuss mutual concerns was viewed as "worth" feeling a little guilty - the question of how those feelings come into play would be explored in later meetings.

Common Themes

Thematic content of the group meetings changed over time as issues arose for continuing group members (which stabilized at ten people). The first seven meetings could be considered as a continuation of the Beginning Stage of group formation in that the co-facilitators pointed out possible topics for future discussion from the issues raised at each meeting. A Middle Stage in group formation occurred when members decided to take turns holding the meetings in their own homes and began to request specific information on areas of concern. In a Later Stage of development, members began bringing in resource persons of their own choosing as well as including friends and relatives in the meetings.

Initial themes for discussion required consultation and planning by the group leaders.

Background information was selected from resource materials chosen on the basis of practicality and availability. Mini-lectures from the "As Parents Grow Older" program were used if requested or required to clarify points of discussion. The goal of normalizing the difficulties both generations were experiencing when faced with growing dependencies was always included in formulating plans for meetings. Information that didn't "fit" the situations in the group was not stressed in discussion, but provided by handouts and outside reading materials. The first twenty meetings of the Fort Garry Group were focused upon the following themes as they arose in discussion:

<u>Beginning - 1985 -</u>

1. "Townhouse" introductory meeting - caregiving and the need for support;
2. Responsibility for parental care - Who is responsible?;
3. Normal aging - sensory changes, physical changes and adaptive behavior;
4. Depression and memory changes - warning signs or normal process?;
5. Caregiver stress - What we can do for ourselves;
6. Stress and distress in our family elders, can it be mediated?;
7. Getting through the Holiday Hassles - ways of

making Christmas and other holidays and anniversaries meaningful for everyone.

Middle - 1985 - 1986

8. Legal questions - Legal aid lawyer at Age and Opportunity acting as resource person;
9. Helping out - what happens when you ask other family members;
10. The Older Family - memories, resentments, siblings, our own kids - how it all feels;
11. Fears about aging - our own, our parents;
12. Alternate Housing - limited options?;
13. More on housing - future choices for ourselves;
14. Death and dying - our experiences;
15. Palliative care - St. Boniface Hospital nurse as resource person;
16. Pot luck supper - celebrating summer and good health;
17. Support from spouses, relatives and friends - can we accept it, can we rely on it?;
18. Catching up - how are we doing individually, as a group? Where do we go from here?;

Later Stage - 1986 - 1987

19. Rupert's Land Respite Care and Support Group - Rev. Barnett, resource person; and
20. Medox - resource person describing services

and cost involved.

On-going issues for each caregiver were "reported" to the group at the beginning of each session. Success in obtaining needed services, getting away for a long needed vacation, trying out the stress reducing exercises learned, involving other family members in sharing tasks, encouraging a parent to try a new plan, looking for, and obtaining a new living environment for parents and learning new coping strategies from each other was mutually applauded as these events occurred.

The discovery of terminal cancer in two parents and the deaths of three parents were events that touched all of the group participants, members and leaders alike. Over time, discussion about parents had created "mental pictures" of these people, their histories, relationships to caregiving children and other family members, their beliefs and behaviors, and their physical and mental health status. Personal experiences with the realities of life and death as loved ones grow older and the process of acceptance of this final lifestage were shared as these turning points in the lives of the families involved

were acknowledged by group members. Mutual support and understanding was demonstrated not only in the group setting but outside of the group as cards,calls and supportive listening were freely given by group members to each other. Hopes and fears about illness, old age and "dying with dignity" were addressed in open discussion. Funeral plans, helping surviving parents during their bereavement, and understanding of the process of grieving were all stressed as questions arose from group members.

Recognition of the "bitter and the sweet" in "letting go" of parents helped those struggling with terminal illness in parents still living. As one group member remarked, "If I can do this *now*, face this *now*, I'll have done the very best that I can for my mother and the end may come easier - but right *now*, I'm numb and I know I'll need help as time goes on."

Repeated "refrains on an old theme" keep group members struggling with everyday tasks and the need to balance their own needs with those of their parents. Additional stress from having to assert themselves with doctors, home care staff and other professionals continued to be reported in almost every group meeting. Mottoes from these encounters became, "Don't *'should'* on me!" and "I'm all '*oughted*' out". Ways of dealing with bureaucratic systems in an impersonal business-like manner had become a lesson learned "the hard way" by several of the group members. Expectations of understanding, recognition of their efforts on behalf of aged family members, and appropriate assistance proved to be unrealistic in actual service delivery. Fully recognizing the limitations and imperfections of the formal system, some members had chosen to pay for some services and rally family members to provide others. Other group members had no option but to continue to re-negotiate for additional services as increased dependencies emerged - always a stressful task. Only one member had to deal with the process, the frustration of waiting, and the sense of failure and helplessness in seeking Personal Care Home placement for her in-laws, both of whom had suffered repeated strokes leaving them both physically and mentally dependent. Her experience gave other group members a very realistic picture of the difficulties involved when faced with this decision and the often unresponsive placement process once that decision is made.

Issues about chronic illness, frailty, cognitive changes, demanding and passive behaviors, loss of mobility, illiteracy, depression and terminal illness were often re-opened as members experienced them in their own families. Legal issues were addressed by contacting a lawyer, questions about medication referred to the Pharmacy line for the elderly at the University of Manitoba, and nutritional matters to a dietician under the health care system.

Both material-arrangemental tasks and psychosocial tasks were recognized as part of the patterns of discussion themes. Emphasis on practical issues and information about available services was often made secondary as group members began to use the forum available for validating both positive and negative feelings about their roles as caregivers. Reading _Making Peace With Your Parents_ (Bloomfield & Felder, 1983) helped group members to let old resentments and expectations about parental relationships get "sorted out". Dealing with what _is_ not what could have been, was seen by some members as a useful way of facing the reality of parental aging and the generation "gap" remaining.

Other materials used by the co-facilitators in preparing for meetings included _Mirror Mirror, The Terror Of Not Being Young_, (Melamed, 1983) and _Growing Older, Getting Better: A Handbook For Women In The Second Half of Life_, (Porcino, 1983). Written from the Feminist perspective addressing society's message that men mature, but women age, the focus of both works is on empowerment of midlife and older women. Emphasis is placed upon self-care, sharing and connecting as keys to maintaining good mental health when faced with change and life transitions.

Process

The process of group formation, development and continued re-contracting paralleled in some regards the self-help group criteria (Mallory, 1984). The beginning stage moved very slowly as people took time to get to know each other, to feel less isolated and helpless in their situations, to develop trust in the leaders and in each other.At several points in group formation, members were asked if new people were welcome, if the group should close for awhile, or if introductions should be handled in a different manner.

The middle stage of development was marked by the decision to meet in each other's homes, to begin to ask for specific resources and information, to ask for and provide feedback to each other, to feel more in control of one's own life, to accept validation from each other for efforts on behalf of parents, and to share emotional support. At this middle stage, group members also decided to share names, addresses and phone numbers - another sign of mutual trust and support.

A later stage in development was marked by members looking for a name to identify the group and its purpose. Still in the discussion process when I left the group as co-facilitator, the permanent nature of "naming" reflects group cohesion, identity and on-going evolution. A core of ten permanent members has given the group stability for the past two years as other participants have come and gone, either with their needs satisfied or searching for help in a different setting.

Resolution

In the later stage of group formation, individuals began taking on a more active role in planning meetings, arranging for resource persons and acting as natural leaders. It was at this stage that I was able to leave the group without breaking the "integrity" of group formation. The project coordinator had left Fort Garry Family Life Information Centre for a new job, but had remained as volunteer facilitator and link to the agency. This link remains crucial in expansion of the group as old members will probably discontinue attending meetings with time. Periodic outreach and personal "recruiting" by group members has brought several newcomers to the group thus maintaining the connecting and sharing role of group "veterans". Follow-up contacts with group members reveals the on-going usefulness of this group, the enhanced coping skills developed and the reduction of "going it alone" in all of their lives.

Saying "good-bye" is always hard to do, but a note from one group member says it very nicely:

> "We missed you at our last "Support" get together and hope you will be able to join us once in awhile. (You always seem to say the right thing at the right time.) The group meetings have been such a help to me this past year. It's so comforting to be with a group who understands."
>
> Sincerely,
>
> S.

It's nice to be missed, but the established network of "a group who understands" remains - a very positive experience for everyone involved in its development - a true "mutual admiration society"!

The evaluation section of this report will include more material on the Fort Garry Group as it is compared and contrasted with the program sponsored by Age and Opportunity Inc.

Agency - Age and Opportunity Centre, Inc. (A&O)

"Serving Winnipeg's older community since 1957", A&O is a cornerstone in promoting a wellness model of growing older. Educational and recreational programs, personal services (counseling, friendly visiting and older victim services), and volunteer programs all provide information, support, and meaningful contact for large numbers of elders in the community. Concerns of family caregivers have been addressed in a variety of ways at the agency, primarily with advice from counseling staff and friendly visiting workers.

The need to recognize family "service providers" in an attempt to balance formal and informal supports for the elderly in today's budget conscious society has become increasingly apparent (Brody, 1985). With the promotion of early retirement and consumer oriented health care, the "55 Plus" programs have been developed to prevent or mediate some aspects of growing older that become problematic for many people. The educational and preventive nature of serving the "55 Plus" population of adult children was conceptualized as an important factor in approaching A&O for sponsorship and supervision of a support group program.

Origin

The possibility of developing a support group for adult children under the sponsorship and supervision of

A&O was first discussed with the counseling staff. Potential barriers to planning and implementing this program were both hidden and readily apparent.

Administrative and staff changes in the spring and summer of 1985 had to be accommodated for at the agency level. While interest in the idea of a support group for adult children remained, the practical process of planning and implementation was difficult to clarify with the agency while the necessary re-organizational tasks took precedence. Past experience with similar target populations and workshops for adult children had met with little success and scepticism remained.

Despite the initial reluctance of the agency to take on another student and another project at this time, the approval for the project to be sponsored by A&O was granted. Referral criteria was distributed at a staff meeting in mid-April with the idea that, by the end of May, inner agency referrals of adult children caring for their parents would provide enough clients for a beginning group.

Appropriate referrals were adult children experiencing distress and uncertainty in their attempts to meet the needs of increasingly dependent parents living in their own residence or with a caregiving adult child. The parent could be dependent for a variety of reasons, including chronic illness and frailty accompanying advancing age.

Using the six week program guidelines from the "As Parents Grow Older" manual, charts for sessional use had been made and handouts selected for inclusion whenever such a program could be implemented. Staff vacations and lack of agency originated referrals made it necessary to continue to recruit potential clients from a larger referral and publicity "net" beginning in September. At the same time, agency sponsored large group workshops for family caregivers were being planned by a Psychology student in a parallel effort to interest people in a self-help group for caregivers. Sharing ideas, knowledge and potential ways to "blend" any groups that came out of these programs served to maintain a sense of purpose and bolster flagging energy throughout the summer months and into the fall.

Pre-Group Planning

Planning over the summer months included a careful review of the relevant literature related to the beginning contact and experience with the group sponsored by Fort Garry Family Life Information Centre. The well defined guidelines in the program manual for publicity and session by session presentation of information were used to create a prototype flyer explaining who, what, why, where, and how. Formal application to the office of Continuing Care for possible referrals from workers in area offices was drafted for final approval by the agency.

Because the agency had been asked to provide meeting space, contact with Senior Centre Directors was made in August to explore the possibility of space being available at several times thought to be appropriate for both working and non-working caregivers. One afternoon and one evening were selected as possible alternate times. This exploratory contact proved to be problematic and was viewed as inappropriate by the agency because of a policy decision not to use Senior Centre space for outside groups. The responsibility for direct supervision for my work on this project had been given to the Personal Services Director during the agency re-organization over the summer months, and, left uninformed of this decision, I had not met with her to discuss procedural changes. Negotiation for space and approval of form letters, memos, and publicity became difficult and time consuming. As a result, available space at Lion's Place was requested and provided for on Tuesday evenings from 7:00 to 9:00 p.m. beginning in October for six consecutive weeks.

Recording was to be done on audio-tape and on the form already selected for use in the on-going group in Fort Garry (see Appendix A-2). Content, group interaction and facilitation skills could be evaluated by tape review.

With approval granted, flyers (and covering letters where necessary) were distributed at A&O Volunteer Recognition Night, at "Networking For Needs" held at the Convention Centre, to Continuing Care central offices for re-distribution, to the hospitals, and to the Senior Centres. Notice of the support group program was placed in the "Growing Older" column of the Free Press for a two week period. Space in the downtown office was provided for answering inquiries and conducting interviews. Messages taken by the office workers were followed up by both students with the idea that some callers would profit from a small group experience, while others were looking for an information presentation in a large group setting.

Beginning - Initial Group

Referrals from agency staff were followed up. Some adult children were sent the flyers explaining both the support group and the workshop series of discussions, others were eager to discuss their situations, but for a variety of reasons were not interested in the programs being offered. Three referrals were received from Home Care Case Coordinators; two of these caregivers were interested in the support group but found it difficult to get out in the evening. Both names were placed on a list to be re-contacted if another six week program could be offered in the future - preferably in the afternoon. Conversations with over twenty-five people resulted in seven persons interested in the six-week program planned.

Following several two hour initial interviews with prospective group members, telephone intake forms were adapted from I Love You But You Drive Me Crazy (Calder & Watt, 1981 - see Appendix B) to facilitate this necessary but lengthy process. Having the time available for a personal interview was often difficult to arrange for many caregivers. Once contact on the telephone had been established and the support group program outlined and explained, people often used this time to "present" their situation or uncertainty to an empathetic "ear".

The initial closed group of seven participants began to meet on October 22, 1985 and continued into June of the New Year when members re-contracted to meet once every three weeks after the six week program ended. Themes for inclusion adapted from the "As Parents Grow Older" manual were:

1. Thinking - Feeling - Acting. (Emotional and Psychological aspects of aging);
2. "Old Is What You Get". (Separating normal aging from illness);
3. Sights, Sounds and Memory Lane. (Sensory changes and communication with elderly relatives);
4. It's Not What It Is, It's What It Means. (Dealing with feelings and situations);
5. What's Out There And How To Get It. (Availability and utilization of Community

Resources);

6. Decisions, Decisions and Anywhere You Hang Your Hat Is Home? (Shared decision making and alternative living arrangements).

From the outset, the support group for adult children sponsored by A&O had a "built in" cohesion factor. Two sisters, two friends, a couple and a mother and daughter joined with another member to "... get some help". Contact with the facilitator had already been established and the purpose of a support group had been clarified so people arrived ready to introduce themselves. Opening remarks about the "pioneering" aspect of mutual exploration between the facilitator and the group members, the "rules" of confidentiality and non-judgmental, informal interchange of ideas, feelings and information were explained and introductory rounds began.

Three people had been informed about the group through the notice in the "Growing Older" column, the couple had seen a poster in the West End Senior Centre, one had been informed by her friend, and one had come across a flyer (posted by another member) on the bulletin board in her apartment building. This "neighbor" had asked her own daughter to join her for the first meeting.

Reasons for coming to the group were based on learning more about aging, services, new ways of coping with changing or long-standing situations, and meeting others "in the same boat". Members' own age-related issues (retirement, health care concerns, responsibilities for grand-children) were also mentioned in introductions.

The chronological age profile of both caregiver and care receiver was very similar to that reported in the literature and evidenced in the Fort Garry Support Group. One member was in her early 60's, the rest in their 50's. Parents were all in their 80's and 90's and were experiencing a variety of mental and physical difficulties that were compounded by advanced age. Arthritis, osteoporosis, heart disease, cognitive impairment, chronic pain following surgery, dementia, diabetes, incontinence, reduced mobility, and depression were pointed out as problems faced by the parental generation.

Remaining "in the picture" was the central task for three daughters whose parents were residing in Personal Care Homes or awaiting placement in the hospital. Acting as advocates for impaired parents who were unable to express their own needs was a role defined by these members as very important to parental well-being and personal peace of mind. Committed to active participation in her mother's care one working member, who was widowed herself, spent most weekends in her home town 300 miles from Winnipeg where her mother lived in a care home. Offering emotional support by her presence alone gave this member some comfort in the face of increasing cognitive impairment in her mother.

The couple was faced with an unusual dilemma because of a well meant "rescue" of her mother from Ireland following a fire and hospitalization there. In Canada under a visitor's visa, the mother remained ineligible for provincial medical coverage and could not, in all probability, become a permanent resident because of her age and obvious dependencies. Financial and personal responsibility for the mother could become overwhelming should she require hospitalization for medical attention, both highly probable given her physical status. Unresolved issues from the past had resurfaced, the daughter had to leave her work to care for the mother, and, in general, both generations were caught in a situation not of their own choosing. The possibility of having to return to Ireland and arranging for her care there was perhaps the only solution. Until a decision could be made however, some equilibrium had to be established in the household in order to meet everyone's needs in a better way.

Following introductory rounds, a chart listing losses and changes in later life was used to point out how individual responses, feelings and thoughts are attempts to cope with these changes. Memory loss, loss of personal privacy, loss of choices - where to live, what to eat, when to get up, when to go to bed, what to wear, loss of important roles, loss of spouse, and loss of mobility were noted by group members as losses experienced by their own parents. Changes in hearing and vision were also noted as challenges to communication with parents (and with several spouses who weren't getting younger either!).

Upsetting to group members was the labeling of parents as "uncooperative" or "resistant" in the formal care setting when loss of personal dignity and privacy were involved. Discussion around trying to let parents remain in control of their own situations as much as possible and the difficulty of doing "something" without taking over when you can do it better and faster led to the issue of losing control of ones own time and space when living with a parent. One single member had taken an early retirement to care for her 89 year old mother whose memory loss had become so great that she could no longer carry out routine household tasks. Parallel responses in both generations were recognized as "normal" and adjustment to situations of steady decline were acknowledged as especially difficult to live with in shared accommodations.

Being always "on call" for parents was troublesome for several members. The idea that parents sometimes phone frequently just to "keep in touch" or to give some element of human contact to their day was introduced. Making demands and wanting instant attention was viewed by several group members as the way their parents coped with helpless feelings and a sense of vulnerability. Others began to look at their own parent's behavior in this light and could see how that could be possible.

With increasing parental impairment, several of the daughters had lost their mothers as friends and confidants. Recollections of the "good times" when their mothers were well and capable of helping their adult daughters were openly shared - the joy and the sadness together.

The closed group from its inception allowed for greater integrity within the group's boundaries. Members felt free to question each other and to link their own feelings and experiences with those of other participants. The pleasant setting provided at Lions Place, ease of parking and bus access, coffee and handouts for the taking, and the informal nature of the discussion itself allowed the members to use the time as they needed - individually and as a group. Over time, members became friends and looked forward to seeing each other and exchanging "the latest". The comment of one member on a post-session report for the first meeting served as a good prediction of future group cohesiveness and interaction. It read, "I felt there was some restraint but am sure as we become better acquainted this will vanish."

Content

Less and less formal structure was used over time despite prepared didactic learning materials. In one way or another all themes that formed the agenda were covered but not in order and only as the topics arose in discussion and were felt to need clarification. From the beginning, people used the rounds opening each session to describe difficulties and successes during the past week. Television programs on Caregiving, Ontario's trial use of "grannie flats", and Alzheimer's Disease were all eagerly discussed. Magazine articles on parental care and care by spouses were shared and used as discussion material.

The impact of chronic illness, the changes in relationships and feelings about parents, parent's unique qualities and past histories as part of their remaining ability to cope with difficulties, and daily struggles with meals, shopping, Doctor's appointments, household tasks, and all of the frustrating "small stuff" were discussed repeatedly as individuals learned new ways to handle these material tasks.

Parental struggles with memory loss, hallucinations, medications, hygiene, loneliness, bereavement, housing problems and changes in mobility were all considered in the context of on-going problem areas. Ways of personal acceptance of some of these non-reversible factors were openly presented by the individuals coping with these aspects of caregiving.

Communication problems with parents and siblings remained difficult for most members. Old ways of "telling", talking and listening were hard to alter. Arguments with both parents and siblings had often been the result of "frustration overload" and anxiety about parental well-being.

Attempts to include other family members in care plans were often difficult to initiate. Grandchildren were often brought into the picture - especially grand daughters. The gender related pattern of caregiving was clearly recognized by these group members - guilt was viewed by most as a "women's issue". Failure to live up to parent's or own expectations of being a "good daughter" was one aspect of caregiving that was evident in everyone's view of that role.

Reports of "good days" spent with parents, small "pleasures" conceived of that "worked", love and admiration for parents' special qualities (even the fiesty, argumentative ones) were equally shared with the group.

Learning ways to set limits and feel good about it were included in the sessions. Getting some time for member's own activities (or even necessary sleep) was a goal often addressed. Many members had their own health problems to deal with as well as parental care (and in one case care of grandchildren). Sharing their own experiences with cancer, respiratory and heart disease led into an on-going discussion of the fears associated with loss of life, aging, chronic illness and the debilitating effects of chronic pain. Future plans for many had been "put on hold" while parents care needs were being met - the uncertain nature of planning too far ahead reflected the reality of many situations.

Abuse of the elderly was discussed for part of one session following the television special "Amos". Some members felt that the abuse portrayed was exaggerated but made abuse in institutions more "visible" to the public. Verbal chastisement, rough handling, and neglect of personal care needs had all been witnessed by group members whose parents were in Personal Care Homes or the hospital waiting for placement - hence their decision to "be there" frequently. The fine line between abusive behavior and necessary action was viewed as being very arbitrary and the ease of frustration and anger turning to abusive behavior recognized.

Finding a good doctor - one for "older" women - was another issue brought up in this group. The stress of taking parents and yourself to one specialist after another was an experience shared by three of the group members. Getting up the courage to call Home Care for an assessment took one group member six weeks. Asking group members to "coach" her to ask for help before a crisis occurred paved the way for appropriate Personal Care Home placement two years later. The link between doctors and Home Care needed clarification - even the doctors weren't certain of their role! Other services had been used by some parents in the past, Meals on Wheels and the Senior Centres were both positively regarded sources of support.

The psychosocial aspects of the content of this initial six week program remained the focus of future support group meetings. Educational components took secondary precedence but were informally introduced when appropriate. Handouts and available books were shared between group members and their families and friends. The use of <u>I Love You But You Drive Me Crazy</u> (Calder & Watt, 1981), in this group wasn't as popular. As one over extended group member said, "If I had the time to read, I wouldn't read <u>anything</u> about taking care of <u>anybody</u>, I'd read a good novel. You read it and tell me what it says".

<u>Process</u>

The initial group composed of seven members had come together to talk and "work things out". While interested in any of the didactic learning materials provided, these group members were more interested in finding out about each other and sharing ways of coping with feelings and the daily tasks necessary for parental care. Finding out how everyone else around their own age was "doing", became a factor in forming a cohesive group. The almost immediate identification with the group and with other members was aided by the already present "natural" connections in the group - family, friends and neighbors were all represented in a "created" network. Elements of mutual trust and increasing comfort emerged quickly and conflict between group members remained low throughout the formation of the group.

Group members were all good story tellers (and, usually, good listeners). The portrayal of family elders was given in such vivid detail during the first two sessions that everyone was asked to bring a picture of her parent(s) to "show and tell" at the third meeting. This familiar ritual linking people and families helped to normalize the group identification and interaction already established. To see a family resemblance, to acknowledge the physical changes that age brings to everyone, and to recall shared holidays and events served to connect everyone at a human level. The importance of family mementos and photographs was acknowledged as becoming more meaningful as everyone became older - even the members of the group!

Other useful elements (techniques) used to unite the group were: rounds to begin each session with everyone participating; humor that emerged spontaneously; and hospitality that included shared rides, shared food and coffee, and shared making "everyone at home" rituals before and after the official meeting times.

As group members were encouraged to define their own needs and wants within the group setting, a middle stage of group development began with re-contracting for continuing as a group after the six week program ended. This on-going group continues to meet once every three weeks at Lion's Place on Saturday morning from 10:00 a.m. to 12 noon. A decision to open the group to new members was made when a second six week program was offered during the afternoon at the downtown office of A&O in February and March of 1986. As their needs were met, group members participating in the initial six week program discontinued their active participation in the on-going group but remain "in touch" with each other and the group facilitators - a good transition for everyone and perhaps reflecting the success of the program for these individuals.

Second Group

The interest of the support group members to continue to meet once every three weeks at Lion's Place gave impetus to the idea that an attempt to run a second six week program would be a good demonstration of the small group experience for family caregivers as a viable way of assisting them with accessing formal supports, promoting an active way of coping with caregiver stress, and dealing with complex transitions and situations at an emotional level

A co-facilitation factor was added to the second group because of:

1. the continued interests of the Psychology student in small group work with family caregivers; and
2. my committments to both the Fort Garry Group and the ongoing group sponsored by A&O.

The fall workshop series using a large group educational format presented by resource persons had not resulted in the formation of a self-help group for caregivers. The mutual support for each other's work as students in this area had been beneficial to both of us and the future possibility of working together had already been discussed.

Each leader's approach was somewhat different but the goals and general philosophy in using preventative intervention at a support group level for family caregivers was shared. It was hoped that the balance of using co-facilitation would allow for a more comprehensive perspective about group interaction, process and content at the group formation and issues brought forward.

Pre-Group Planning

With the approval of the agency, publicity was organized based upon the pathways to service noted for participants in the original six week support group program. It was hoped that any members from this second six week program who felt the need to continue in a support group could eventually join the on-going group sponsored by the agency. Future evolution of the on-going group to a self-help program remained a possibility.

Based upon the results of the first group, the second support group program was promoted and publicized in the following ways:

1. A notice in the "Growing Older" column was repeatedly run for a three week period prior to the projected starting date;
2. A letter outlining the purpose of a support group for caregivers and proposed themes for discussion was sent to all potential clients who had contacted the agency when the first group was formed. Date, place, time and frequency of the meetings was clearly presented along with a contact number at the agency; and

3. A "surprise" interview resulting in a feature article in the <u>Free Press</u>, served to act as publicity not only to interest potential group members, but other persons as well.

Telephone interviews were conducted by both of the co-facilitators for three purposes:

1. To establish contact, develop a contract for work and assess the situation and potential needs of the client;
2. To normalize the active process of looking for information and assistance as a sign of healthy coping with complex transitions in family life; and
3. To promote the use of support networks for problem-solving and stress reduction related to caring for older adults.

All recording was done on forms previously chosen. Audio-tapes were used to provide feedback on group process, content and facilitation factors.

Using "As Parents Grow Older" as a guide, the educational component was planned as back-up material. Handouts would be made available at each session and, as issues arose in group discussion "mini-explainations" could be made available from the didactic material gathered for use in previous group settings.

Many inquiries were made about the program. Each facilitator spoke to more that fifteen people in the course of three weeks. Out of the eleven people who had decided to take part in the afternoon program, only eight were able to participate at the start of the second closed small group sponsored by A&O.

Beginning

Meetings for the second six week program for family caregivers were held in available rooms in the downtown office of A&O on Monday afternoons from 1:30 to 3:30 p.m. The element of February and March weather seemed to be more easily accommodated for during the day in a location easily accessible by bus. The choice of trying an afternoon meeting was based on the requests of several callers who required a sitter from Home Care in order to attend.

This group was welcomed with a statement about the mutual exploration of the rewards and difficulties of meeting the needs of increasingly dependent parents. The gathering of useful information about aging itself, support services, and new ways of coping were some of the purposes for coming together. Members were encouraged to share any information and ways of doing things that had proved to be useful in their own situations. The roles of the co-facilitators as "fellow explorers" and caregivers themselves were stressed in this introduction with the future possibility of self-help in mind. The importance of finding some relief from the stress of caregiving was included as part of this introduction. Confidentiality "rules" and non-judgmental active participation were also explained as part of the trust in sharing aspects of support group formation.

Because every group is a "new" group, the age ranges in this group varied from those of the first group. Two sisters in their 50's were joined by three other women of the same age. The youngest caregiver was 39, another was 41 and the eldest daughter was 70. Although this group had been opened to all family caregivers including spouses, those attending were all daughters struggling with their parents' needs. The two younger women had school age children and left the group early each week to be home for them. Parents were in their 70's, 80's and 90's - a rich mix of possible age ranges between generations! None of these women worked outside of the home and only the eldest participant shared her home with a parent. Three women had only one parent - a widowed mother in each case; everyone else had both parents and were coping with multiple changes in the parental generation.

Group interaction grew very naturally out of opening rounds at this meeting. The two sisters spoke together about their mother's deteriorating mental status and the difficulty of having her accept outside assistance. Confusion and memory loss placed her at risk so the sisters had been taking turns "checking up" (making sure she was eating, taking her medications and bathing). Cooperative planning and problem solving had helped them maintain their mothers' independence until recent night terrors and hallucinations had created new concerns. Three other members had also been coping with cognitive changes in their parents. The eldest member had had Home Care support for her mother for several years and was waiting for Personal Care Home accommodation for her. Her current problem was getting enough sleep and some time for herself with the constant supervision her mother required, even at night. The shared experience of the unpredictable nature of these changes allowed the group members to freely exchange questions and comments about memory loss and aging.

Conflicts between parents as their relationships changed with the increased dependency of one spouse was also a common issue that served to link the group. Reduction of isolation and the mutual recognition of caregiving efforts on the behalf of parents were uniting elements in this first meeting.

Content

The heavy focus on confusion and memory loss remained part of the discussion for the remainder of the six weeks. Seeking aid from doctors and struggling with parents resistant to all "outside" help continued to re-emerge as needs for medical investigation continued to be a problem for two group members.

The frustrations of endless shopping, cooking, cleaning and being "on call" were common issues. Practical hints were shared as were the feelings of anger, resentment and dismay at being "caught" in these tasks - and unrewarded for carrying them out. One member, who was not close to her parents, was becoming aware that she was "expected" to assist them now that they were in need and was struggling with old angers and resentments. More negative feelings were expressed in this group, both about relationships with parents and siblings and about the loss of freedom of choice for caregivers.

Several members were committed to caring for parents out of duty, love, and responsibility in contrast to those who had not chosen to become a caregiver. The lack of communication between parents was common to all with both parents still living. Everyone expressed concern that their own marriages would end up that way.

Discussion about housing options and changes in living arrangements also illustrated parental conflict and unwillingness to compromise. Often one spouse wanted to move and the other wanted to remain and the caregiver was caught in the middle. The issue of illness and death remained present throughout this six weeks. One member's father did die several weeks after the group held its last meeting and her struggle before that time was shared in the group.

Process

This group was, in its own way, united and connecting through shared negative situations and feelings. Most group members were struggling with feeling aspects of caregiving and getting a respite from their concerns. People had a difficult time attending all of the sessions and the integrity of the group was broken several times.

Despite this lack of continuity, feedback for all of the sessions was positive and three members continue to take part in the on-going group sponsored by the agency. Shared problems and feelings even though unbalanced reduced the sense of isolation for many members. As one member wrote following the second session, "Hope we can all be supportive in this group - It appears there is a great need to voice our concerns, our angers, our resentments - in this type of atmosphere where no one condemns or blames!"

On-Going Group

The contract to continue to meet established by the first group members remains in place. Following the end of the six weeks that brought the second group together, the group was opened to new members and has remained so since that time. Co-facilitation of this group was introduced in April 1986 and remains an important factor in group cohesion and planning. Members with longer connections to the group continue to welcome newcomers and include them in the group process as it has evolved. Time is spent with rounds, summaries of past content, and linking newly emerging situations with the experience of others. The group is not for everyone, but people are encouraged to join to "test the waters" with this in mind.

Themes for discussion emerge from issues emerging or on-going that concern group members. Content related to parental care is balanced with issues specific to women in mid and later life as members sort out changing priorities and personal concerns. Eight people attend the on-going group on a regular basis with others joining in when new concerns and events make them re-connect. No further "recruitment" of potential members has been initiated because of the remaining questions about the direction of the group in the year to come. A break for summer months was established in 1986 and may also be changed as new members feel the need to continue.

The purpose of the group remains that of support, mutual recognition and empowerment, knowledge building and self-care.

For many group members, the on-going group has served as a "safety net" when situations have become very difficult to cope with. For others a better, more balanced, understanding of their parents and themselves has been the best outcome of their group experience.

Accepting the unchangeable, changing the unacceptable, and getting pleasure out of life again is possible if people "don't go it alone".

Presentations

One of the proposed objectives of this practicuum was "to promote awareness of the impact of assuming a caregiving role upon the older family through information and discussion at the community level as a preventative and normalizing strategy." In the past two years I have given formal presentations to large groups at:

1. Creative Retirement - "The Older Family In Crisis - How To Cope With Grown Children";
2. Smith Street Senior Centre - "Bridging The Generation Gap - Caregiving In The Older Family";
3. Catholic Women's League - Convention - "Family Caregivers - Responsibility To Ourselves An To Others".

and informal presentations and discussions with groups of Social Work students at:

1. A&O - Field placement students "Support Group Intervention With Adult Children Acting As

Caregivers To Their Parents";

2. University of Manitoba - Transitions Class - "Shattering The Walton Myth"; and
3. University of Manitoba - Aging Class - "The Older Family: Mid-Life Passages And Pitfalls."

Useful articles and books were shared with: three Social Work students interested in the topic, faculty members in the Human Ecology Department at the University of Manitoba, an Occupational Therapy student, a local Personal Care Home Director, and a student in Gerontology at Cambrian College in Sudbury, Ontario.

Two interviews for the press and one on CKND's "Senior Show" also provided a "public forum" for the discussion of informal caregiving in the older family and the useful aspects of support groups for caregivers.

Materials used in these presentations and discussions was selected from those easily obtainable in books available in the local library systems and in bookstores. Especially useful for presentation materials are:

1. <u>You And Your Aging Parents</u> (Silverstone & Hyman, 1976);
2. <u>Aging Is A Family Affair</u> (Bumagin & Hirn, 1979);
3. <u>I Love You But You Drive Me Crazy</u> (Calder & Watt, 1981);
4. <u>Making Peace With Your Parents</u> (Bloomfield &

Felder, 1983); and

5. <u>The Perilous Bridge: Helping Clients Through Mid-Live Transitions</u> (Golan, 1986).

Each of these works approaches parental aging from the view point of the caregiver, but balances the caregiving stresses with information bout aging, the older family and parental concerns. Coping with adult children can be as problematic as coping with aging parents!

Many requests to speak about the "Sandwich Generation" have provided the opportunity to present the entire Older Family and the rich texture of intergenerational pushes and pulls for consideration as we enter the future with an ever growing population of older and even ancient adults. Dealing with societal, familial and personal transitions in an informal way may help prevent the perpetuation of agism and the myth of family abandonment of the elderly. Personally and professionally, these opportunities to share information with interested people of all generations has been an additional bonus in my work with caregivers - another link in a supportive chain.

Conclusion

1. The framework for intervention and support group method of intervening with adult children looking for information, assistance, and recognition of their

caregiving role builds upon strengths and promotes an active coping style when faced with transitions.

2. The groups for family caregivers sponsored by Fort Garry Family Life Information Centre, Inc. and Age and Opportunity, Inc. are now entering their third year of existence.

3. The "veterans" who remain active in the on-going groups sponsored by the two agencies are still linked to those whose needs have changed and no longer join them. "Connecting caregivers" has had a positive impact on many lives, children and parents, during the past two years and serves as a basis for future work with this target population.

EVALUATION

Introduction

Evaluation of support group process and outcome has not been established to any extend in the available literature.

The literature reporting support group work with family caregivers relies on case examples, anecdotal information, and leader's observations and conclusions as evaluation components (Clark and Rakowski, 1983).

Criteria based upon Support group definitions, agency mandates, purpose and objectives of the "As Parents Grow Older" model, client centered criteria, and worker's subjective evaluation will be presented as factors to be considered in evaluating the effectiveness of the support group intervention sponsored by A&O and Fort Garry Family Life Information Centre. Between group comparisons and contrasts will also be included in the evaluation section of this report.

Agency Related Criteria

The relationships of the purpose of intervention with adult children (and other family caregivers) coping with the increasing dependency of older adults in the family to the sponsoring agency's policy directives and mandate can be viewed from several perspectives.

As stated in a previous section of this report, the Fort Garry Family Live Information Centre central goal is to enhance the quality of family life. The provision of "... learning experiences for ... family members related to their individual needs and roles within the family" and the provision to "... residents in the community with information on family-related resources", can be interpreted to mean the family from birth to death. The upward "shift" of the population in general may mean that agencies like Fort Garry may begin to view the older family as a necessary inclusion in program planning. The educational/support group for family caregivers seems a natural adjunct to established programs for caregivers of children. "Consultation with existing social service agencies and institutions" remains a necessary element in preventing the perpetuation of agism and the illness model of late life still found in the literature. The expansion of programs to include the support group for family caregivers is a natural one for this particular agency.

Finding a "good fit" with the mandate and policy directives of A&O is not as readily apparent as that of Fort Garry Family Life Information Centre. Mandated to meet the needs of those within the well elderly community who are sixty years of age or retired, the agency has traditionally provided educational programs, volunteer opportunities, and personal services. An advocate for preventive, consumer oriented programs, the agency is experienced in setting up large and small group presentations related to housing, transportation, preventative health care, pre-retirement, and other issues of concern to the older population.

As the chronological age "shift" of the population moves upward, the relative age of caregivers (especially adult children) will also rise. Two generations of the older family - the "young" old caring for the "old" old - may well fall within the target population currently served. Many members of the support groups have given up work or retired early from the work force in their late 50's in order to care for impaired elders. They may also fall under the mandate as it exists.

Based upon informal network intervention with the elderly community, existing volunteer and newly established peer-counseling training programs could be viewed as parallel to some aspects of caregiver's support group. The need for increased recognition and utilization of informal supports for the elderly is well known. Educational materials utilized for all of these "training" programs is very similar in content and may be borrowed from one program for use in another. Training for future support group leaders could easily be incorporated into the peer-counseling program. The peer-counseling model of support group work would be closer to self-help in many regards but retain a consultation link with agency staff.

Experienced in working with older adults, a natural consulting team exists within the agency staff. Group facilitators, either professional or peer-counselors, can call upon this team for advice when necessary. Small group experience already exists within the staff as an additional factor for the continuation of a support group within this setting.

Adult children often act as advocates for their elders within the formal system of care. Self advocacy is a natural progression as this population ages - A&O supports such a stance, now and into the future for this client population.

Easy discovery of services available for older family members can be implemented by A&O through the already available Senior's Housing Directory and service directory. Familiarity with the services A&O provides may assist family caregivers in asking other agencies for assistance before a crisis occurs.

The possible use of caregiver support groups as a preventative intervention for elder abuse may be a future consideration for the continuation of support groups within the agency programs.

Support Group Criteria

Support groups are not for everyone. Caregivers may find itt difficult to get to meetings consistently or find the open discussion of problems very threatening to their personal sense of integrity and family loyalty. Active crisis states need crisis intervention on an individual or family basis - the group cannot respond quickly to the needs of one member because limited resources of time and energy.

However, the group model of intervention does expand the network of the individual caregiver immediately and reduces the sense of isolation often present. The group experience may be more or less comfortable or appropriate depending upon the client's previous group experience and coping strategies.

Compared to individual counseling, the cost of therapist/agency efficiency is much less in the use of group interventions. Temporal issues are another variable factor. Complex transitions with a variety of intergenerational "pushes and pulls" may take months or years. Help may be sought out at various points along this continuum and with varied intensity and tempo. Termination and agency related limited resources then become issues of concern (Golan, 1981, p. 268-270). It is in this regard that the informal, on-going, support group model may be of value along with some "checkups" with counseling staff during times of particular stress. In general, short-term, intensive intervention may be the most appropriate to help the caregiver get "on track" again.

Client Centered Criteria

Both the client and practitioner share in defining the criteria for evaluating progress and outcome.

The extent of change observed and reported by the client is the central criteria for evaluating outcome for the caregiving adult child as she accomplishes the tasks necessary to reach an acceptable level of ease in this role. No norms for social comparison are available, so the client/consumer must be the judge of the appropriateness and helpfulness of the short term intervention provided. In addition, clients may report that a spouse or other family members recognized a positive change and has increased their own support in a more meaningful way.

The following variables were observed/reported by many clients in the support groups previously described:

1. To recognize and enhance active coping strategies:
    a. Expansion of support network:
        1. client reporting positive changes in helpfulness of support network;
        2. verbally reporting reduction in feelings of isolation in coping with parents;
        3. report of increased sharing of caregiving tasks with family, friends, formal services; and
        4. report of increased sharing of feelings, concerns with support persons.
    b. Increase in self care:
        1. increased use of time management to plan for more personal time;
        2. increase in diversion/release of tension:
            a. reported increase in pleasure and fun; and
            b. increase in sense of well-being:

            1. observable in posture changes, better diet, more rest.
        3. reduction in feelings of guilt; and
        4. reduction in feeling burdened.
2. To increase knowledge of normal aging:
    a. verbal report of increased ability to accept/understand parent as unique individual regardless of chronological age;
    b. expressed empathy for parents faced with increased loss and change in later life;
    c. reduction of expressions of impatience with parental behavior, choices; and
    d. increased report of ability to discuss own aging process/fears about aging.

Post-session reports and the Client Satisfaction Questionnaire (Larsen et al, 1979 - see Appendicies C & D), serve to inform the therapist and agency of actual (and future) client's satisfaction with the program provided, and is an adjunct to other client centered criteria.

The subjective nature of this criterion remains its greatest disadvantage. Observations and assumptions on the part of the practitioner may color the interpretation of this information and add to the bias already present. all that can be said of this information is that, for the individual sharing the group experience previously outlined, positive changes occurred. These reports cannot be generalized and the extent and durability of change over time remains imprecise.

Clients sometimes failed to fill out the reports and Questionnaire because they forgot or were absent from a session. Most reports found the individual sessions rated at a 7 on a scale of 1 to 9 (not productive at all to extremely productive). Little variation was noted between sessions or between members completing the reports for the same session. Comments from most members were very similar to the following examples of positive incidents:

1. "Learning that what I feel and what my parent feels is normal and O.K.";
2. "Every meeting shows me something new that I might never have thought of without group support"; and
3. "What was positive was hearing what others had to say and that I wasn't the only one with the same problems".

Of the eight members who completed The Client Satisfaction Questionnaire (combining the two groups sponsored by A&O) the following answers can be reported:

1. Six members rated the quality of service as

excellent; two as good.

2. Six answered "yes generally" and two "yes definitely" to the question of getting the kind of service they wanted.
3. Two answered "almost all of my needs have been met" Five felt "most of" their needs had been met and one had "only a few" of her needs met by the program.
4. Two thought they would recommend the program to a friend in need of similar help. Six said "yes definitely".
5. Five were "very satisfied" with the help received. Three were "mostly satisfied".
6. Five felt that the services received helped them a "great deal" in dealing more effectively with their problems; Three felt they "helped somewhat".
7. In an overall sense, six participants were "mostly satisfied" with the service received; two were "very satisfied".
8. Seven would "definitely" come back to the program for more help; One thought she would do so.

All reports are positive and support the idea that, on the basis of consumer criteria, the program met the needs of the individuals answering the questions.

Assumptions about the relative success of the program can only be related to the continuation of the on-going support group.

Follow-up contacts with participants, reveal that the group participation assisted them greatly. Even when their situations changed at a later date, they were able to cope and problem-solve in an active, informed manner.

Subjective Worker Evaluation

As a student, I remain forever curious about "what might have been" or "what could have been done" in both the process of group formation and the skills used in practice. During the course of this practicum, I feel that I have used, in one way or another, in one place or another, most of my past and present formal learning in behavioral science. My recent exposure to Social Work theory and practice has allowed me to re-think, blend and utilize those elements which seemed to mesh with what I thought might assist my clients and what I felt comfortable about using in practice. This experience has clearly added to my "practice wisdom" and my belief in mutuality and reciprocity between client and worker as a positive connection.

Working with "normal people with normal problems" was both challenging and rewarding. I liked and admired my clients, they made my work a doubly meaningful experience, both personally and professionally.

Working as an "outsider" in an agency setting was, at first, an unsettling experience. Neither "fish nor fowl", I learned to pursue the objectives I had set for myself and ignore the "small stuff" - a great lesson for the real world of Social Work practice!

As a practitioner, I know I could have helped some clients more easily in individual counseling - I had to "be brave and do nothing" in these cases and trust that the capacity of these individuals to become "un-stuck" would occur through group interaction and discussion - leaning on the created network for support!

I think that networks remain potential sources of support for many people. How and to what extent they can be activated in times of stress and crisis remains unanswered. Every time someone enters and leaves a group it is a new group defining again and again its needs and capacity to respond with mutual support. Flexibility has to be built in, both in the group and in the practitioner.

The very rich mixture of the group members who were brave enough to venture into "unknown territory" with me was an important factor for consideration. Elements in common were probably fewer than unique differences and yet people hunter for and found them in each other.

Co-facilitation works best when partners work from a similar frame of reference and belief system. Mutual trust is crucial and allows for "breathing space" when your own energy level is low or you must deal with your own family crises - really a better way of good group practice.

Self disclosure when appropriate helps in normalizing, modeling, and maintaining the "horizontal" nature of support group leadership. My clients know almost as much about me as I know about them - at least with respect to my role in the care of my father and support of my mother. I've always said people know nothing about care of the elderly unless they've fed, dressed, and bathed someone; knowing how that is has helped me in my work - everyone does the best they can.

Knowing when to say good bye becomes part of this practice too. Clients need to know that they are free to "move on" once their needs re met. Like all of us, an element of closure helps - I like pot luck suppers and picnics for endings and beginnings.

As a person, I remain in a state of self-discovery and transition like all mid-life women. I'm better off for having had the experience of knowing all of the people I've worked with in the past two years. My life and my work were one and the same. I don't handle either one perfectly. I like to think that the groups I've assisted were safe havens for the people who came to them.

I know the "personal touch" and acceptance of the "whole client" helped in working with family caregivers. People need to be told they're O.K. when they are O.K. I think that Garbarino's (1983) statement rings true, "How do we respond? ... We must lose ourselves in the social landscape, blend in with the human terrain, become part of the natural ecology of human social life" - that's when we do our best work!

The groups sponsored by Fort Garry Family Life Information Centre and Age and Opportunity have in common their small size and informal tone of discussion. The stress on material-arrangemental tasks of caregivers at Fort Garry and on the psychosocial tasks of caregivers at Age and Opportunity is a different factor, but clients seem to get their needs met just the same. Ideally, the six week program brings people together more quickly and unites them in their purpose for work. Realistically, the other way of forming a group does it just as well, only more slowly and unevenly. In both groups,people are actively searching for help and information. Neither program has accessed the very exhausted, withdrawn caregiver who may need assistance even more but cannot ask.

All of these groups are just beginnings in finding useful ways of assisting family caregivers to the elderly in our community. The method of support group intervention needs better ways of evaluation that are presently developed. Continued work in this area will play an even more critical role in the future as more older families experience the difficulties and rewards of caregiving.

CONCLUSION

"All real living is meeting."

- Martin Buber

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APPENDIX A-1

Ft Garry Family Life

SUPPORT GROUP FOR THOSE CARING FOR AGING RELATIVES

DATE:

NUMBER OF MEETING:

MEMBERS PRESENT/ABSENT:

GROUP INTERACTION:

SUMMARY:

PLAN FOR NEXT MEETING

(Adapted from Wilson, 1980, p. 127 - 129)

APPENDIX A-2

AGE AND OPPORTUNITY

SUPPORT GROUP FOR ADULT CHILDREN CARING FOR AGING PARENTS

DATE:

NUMBER OF MEETING:

MEMBERS PRESENT/ABSENT:

GROUP INTERACTION:

SUMMARY:

PLAN FOR NEXT MEETING

(Adapted from Wilson, 1980, p. 127 - 129)

APPENDIX B

THE SITUATION AT A GLANCE

GROUP:

HOW SERVICE WAS FOUND:

CARE-GIVER	CARE-RECEIVER
Name ____________________	Age ____________________
Age ____________________	Relationship to Care-giver __________
Address ________________	
Telephone ______________	

	Yes No		Yes No
Works for wages	/	Health Problems	/
Regular outside activities	/	Financial problems	/
Health problems	/	Residence problems	/
Financial problems	/ /	Mobility/ transportation problems	/
Transportation problems	/		
Spouse/partner- lives with	/	Spouse/Partner- lives with	/
Dependents	/	Dependents	/

REASON FOR CONTACT: ____

ASSISTANCE PROVIDED: TYPE HOW OFTEN

OTHER ASSISTANCE

FROM: Person/Agency/Organization TYPE HOW OFTEN

Adapted From: I Love You, But You Drive Me Crazy (Calder and Watt, 1981)

APPENDIX C

POST SESSION REPORT

_______________ _______________ Date:____________

Please circle the number that comes closest to describing your feelings about the session you just completed.

1 2 3 4 5 6 7 8 9

Not Productive at all Moderately Productive Extremely Productive

Please try to describe at least one positive and one negative incident or a part of the discussion that occurred during the session that might help explain your rating.

POSITIVE INCIDENT

NEGATIVE INCIDENT

OTHER COMMENTS

SUGGESTIONS

CONCERNS

From Bloom and Fischer, 1982)

APPENDIX D

THE CLIENT SATISFACTION QUESTIONNAIRE (CSQ)

Please help us improve our program by answering some questions about the services you have received. We are interested in your honest opinions, whether they are positive or negative. Please answer all of the questions. We also welcome your comments and suggestions. Thank you very much, we appreciate your help

(Circle Your Answer)

1. How would you rate the quality of service you received?

4	3	2	1
Excellent	Good	Fair	Poor

2. Did you get the kind of service you wanted?

4	3	2	1
No definitely not	No not really	Yes generally	Yes definitely

3. To what extent has our program met your needs?

4	3	2	1
Almost all of my needs have been met	Most of my needs have been met	Only a few of my needs have been met	None of my needs have been met

4. If a friend were in need of similar help, would you recommend our program to him/her?

4	3	2	1
No definitely not	No I don't think so	Yes I think so	Yes definitely

5. How satisfied are you with the amount of help you received?

4	3	2	1
Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly satisfied	Very satisfied

6. Have the services you received helped you to deal more effectively with your problems?

4	3	2	1
Yes they have helped a great deal	Yes they have helped somewhat	No they really didn't help	No they seemed to make things worse

7. In an overall, general sense, how satisfied are you with the service your received?

4	3	2	1
Very satisfied	Mostly satisfied	Indifferent or or mildly dissatisfied	Quite dissatisfied

8. If you were to seek help again, would you come back to our program?

4	3	2	1
No definitely not	No I don't think so	Yes I think so	Yes definitely

<u>ADDITIONAL COMMENTS</u>:

(Please attach additional sheets if you wish)