

THE BREAKFAST CLUB: PROVIDING SUPPORT FOR MALE CAREGIVERS OF PERSONS WITH ALZHEIMER DISEASE OR RELATED DEMENTIA

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BACKGROUND: *The Breakfast Club* is a facilitated support group developed for males caring for an individual with Alzheimer disease or related dementia. A study was undertaken to examine the participants' experiences based on two major considerations: the conceptualization of male spouses and sons providing care to individuals with Alzheimer disease or related dementia and, secondly, participation in a male caregiver support group.

METHODS: 7 male participants who attended the group regularly over a 3-year period beginning in 1995, were interviewed in 1-hour in-depth sessions, to gain the male caregiver perspective and the efficacy of their involvement in a support group. From the taped, narrative comments of the participants, the researcher extracted themes that reflected the men's responses, based on their experiences both as a caregiver and group participant.

RESULTS: Information shared by the participants provided further insight into the caregiving experiences of men who face conflicting demands, often without support or the necessary outlets for reducing stress. The group intervention was successful in providing support and socialization with other men experiencing similar caregiving issues, as well as an educational component that included sharing strategies for coping with caregiver stress.

CONCLUSION: As caregivers, the men shared common perceptions of stress and burden. They learned from each other how to adapt to the ever-changing experiences related to Alzheimer disease. The Breakfast Club is a successful intervention approach providing an opportunity for men to deal with their emotions in a safe, confidential, supportive environment throughout the caregiving experience.

Key words: Alzheimer disease, male caregivers, support groups

CAREGIVING AND ALZHEIMER DISEASE

With the increasing aging population and the subsequent higher incidence of Alzheimer disease, there is recognition of the growing number of individuals and families caring for persons at home who have dementia. The Alzheimer Society of Canada estimates that almost 25% of Canadians

have someone with Alzheimer disease in their family.¹ Currently one in 13 Canadians over the age of 65, or 364,000 individuals, are diagnosed with Alzheimer disease or related dementia, with numbers increasing to one in three over the age of 85.² Half of these individuals live in the community, while half, often the more severely affected, reside in institutions.² It is usually the lack of informal caregiver support, rather than ill health, that determines the time-frame in which institutionalization becomes necessary.³

Caregiving is unplanned, unexpected and not entered into by choice.⁴ Two decades of research have documented that family caregiving is a stressful role with deleterious consequences for the person providing care.⁵ It is estimated that 75 to 85% of all personal care received by seniors is provided by the informal caregiver network comprised of spouses, adult children, family members and friends.³

The number of male caregivers, especially spouses, is also increasing, as Canadian statistics indicate a two to one ratio of female to male cases of Alzheimer disease in every age group over the age of 65.² Gender differences in psychological, social and physical well-being are specifically associated with the caregiver role.⁶ Much of the literature to date has explored the caregiving experiences of female caregivers. While it is estimated that 28% of the total informal caregiver population is male, there is limited literature on the male caregiving experience, their stresses, needs as caregivers and what resources are needed to perform the caregiving role, particularly for elderly male spouses.⁷⁻⁹ Identifying the ways in which the transition into the caregiving role may reorganize the internal and external world of the older man is vital to planning interventions and services for this unique and growing population.¹⁰

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It is recognized that a supportive social network can substantially reduce feelings of stress experienced by caregivers. The literature indicates that women form more intimate relationships with others and, therefore, have a stronger support system. This leads to the assumption that men would be more socially isolated and would experience greater caregiver burden.¹¹ It is reported that gender differences in caregiver distress appear to be related to differential coping styles.¹² Although not supported in the literature, a number of studies revealed that male caregivers experience less burden than females, coping effectively with life's stresses, particularly with caregiving. Males reported greater satisfaction and emotional gratification in their caregiving role for elderly family members.^{8,13} Many male caregivers reported an improved relationship with their spouses and an improvement in their mental health, the longer that they were in the caregiving role.^{14,15} However, when their loved one had to be institutionalized, males experienced significant increases in levels of stress, contributing to isolation as a result of lack of mobility, the loss of companionship and the friendship of others. It is further indicated that males appeared to be more reserved when confiding with others and discussing personal matters, often turning to their adult children, usually sons and sons-in-law.¹⁶

Research implies that sons as caregivers have been on the fringes of caregiving.¹⁷ They are more often involved in authority issues regarding the care and medical needs of the individual, including the management or monitoring of parental care, particularly in an institution. A comparison of sons and daughters concluded that sons find caring for cognitively impaired parents more difficult and stressful, experiencing increased feelings of impaired health as they become aware of the emotional toll of caregiving.¹⁸

SUPPORT GROUPS

Support groups are the most popular and efficient means to provide emotional support and information to caregivers. They provide a safe and supportive environment for the introduction and validation of feelings that might otherwise be suppressed.¹⁹ While support group intervention is capable of producing significant reductions in anxiety, stress and depression for the caregiver, it is not always successful in terms of design to attract and maintain member involvement and participation, particularly

for men.¹⁹ Many groups are time-limited, not recognizing that caregiving is an ongoing, long-term commitment. While little research exists regarding the experiences of male caregivers who are members of community support groups, the literature indicates that males who attend groups often express a need to talk to others in similar situations and to distance themselves emotionally from their caregiving tasks.²⁰⁻²³

THE BREAKFAST CLUB

The participation of men in existing support groups offered by the Alzheimer Society of Thunder Bay was marginal. In 1995, the Executive Director and an undergraduate male social work student completing a field placement with the Society, conducted a needs assessment survey among professionals in the community, exploring ways to support male caregivers in a group setting. They also obtained relevant information from other Alzheimer Society chapters in Ontario. Results indicated a perceived need and thus supported the implementation of a support group for men. The feedback also suggested that the term *support group* may be inappropriate, as it might suggest the requirement to disclose personal details about one's experience as a caregiver rather than a focus on sharing information with other caregivers. The literature indicated that men are more likely to respond when a program is not labelled as a support group.²⁴

The initial meeting in 1995 was advertised as a Breakfast meeting for male caregivers by means of posters at the Alzheimer Society, the Alzheimer Day Centre, long-term care facilities and hospitals, as well as through referrals from professionals in the community. Based on both interest and experience in gerontology and the caregiving role, the social work student volunteered to facilitate this group as a new approach to provide support for male caregivers. Initially three men attended and discussed the group purpose, structure, the format for future meetings, location and meeting time limitations, recognizing that respite could be an issue. The Breakfast Club was formed, and 6 years later, the group has continued to meet on alternate Saturday mornings at the Alzheimer Society office with the same male facilitator. The open-ended format provides an opportunity for new caregivers to join, adding a new and varied dimension to the group structure, including complexity of issues discussed. The meetings are informal, beginning with

a continental breakfast, introductions, check-ins, recap of the goals of the group, discussions of confidentiality and an invitation for individuals to share an experience or discuss concerns. The facilitator invites suggestions for future topics and issues, arranging guest speakers, educational materials, films and resources. Topics of interest range from practical information and skill development to emotional and social issues.

At the time of the study, membership included 10 active members of varying ethnic backgrounds and occupations, including both spouses and sons, ranging in age from 48 to 85 years, with an average age of 65. The average age of the care recipient was 76 years. The care recipients had been diagnosed with Alzheimer disease for 2 years on average; however, most respondents indicated that they noticed symptoms of the disease with their family member on average 3 years before diagnosis. Family members, especially spouses, often function as caregivers before they self-define in this role.⁵ Recognizing that caregiving remains a long-term commitment, the group promoted continued group involvement, whether the care recipient remained at home or in a long-term care facility. Four of the participants were caregivers to their loved one in a long-term care facility.

METHODS

Seven male caregivers, who regularly attended the Breakfast Club from 1995 through 1997, agreed to participate in this exploratory qualitative study. Using the "long interview" method for qualitative research, the researcher interviewed each participant individually for 1 hour at the Alzheimer Society office.²⁵ A standard formalized interview guide, using an in-depth, open-ended format, provided equal access to the subjective perceptions of each respondent. This guideline was adapted from an exploratory study of support groups for female caregivers.²⁶ The questions presented related to the male caregiver experiences, the history of the care provided, the physical/psychological effect of the disease on the caregiver and receipt of support. Participants were asked to comment on the effectiveness of the Breakfast Club as a form of support group, including: did the group meet their needs for information, what did they like best or least about the group, did the group offer the opportunity to deal with their feelings, and did they notice any sig-

nificant difference in the way they were dealing with caring for the individual with Alzheimer disease as a result of the group participation? The interviews were tape-recorded and transcribed verbatim by the researcher, to examine the qualitative narrative of the participants, identifying emerging themes reflective of the men's views.

RESULTS

Of the four spouses and three sons who participated in the study, four men were providing support to a family member in a long-term care facility. Each male respondent provided a unique reflection of their role as a caregiver, as well as their perception of group participation as a form of support. The identified themes providing insights into the male caregiver experience included: caregiver responsibilities and other expected roles, changes in their relationships, the need for alternate activities and family support.

CAREGIVER ISSUES IDENTIFIED

Respondents related feeling torn between caregiving responsibilities and other life commitments. They identified a need to be available to others who required their attention, expressing feelings of guilt about their inability to fulfill familial responsibilities. Sons especially felt torn between meeting obligations to their parent as well as the needs of their wives and children.

Participants identified the curtailment of other social activities, sacrificing other interests to respond to the care recipient's needs, even after their loved one was institutionalized. All of the respondents indicated that they had some hobby, outside interest or distraction to distance themselves, which assisted in coping and recharging their energy. Involvement in most activities were related to Alzheimer disease, such as volunteering for the Alzheimer Society or in the long-term care facility where their family member resided.

The caregivers identified dealing with emotional changes in their relationships affected by the behavioural effects of Alzheimer disease on their loved one, including changes in personality, disposition and relationships (eg. spousal, parent/child). While some recognized that sometimes these changes brought them closer together, generally difficulties arose as the care recipient did not accept the diag-

nosis or admit that there was a problem. The changes in the care recipient's mood left caregivers questioning how to adapt to the ever-increasing changes. Sons expressed an increased sense of strain at the often disruptive behaviour of their parent.

An issue for all participants was the limited amount of family involvement, both in the provision of direct care to the individual with Alzheimer disease and lack of contact or offers of support to them as care providers. They recognized the inability of some family members to accept or cope with the diagnosis, often abdicating their role as a caregiver, allowing one sibling to assume major responsibility. Sons particularly expressed concern and displeasure about the lack of sibling involvement.

SUPPORT GROUP EFFECTIVENESS

All participants agreed that they enjoyed the "Breakfast Club" meetings, appreciating the openness of the group as a safe, trusting, supportive environment where they could share feelings openly with other men. They shared how they would be uncomfortable discussing some of the topics raised with women present. The men noted that the group's responsiveness was important when the communication with their spouse broke down and they needed emotional support. This need continued for those whose loved one was placed in a long-term care facility.

Participants indicated that they learned from each other. The group provided a good exchange of information where everyone contributed, often from their own research and reading. The educational component of the group provided information on a range of matters, including the provision of care, the disease and treatment modalities, as well as financial, legal and placement planning. The information helped members face the realities of the disease and learn alternative coping skills to handle the responsibilities of caregiving. For some, it was distressing to hear about the challenges of caring for a family member in the advancing stages of the disease and the caregiving role ahead. Other group members were sensitive and reassuring, helping them to develop a dementia management plan to select a course of action to effectively control behaviours and establish reasonable expectations regarding the quality of life.¹⁴

DISCUSSION

The qualitative narrative of the group members perceptions, indicates that they share similar caregiving issues recognized in previous research studies. Alzheimer disease presents chronic stressors. Dealing with the negative effects of Alzheimer disease is an arduous and often painful experience. It is not only the responsibility that leads to strain, but how one perceives the role as interfering with other aspects of one's personal and social life.¹⁸ The men experienced instances of questioning their own competence and their decision to provide care while coping with caregiving responsibilities and other life commitments. As reported in other studies, participants felt isolated in their role, particularly when family support was lacking, expressing a need for diversions and respite from the caregiving tasks.²⁷ The informal structure of the group provided social interaction and the opportunity to detach themselves from the caregiving role for a regularly scheduled brief period of time.

The effectiveness of any stress-reducing intervention depends largely on how the individual perceives its value. The participants identified the benefits of attendance in the "Breakfast Club", and their intent to continue their participation in the group could be interpreted as a strong indicator of the group's success. The group enabled the men to deal with their emotions in a safe, confidential, supportive environment that promotes the "interactional processes" with other men sharing similar experiences.²⁰ It provided validation of their feelings while offering alternative coping skills, contributing positively to how they perceived and handled their burden of caregiving.

Recognizing that men experience significant levels of stress when the care recipient is institutionalized, the participants appreciated the open-ended approach to group participation throughout the caregiving experience, even following placement of their family member.

Caregivers are not a homogeneous population, and the burden of care varies for men, women, spouses and children. The magnitude of gender differences are large enough that multiple approaches to programs and policies will be required to address caregiver needs that are gender sensitive.²⁴ It is recognized that multiple rather than single intervention approaches have greater impacts on reducing caregiver burden, as do intervention programs tailored

to particular caregiver situations, providing knowledge and enabling caregivers to acquire skills for particular tasks.²⁸ Support groups can provide an effective measure of intervention to complement and enhance existing or developing services. The increased efficacy of the caregiver abilities demonstrated by the participants in this study, lends to the acceptance that male support groups provide a supportive network, the development of skills and caregiver strategies and are an effective measure of intervention with the format, content and approaches reflecting the diversity of group needs.²⁹

REFERENCES

1. The Alzheimer Society of Ontario, Report of the Annual General Meeting, Alzheimer Society of Ontario, 1999.
2. Canadian Study of Health and Aging Working Group: Canadian Study of Health and Aging: Study methods and prevalence of dementia. *CMAJ* 1994; 150: 899-913.
3. Chappell N L. Implications of shifting health-care policy for caregiving in Canada. *J Aging Soc Policy*. 1993; 5:39-55.
4. Pearlin L I., Aneshensel C S. Caregiving: the unexpected career. *Social Justice Research* 1994; 7: 373-90.
5. Seltzer M M, Wailing-Li L. The dynamics of caregiving: transitions during a 3-year prospective study. *Gerontologist* 2000; 40: 165-78.
6. Rose-Rego SK, Strauss ME, Smyth KA. Differences in the perceived well-being of wives and husbands caring for persons with Alzheimer's disease. *Gerontologist* 1998; 38: 224-30.
7. Horowitz A. Sons and daughters as caregivers to older parents: differences in role performance and consequences. *Gerontologist* 1985; 25: 612-7.
8. Chang C F, White-Means S I. The men who care: an analysis of male primary caregivers who care for frail elderly at home. *J Appl Gerontol* 1991; 10: 343-58.
9. Hirsh C. Understanding the influence of gender role identity on the assumption of family caregiving roles by men. *Int J Aging Hum Develop* 1996; 42: 103-21.
10. Kramer B J, Lambert J D. Caregiving as a life course transition among older husbands: a prospective study. *Gerontologist* 1999; 39: 658-67.
11. Fitting M, Rabbins P, Lucas M J et al. Caregivers for dementia patients: a comparison of husbands and wives. *Gerontologist* 1986; 26: 248-52.
12. Lutzky S M, Knight B G. Explaining gender differences in caregiver distress: the roles of emotional attentiveness and coping styles. *Psychology and Aging* 1994; 9: 513-9.
13. Billings A G, Moos R H. The role of coping responses and social resources in attenuating the stress of life events. *J Behav Med* 1981; 4: 139-57.
14. Corcoran M A. Gender differences in dementia management plans of spousal caregivers: Implications for occupational therapy. *Am J Occupat Ther* 1992; 46: 1006-12.
15. Gilhooly M L M. Senile dementia: factors associated with caregiver's preference for institutional care. *Br J Med Psychol* 1986; 59: 165-71.
16. Barusch A S, Spaid W M. Gender differences in caregiving: why do wives report greater burden? *Gerontologist* 1989; 29: 667-76.
17. Stoller E P. Males as helpers: the role of sons, relatives, and friends. *Gerontologist* 1990; 30: 228-35.
18. Mui A C. Caring for frail elderly parents: a comparison of adult sons and daughters. *Gerontologist* 1995; 35: 86-93.
19. Greene V L, Monahan D J. The effect of a support and education program on stress and burden among family caregivers to frail elderly persons. *Gerontologist* 1989; 29: 471-7.
20. Kaye L W, Applegate J S. Family support groups for male caregivers: benefits of participation. *J Gerontol Soc Work* 1993; 20: 167-85.
21. Monahan D J, Hooker K. Health of spouse caregivers of dementia patients: the role of personality and social support. *Social Work* 1995; 40: 305-14.
22. Braudy-Harris P. The misunderstood caregiver? A qualitative study of the male caregiver of Alzheimer's disease victims. *Gerontologist* 1993; 33: 551-6.
23. Archer C K, MacLean M J. Husbands and sons as caregivers of chronically-ill elderly women. *J Gerontol Soc Work* 1993; 21: 5-22.
24. Yee J L, Schultz R. Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *Gerontologist* 2000; 40: 147-64.
25. McCracken, G. *The Long Interview: Qualitative Research Methods Series 13*, Newbury Park, California: Sage 1988.
26. Haydon D E. Women in the middle: an exploratory study of support groups for daughters who provide care for a parent with dementia of the Alzheimer type. Unpublished graduate thesis. Carleton University, Ottawa, ON 1994.
27. Schultz R, Quittner A L. Caregiving through the lifespan: an overview and future directions. *Health Psychology* 1998; 17, 107-11.
28. Ostwald S K, Hepburn K W, Caron W et al. Reducing caregiver burden: a randomized psychoeducational intervention for caregivers of persons with dementia. *Gerontologist* 1999; 39: 299-309.
29. Toseland R W, Rosisiter C M. Group interventions to support family caregivers: a review and analysis. *Gerontologist* 1989; 29: 438-48.