

2006

# Perspectives of Women with Dementia Receiving Care from Their Adult Daughters

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## Citation of this paper:

Ward-Griffin, Catherine; Bol, Nancy; and Oudshoorn, Abram, "Perspectives of Women with Dementia Receiving Care from Their Adult Daughters" (2006). *Nursing Publications*. 280.

<https://ir.lib.uwo.ca/nursingpub/280>

Résumé

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## La perspective des femmes atteintes de démence et recevant des soins de leur fille adulte

Catherine Ward-Griffin, Nancy Bol, Abram Oudshoorn

Le vécu inhérent à la prestation des soins aux personnes atteintes d'Alzheimer est relativement bien documenté. Toutefois, peu de recherches ont été réalisées du point de vue de la personne souffrant de démence. L'objectif de cette étude, qui s'inscrit dans une recherche qualitative sur les relations mères-filles en contexte de démence, notamment sur le processus de soins, est de recueillir les perceptions et les expériences des mères soignées par leur fille adulte. Guidés par des perspectives féministes et axées sur les étapes de vie, les chercheurs ont mené des entrevues en profondeur et semi-structurées auprès d'un échantillonnage diversifié de 10 femmes non-institutionnalisées et atteintes de troubles cognitifs légers à modérés. En général, les perceptions et les expériences des femmes sur le plan de la santé étaient façonnées par les rapports sociaux entre les sexes et par la manière dont ils sont construits. Bien que les mères rapportaient des interactions surtout positives avec leur fille, les idéologies culturelles de l'individualisme et des rapports axés sur la famille se traduisaient par des sentiments de « culpabilité-reconnaissance ». Les participantes géraient leurs expériences contradictoires dans la situation où elles recevaient des soins de leur fille en *donnant elles-mêmes des soins*, en *s'abstenant de demander des soins*, en *déterminant les soins* et en *acceptant les soins*. Les auteurs recommandent l'apport de changements à l'échelle des pratiques, des politiques et de la recherche, qui doivent tenir compte de déterminants sociaux de la santé pertinents, comme les rapports sociaux entre les sexes et le soutien social. Ces changements contribueraient à la santé et au bien-être des femmes atteintes de démence.

Mots clés : femmes

# Perspectives of Women with Dementia Receiving Care from Their Adult Daughters

Catherine Ward-Griffin, Nancy Bol,  
and Abram Oudshoorn

The caregiving experience within Alzheimer disease is fairly well documented. However, little research has been conducted from the perspective of the person living with dementia. The purpose of this study, part of a larger qualitative investigation of mother-daughter relationships within the care process of dementia, was to elicit the perceptions and experiences of mothers receiving care from their adult daughters. Guided by feminist and life-course perspectives, the researchers conducted in-depth, semi-structured interviews with a diverse sample of 10 community-dwelling women with mild to moderate cognitive impairment. In general, the health perceptions and experiences of the women were shaped by gender and how its meaning is constructed. While mothers reported mostly positive relationships with their daughters, cultural ideologies of individualism and familism manifested in feelings of “grateful guilt.” Participants managed their contradictory experiences of receiving care from their daughters by *doing care*, *undemanding care*, *determining care*, and *accepting care*. The authors recommend changes in practice, policy, and research, with the aim of addressing relevant social determinants of health such as gender and social support, thereby promoting the health and well-being of women with dementia.

Keywords: aging, dementia care, women, health promotion

## Background

Alzheimer’s disease (AD) is an insidious, pervasive, debilitating disorder that destroys the affected person’s capacity for self-care (Wuest, Ericson, & Stern, 1994). It not only has a profound impact on individuals diagnosed with the disease, but also affects the lives of family members caring for them (Wuest, Ericson, Stern, & Irwin, 2001). As Canada’s elderly population grows, an increasing number of individuals will require care for AD. The prevalence of dementia nearly doubles with every 5-year increase in age from the age of 60, rising to 32% in those aged 90 to 94 (Hofman, Rocca, & Brayne, 1991). Studies have found that the prevalence of AD is higher in women (Evans, Ganguli, Harris, Kawas, & Larson, 1999). Moreover, the prevalence of AD in Canada is expected to

increase from approximately 364,000 persons in 2000 to over 750,000 persons by 2030, with roughly half of those individuals living in the community (Canadian Study of Health and Aging [CSHA] Working Group, 1994).

There has been significant emphasis on the development of services that enable people with AD to remain in their own homes whenever possible. Although there is a growing commitment to assist the individual with dementia and his or her family, there are many challenges to achieving optimal dementia care in the home. Restructuring of hospital and social services, closure of long-term-care facilities, and underfunding of home care (Aronson, 2004; Chappell, 1999) have led to an increasing reliance on family care. The current trend towards the favouring of home care over care in a hospital or other institution is motivated in part by concerns about spiralling health-care costs (Armstrong & Armstrong, 2004; Neysmith, 1991; Strang & Koop, 2003). Only one in four people caring for a relative with dementia receives formal care services (CSHA Working Group, 1994). Consequently, families rather than paid caregivers assume and/or coordinate the majority of home-based care (Armstrong et al., 2003). Since most care recipients and family caregivers are women, these shifts in the delivery of health care tend to affect women to a greater degree than men (Armstrong & Armstrong; Gregor, 1997; Morris, 2004).

Given these challenges to the achievement of optimal home-based dementia care, the needs of women involved in dementia care, particularly those afflicted with AD, demand careful attention. The inclusion of the perspectives and voices of women who receive care is essential to the analysis of how social determinants, such as gender and social support, affect women's health. Health Canada identifies gender as one of the 12 determinants of health, because gender is a factor in both participation in and the consequences of health care (Armstrong, 2004). The purpose of this qualitative study, guided by feminist and life-course perspectives, was to explore the perceptions and experiences of women with mild to moderate dementia and their adult daughters in the giving and receiving of care. The aim of this paper is to report on the mothers' accounts of receiving care from their daughters, thereby bringing elderly women from the margin to the centre of the debate on dementia care. The daughters' perspectives on providing care to their mothers with dementia are reported elsewhere (Ward-Griffin & Bol, in press). The paper will conclude with recommendations for change in practice, policy, and research, with the aim of promoting the health and well-being of women with dementia.

## **Literature Review**

### ***Relationships between Persons with AD and Family Caregivers***

The literature is replete with studies of the problems of caregiving, many of which view the individual with AD as a significant source of caregiver burden (Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000; McCarty, 1996, Stevenson, 1990). Recently, however, researchers have focused on the relational aspects of dementia care (Globerman, 1994; Ward-Griffin & Bol, in press; Wuest, Ericson, & Stern, 1994). In a grounded theory study with 15 family caregivers, Wuest, Ericson, and Stern found that the interactions of persons with AD and family caregivers fell on a continuum from intimacy to alienation through dimensions of dawning, holding on, and letting go. Similarly, Ward-Griffin and Bol found that daughters caring for women with dementia reported difficulties in maintaining a reciprocal relationship with their mothers, using negotiating strategies such as “finding a balance,” “leading the way,” and “carrying the load.” In another qualitative study with relatives of persons with dementia, Globerman suggests that families in crisis may find their usual roles and relationships inflexible and need help negotiating their relationships, particularly around their expectations of one another. Other investigations have found that the quality of interactions between persons with dementia and their family members prior to the onset of dementia is an important factor for predicting emotional strain, quality of life, and caregiving satisfaction (Mui, 1995; Spaid & Barusch, 1994). While the effects of the quality of this dyadic relationship on the well-being of the caregiver have been documented, a gap remains in the literature regarding the effect of such relationships on the health and well-being of the person with dementia.

Another limitation of the published research on individuals with dementia and their caregiving relatives is a tendency to distort the reciprocity in their relationships. Neufeld and Harrison (1995) report that 20 women caring for older family members with cognitive impairment described reciprocity as “give and take”; however, caregivers were unable to establish the same kind of reciprocal relationship with the person with dementia as they did with others. Keefe and Fancey (2002) also explored the importance, for caregiving daughters and their older mothers without dementia, of giving and receiving. They found that mothers and daughters had different perspectives on reciprocity, with mothers minimizing their past contributions. In contrast, Talbot (1990), in a study with 55 elderly widowed mothers without dementia, found that mothers gave much and received little, which may contribute to the negative effects of these relationships on the mothers. Finally, Carruth (1996) explored reci-

procuity among adult children of persons with and without dementia and found that the diagnosis of dementia did not contribute to the explained variance of caregiver reciprocity. These findings suggest that incongruent perspectives of reciprocity between mothers and their adult children may shape the experiences of giving and receiving dementia care. Clearly, further research in this area is warranted.

### ***Research on the Perspectives of People with Dementia***

Although the aforementioned studies increase our knowledge about the process and outcomes of caregiving within dementia, we have limited knowledge about the relationships between individuals with dementia and their family caregivers, particularly from the perspective of the individual with AD. Most research in dementia has relied solely on the perspectives of the caregiver, whose stresses and coping strategies have been of much interest. Although there is a tendency to “bind together” the interests of individuals with dementia and their caregivers, especially within community care (Reid, Ryan, & Enderby, 2001), the interests of people with dementia and their caregivers do not always coincide (Askham, 1991). Rarely have the perceptions of the persons with AD been examined, because of their dementia (Cotrell & Schultz, 1993) and the difficulty in recruiting individuals with AD (Long, Sudha, & Mutran, 1998). However, the belief that it is impossible for people with dementia to express their views or describe their experiences has been increasingly rejected in recent years (Clarke & Keady, 2002; Gilmour & Huntington, 2005; Whitlatch & Feinberg, 2001). Research has demonstrated that individuals with mild to moderate cognitive impairment are able to answer questions about their own care with a high degree of accuracy and reliability (Whitlatch & Feinberg) and are willing and able to share their personal narratives (Moore & Hollett, 2003; Svanstrom & Dahlberg, 2004; Usita, Hyman, & Herman, 1998). The exclusion of persons with dementia indicates a failure to acknowledge their ability to report accurately on their current situation (Cotrell & Shultz), rendering them as passive participants in the care process — as if they were the objects rather than the subjects of their circumstances (Aronson, 1991).

Although persons with dementia and their families are uniquely qualified to define priorities for improving dementia care, they have rarely been asked to do so. In recent years, however, there has been increasing interest in the experiences of people who have been diagnosed with dementia (Aggarwal et al., 2003; Gilmour & Huntington, 2005; Moore & Hollett, 2003; Morhardt, Sherrell, & Gross, 2003; Reid et al., 2001; Sabat, 1998; Svanstrom & Dahlberg, 2004; Werezak & Stewart, 2002). Gilmour and Huntington, in their qualitative study with five men and four women with dementia, found a need to maintain control and

independence with the increasing need for support in everyday tasks. Similarly, Cox, Anderson, Dick, and Elgar (1998) found that individuals with dementia expressed a desire for reliable health-care workers who support their independence and treat them as individuals. Reid et al. interviewed 19 people with dementia as part of a larger study on unmet respite-care needs among caregivers and day-care attendees in England; they found that those who attended groups valued them for the support offered and provided, the potential for developing friendships, and the company offered. Similarly, Aggarwal et al., using a flexible, individualized approach, interviewed 27 people at all stages of dementia in residential and day-care settings, as well as their relatives, on the subject of care services and their experiences; the persons with dementia reported lack of choice and the need for independence and more social aspects of care, while their relatives were more positive about the services. This discrepancy in response between persons with dementia and their relatives suggests a need to approach people with dementia to elicit their views.

Based on two semi-structured interviews with each of three women and three men with dementia who lived at home with their spouses, Werezak and Stewart (2002) developed a theoretical framework outlining the continuous process of adjusting to early-stage dementia, which comprised five stages (antecedents, anticipation, appearance, assimilation, and acceptance). Similarly, Pearce, Clare, and Pistrang (2002) conducted separate interviews with 10 community-dwelling older men with dementia and their wives to elicit the men's appraisals of their illness and coping strategies. The participants' accounts suggested that the men were engaged in a process of attempting to manage their sense of self. The ways in which the men attempted to manage sense of self were thus affected by their appraisals of and reactions to their difficulties, which in turn had an influence on and were influenced by their relationships and social identities. As previous studies suggest (Evans et al., 1999), women and men may cope with dementia differently, which warrants a more detailed gender analysis of dementia care.

Proctor (2001), in a qualitative study with elderly women with dementia, focused on relationships, gender, and issues of power. Using Brown and Gilligan's (1993) Voice Relational Method, Proctor interviewed four women twice about their experiences with health services. The findings illuminated the situation of power in the women's relationships, particularly their relationships with health professionals. The women felt that they could not challenge doctors and nurses about decisions regarding their welfare, thereby illustrating how gender and (dis)ability shape interactions between caregivers and care recipients.

Although dementia is usually seen as an older person's disease, a grounded theory study (Harris & Keady, 2004) with younger people with dementia in the United States ( $n = 23$ ) and families of younger people with dementia in the United Kingdom ( $n = 15$ ) resulted in the emergence of eight inductively generated themes: (1) difficulty obtaining a diagnosis, (2) issues of self-hood and self-esteem, (3) changing relationships within the family structure, (4) awareness of changes in self, (5) workforce and retirement/financial issues, (6) feelings of extreme social isolation and exclusion, (7) "off-time" dependency, and (8) lack of meaningful occupation. While the findings suggest that people with dementia and their families are confronted with unique social issues, there is a need to explore common experiences among people of any age diagnosed with dementia, such as the feelings of isolation associated with the loss of social roles. It is also important that the life course not be segmented, as this can lead to divisive conceptualizations of care and service provision between and among those receiving care and those giving it. Moreover, the tendency in the literature to focus on static life stages indicates a failure to capture the continuity of gender identity and experience over the life course, particularly for women (Aronson, 1991).

In summary, despite increasing interest in the experiences of people who have been diagnosed with dementia, there is still a dearth of research into the ways in which persons with dementia negotiate relationships in their social world. In particular, little is known about the specific relationship between women with AD and their adult daughters, and how the care process influences their health and well-being, particularly from the mother's perspective. If we are to broaden our understanding of the complexities of the care process in AD, research will have to consider the perspectives of both the caregiver and the care recipient (Cox & Dooley, 1996). Finally, we need to increase our knowledge about gender and how it shapes intergenerational care within the mother-daughter relationship. This information will help us to identify those societal conditions that require change, with the aim of promoting the health of women with dementia.

### **Method**

As part of a larger qualitative investigation of mother-daughter dyads within the care process of dementia, we were interested in developing a better understanding of the experiences of community-dwelling women with AD receiving care from their daughters. Evidence suggests that the care experience differs by gender, family relation, and health status of the care recipient (Dupuis & Norris, 2001). Therefore, this study focused



exclusively on women with mild to moderate cognitive impairment receiving care from their adult daughters. Specifically, we were interested in addressing the following research questions: (1) *How do women with AD and their adult daughters describe their experiences of receiving/providing care?* (2) *How do women with AD and their adult daughters describe their relationship?* (3) *What contextual factors influence the care provided/received?*

### ***Theoretical Framework***

This qualitative study was guided by socialist-feminist theory and a life-course perspective. This type of inquiry gives primacy to individual subjective perceptions of care experiences, while at the same time seeking to understand the fluctuating nature of the mother-daughter relationship over time. Feminist scholars have identified the importance of the tie between mother and daughter. Given their skills and expectations in maintaining social ties, it is not surprising that, in adulthood, mothers and daughters share stronger relationships than fathers and sons (Fingerman, 2001). Feminist theorists have also questioned the premise that autonomy is the final virtue to be equated with maturity. Thus the emphasis in feminist writing has been on the bond between mothers and daughters (Fingerman).

Social-feminist scholars, most notably Stoller (1993) and Ungerson (1990), have provided explanations for the ways in which caring is defined and how it is organized. Since a feminist perspective views women's everyday caring experiences as inextricably connected to the larger political, social, and economic environment (Hall & Stevens, 1991), elicitation of women's narratives about the intergenerational care process identifies larger cultural values and ideologies. As discussed earlier, the caregiving literature tends to portray elderly mothers as burdensome to their overworked daughters. Feminist inquiry offers an alternative view — that caring is an intergenerational process between two women. Finally, the goal of feminist research is to develop knowledge, thereby creating positive changes with the aim of improving the lives of women in this intergenerational relationship.

This study also took a life-course perspective in order to understand the interactions and exchanges between mothers and adult daughters throughout their lives. This perspective is appropriate since it assumes that the meaning of care (giving and receiving) is based on a lifetime of experiences rather than on the current event or situation (i.e., dementia) (Fingerman, 2001). A life-course perspective also captures the care relationship between two generations of women and its shaping of women's health and well-being.

### ***Recruiting and Sampling Methods***

After approval had been secured from the Ethics Review Board of the affiliated university, multiple recruitment strategies (e.g., key community agencies, doctors' offices, community centres) were used to obtain a diverse sample of community-dwelling women with mild to moderate cognitive impairment and their adult daughters. In an attempt to reach participants who may not have had access to these services, colourful flyers and notices about the study were sent out and posted in the offices of family physicians and at community sites such as libraries and seniors' centres. Also, health professionals providing services to women with dementia and/or their families, such as clinical nurse specialists, community nurses, and social workers, were contacted by telephone or in person to enlist their help in identifying potential participants. Follow-up letters and telephone calls to community agencies were made 2 to 3 weeks later. Finally, through use of the snowball technique, some daughter participants indicated that their sister(s) would be interested in taking part in the study. Consequently, three mothers had two or more adult daughters participating in the study.

Inclusion criteria for mothers and daughters were consent to participate, ability to speak English, and receiving/providing at least 2 hours of care per week. In addition, mothers had to score 17 or higher on the Standardized Mini-Mental Status Examination (SMMSE) and to demonstrate good verbal and comprehension skills (e.g., ability to state date of birth). According to Molloy and Clarnette (1999), a SMMSE score of 21 to 24 is indicative of early dementia and a score of between 10 and 20 is indicative of moderate dementia. Based on the clinical experience of one of the investigators, the cut-off score was set at 17, to ensure accurate, reliable interview data. In the end, of the 20 mothers with dementia in the larger study, 10 were unable to participate in the interview due to low SMMSE scores.

All potential participants were given written information about the purpose and nature of the study and were asked to take part in two interviews 6 to 9 months apart. Multiple interviews are often necessary with persons with dementia, to ensure sufficiently rich data and to compensate for the day-to-day fluctuations in their abilities (Moore & Hollett, 2003). Moreover, since we were interested in understanding how the progress of dementia may shape the mother-daughter relationship, we selected an intermediate time frame, one that would potentially capture this aspect of the relationship without risking participant attrition. However, two mothers who were interviewed at time 1 could not be interviewed at time 2 due to a low SSME score. Written consent was

obtained immediately prior to the first interview and all participants were assured of confidentiality (e.g., use of pseudonyms). The assent of each participant was reaffirmed at the beginning of the second interview.

### **Sample**

The participants ranged in age from 75 to 98 years (mean age = 88) and obtained SMMSE scores of 18 to 28 out of a possible 30 (mean = 22). Six of the women identified as Canadian, seven were widowed, and most had two or more adult children involved in their care. Four of the women had not completed secondary school. Incomes ranged from less than \$20,000/year ( $n = 4$ ) to \$60,000/year ( $n = 1$ ). All but one of the mothers lived in the same city as at least one of her daughters. At the time of the first set of interviews, four of the mothers lived in their own home, four lived in their daughter's home, and two lived in a retirement home in the community.

On average, the mothers and daughters saw one another 3 days per week. The daughters reported that they had been providing daily to weekly assistance to their mothers for an average of 49 months, with a range of less than 1 year to more than 6 years. All mothers received some degree of help, such as personal care, transportation, housekeeping, or meal preparation, from their daughters.

### **Data Collection**

If both mother and daughter in a dyad consented to participate in the study, separate in-depth interviews were arranged at a mutually convenient time and place. The decision to not conduct conjoint mother/daughter interviews was largely based upon the belief that the participants would be more forthcoming in their reports if interviewed alone. Furthermore, there is considerably less research documentation on the perspectives of persons who receive care (Allen & Walker, 1992), and the research team believed it was important to capture voices previously unheard. On three occasions, however, mothers required or requested the presence of a relative, usually the daughter or a granddaughter. During these interviews, one of the two parties occasionally drew the other into the conversation to confirm or verify some information. Therefore, it is possible that the mother's responses in these situations were influenced by the presence of her relative. One advantage of the conjoint interviews was the opportunity to collect observational data with respect to mother-daughter interactions. Thus, interviewing the mother and daughter together did not necessarily yield a less complete picture of the relationship, although it did yield a different one.

Audiotaped interviews, lasting approximately 45 minutes, were conducted initially, followed by a second set of interviews with a total of eight mothers (the SMMSE scores of two of the original 10 participants were below 17). One mother was interviewed twice because she needed extra time to fully discuss her relationships with her four daughters. All of these interviews were held at the mother's residence. At the end of the first interview, all participants completed a brief demographic questionnaire. Finally, full field notes were written after each interview.

Using an in-depth, focused interviewing approach (Merton, Fiske, & Kendall, 1990), the interviewer asked the participant non-directive questions designed to trigger dialogue about her experiences in providing/receiving care, the mother-daughter relationship, and the factors influencing the process of care. Through this approach, the participants were encouraged to discuss what they considered to be the most important aspects of the care process and of their relationships. The research team's use of this approach to interviewing was informed by the work of feminist scholars (Oakley, 1982; Reinharz, 1992) and other researchers who interview persons with dementia (McKillop & Wilkinson, 2004; Moore & Hollett, 2003; Reid et al., 2001). All three investigators strove to build rapport with the participant and to provide support and information during the interview. Guided by clinical evidence in dementia care, the research team employed additional interview strategies for use with individuals with AD (e.g., using visual aids, providing questions on yellow paper, ensuring a quiet environment). Thus, the study sought to include people with dementia in research about their experiences, creating the potential for personal empowerment consistent with feminist goals.

### ***Data Analysis***

The major procedures for qualitative data analysis followed the guidelines of Lofland and Lofland (1995). After each interview, full field notes were written to record perceptions, insights, and observations (Morse & Field, 1995). The field notes, a method commonly used in qualitative research, added richness and depth to the data and also guided the planning of interviews. As data analysis proceeded, memos or notes were used to keep track of the researchers' insights and included justifications for making analytic decisions.

Gathering and analyzing data were simultaneous processes (Lofland & Lofland, 1995). Transcription and analysis of the interviews began immediately after the first interview and proceeded as data were collected. Shortly after each interview, individual researchers read the transcription and independently made a preliminary data analysis. Team

analysis was used to clarify concepts (e.g., guilt, gratitude) and themes (e.g., undemanding care). Ultimately, the principal investigator explored the connections among the themes and prepared an overarching conceptual interpretation of participants' experiences, which was finalized through team analysis.

Throughout data analysis, Guba and Lincoln's (1989) criteria for establishing credibility, transferability, dependability, and confirmability were used. Credibility was established through prolonged engagement with the data, persistent observation, and audiotaping and verbatim transcription of all interviews. Transferability of the findings to other settings was promoted by providing a rich description of the context and methods entailed in generating the data. Dependability and confirmability of the data were promoted by maintaining an extensive audit trail.

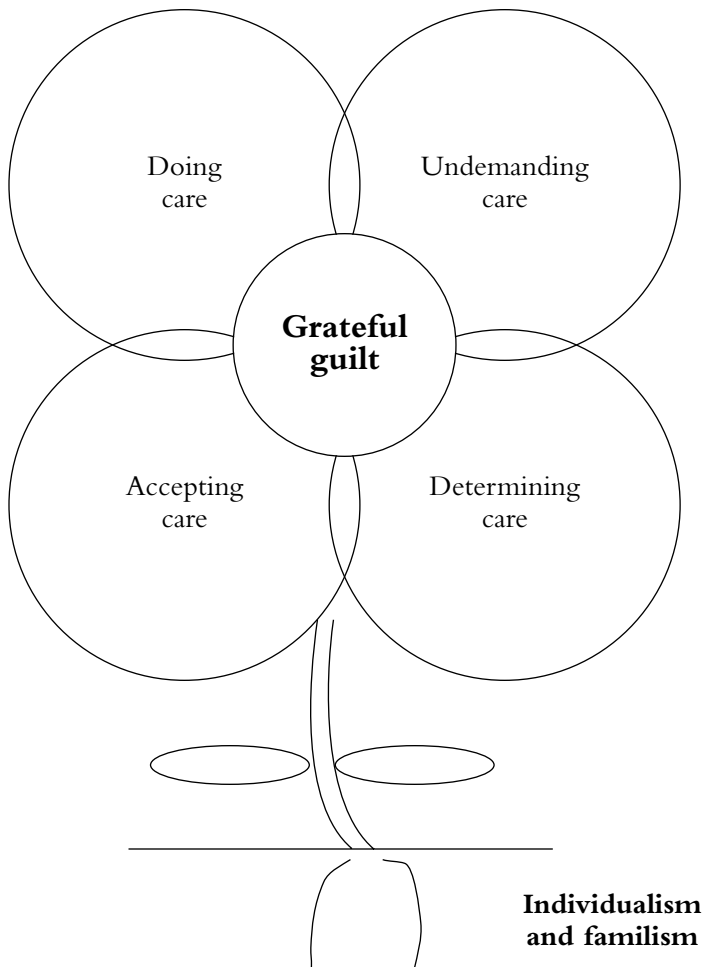
### **Findings**

Building on the theoretical perspectives outlined above, the accounts of mothers and daughters were treated as both individual perceptions of caregiving and care receiving and "points of entry" into social processes far beyond the realities of the participants (Smith, 1987). In adopting a method that addresses both sides of the care relationship, the research team sought to uncover a number of features that are not addressed in policy, such as the relationship itself, emotional labour, and the complex exchanges of care (Henderson & Forbat, 2002). The goal of the study was to explore the perceptions and experiences of community-dwelling women with dementia and their daughters. In this paper we report only on the perspectives of the mothers. A full account of the different types of mother-daughter relationship, using the dyad as the unit of analysis, will be published elsewhere.

Based on our interview and field-note data, the mothers' perceptions and experiences of receiving care from their daughters are conceptualized in the form of a flower (see Figure 1). The familiar AD logo, the forget-me-not, was purposely selected to depict how mothers managed their contradictory experience of needing care. Each petal of the flower represents one of four responses: *doing care*, *undemanding care*, *determining care*, and *accepting care*. The appraisal of the situation, the conceptualization of need, and the acceptability of the care received were all subject to negotiation between the mother and daughter. Implicit in the process of negotiation is the recognition that people are active participants, capable of constructing their actions to deal with social situations (Gerson & Peiss, 1985). All mothers spoke of feeling grateful for the care received, but at the same time they felt guilty for being a burden to their daughters.

While the mothers reported mostly positive relationships with their daughters, the findings revealed that cultural ideologies and constraints manifested in feelings of “grateful guilt.” The two major underlying ideologies, individualism and familism, appeared to be at the root of these responses. The mothers’ experiences of receiving care from their daughters and the contextual factors shaping those experiences will now be described and illustrated through the use of comments by the participants.

Figure 1 *Receiving Care within Dementia: Mothers’ Perspectives*



### ***Mothers' Experiences of Receiving Care***

Analysis of the mothers' experiences of receiving care from their daughters illuminated four interrelated responses.

***Doing care.*** The first response was *doing care*. Simply stated, this was the mothers' perceived ability to perform self-care. Although the focus of the study was care *received* by the mothers, this finding highlighted how mothers' *provided* care, primarily to themselves. Most of the mothers asserted that they continued to live independently, apart from their daughters. They claimed that they would not "do that" to their daughters, implying that they did not wish to be "a burden" to their children. When the mothers were asked if they felt it was better to live with or apart from their daughters, many were explicit in their views about being independent:

*I think it [living apart] is better. We each have our own sense of independence... I think people need their independence as much as possible... I think it's better to be apart if it's at all possible. (Margaret)*

*I wouldn't want to live with my kids, not one of them. I'd go into a home first. I've been independent. I wouldn't want to interfere with their lives... I was brought up to be independent. (Georgina)*

Adherence to cultural values of independence was driven mostly by the need to be productive and self-reliant:

*I clean my own windows, do my own housework... When I have to stop doing that, then it's time to go. (Anne)*

*I try not to give up the things that I'm interested in, and things that I do, to keep myself busy. (Helen)*

*I don't ask her [daughter] to do anything for me. I'm an independent person and I do things for myself. (Bess)*

*Never ask anybody for anything and you have nobody to thank. (Georgina)*

***Undemanding care.*** Closely aligned with doing care, *undemanding care* emerged from the women's accounts as a second thematic response. Withholding requests for assistance was the predominant response reported by the participants. Consistent with Aronson's (1990a) finding of mothers appreciating their daughters' "busy family and work lives" and not wanting to add to their burden, many of the mothers in this study attempted to prevent their daughters from doing too much by suppressing their own wishes and needs. This was particularly noticeable with respect to their need for social interaction:

*It's very, very difficult for me to stay here all the time by myself...there's always this empty feeling of sitting by yourself... But I don't complain. I never tell her I'm lonely. (Helen)*

*I don't want to take her life away from her. I've had mine. But I hate when she goes, when she says, "I'll just lock up the door, you know, for security." Oh yeah, now I'm all by myself again. (Anne)*

For fear of asking too much of their children, the mothers sometimes found it easier to ask for nothing. The following comments also shed light on the Western cultural belief that the family of procreation takes primacy over the family of origin:

*I don't bother them. I never call them. [If] they come, they come, if they don't, they don't. They're busy and they have families... I can't expect them to...they all have responsibilities and families... I don't demand nothing from them. (Georgina)*

*I don't see her as often as I'd like, but she's busy, like all young people are. Her time is taken up with important things now and you have to respect that... She's grown up and has a lot of responsibility... She needs to take care of her own home. I don't ask her to do anything for me. (Bess)*

**Determining care.** Torn between wanting to be independent and needing assistance, the participants actively responded to the dilemma by *determining* the extent and type of care they would receive from their daughter. They tended to ask for or were prepared to accept care only under certain conditions, thereby maintaining some degree of control over the care received, as well as addressing the tensions they experienced in needing help. Moreover, all of the participants accepted assistance from their daughter only if it did not restrict or jeopardize the daughter's independence. As illustrated in the following comments, the mothers were mindful of the demands on their daughters' lives and made an effort to restrict care to the absolute minimum:

*I know that if I called and said, "Hey, I'd like to see you — I'm lonely," she would be here. But I don't do that. She has her own life to lead. (Helen)*

*You want your daughter to have a full life. You want her to have time to do what she wants to do...so I feel better when I know she has her things to do too. (Margaret)*

*I mustn't bother her too much. She's a busy lady. (Bess)*

Determining care also entailed decisions about what types of assistance were acceptable. Shopping, laundry, and banking were considered "normal" daily chores for adult daughters to perform for their mothers:



*It's part of her day to come and take me shopping, like it would be if my mother was around. (Margaret)*

*She's been kind enough to do some of my laundry, because I hate to send my good clothes to the laundry here. So if I have two or three pieces of laundry, she does it for me and brings it back. (Helen)*

*She helps me with the banking. It's not because I can't do it myself. She has a car and it's handier for her to get my stuff than for me to do it. (Bea)*

However, some participants realized that, due to deteriorating memory, they needed their daughter's assistance with other activities, such as dispensing medication and keeping doctors' appointments:

*She sometimes gets my pills out...but I quite often do them myself... I think last week I goofed. I don't know. I think I missed a couple of pills. I think it mixed me up. I was trying to think, how can I do this to get the right ones in? So sometimes she helps me with that. (Elizabeth)*

*When I was in the hospital she was able to talk to the doctors and the nurses in a way that I couldn't... Sometimes when I wasn't getting the drift she would get that across... She also goes to the doctor's [office] with me. She listens. She keeps it all straightened in my mind. (Margaret)*

*She took me to the eye doctor's today, but I don't like to put too much on her shoulders because she's got enough to do already... I try not to bother her because God only knows...how she does what she does. I hate to be a pest or a nuisance...so I make that [requests] a minimum. (Helen)*

Finally, the participants not only exercised their right to restrict the care being provided currently, but also spoke about the future. Moreover, such responses seemed to serve the purpose of lessening their sense of dependency and preserving their sense of pride:

*I'll ask for help when I need it... If I was at that stage [of needing more help], I'd put myself in a nursing home. (Ethel)*

**Accepting care.** The final response, *accepting care*, occurred when mothers passively accepted assistance from their daughter regardless of whether, in their opinion, they needed it or not. This response was particularly common among mothers who were receiving regular, almost daily, care from their daughter. In fact, some daughters occasionally reminded their mothers of the care that they received:

*My kids tell me, "You never had it so good, Ma." (Helen)*

*I know that I'm not really with it...so I know that she helps me out, which is fine. Sometimes we joke about it. I think that was what she was saying when she came home last night. She said, "You know what, Mom? You got it made, really." (Elizabeth)*

Clearly, many participants were well aware of the time and energy their daughters spent providing care and did not want to appear ungrateful. In response, they gradually relinquished control of their care to their daughters:

*I really do rely more on her. When she makes a plan or something like that, I try to make sure I go along with it because that's something she's spent some thought on... Now she just goes ahead and does things for me. (Margaret)*

*I'm lucky. I'm lucky to have the help when I need it. [Daughter] was right here when I needed her. She took care of me like a little sister, which was wonderful. (Helen)*

*I see her quite frequently and she is very, very good... She brings me my meals... She does all she possibly can and I look forward to her coming over. I can depend on her. (Georgina)*

Other participants were aware of their reliance on others and did not want to risk losing their assistance. This placed the mothers in a precarious position, which often led to their relinquishing the right to control their lives:

*My daughter is my mainstay and I accept what she tells me. (Sarah)*

*If she thinks it's better for me [living with daughter], then it's alright... I take her word for it. She should know more than I do...and I'm exceedingly grateful to her for doing what she does, because a lot of young people that I know of nowadays wouldn't be so willing... She takes care of everything here and everything I need is covered. She takes the money out of the bank if she thinks I need it. And I don't have any responsibilities like that. Sometimes I wish I had, but if that's what she wants to do, then I don't care. All my life I took care of myself and all of a sudden I don't have to, but now I realize how wonderful it is, that I don't have to do anything. (Helen)*

### **Context of Receiving/Providing Care**

Two factors tended to account for and shape the mothers' responses to the care they received from their daughters: individualism and familism. The personal values and belief systems that we develop and follow throughout our lives are rooted in the societal ideologies of individualism

and familism (Hooyman & Gonyea, 1995). An ideology is a set of beliefs and attitudes about our social reality, as well as the practices and motives they manifest. Ideologies are powerful in that they are often invisible and therefore difficult to contest (Anderson, 1990). In other words, since care provided and received between mothers and daughters is viewed as “natural,” ideologies often hinder our ability to imagine otherwise.

The values of individualism include self-reliance, self-determinism, privacy, living one’s life independently, freedom from intrusion, and freedom from dependence on the will of others (Dalley, 1996). Many of the accounts described above reflect these values. Self-reliance and resisting dependency on others were the attributes of individualism most commonly described by the participants:

*I think I'm independent, very independent. We were brought up to be like that. One thing that Daddy used to say, "Don't ask for favours, then you don't have to return them." (Georgina)*

*I do the dishes...she didn't like how I did them but I still went ahead and did them anyway. I don't care if she gets mad or not, I'm gonna do it!... She doesn't need to have all this to do. (Elizabeth)*

The following comment illustrates the women’s attempts to resolve the tension between being independent and being dependent, while also being grateful for any assistance offered:

*She would do anything I ask her, and I don't ask her because I'm an independent person and I can do it myself. But if they want to do some little thing for me, I'm always very happy and genuinely grateful... I wouldn't ask them to... They're ready to help me in any way, shape, or form if I said the word, but I try to be independent. (Bess)*

The ideology of individualism depends on familism (Dalley, 1996), the second contextual factor that shaped the women’s responses. When the emphasis is on family commitment and obligation, family members are expected to “care for” one another because they “care about” one another. With the notion of privacy of the family unit and minimal state interference, women’s caring role within the family is perceived as “natural” and freely given. The participants respected these prevailing assumptions and values with regard to women’s role as primary caregiver within the family. Iris, who had both daughters and sons, quoted a common saying to explain her son’s limited ability to assist her, thus illustrating the intertwining of gender-role expectations and “family” caregiving:

*A daughter is a daughter for life. A son is a son 'til he takes a wife.*

Indeed, another participant noted her good fortune in having a daughter who cared about her and sympathized with those who did not:

*It's a wonderful feeling to know that your daughter cares enough about you to do these things, because I've met some people who don't have anybody to do anything for them and it's pitiful, but whatever she does for me seems to be of her own free will, and if I need anything...she's there for me, and you really can't ask for much more. (Helen)*

This comment also illustrates the participants' internalizing of ideologies — judging others and oneself against normative rules of conduct. Nourished by the strong roots of individualism and familism, “grateful guilt” was at the centre of the mothers' experiences in receiving care from their daughters. Conflicting emotions, such as guilt and gratitude, illustrate the invisible process of social control described by Hochschild (1979). Covert forms of power, particularly at the ideological level, reflect and reinforce dominant cultural assumptions about women and care. The following comments illustrate the mothers' questioning of whether they deserved or were entitled to the care they received from their daughters:

*I don't want my daughter to feel that I'm going to be an anchor underneath... It makes me feel so guilty... I'm happy when she helps me, but at the same time I feel guilty. (Anne)*

*She's very thoughtful. She brings me little dinners and stuff like that. I have no complaints...but I hope I deserve it. (Georgina)*

Most of the participants refrained from asking for their daughters' help for fear of “being a burden.” The provision of assistance frequently led to feelings of guilt, mixed with gratitude. Some mothers reported that others reinforced these feelings of gratitude:

*I'm very lucky, and many people have told me that too. (Margaret)*

## Discussion

Despite the limitations of a small, homogeneous sample of women with mild to moderate dementia, the findings from this study extend our knowledge of the perceptions and experiences of older women living with dementia, with a particular focus on mothers' relationships with their caregiving daughters. The findings highlight a number of areas that need to be addressed by practitioners, policy-makers, and researchers as they work together to promote the health of older women with dementia. Specifically, we need to better understand how social determinants of health, such as gender, income, and social support, influence the health of women living with dementia.

First and foremost, we need to listen closely to what women with dementia have to say. Similar to the findings of other investigators (Aronson, 1991; Proctor, 2001), the accounts of women in this study revealed that their needs for care and social support were stifled by the internalization of dominant societal ideologies of individualism and familism. The findings affirm the wish of most people with disabilities not to be a burden to their families. Since there are few publicly funded supports to assist with the care of older women with dementia and other chronic conditions (Dalley, 1996; Guberman, 2004; Krogh, 2004), the mothers in this study had little choice but to depend on their daughters to meet their needs, which led to feelings of “grateful guilt.” Nurses and other health professionals need to be aware of the extent to which they may perpetuate these feelings. For instance, praising the efforts of care-giving daughters may inadvertently reinforce the mothers’ feelings of guilt and unworthiness. Changes in health-care practice have the potential to address older women’s sense of disentanglement and marginal social status.

Second, the findings affirm the need to radically alter the home-care system to better meet the needs of community-dwelling women and their families. We must challenge the pervasive gendered ideologies of familism that undergird the implicit and explicit policies of family care (Hooyman & Gonyea, 1995) and develop alternative types of care. Policies that view families as the cornerstone of home care and women’s proper role as caregiver within the family are harmful to women’s health, both as caregivers and as care recipients (Guberman, 2004). References to “the family” in home-care policies that hide the gendered nature of family caregiving must be openly criticized, while alternative models of care based on the belief that the care of disabled members of society is a social responsibility, such as those models proposed by Neysmith (1991) and Guberman, must be developed. Empowerment, genuine choice, and partnerships between all concerned stakeholders are central to this approach to community care. Since public services are available to people who need them within this innovative approach to community care, mothers with dementia would have their needs met without having to rely solely on their daughters.

Third, genuine partnerships among care recipients, family caregivers, professionals, and policy-makers will be possible only when all voices are heard. Although the perspectives of women — as either providers or receivers of care — are seldom considered central to the policy debates on health and social care in an aging society (Aronson, 1990b), women with dementia are beginning to speak up about their personal experiences in living with AD (Sterin, 2002; Truscott, 2003). Morris (1992) urges the disability movement to adopt the feminist perspective of “the

personal is political” by giving voice to the subjective experiences of individuals with a disability. A feminist perspective runs counter to the individualist ethic inherent in the focus on personal health behaviour by situating women’s health within current social, economic, and political conditions. It fosters a collective rather than an individual response and challenges governments and other social institutions to assume responsibility for the health of women and the population as a whole (MacDonald, 2002).

Pringle (2003) makes a strong case for not only deepening our understanding of the lives of severely cognitively impaired people but also finding ways of “making moments matter” in the activities of daily living of those with dementia. Pringle asks, “How do we get nurses to sew a tapestry using multiple colours and strands?” with the aim of improving the quality of life of persons with dementia. One response would be for nurses to sit down with persons with dementia and their families and sew this tapestry together. In other words, women with AD not only need to be heard, but need to actively contribute to the construction of equitable policies that promote their health and well-being. Policy rarely reflects the voices of both sides of the care relationship, and indeed often fails to acknowledge the role of the relationship itself in how people construct meanings of their situation (Henderson & Forbat, 2002). Only when we acknowledge the overriding importance of this relationship in the provision of care, allowing for relationship-based social policy, will we be able to create a representative, colourful tapestry that promotes the health and well-being of women.

The fourth and final area that needs to be addressed in light of the present findings relates to future research directions. We need to explore how other social determinants of health, such as income and social inclusion, shape women’s health experiences. Previous research shows that elderly people of financial means generally buy services and hire people to meet their needs, instead of choosing to be cared for by family and friends (Guberman, 2004). Most of the women in the present study lacked the financial resources to purchase caregiving assistance. This may have contributed to their sense of lack of control and their ambiguous relations with their daughters. It is essential that nurses and other health professionals understand the complex dynamics inherent in the relationship between the social determinants of health and inequities and address those inequities by speaking out against poverty, social exclusion, and gender-based discrimination.

It is also important that a variety of research methods be used to increase our understanding of the health experiences of women with dementia. According to Perry (2005), the biomedical model that guides the assessment and diagnosis of dementia is based on assumptions and

approaches that, while critical to medicine, may be less consequential for nursing. Although screening tools are often employed in dementia research, Perry recommends that we consider extending our views of assessment and evaluation to include the individual's narrative. The present study collected narratives from individuals with dementia and their daughters, making it possible for us to hear the voices of both care recipients and caregivers. Regrettably, however, it included only those women with an SMME score of 17 or higher. Since those individuals in the later stage of dementia still possess an intact sense of personal identity (Sabat, 1998), future research in dementia care should include stories by individuals at all stages of dementia, thereby recognizing and supporting their personhood.

In conclusion, this study explored the perceptions and experiences of older women with mild to moderate dementia receiving care from their daughters. A feminist perspective helped us to uncover the ideological roots of dementia care and further our understanding of how these gendered ideologies shape the lives and health of older women with dementia. As well, we have suggested changes in practice, policy, and research, with the aim of transforming older women's feelings of "grateful guilt" into feelings of self-worth and dignity. These health-promoting practices and policies represent optimal growing conditions, which will ultimately support and nourish older women with dementia and their families.

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