

# Learning to Live With Early Dementia

Leona Werezak and Norma Stewart

Les études sur la démence précoce se concentrent en grande partie sur la perspective des prestataires de soins, si bien que l'on sait peu de choses sur l'expérience des personnes atteintes aux stades débutants. La présente étude a été conçue dans le but de découvrir comment elles apprenaient à vivre avec cette maladie durant cette période. On a mené des entrevues auprès de 6 participants (3 hommes et 3 femmes) âgés de 61 à 79 ans. On a élaboré un modèle théorique sur la base d'une approche qualitative et d'une théorie à base empirique. On a ensuite établi un cadre théorique préliminaire à partir des données obtenues : les sujets s'approprient à la démence selon un processus en cinq étapes, commençant avec les antécédents et se poursuivant avec les stades de l'anticipation, de l'apparition, de l'assimilation et de l'acceptation. Cette démarche évolue à mesure que la perception des sujets sur eux-mêmes et le monde extérieur se transforme. En définitive, les implications découlant de cette recherche sont nombreuses pour les cliniciens et les chercheurs qui interviennent auprès des personnes atteintes de démence aux stades précoces.

Much of the literature on early dementia is focused on caregiver perspectives, while little is known about the perspective of persons with early-stage dementia such as what it is like to live with this syndrome. This study was conducted to explore the process of learning to live with early-stage dementia. Interviews were conducted with 6 early-stage participants (3 men and 3 women) ranging in age from 61 to 79 years. Theory construction was facilitated using a qualitative approach and grounded theory. A preliminary theoretical framework was developed from the data which outlines a 5-stage process of learning to live with dementia that begins with various antecedents and proceeds through the stages of anticipation, appearance, assimilation, and acceptance. This process evolved as participants' awareness of themselves and their outer world changed. Ultimately, the findings of this study have several implications for clinicians and researchers working with persons in early-stage dementia.

## Context of the Study

The term *dementia* refers to a clinical syndrome comprising a wide range of neurological diseases that typically occur with increasing age and are distinguished by progressive memory loss, impaired judgment, and a decreased capacity for abstract reasoning (Langston Lind, 1995). The most common cause of dementia is Alzheimer's disease,

---

Leona Werezak, RN, MN, is a nursing instructor at the Saskatchewan Institute of Applied Science and Technology, Kelsey Campus, Saskatoon, Saskatchewan, Canada. Norma Stewart, RN, PhD, is a Medical Research Council Scientist and Associate Professor, College of Nursing, University of Saskatchewan, Saskatoon.

with an overall prevalence rate of 5.1% in Canada for people over the age of 65 (Canadian Study of Health and Aging Working Group, 1994). In order to provide effective care and services for people with dementia, health-care providers have to understand the needs and issues facing this client group. Unfortunately, though, the views of people with dementia have been conspicuously absent from the literature until recently. At present, most of the information about the needs and concerns of dementia clients has been obtained from family members (McWalter et al., 1998) or formal caregivers (Gordon, Carter, & Scott, 1997). The few existing studies from the perspective of persons with dementia suggest that their views may differ from those of their caregivers (Cotrell & Schulz, 1993). Consequently, there is growing recognition in the literature that the perspective of persons with dementia must be sought out, particularly in the early stages of the disease process when language skills are relatively intact (Cotrell & Schulz).

To address this gap in the literature, we designed a study to explore and conceptualize the process of learning to live with memory loss in older adults with early-stage dementia. Through the use of grounded theory methodology, participants' experiences were examined and a broad theoretical framework evolved that outlined how persons with dementia gradually learned to live with early memory loss (Werezak, 2001).

### *Persons With Dementia as Research Participants*

An extensive literature review revealed little research that included self-reports by persons with dementia as research participants. As one might expect, the paucity of information in this area is due to methodological problems of self-report reliability as cognitive decline occurs (Ballard et al., 1991; Burgener & Dickerson-Putman, 1999). Therefore, most of the literature is focused on caregiver needs (Luscombe, Brodaty, & Freeth, 1998; Nankervis, Schofield, Herrman, & Bloch, 1997) and level of caregiver burden (Freyne, Kidd, Coen, & Lawlor, 1999; Schneider, Murray, Banerjee, & Mann, 1999) rather than on the perspective of persons with dementia.

The studies that have included persons with early-stage dementia as participants have addressed the issue of reliability and staging of the disease in various ways. In the study by Burgener and Dickerson-Putman (1999), participants were "mostly in the early disease stages" (p. 35), as assessed by a diagnosis of Alzheimer's disease or related disorder within the previous 12 months and a Mini-Mental State Examination (MMSE) score between 12 and 26 ( $M = 20.5$ ) — with a

maximum score of 30 representing no cognitive impairment. Although no specific reliability testing was conducted, consistency was found in participants' responses from baseline interview to 6-month follow-up. Other researchers have also begun to demonstrate that information provided by persons with early-stage dementia is reliable (McAuslane & Sperlinger, 1994) and "insightful" (Keady & Nolan, 1995, p. 1338); hence, the importance and feasibility of continued research in this area with persons in early-stage dementia have received increasing support.

### *The Experience of Living With Dementia*

In order to better understand the issues related to living with dementia, researchers have outlined two preliminary models that conceptualize the experience of persons with dementia on a continuum with identifiable stages or phases (Cohen, Kennedy, & Eisdorfer, 1984; Keady & Nolan, 1994). Cohen et al. delineate six psychological phases in the cognitively impaired individual based on several hundred clinical interviews with dementia sufferers. These phases are: prediagnosis — recognition and concern; during diagnosis — denial; post-diagnosis — anger, guilt, and sadness; coping; maturation; and separation from self. Similarly, Keady and Nolan (1994) propose a preliminary nine-stage model defining the experience of dementia from the perspective of persons with the disease. The nine stages are: slipping, suspecting, covering up, revealing, confirming, surviving, disorganization, decline, and death. Both of these frameworks suggest that persons with dementia undergo a process beginning with initial memory impairment and ending with terminal disability. However, what has yet to be determined is how individuals progress through the early stages of the disease, and it is during these stages that they may be most involved in their own care and planning for the future. Although the above-noted authors propose two different models that explicate the entire process of dementia from diagnosis to death (based on research in the United States and the United Kingdom), the model proposed in this paper is unique in that it describes the early stage of dementia exclusively while offering a Canadian perspective on this devastating syndrome.

## **Methods**

### *Design and Sampling*

A qualitative grounded theory approach was used to explore the subjective experience of persons with early-stage dementia (Strauss & Corbin, 1998). Theoretical sampling was carried out to obtain six par-

ticipants (three men and three women) with early-stage dementia (five with Alzheimer's disease and one with vascular dementia). Participants ranged in age from 61 to 79 years. All participants were in Global Deterioration Scale (GDS) (Youngjohn & Crook, 1996) stage 3 out of seven possible stages, with Modified Mini-Mental State examination (3MS) scores (Teng & Chui, 1987) ranging from 79 to 91 out of a possible 100. All participants were living in their home communities with their spouses. Four participants stated that they had participated in a support group for persons with early-stage dementia. Each participant was assigned a pseudonym. To ensure anonymity, the pseudonyms were assigned alphabetically in the order in which the participants were interviewed (e.g., participant #1: Mr. A. = Mr. Arnold). Inclusion criteria were: (1) diagnosis of Alzheimer's disease or related disorder, (2) early stage of dementia, and (3) all ages of onset of dementia (< 65 and > 65 years). In addition to meeting the above criteria, participants were selected on the basis of their ability to provide data relevant to the development of emerging conceptual categories.

### *Ethical Considerations*

When recruiting people with dementia as research participants, the investigator should consider three issues: competence, ability to provide informed consent, and use of proxy consent. Resau (1995) notes that "a diagnosis of dementia is not necessarily synonymous with incompetency," since a person with mild or early-stage dementia may still be able to perform relatively simple routine tasks such as handling small sums of money (p. 57). The current consensus in the literature is that many individuals with dementia, particularly those in the earliest stages of the disease, are still capable of making numerous decisions competently, including the decision whether or not to participate in research (American Geriatrics Society Ethics Committee, 1998; Resau).

With regard to proxy consent, there is recent evidence that proxy decisions in favour of research participation do not always match dementia persons' decisions to participate in research (Sachs et al., 1994). As a result, the current best practice is to obtain informed consent from both the potential dementia participant and that person's proxy (Sachs et al.). The present study was approved by a university-based ethics committee and received consent from all dementia participants and their proxies.

### *Recruitment and Screening*

In order to recruit participants from various agencies, the researchers supplied the agency contact persons with a one-page letter describing the study. Agency personnel distributed the letter to potential participants and then provided contact information for the study. The first author then phoned potential participants to arrange a meeting in their homes to further inform them about the study. Participants who provided signed consent (with their proxies) were interviewed during this first visit.

The first level of screening was the clinical assessment of early-stage dementia by the agency contact person. Interviews were conducted based on this initial screening. After the first interview, two screening instruments were used to confirm the participant's degree of cognitive decline (3MS; Teng & Chui, 1987) and stage of dementia (GDS; Youngjohn & Crook, 1996). Two potential participants were excluded from the study because their 3MS scores fell below the cut-off of 78 (McDowell, Kristjansson, Hill, & Hebert, 1997). Finally, participants' family physicians or specialists were contacted by mail in order to confirm the diagnosis of dementia. The authors did not ask participants the length of time since diagnosis, since their possible inability to remember due to dementia could cause undue stress and anxiety during interviewing. Neither was this information sought from physicians, since frequently a definitive diagnosis is not made on a specific date, but rather the diagnosis is made over time as the symptoms worsen and various tests rule out other possible diagnoses.

### *Data Collection*

Data were initially collected from participants using a semi-structured interview format based on previous research (Keady & Nolan, 1995). Each participant was interviewed twice. Proxies were allowed to be present during the interview process but were informed that the purpose of the interview was to elicit the perspective of the person with dementia. Once transcripts from the first interviews were coded and analyzed, a preliminary theory comprising six categories was identified. A second interview was conducted with each participant for the purpose of verifying and clarifying the emerging theory. During this second interview (1 to 3 months later), the interview process evolved and became more unstructured and open-ended as clarification was sought on issues that emerged in the previous interview.

### Data Analysis

Data were analyzed using constant comparison analysis to identify core concepts that described the experience of living with dementia from the perspective of the person with early memory loss (Strauss & Corbin, 1998). Negative case analyses were also carried out by including participants who had different types of dementia (i.e., Alzheimer's disease and vascular dementia). Data analysis was conducted using three types of coding: open coding, axial coding, and selective coding (Strauss & Corbin). Coding was facilitated by the use of Nvivo qualitative analysis software. During the process of coding the first interviews, five preliminary categories emerged from the data, which the first author "validated" and expanded on based on the second interviews (Strauss & Corbin, p. 159).

### Findings

The theory that emerged from the interviews can best be described as a *continuous process of adjusting to early-stage dementia*. The process consists of five core categories or stages that evolve over time, namely *antecedents, anticipation, appearance, assimilation, and acceptance* (see Figure 1). The participants described a process of adjusting to early-stage dementia beginning with various *antecedents* and progressing through the next four stages of the model with differing levels of *awareness* connecting each stage to the next. The findings that follow explicate the sub-processes of these stages in greater detail based on the information obtained from the participants. Negative case analyses did not reveal any differences among participants.

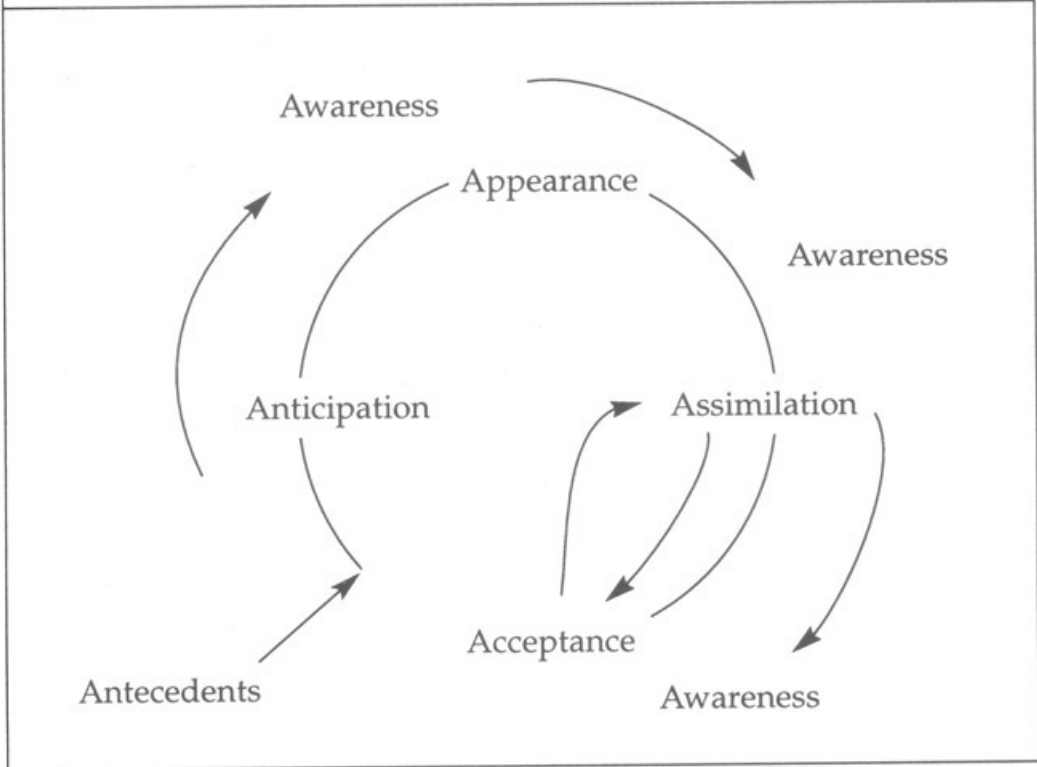
#### *Antecedents*

There were several sub-processes that preceded participants' being diagnosed with dementia. These made it difficult for participants to obtain a diagnosis of dementia.

***Recognizing that a problem exists.*** At the beginning of the interview process, participants were asked what they first noticed when they began experiencing difficulties with their memory. Not surprisingly, five of the six participants responded that they were not aware that they even had a problem with their memory when the dementia began. The following statement illustrates this point:

*Actually, I don't think I really realized at the beginning that I had memory loss. I'd say, "I can't think of it right now," if somebody asked me something, and I didn't realize I had memory loss.*

**Figure 1** *The Continuous Process of Adjusting to Early-Stage Dementia*



This initial reaction appeared to be due to the insidious onset of symptoms that the participants with Alzheimer's disease referred to, which some attributed to benign forgetfulness or stress at work. Unlike the other participants, who described an insidious onset of symptoms, one participant described experiencing an acute onset of what she said her physician called "vascular dementia." She described the beginning of her memory loss as follows:

*I was crocheting this one day and all of a sudden it was just like if somebody had taken something sharp and just jabbed it into here [pointing to her forehead] and it cracked, and I just yelled, "Ouch!"*

The other five participants cited various reasons for deciding to seek medical assessment, most commonly due to the progression of their memory loss.

**Recalling previous memory quality.** When participants discussed the onset of their memory loss, many inevitably spoke about what their memory was like before the dementia began. During the first interview, one participant suggested that his memory was not good even before he was diagnosed with Alzheimer's disease:

*Remembering at any time in my life, I mean, playing bridge was never a big thing, and any card game for that matter, you had to remember...memorize your numbers.... It wasn't my bag.*

In sharp contrast, one participant remarked that her memory was excellent before the onset of dementia. Because the change in her memory was so drastic, both she and her husband were initially quite upset about her memory loss:

*I feel I'm very forgetful, and I think that bothered [my husband] so much...because I've never been like that. I've always had an excellent memory. But that was a very hard, hard thing for me, to not be able to remember things, because I just never had that experience before.*

**Identifying family members with and without dementia.** Another issue participants raised in relation to being unaware, initially, of their memory loss was whether any family member had ever been diagnosed with dementia or Alzheimer's disease. Participants who had a family history of other diseases such as cancer or heart disease often said they expected to develop one of these diseases rather than dementia:

*I was thinking I'd maybe [get] cancer or heart disease or some damn thing, because that's what was in my family. My dad died of...angina, and my mother had cancer.... I expected one of them anyway [laughs] ...not this one.*

**Confounding health problems.** Finally, some participants described facing other complex health problems prior to being diagnosed with dementia, which made it difficult for them to identify which disease process was causing the memory loss, decreased attention span, and fatigue. For example, one participant explained that he had suffered from attention deficit since childhood and initially attributed his memory problems to his attention deficit disorder rather than dementia. Another participant, who was receiving radiation treatment for prostate cancer, voiced the following concern:

*I'm overly tired, but I don't know whether that has anything to do with Alzheimer's or whether it's something else.*

In summary, the sub-processes of the *antecedents* stage were precursors to participants seeking medical attention and subsequently obtaining a diagnosis of dementia.

### **Anticipation**

Once participants recognized that they were experiencing difficulties with their memory and sought medical help for this problem, they



described moving to the next step, *anticipation*. They discussed *anticipating* the diagnosis, their reactions to learning that they had dementia, and speculating about possible causes. Many participants recalled *anticipating* what losses they might face in the future, how they would become dependent on others for their basic needs, and how others would react when they learned that the participant had memory loss.

***Obtaining a diagnosis.*** Although they used different words and phrases to describe their feeling when they learned they had early dementia, the participants' common reaction could be described as shock, horror, and disbelief. The following excerpt vividly describes one participant's response to the news:

*That was quite an experience...because he did all these tests. He sat down and he said, "Well, I think you've got Alzheimer's." Like, there was no...nothing else but... No, he didn't say, "I think"; he said, "You have Alzheimer's." Well, I was just devastated.*

Some participants also tried to determine what might have caused their dementia. One participant wondered whether having his eardrum punctured accidentally by a physician and needing to have it surgically repaired could have caused his memory loss. Another participant described consistently waking up with severely reddened eyes, which she thought might be related to her memory loss.

***Considering future losses.*** After the initial reaction to their diagnosis, the participants soon wondered what restrictions the dementia would impose on their lives. The issue of "becoming a burden" to their spouses became central as they anticipated slowly losing the ability to care for themselves. One participant described her reaction to being diagnosed with Alzheimer's disease as follows:

*I think maybe I could probably handle somebody telling me I had whatever, but when it's your mind it's just really devastating, because you think, oh, how long is it going to be until I'm going to be a burden? That's one of the first things you think of...like, how long is it going to be before I'm a...I'm not able to look after myself and I have to have [my husband] doing everything for me.*

Other participants expressed concern about losing the intellectual and social abilities and skills necessary to function as productive members of society: "I'm staying in contact with everybody, just so I don't just become a blob."

Some participants remarked that they expected to need help as their disease progressed. Indeed, some pointed out that they were already relying on the assistance of others, especially their spouses, to

serve as a memory aid. Most participants were observed doing this during the interviews. For example, when asked if he was still working, one participant replied, "Oh, I retired," and, after pausing for a few seconds, turned to his wife, who was sitting in the adjoining room, and asked, "What year did I retire?"

*Telling others.* Finally, in the anticipation stage, participants unanimously recalled feeling anxious about how others would respond if and when they discovered that the participant had memory loss. Two primary factors they considered when contemplating whether to disclose their memory loss were how people might react if they knew about the dementia and how people had reacted when they discovered the participant had memory loss. One participant explained why she had not disclosed her memory loss:

*I haven't really told anyone else, because I figure if they know they're always watching for you to do things that are not what you should be doing. [chuckles]*

### *Appearance*

*Telling others* was closely linked to the next stage of the process, *appearance*, in which participants began to consider that others were *noticing* their memory impairment, how others viewed them in light of their memory impairment, and how they saw themselves as persons with memory loss.

*Noticing the sufferer's memory loss.* Two different components of this category became evident in the data. Looking back at the onset of their dementia, the participants recalled slowly becoming aware that family members, friends, or co-workers were "noticing" their memory loss although they themselves were not aware or were only beginning to become aware of their memory deficits. Similarly, as participants became increasingly aware of their memory impairments, they became greatly concerned that others were also noticing these deficits.

Most of the participants recounted hurtful situations in which others were insensitive or indifferent to what the dementia sufferer was experiencing as a result of the disease process. Perhaps most unsettling was the fact that often these painful situations occurred at the hand of a family member, friend, or co-worker. For example, when the first author asked one participant how she knew that members of her women's group were "gossiping" about her memory loss, she replied, "Well, because they'll go and talk to themselves...and then look at me." As a result of this experience, the participant and her husband decided

not to tell anyone about her memory loss when they moved to a large city. She said, "I just cover it up and no one knows."

*Seeing self as the "same person."* Finally, the participants also addressed how they viewed themselves since being diagnosed with dementia. All the participants described feeling that they were "still the same person" despite the memory impairments they faced. When asked what she thought other people should know about living with memory loss, one woman eloquently summarized what other participants expressed in different words:

*Maybe it's important that, although you have a memory loss, you haven't lost your mind completely, you know.... You've lost your memory but you haven't lost your mind. And you're still the same person, and you do make mistakes when you're...when you repeat yourself, but you're still knowledgeable, you're still the same person, and I think it's important that people realize that you don't change. I mean, things...your life changes, of course, but you're still the same person inside...at least I think I am. [laughs]*

### **Assimilation**

The fourth stage in the process of adjusting to early dementia was a sub-process called *assimilation*. *Assimilation* refers to the process of "fitting the dementia" into one's life, similar to the way one might learn to adapt to a physical disability such as adult-onset blindness. First of all, the participants described assimilating the disease into their *inner world*, which included their personal feelings and thoughts about the disease, the need to educate themselves about memory loss, and some of the physiological changes that occurred as a result of the disease. When asked if he had any concerns at the time of diagnosis about things he eventually might not be able to do, one participant replied:

*When we walked out from [the physician's office] we were handed a brown envelope about it.... And that's what you got from [the physician], and he is a specialist...I didn't feel that they really gave us anything to guide us. I mean, he said, did we know ourselves. Well, we didn't know. I mean, we were looking for answers. So we finally said, hey, something's got to happen here. I mean, we hear about things in brochures, we hear about things on the radio and stuff like that, and we are not getting any smarter here, which is when we sort of decided to drop in to [the Alzheimer's Society].*

Secondly, participants described assimilating the disease into their *outer world*, which included incorporating lifestyle changes related to their memory loss, interacting with supportive and unsupportive significant

others, and relating to other persons with dementia. Referring to the support group she attended, one participant explained:

*...there's people that are about in the same stages as I am, and I think that's important.... And we talk back and forth about things we do and things we do wrong and stuff, and I think that helps a lot. It doesn't make you feel so isolated.*

Discussions with participants revealed that, like the larger process of adjusting to early memory loss, this sub-process of *assimilation* was cyclical and continuous, the end result being increased *acceptance* of the disease. The transition from the *inner world* to the *outer world* was facilitated by *positive mediating experiences* such as feeling supported and accepted by significant others, retaining certain skills and abilities that gave life meaning and purpose, and being able to relate to others who were experiencing memory loss or other conditions. *Negative mediating experiences* such as progression of the disease, feeling unsupported or unaccepted by others, feeling unable to function in social or work situations, or simply having an unexplained setback and wanting to "give up" or "quit" resulted in participants "retreating" or "withdrawing" into their *inner world*. Retreating into their *inner world* served as a coping mechanism whereby participants were able to deal with the negative experience internally and decide how they wanted to proceed with their life from that point on.

### *Acceptance*

The last step in the process of adjusting to early dementia was *acceptance*. Throughout the interviews, participants discussed various aspects of *acceptance* in relation to having dementia. Clearly, the most salient step in the process of adjusting to dementia was learning to *accept* the disease as an integral, albeit unwelcome, component of one's life. One woman summarized her acceptance of her memory loss as follows:

*I think I am very fortunate. I have really managed to accept it and to say that I'm a lot luckier than a lot of other people. I could be a lot worse. I still can do my [lay ministry work], I still can see my kids, I can still do things that I like doing, and I think you have to sometimes just be grateful for what you have.*

Participants recounted a number of factors in their acceptance of memory loss, notably others' acceptance of the disease, using humour to cope, maintaining hope, and, finally, wanting to help others. Alluding to his sense of hope, one participant confessed during the second interview:

*In my mind I still feel like I'm going to beat this, but then after reading about it I know there's no cure.*

Later in the interview, the first author tried to determine whether he believed this was his way of maintaining some hope about his illness, to which he replied:

*Yeah, yeah. And it helps me in a way, because I think I am accepting the fact but I still have a bit of hope that it may not be actually Alzheimer's.*

Having adopted a variety of these coping methods, the participants unanimously described having achieved a degree of acceptance of their disease, which permitted them to focus on enjoying the remainder of their lives rather than dwelling on their illness.

### *Awareness*

*Awareness* was a common link connecting each stage of the adjustment process to the next. It became readily apparent after all the first interviews had been completed that the participants' *awareness* had gradually developed and changed. Reflecting back on her reaction to the news that she had Alzheimer's disease, one participant described her thoughts as follows:

*One of the things I thought of right away was, oh, I hope I live to see my grandchildren graduate. But I think that was quite normal because I just...of course, being a grandmother, you always do adore your grandchildren, and I always thought it would be so wonderful to see them graduate and get married and...all of a sudden I thought I might not ever be able to do that. And that would really bother me.*

As the participants discussed moving through the various stages in the process of adjusting to their memory loss, they demonstrated considerable insight and awareness about themselves, their disease, and, finally, those around them. An example of this insightfulness is one participant's description of his family as treating him "like a leper" upon learning he had Alzheimer's disease. When the first author asked how he currently felt about his family's attitude towards him and his dementia, he replied:

*It doesn't bother me any more, but it did at first...I had the concept that, well, "he's not all there," and [I was] very seldom asked for an opinion or anything of that nature.*

As participants became more comfortable living with their memory loss, their awareness began to change from highly introspective to more outwardly focused, particularly in their interactions with others.

## Discussion

### *Theoretical and Clinical Implications*

Support for the various components of the proposed model are found interspersed throughout the literature on early dementia, chronic illness, mental illness, and stigma. One of the concerns Phinney (1998) identified through interviews with dementia sufferers was that the unpredictability of changes in symptoms left them "with a feeling of uncertainty" (p. 11). In other words, escalating anxiety and uncertainty during the *anticipation* stage may be the result of participants perceiving their memory loss as a threat to their sense of order and personal control (Bahro, Silber, & Sunderland, 1995; Gwyther, 1997; Nygard & Borell, 1998). Nurse-clinicians and researchers should be cognizant of the emotional strain endured by dementia sufferers and seek to minimize any further emotional distress that may result from the interview process during a nursing assessment or research study. One means of minimizing distress may be to conduct assessments or interviews in the dementia sufferer's home, as was done in this study and recommended by Cotrell and Schulz (1993).

Although denial has been identified as a common coping method among individuals with early memory loss (Bahro et al., 1995; Cohen et al., 1984), evidence of denial did not surface in this study. On the contrary, participants demonstrated a striking openness and willingness to talk about their memory impairment and its effects on their lives. However, some participants did describe employing avoidance and conscious detachment in response to negative events (e.g., gossip), as opposed to unconscious defence. Intellectualizing the disease (e.g., by educating oneself about it) was another conscious means used by participants to assimilate it into their lives.

One of the factors participants saw as instrumental in the assimilation process was connecting with and learning from other dementia sufferers in support groups. The literature cites numerous ways in which self-help and support groups help people to adapt to chronic illness. In a phenomenological study with chronically ill adults, Michael (1996) found that "seeking support helped people feel connected/less isolated and helped them understand what others had done to deal with their illness" (p. 261). Similarly, Collins, Hooton, and Thirkettle (1999) found that participants who were members of a support group appreciated the opportunity to talk with other dementia sufferers about their life situations, feelings, and experiences. The participants in the current study who attended a support group identified all of these ben-

efits. These findings clearly indicate that more support groups should be established for persons with early-stage dementia. Research into the design, function, and efficacy of such groups, once established, could serve to ensure maximum benefit for participants and to secure funding to staff them with educated personnel such as nurses.

Many of the participants in the current study indicated that lack of support from family and friends hindered them from accepting their dementia. Collins et al. (1999) report similar findings. These researchers also found that family members treated the person with dementia "very differently," which contributed to the sufferer's stigmatization and negative self-perception (p. 98). In the current study, supportive family and friends played a key role in enabling participants to come to terms with their memory loss. Based on this finding, nurses can play a role in educating family members and others in the importance of learning to understand and support persons in the early stages of the disease.

Another implication concerns the clinical approach of health-care professionals who work with people with early-stage dementia. For example, one participant explained that the insensitivity of her physician in blurting out to her the news that she had Alzheimer's disease had discouraged her from asking the physician questions about the diagnosis. Michael (1996) found that the insensitivity of health-care professionals contributed to feelings of loss among chronic disease sufferers: "In seeking health care, patients had hoped to be seen as more than their illness and to find help in living with their illnesses. Instead participants felt insignificant and misunderstood" (p. 263). Participants in the current study shared similar feelings about their experiences with health-care professionals. These findings suggest that nurse clinicians and researchers must become aware of the impact of their verbal and non-verbal communication on early-stage sufferers. Clinicians and researchers should adopt an individualized, unhurried approach in working with early-stage sufferers, and should demonstrate their recognition of and respect for the unique difficulties and concerns of these persons.

### *Research Implications*

Some of the participants commented that they received insufficient information from their physician at the time of diagnosis. Research into this area could look at the kinds of information that newly diagnosed sufferers want, who they would expect to dispense such information, and the form that such information should take. Based on the participants' comments as well, an equally important area of dementia

research concerns the issues of stigmatization and its effect on self-esteem, adaptation, and acceptance of the disease. As persons are being diagnosed earlier in the disease process, it is becoming increasingly important to identify the coping methods that early-stage sufferers employ and whether they facilitate or hinder adaptation to early dementia.

### *Limitations of the Study*

Several factors may influence the transferability of these findings. First, it should be noted that saturation was reached relatively quickly in the study, with a sample size of only six due to the homogeneity of the sample. For example, these participants represented a relatively well-educated group (all had completed Grade 10 and several had some post-secondary education), which would account for their ability to articulate and describe their experiences in living with the disease. In addition, all of the participants were married, financially secure, and retired from work outside the home. Second, the participants volunteered to take part in the research, which suggests that they had achieved a measure of acceptance of their disease before enrolling in the study. As a result, the findings of this study should not be generalized to all early-stage sufferers but rather be used as preliminary findings that may shed some light on the issues to consider when sampling early-stage sufferers for dementia research.

Another factor to consider is that four of the six participants had attended or were attending a support group for persons with early dementia. The support of and contact with other sufferers was instrumental in their adjustment to early dementia. Dementia sufferers who do not have contact with other sufferers may in fact experience greater difficulty in adjusting to their memory loss. Because support-group participation significantly influenced the findings of this study, it would not be appropriate to generalize the results to early-stage sufferers who have not been part of an early-stage support group.

A final possible limitation concerns the technique of negative case analysis as used in this study. Many factors, such as the stigmatization of the disease and the fact that the disease is often not diagnosed until it has progressed, made it difficult to obtain a sample of early-stage sufferers. Because of this difficulty in obtaining a sample, true negative case analyses could not be conducted by selectively sampling participants to expand on emerging categories. Nevertheless, some negative case analyses were performed indirectly by sampling participants



based on characteristics such as age, gender, type of dementia, and age of onset.

### **Conclusion**

Although the current study began as a general exploration of the process of learning to live with early dementia, the depth and breadth of insight revealed in the interviews permitted the development of a preliminary theoretical framework of how persons with early-stage dementia learn to live with their memory loss. Theory development from the voice of the person with dementia makes this study unique. Previous studies have been almost exclusively descriptive in design (Bahro et al., 1995; Phinney, 1998) and have focused on caregiver perspectives (Freyne et al., 1999; Luscombe et al., 1998; Nankervis et al., 1997). From a nursing perspective, the proposed framework offers a base of valuable information to nurses working with persons who have early-stage dementia, while the core concepts provide a foundation for future research to test the applicability of the model in the larger population of persons with this devastating syndrome.

### **References**

- American Geriatrics Society Ethics Committee. (1998). Informed consent for research on human subjects with dementia. *Journal of the American Geriatrics Society*, 46, 1308–1310.
- Bahro, M., Silber, E., & Sunderland, T. (1995). How do patients with Alzheimer's disease cope with their illness? A clinical experience report. *Journal of the American Geriatrics Society*, 43(1), 41–46.
- Ballard, C. G., Chithiramohan, R. N., Handy, S., Bannister, C., Davis, R., & Todd, N. B. (1991). Information reliability in dementia sufferers. *International Journal of Geriatric Psychiatry*, 6(5), 313–316.
- Burgener, S. C., & Dickerson-Putman, J. (1999). Assessing patients in the early stages of irreversible dementia: The relevance of patient perspectives. *Journal of Gerontological Nursing*, 25(2), 33–41.
- Canadian Study of Health and Aging Working Group. (1994). Canadian Study of Health and Aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150(6), 899–913.
- Cohen, D., Kennedy, G., & Eisdorfer, C. (1984). Phases of change in the patient with Alzheimer's disease: A conceptual dimension for defining health care management. *Journal of the American Geriatrics Society*, 32(1), 11–15.
- Collins, C., Hooton, S., & Thirkettle, B. (1999). Shared experience. *Mental Health Care and Learning Disabilities*, 3(3), 96–99.

- Cotrell, V., & Schulz, R. (1993). The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. *Gerontologist, 33*(2), 205-211.
- Freyne, A., Kidd, N., Coen, R., & Lawlor, B. (1999). Burden in carers of dementia patients: Higher levels in carers of younger sufferers. *International Journal of Geriatric Psychiatry, 14*(9), 784-788.
- Gordon, D., Carter, H., & Scott, S. (1997). Profiling the care needs of the population with dementia: A survey in central Scotland. *International Journal of Geriatric Psychiatry, 12*(7), 753-759.
- Gwyther, L. P. (1997). The perspective of the person with Alzheimer's disease: Which outcomes matter in early to middle stages of dementia? *Alzheimer Disease and Associated Disorders, 11*(6), 18-24.
- Keady, J., & Nolan, M. (1994). Younger onset dementia: Developing a longitudinal model as the basis for a research agenda and as a guide to interventions with sufferers and carers. *Journal of Advanced Nursing, 19*(4), 659-669.
- Keady, J., & Nolan, M. (1995). FADE: A strategy for action in the mild stage of dementia. *British Journal of Nursing, 4*(22), 1335-1339.
- Langston Lind, A. (1995). Delirium, dementia, and other cognitive disorders. In M. O. Hogstel (Ed.), *Geropsychiatric nursing* (2nd ed., pp. 171-207). St. Louis, MO: Mosby.
- Luscombe, G., Brodaty, H., & Freeth, S. (1998). Younger people with dementia: Diagnostic issues, effects on carers and use of services. *International Journal of Geriatric Psychiatry, 13*(5), 323-330.
- McAuslane, L., & Sperlinger, D. (1994). The effects of relocation on elderly people with dementia and their nursing staff. *International Journal of Geriatric Psychiatry, 9*, 981-984.
- McDowell, I., Kristjansson, B., Hill, G. B., & Hebert, R. (1997). Community screening for dementia: The Mini-Mental State Exam (MMSE) and Modified Mini-Mental State Exam (3MS) compared. *Journal of Clinical Epidemiology, 50*(4), 377-383.
- McWalter, G., Toner, H., McWalter, A., Eastwood, J., Marshall, M., & Turvey, T. (1998). A community needs assessment: The care needs assessment pack for dementia (CarenapD) - its development, reliability and validity. *International Journal of Geriatric Psychiatry, 13*(1), 16-22.
- Michael, S. R. (1996). Integrating chronic illness into one's life: A phenomenological inquiry. *Journal of Holistic Nursing, 14*(3), 251-267.
- Nankervis, J., Schofield, H., Herrman, H., & Bloch, S. (1997). Home-based assessment for family carers: A preventative strategy to identify and meet service needs. *International Journal of Geriatric Psychiatry, 12*(2), 193-201.
- Nygaard, L., & Borell, L. (1998). A life-world of altering meaning: Expressions of the illness experience of dementia in everyday life over 3 years. *Occupational Therapy Journal of Research, 18*(2), 109-136.
- Phinney, A. (1998). Living with dementia from the patient's perspective. *Journal of Gerontological Nursing, 24*(6), 8-15.

- Resau, L. S. (1995). Obtaining informed consent in Alzheimer's research. *Journal of Neuroscience Nursing*, 27(1), 57–60.
- Sachs, G. A., Stocking, C. B., Stern, R., Cox, D. M., Hougham, G., & Sachs, R. S. (1994). Ethical aspects of dementia research: Informed consent and proxy consent. *Clinical Research*, 42(3), 403–412.
- Schneider, J., Murray, J., Banerjee, S., & Mann, A. (1999). Eurocare: A cross-national study of co-resident spouse carers for people with Alzheimer's disease: I – Factors associated with carer burden. *International Journal of Geriatric Psychiatry*, 14(8), 651–661.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.
- Teng, E. L., & Chui, H. C. (1987). The Modified Mini-Mental State (3MS) examination. *Journal of Clinical Psychiatry*, 48, 314–318.
- Werezak, L. J. (2001). *Learning to live with early stage dementia*. Unpublished master's thesis, University of Saskatchewan, Saskatoon.
- Youngjohn, J. R., & Crook, T. H. III. (1996). Dementia. In L. L. Carstensen, B. A. Edelstein, & L. Dornbrand (Eds.), *The practical handbook of clinical gerontology* (pp. 244–246). Thousand Oaks, CA: Sage.

#### **Authors' Note**

The research for this paper was completed as part of the first author's master's thesis at the University of Saskatchewan.