



## Living with Dementia

### *From the patients perspective*

#### ABSTRACT

This study describes the illness experience of dementia from the patient's perspective. Five people with Alzheimer's disease and their spouses were interviewed and observed during home visits. Thematic analysis revealed two themes: being unsure and trying to be normal. Being unsure describes people's fluctuating experience of symptoms that leaves them feeling unsure of themselves in a world that is increasingly unfamiliar. Trying to be normal describes people's efforts to counter the impact of dementia to maintain continuity in their lives. These findings point to the importance of taking into account the patient's perspective to better understand the experience of living with dementia and develop improved treatment and care practices.

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Dementia is a chronic, progressively debilitating condition affecting large numbers of elderly people. Recent studies from Europe, North America and Asia have estimated a prevalence of at least 8% in those age 65 and older (Rockwood & Stadnyk 1994). Given the pressing concern of how to best care for those afflicted, the study of dementia (most often Alzheimer's disease) has gained a prominent place in the health care research arena. Literature on the biomedical nature of Alzheimer's disease is voluminous as scientists struggle to identify an underlying cause and find an effective treatment or cure. At the same time, there is a significant body of literature that has attempted to understand the disease by defining its clinical presentation. Researchers and clinicians have documented stages of decline, patterns of cognitive deterioration and behavioural symptoms (Overall, Scott, Rhoades & Lesser 1990; Reisberg, Ferris de Leon & Crook 1988; Taft & Cronin-Stubbs 1995).

More recently, research has been directed toward finding better ways of caring for people with dementia. This includes developing effective behaviour management interventions (Beck & Shue 1994; Maas & Buckwalter 1991; Teri 1994) discovering new pharmacologic treatments for the underlying disease and its symptoms (Whitehouse & Voci 1995), and understanding how to meet the needs of family caregivers (Given & Given 1991; Ory et al 1985). However, in all of this research the experiences of the people themselves have been largely overlooked (Cotrell & Shultz 1993).

## PURPOSE

There is a growing recognition that the social dimensions of dementia need to be better understood (Kitwood 1990;

Lyman 1989). This includes understanding the experience of living with dementia from the perspective of people with the diagnosis. A body of literature is evolving to address this issue by asking questions about people with Alzheimer's, their responses to the illness, their feelings, and the ways in which they cope with the disease (Bahro, Silbert & Sunderland 1995; Cohen, Kennedy & Eisdorfer 1984; Orona 1990). However, most of this work persists in adopting an outsider's perspective insofar as findings are based on the reports of caregivers or clinicians. While this approach may be unavoidable when the dementia has become very advanced, people with mild to moderate dementia are often able to talk about their experiences and express their feelings with clarity and insight. Patients' reports offer an important perspective which allows greater understanding of the experience of living with dementia.

A few studies have shown that with careful interviewing and supportive data from other sources, it is possible to give people with dementia the opportunity to speak for themselves (Burgener, Shimer & Murrell 1993; Gillies 1995; Sabat & Harre 1992).

This has important implications for clinical practice. For example, the efficacy of interventions could be assessed more completely by taking into account the patients' perspective on the care they have received (Goldsmith 1996). Furthermore, by taking account of the person living with the disease, such research carries the potential to humanize care. In considering the patient's perspective, nurses may be led to develop care practices that support the individuals' sense of self-worth and their capacity to cope with and find meaning in their day-to-day lives.

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Because little research has been done in this area, this qualitative descriptive study was developed to interview people with mild to moderate Alzheimer's disease. The purpose of this study is to gain greater understanding of the perspective of the person with dementia, to hear and try to understand their descriptions of their experiences living with Alzheimer's and what it means to them.

## RESEARCH QUESTIONS

In seeking to understand the experience of living with dementia from the perspective of people who have a diagnosis of Alzheimer's disease, this study asked three research questions:

1. How do people with early Alzheimer's disease experience and interpret symptoms?
2. What is the meaning of Alzheimer's disease for people who have been diagnosed with the disease?
3. What are their concerns in living with Alzheimer's disease?

## STUDY PARTICIPANTS

The study participants were a convenience sample of community dwelling older adults with a diagnosis of probably Alzheimer's disease who had previously taken part in an Alzheimer's research study at a university-affiliated clinic research centre. Permission was obtained from the centre director to contact people who had expressed interest in taking part in other research and who were known to be functioning highly enough to provide informed consent.

Informed consent was obtained from both the participants and their spouse or other family member. Although the sample size was small it was deemed sufficient for a design where extensive interview and observational data were collected over time, thus permitting in-depth analysis both within and across cases.

Participants included four women and one man. Their ages ranged from 75 to 89 years and all were in good physical health. Four of the participants lived in their own homes (three with a spouse), while the oldest participant was a widow who had been living for 5 years in a seniors' residence with daily assistance for meals, medications and bathing. On average, the individuals had been experiencing symptoms of dementia for 5 years and had been diagnosed 2.5 years prior to being interviewed. Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh 1975) scores fell within a narrow range (17 to 23 points), with a mean score of 19 out of a possible 30 points. Global Deterioration Scale (GDS) (Reisberg, Ferris de Leon & Crook 1988) scores fell between 3 and 5 on a 7-point scale (mean = 4). These findings are consistent with mild to moderate levels of dementia where people might be somewhat disoriented (especially to time), have short-term memory loss, and at the lower end of this range, be unable to live by themselves (Folstein et al., 1975; Reisberg et al. 1988). This level of dementia is being defined here as early Alzheimer's with the recognition that even within this stage, there is considerable variation in the individuals' cognitive capacity and the potential range of experiences they could be expected to have.

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## DATA COLLECTION

In an effort to enrich and confirm findings, data were obtained from several sources:

Interviews: each person with dementia was interviewed twice in their home over a 2-week period. These interviews were 45 to 60 minutes long and were audiotape recorded and transcribed verbatim.

- Spouse interviews: Three spouses were interviewed once for approximately 1.5 hours.
- Observation: Extensive field notes were written describing observations made during the home visits. As well, three participants and their families were observed for a total of 6 hours.

Quantitative measures: Two measurement scales were used to characterize the individuals' level of dementia. Cognitive functioning was evaluated using the MMSE (Folstein et al. 1975) and the stage of the dementia was evaluated by the Global Deterioration Scale (Reisberg et al. 1988).

## INTERVIEW FORMAT

The interviews were semi-structured, with the intent to create a comfortable conversational atmosphere (van Manen, 1990). In the first interview, participants were invited to talk about the regular routines of their day-to-day lives, including those things they particularly enjoyed and those they disliked. They were also asked to describe what it was like for them to have Alzheimer's in terms of what stood out for them and about changes they noticed and what those changes meant to them. Participants were asked to talk about their past in terms of what they had done and experienced in previous years. They also discussed their families and what their relationships were like with their spouses and children. The second interview followed the same format and provided the opportunity to review, clarify and expand on what had been discussed the previous time. The spouse interviews covered similar areas of discussion, with the spouse answering questions about what they thought their partner was experiencing, a kind of circular questioning (Wright & Leahey 1994).

## ANALYTIC METHOD

The findings of this study are based on the results of a thematic analysis, where the emphasis was on revealing the patterns and meanings of lived experience (van Manen 1990). Interviews and field notes were read in their entirety several times, with notes being made in the margins about issues and concerns the participants raised. These were formulated into more general themes, which were compared across the five cases of similarities and differences. As well as looking for themes across the entire text, each set of interviews and notes were summarized in a way that captured some of the important meanings in each person's experience. In this way, the analysis was a process of going back and forth between the specific and the general, of understanding the particular in the light of the universal (van Manen, 1990). This process was made more rigorous by including colleagues in repeated reviews of the raw data and critical discussions of the analyzed text.

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## FINDINGS

Analysis of data from five participants has revealed two main themes: being unsure and trying to be normal (Table). Being unsure captures something about the meaning of living with Alzheimer's disease. It describes how people's fluctuating experience of symptoms leaves them with a feeling of uncertainty. They are often unsure of themselves and are not fully at ease as they live their day-to-day lives in a world that is becoming increasingly unfamiliar. Trying to be normal is a prominent concern for those living with Alzheimer's disease. It describes people's active efforts to counter the impact of dementia to maintain continuity in their lives.

*Names have been changed to protect participants' anonymity.*

### Being Unsure

Being unsure is an experience wherein people can no longer take themselves for granted in how they are in the world. They experience symptoms of forgetfulness, language difficulties and disorientation that create gaps in the flow of their day-to-day lives. Moreover, gaps of unawareness occur when they do not recognize their symptoms. As a result, people find they cannot fully trust themselves anymore; they may be forgetting something important or embarrassing themselves unknowingly.

**Memory Loss.** All the participants spoke of their memory problems, although each was affected in different ways and to different extents. For some, their failing memory defined their experience. Mrs. Irving felt that her poor memory caused her to have trouble understanding what was happening around her. Indeed, she often looked perplexed and relied heavily on her friends to fill in the gaps, to tell her again their names or remind her of lunch time.

She explained: "I don't have the grasp as the way I had back then, and uh, on the whole I guess you might say I don't have the...what is that word now?... the ... I can't even tell it, tell, tell it to you.. I don't have the ability to grasp and understand things the way I did years ago. I don't remember. That's my whole problem, my memory."

Even those who felt their memory problems were mild still saw memory loss as a serious concern.

For example, Mr Larkin felt that his memory failed him very rarely, saying that "at least 90%, maybe 95%, of the time I'm in command of myself." In saying this, he implied the importance of his memory to his ability to feel confident and trusting in himself.

**Conversation Breakdown.** People also spoke of how they were less comfortable speaking with others. They found they had trouble following what was going on in a discussion or were less confident that they could find the right words to express their thoughts. Mrs Swenson spoke of sometimes "things coming out the wrong way." An excerpt from field notes describes her hesitant participation in a conversation with her and her husband.

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As I talked with him, Mrs Swenson sat a little behind us, listening intently and occasionally speaking up a word or two. Sometimes these comments made sense, but other times they were just a little “off line.” Mostly, she would repeat the last few words of someone’s sentence, or would nod her head knowingly, laughing when others laughed, etc. She was clearly following a lead as best she could.

**Disorientation.** People spoke of being disoriented, feeling unsure of the time or date, or worrying about getting lost or not knowing where they were. They could no longer take their world for granted. It had become unpredictable and unfamiliar terrain. For Mr. Larkin, his community for 40 years had become one of too many new buildings he does not recognize. He could not find his way around. He said “I do stupid things at times. I did one the other day. I just wasn’t thinking. I was heading for one place and ended up in another. If I’m out someplace, there have been some times when I’ve been concerned about how to get back to the house.”

Mrs Swenson saw her world as constantly changing. It had lost its continuity. She explained: “I try to go out and walk every day, just to see if things have changed that much. But they do. I can see the same things I’ve seen for years, and they’re different. Everything is different. I can’t explain it.”

Mrs. Irving, too, lives in a world where she does not feel fully at ease. Things aren’t always familiar. This was obvious in a field not excerpt describing the way she moved about the seniors’ residence:

Mrs Irving lives in room 327. She cannot tell anyone that, but her feet know the way there. She never makes a mistake, but she is not certain either. At every junction along the way, she pauses to consider her options. Left or right? She looks both directions before proceeding. She is only sure once the door is open, the lights are on, and she sees her own furniture. Only then does she relax and smile, and invite her visitor in.

**Fluctuating Awareness.** Awareness of symptoms does not fail all at once; rather, it fluctuates over time. Several spoke of having a heightened awareness of their memory loss, but at the same time they realized that there were occasions when their spouse was aware of lapses when they were not. Mrs. Kelly said that her partner told her she had much more trouble making up her mind than she had ever had before. She was “I was not particularly aware of this, that I’m indecisive.” Mr. Larkin described how his wife was much more aware that he was of his lapses in memory.

People are left then with the uneasy feeling that they cannot always be sure of their own behaviour. Two participants described it as not being in command or in control. Also, they may recognize the possibility of there being a difference between their experiences and what others observe. Such a realisation led Mr. Larkin to question the certainty of his diagnosis. He pondered:

I don’t know what constitutes Alzheimer’s, that is in the sense that it’s obvious to other people, or obvious to yourself?

Mrs. Crenshaw, on the other hand, questioned herself, saying that what was most difficult was “not feeling sure of myself.” Mr. Crenshaw described this further, telling how invariably after returning from an evening

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out with friends, his wife would turn to him and ask, “Was I all right tonight? Did I say anything I shouldn’t have?”

## Trying to be Normal

The main concern for people living with Alzheimer’s was how they could continue to be normal, where being normal meant living as they had before being diagnosed with Alzheimer’s. While everyone stated clearly that they did not really feel different, they knew that their lives were changing. Their world was becoming more narrow as they socialised less and did fewer activities.

Their relationships were changing as they found they had to rely on and trust others for help and support. Trying to be normal was an effort to diminish the impact of those changes. They did this in a number of ways.

**Self-monitoring.** People spoke of watching over and monitoring their failing memory. Mrs. Kelly spoke of it as having a “heightened awareness”. Mr. Larkin explained how he did “memory work” paying careful attention to what he did and then going over it later to be sure he had not forgotten anything.

**Keeping an Active Mind.** Everyone made time for activities that would help them keep their minds active. They saw this as a way of staying on top of a disease that threatened to take away their thinking abilities. Mrs. Swenson spent much of her day reading, so she could “keep her brain active”. She saw this as exercise for her damaged brain. She explained:

“When I got Alzheimer’s it was very difficult at first, but now I can sit back and I do a lot of reading, so that things don’t come out all garbled. And they will if you don’t”.

To her, reading was preventative, guarding against further breakdown. Three participants also explained that they kept their minds active by working every day on crossword puzzles.

**Staying Engaged.** Continuing to stay engaged in the world was an important way for people to feel that they were leading normal, meaningful lives. Mrs. Kelly went out of her way to maintain relationships with her family and friends. She also attended many concerts and travelled extensively, wanting to do everything she could while she was still able. Mrs Crenshaw, too, was able to keep up with all her friends and family, to remember their names, and to enjoy time spent with them.

This was important to her in every effort to “be normal”. Even Mr. Larkin, who had never been a very gregarious person, kept engaged through his books, enjoying reading about other places and times.

Mrs. Irving was the most impaired participant, having had symptoms of dementia for 8 years. Her family was mostly gone, and staying engaged was a struggle for her. She lamented that her poor memory made it diffi-

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cult for her to contribute in any way.” She felt that she was no longer productive and, as a result, was no longer an interesting person. However, she tried to watch interesting television programmes and she read books. As well, she met every day with women who liked to sit together and “be sociable”. All these were ways she found to “stay interested.”

**Downplaying.** Three of the participants downplayed the place of “disease” in their experience, questioned the diagnoses and interpreted their experiences in the context of themselves growing older. Mrs. Crenshaw compared herself to others with severe Alzheimer’s who did not recognise family members and close friends and she wondered if maybe she did not really have the disease after all. Mr. Larkin said he was “resisting being classified” because Alzheimer’s was “a crutch” used to explain any behaviour at all. He wondered if his forgetfulness was just normal ageing because a “disease has little microbes at work, whereas this is just a wearing out or a breaking off of a stable situation.” Mrs. Swenson felt that Alzheimer’s was God’s way of “making her slow down.” She has fulfilled her life’s purpose in raising her children well, and she had Alzheimer’s because her father had it. She felt it was her destiny.

Two participants did not overtly downplay the disease. Rather, they emphasized how catastrophic it was for them. It is noteworthy that these two people were not at a similar point in the trajectory of their experience. One had been very recently diagnosed and was the least impaired, and the other had been demented for 8 years and was the most impaired of all the participants.

## DISCUSSION

The purpose of this qualitative study was to gain a better understanding of the experiences of people who have been diagnosed with early dementia – how they experience symptoms, the meaning of the illness and their concerns. There were important methodological issues to consider in this project. An obvious question was to what extent interviews with cognitively impaired older adults could be expected to produce valid data that could be meaningfully analyzed. This study provides some answers to this question. First, this study demonstrated that people with early Alzheimer’s are able to participate actively in interviews up to 1 hour in length. Although these were not always easy interviews, this study relied on the words of the participants themselves as much as possible. Sometimes a single interview did not provide sufficient data for analysis. Therefore, follow-up interviews and other sources of data were necessary to enrich and validate findings.

The follow-up interviews provided an opportunity to confirm and clarify statements made by participants in the first interview. In practice, this was sometimes difficult to do. When asked about something they said on the previous visit, participants might admit that they could not remember and were not sure what they meant at the time. For this reason, alternate sources of data were used to support or refute the analysis. The spouse interviews were used to clarify and corroborate the findings from the participant interviews. The use of circular questions proved to be particularly helpful. For example, when a husband described the changes he observed in his wife, he was asked if he thought she saw the same kinds of things, and if not, what did he think she experienced? These were difficult questions, but people gave rich insightful answers that informed the ongoing analysis. The use of observation was also a valuable contribution to the study. Not only did it help confirm the analysis of the interview texts, but it provided a way to garner a sense of the rhythm of daily life and how people interacted with each other and their environment.

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Two main themes emerged from the data to reflect aspects of the experiences of people who have early Alzheimer's disease. Being unsure reflects how people's fluctuating awareness of symptoms causes them to be unsure of themselves and uncertain in their world. Trying to be normal reflects people's active efforts to continue living their lives as they always have.

These findings inform current understandings of the patient's experience of dementia. Patient reports of dementia symptoms have often been dismissed as unreliable (Geldmacher & Whitehouse, 1996). It is often assumed that those with Alzheimer's disease are unaware of their deficits and that the ability to accurately self-reflect fails all at once early in the course of the disease. Current research suggests that 20 to 25% of people with mild to moderate dementia either deny or are not aware of their memory deficits (Lopez, Becker, Somrak, Dew & DeKosky, 1994; Migliorelli et al., 1995; Sevush & Leve, 1993). These studies have been based on the view that unawareness or denial is itself a symptom of dementia and that it is irreversible. This view is reflected in a methodology that relies on brief assessments carried out at a single point in time.

In contrast, by incorporating more in-depth interviews conducted over several occasions, the current study found that people with Alzheimer's disease were indeed able to report their symptoms, often in rich descriptive terms. Moreover, the symptoms they described were consistent with what is known about the early course of Alzheimer's. However, it appeared that their awareness of these symptoms fluctuated over time. At times, people were very conscious of their forgetfulness and disorientation, while at other times their failures went unnoticed until someone else pointed them out. These findings suggest that awareness in early Alzheimer's is not a unitary phenomenon that breaks down all at once. It seems to come and go, fluctuating over time and across realms.

Fluctuating awareness may be fundamental to the experience of living with early Alzheimer's. It suggests the possibility that people can be unaware of their deficits at the same time they are conscious of their lives changing, and they are not fully sure of themselves any longer. They can describe their symptoms but, at the same time, recognize that they are not always aware when they occur. Their experiences of symptoms may be very different from what others observe. Moreover, it may be that experience of symptoms is not the most important issue for people. Indeed, participants spent more time discussing the broader experience of living with Alzheimer's in terms of its meaning to them and their concerns. They spoke of the difficulty of being unsure of themselves and trying to diminish the impact of the symptoms to maintain a sense of continuity and normality in their lives.

## NURSING IMPLICATIONS

These findings are potentially important for clinical practice. Jones (1993) found that nursing home staff limited their interactions with demented patients largely because they could not make sense of the patients' behaviour or understand their needs. Learning more about the patient's experience of dementia may be an important way for nurses to foster their relationships with these people and provide care that is more responsive to the needs of the individual. Findings from this study suggest it is important for nurses to assess not only the person's cognitive and functional status but also what they understand about their symptoms and the coping strategies they use in their day-to-day life.

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The question of fluctuating awareness also has important bearing on nursing practice. Care practices and assessment methods may need to be uniquely tailored, depending on the extent to which the person is aware of particular symptoms. For example, daily written reminders to take medication may be an effective intervention for someone who is always aware of their memory loss but will serve little purpose for someone who is usually unaware of their deficit. Further research is necessary to address these kinds of questions.

## CONCLUSION

These findings are based on a small number of people who were observed and interviewed on two or three occasions. Further study of more families over a longer period of time will enrich and clarify findings. Nevertheless, the themes point to the potential richness of the subject area.

Providing direction for both clinical practice and future research.

The ongoing challenge in this work will be to combine different sources of evidence – both interviews and observation – in a way that does not remove the research and clinical gaze from people with dementia nor fail to hear their voices.

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