

DEMENTIA ADVANCES: PROVIDING CARE  
FOR PERSONS WITH LATE-STAGE DEMENTIA

---

*Giving Voice to  
Expressions of Quality  
of Life for Persons  
Living With Dementia  
Through Story,  
Music, and Art*

BY CHRISTINE JONAS-SIMPSON, PhD, RN, AND GAIL J. MITCHELL, PhD, RN

*The purpose of this qualitative descriptive study was to give voice to expressions of quality of life for persons who live with dementia and who reside in long-term care, primarily on locked cognitive support units. With the assistance of music and art therapists, mediums of music and art were offered as a way for participants to further describe their quality of life. Eight key messages emerged from the descriptions about what life was like for the 17 participants: feeling content, importance of relationships, choosing an attitude for living on, feeling worthy, wishes for freedom amid restrictions,*

living with loss, struggles with thinking and communicating, and persisting with life patterns. *The open-ended questions used in this study may be considered for future research as well as in practice with persons who live with dementia even in the latter part of their journey. Ultimately, it is hoped that the findings described here will enhance understanding of what life is like for persons living with dementia, in order to diminish any unnecessary suffering that can emerge with lack of understanding.*

**Key words:** communication, listening, living with dementia, meaning, qualitative research, quality of life, understanding

The call for hearing the voices of persons with dementia<sup>1-3</sup> has been heard as there is a growing body of knowledge that presents Alzheimer's disease and related dementias, herein referred to as dementia, from the perspective of persons living with dementia.<sup>4-9</sup> Harris<sup>6</sup> stated that this decade must be a time of learning more about the lived experience of dementia. Several researchers and writers who present the perspectives of persons with dementia contribute to what Tom Kitwood began—seeing the person *first*—beyond their diagnosis. Many persons who live with dementia are propelling this shift in discourse in various books and articles.<sup>10-17</sup> These authors have written about their lived experiences, including the losses and gains, as well as the joys and sorrows of living with dementia. While the voices of persons in the early to middle stages of dementia are emerging, the voices of persons who are experiencing the latter part of the journey must also be heard, especially those who reside in long-term care on locked cognitive support units. Numerous authors have noted that even though persons who have moderate or severe impairment and who *seem* to be incoherent and unable to communicate, there are ways to connect and understand their meanings and messages.<sup>4,18-21</sup> Persons with dementia wish to be listened to and understood. In the course of one research study, it was reported that after viewing long hours of videotape it was evident that persons living with dementia, whose caregivers believed to be unable to communicate, did in fact try to give messages and seek understanding, but their messages went unnoticed or were not understood.<sup>22</sup> Consistent with our experience, it has been reported that when researchers and practitioners listen with the intent to understand persons with moderate to severe impairment, clarity of thought and meaning can emerge amid the bewilderment.<sup>4,18,23,24</sup> This supports

the understanding that persons with dementia can convey meaning and desires amid the swirling thoughts that sometimes emerge in their patterns of speaking and being silent. Attending to the meaning and desires of others conveys respect for the dignity inherent in every human being.

#### RESEARCH FROM THE PERSPECTIVES OF PERSONS LIVING WITH DEMENTIA

Research exploring the experience of living with dementia from the perspective of persons living with dementia has focused on different aspects, such as, quality of life, feeling confined, successful coping and adaptation, lessons learned, and awareness of diagnosis. Findings from these studies contribute understandings of living with dementia from the perspective of persons such as feeling *unsure* and *trying to be normal*<sup>25</sup> or feelings about *losses* and *attempts to manage losses*.<sup>26</sup> Findings about coping, adaptation, and lessons learned generated themes of *acceptance and ownership, disclosure, positive attitude and self-acceptance, role relinquishment and replacement, innovative techniques, the use of technology, fluidity (going with the flow), connection with past activities, altruism, taking a proactive stance, anticipatory adaptation, holistic practice, and spirituality*.<sup>27</sup> Researchers concluded that the range of positive coping behaviors provided persons with early-stage Alzheimer's disease with "a sense of control over a devastating illness, hope, and the will to continue the struggle of living."<sup>27(p177)</sup> Symptom awareness was also explored with 5 women and 4 men living with mild to moderate dementia.<sup>28</sup> These researchers reported on 3 meaningful narratives that emerged from the data. The narrative of awareness was *everything works more slowly*; the narrative of unawareness was stated as, *it's just old age*

and, the third narrative of mixed awareness was *it does not stick in the brain*. Researchers concluded that symptom awareness varied considerably with participants with mild to moderate dementia and that the persons awareness would be important to evaluate in clinical practice to "better understand and respond to the needs and perspectives of their patients with dementia."<sup>28(p10)</sup> A main theme from another study described dementia as an *age-related construct* whereby memory loss was viewed by participants as a normal part of aging based on interviews with persons with dementia living in the community.<sup>29</sup>

Recent research<sup>30</sup> is contributing to the understanding of the unique experiences of persons who live with early-onset dementia, that is, persons diagnosed with dementia who are younger than 65. Based on data from interviews with younger people diagnosed with dementia in the United States and families of younger people with dementia in the United Kingdom, the following themes emerged: *difficulties in obtaining a diagnosis; issues of self-hood and self-esteem, changing relationships within the family structure, awareness of changes in self; workforce and retirement/financial issues; feelings of extreme social isolation and exclusion; off-time dependency; and lack of meaningful occupation*.

A few researchers have studied the lived experience of quality of life for persons living with dementia with moderate to severe impairment from a human becoming perspective.<sup>23,31,32</sup> Descriptions from participants in these studies related to daily struggles, triumphs, hopes, dreams, and ways of living on. Participants spoke about the importance of family and caring providers who helped them stay connected and enabled them to attend to daily matters of personal care and living with others. Paradoxically, participants also spoke about the restrictions, daily struggles, and concerns about not wanting to rely on others and yet having to have help and assistance. One human becoming study specifically explored the experience of *feeling confined* for persons with dementia who were residing on a locked unit.<sup>32</sup> Seven residents from the locked long-term care units of a large urban teaching hospital described feeling confined as experiencing captivity that was *bewildering and disquieting*. These same residents also reported *seeking respite* in different ways such as playing the harmonica or doing something to take their thoughts off of not being able to leave the unit. The study reported here on giving voice to expressions of quality of life contributes further to the knowledge of what it is like to live with dementia from the perspective of persons living with dementia through the lens of the human becoming theory.<sup>33</sup>

## RESEARCHERS' CONCEPTUAL FRAMEWORK

The human becoming theory<sup>33</sup> was the chosen conceptual framework for this research. This theory focuses on human lived experience from the perspectives of the persons living the life. There are 3 themes—*meaning, rhythmicity, and cotranscendence*. From the human becoming perspective, human beings give meaning to life experiences and live the rhythms of life in paradoxical ways such as experiencing joy-sorrow, hope-no hope, restriction-freedom, while at the same time thinking about tomorrow and moving beyond to new ways of being.<sup>33</sup> Quality of life, from the human becoming perspective, is what life is like for people. It is the "*whatness* . . . or the *essence* of life."<sup>34(p17)</sup> Parse<sup>34</sup> proposes that quality of life is the day-to-day flow of meanings and values that people give to their situations. The goal of research guided by the human becoming theory is an enhanced understanding of lived experience. Researchers contend that new understandings can change perspectives, thoughts, attitudes, and actions. Thus, if understanding quality of life from the perspective of people living with dementia can be enhanced, there is hope for shifts in the actions, images, and words used by healthcare professionals who care for persons living with dementia, their families, and the public.

## RESEARCH METHOD AND RESEARCH QUESTION

The qualitative descriptive method as described by Parse<sup>35</sup> was used to guide this research and answer the research question: *What is life like for persons diagnosed with dementia who reside primarily on locked cognitive support units?* Inspired by artwork created by persons living with dementia found in calendars, on websites, and on exhibit in the long-term care setting where this study took place, researchers invited art therapists and music therapists to be involved in the study. The guiding framework, human becoming, supports the integration of art in the research process and thus we asked persons with dementia to share their expressions of quality of life through story, music and art.

## Research objectives and interview questions

The research objectives and the interview questions flow directly from the theoretical themes of *meaning, rhythmicity, and cotranscendence* as follows:

**Objective 1: To describe the meaning of quality of life**

- Please talk to me about what life is like for you
- How would that look on paper? Or, how would that sound on the drum or chime?
- What is most important to you?
- What enhances the quality of your life? What makes it better?
- What diminishes your quality of life? What makes life more difficult?

**Objective 2: To describe patterns of relating connected with quality of life**

- Who is most important to you?
- What do you like to do day-to-day?

**Objective 3: To describe what is hoped for with regard to quality of life**

- What are your hopes and dreams?
- What are your concerns?

**Participants and setting**

Once this study received approval from the research ethics board, participants were recruited through music and art therapists in a long-term care facility, with approximately 550 residents, located in a large urban area of Canada. Music and art therapists requested permission of the family members of the potential participants for a researcher to call them in order to discuss the study. A researcher contacted family members who were substitute decision makers of potential participants. Once questions were answered to the satisfaction of family members, informed consent was given for all participants. A time for the interview was set within the music therapy or art therapy session, and assent was sought and received from all participants. Several times throughout the interview, the researcher sought permission to continue with another question in order to provide real opportunities to exit the interview.

There were 17 participants, 15 men and 2 women who participated in this current study. Sixteen of the participants lived on locked cognitive support units and one participant lived on a physical support unit. All participants were diagnosed with a type of dementia such as Alzheimer's disease, vascular dementia, multi-infarct

dementia, frontal lobe dementia and Parkinson's dementia. Six participants were diagnosed with moderate impairment, 6 with severe impairment, 3 with moderate/severe impairment and 2 with mild impairment.

**DATA GATHERING**

Researcher-participant interviews were conducted with the participant and either a music therapist or an art therapist. The interview began with, *Please talk to me about what life is like for you.* With the assistance of the music and art therapists, music or art were used as mediums for participants to further describe their life if they wished. For instance, when a participant said that he/she felt, "happy," a researcher asked how "happy" would look on paper or what color would "happy" be or how it would sound in music. All participants used story to express their quality of life, and the interviews ranged in length from 15 minutes to 1 hour. Two participants chose to express themselves through the use of art. One man created a painting while another man drew two lines on paper, one in pink and one in grey, to describe his love for his wife (pink) and the importance of freedom (grey line). He said the pink represented his love for his wife as this was the color of the dress she wore the day he met her and fell in love, and the grey represented freedom to him as he said the animals in the woods who are free are grey. Most of the other participants used music to further express their quality of life and how they felt by using an instrument that was provided to them such as a drum, chime, or keyboard. Some sang a song or hymn with the music therapist and researcher that reflected their quality of life. One man who lived with moderate/severe impairment expressed what life was like for him on the chimes. When his wife watched the videotape with the researcher we were surprised to learn that the melody he played was his favorite piece of music.

One group of 5 participants was interviewed as a group during their song-writing session with their music therapist using the same questions as in the one-to-one interviews. The session began with a song and then the researcher started to ask questions about the participants' quality of life. Many times the group broke into song during the interview singing, "there are songs that make us happy, there are songs that make us blue," or "I want to be happy and I won't be happy, till I make you happy too!" Based on the transcript from the group interview, a song was created about quality of life.

## DATA ANALYSIS

The data analysis processes outlined by Parse<sup>35</sup> for the qualitative descriptive method was used. This involved intense reading and re-reading of the transcripts to extract and synthesize the core ideas from each of the transcripts and then across transcripts. Researchers identified themes that were common, but not universal, across all the transcripts. Every participant spoke about quality of life; however, some participants spoke minimally compared to others. It was decided that all transcripts that described quality of life would be included—even those with minimal description in order to maximize description of what life is like for persons living with dementia. Thus, the researchers decided to draw upon the key messages that arose in the transcripts from the 17 participants.

## FINDINGS

Eight key messages emerged from the 17 descriptions of quality of life that give voice to experiences of quality of life for persons who live with dementia. The first 2 key messages were in all of the participant interviews while the 3rd key message was in most (12/17) and the last 5 were discussed by half to a few of the participants. The key messages are as follows:

### Feeling content

This key message was found in all of the participants' transcripts. Participants spoke of feeling satisfied, at ease, comfortable, full, happy, calm, content, pleasure, cheerful, relieved, relaxed, and quiet. One participant with severe impairment created a painting of a cabin on the Arabian sea and sand where he described his quality of life as the past and present all at once. In describing the grey and blue brush strokes he said, "veil in the sky . . . peace, peace, and quiet . . . soldiers sleeping . . . waves on the ocean." This quiet contentment is felt when viewing his painting. Another participant described how he was content since he did not experience the change he expected to experience, "the biggest change is that these changes are not as big as I expected it originally to be . . . Oh, my life is about as good as I ever enjoyed." Another participant said, "there's nothing important. I'm just living from day-to-day and I'm quite happy. I seem to have good health, I have a good appetite, nice friends and that, so I'm quite satisfied and nothing else." One participant spoke of the peace he feels, "I like to spend my days

quietly. Not too much pressure, not too much tension . . . I like being at ease with people." When asked, "What helps you to be at ease with people?" this man answered, "When they [the staff] are relaxed with me. I don't find them taxing." Another man simply said, "Life for me is pleasant." For one participant feelings of contentment emerged as he showed a battleship he created through sculpture during one of his art therapy sessions. He said seeing this recreation of his battleship "brings back memories," and for him, this felt "good."

### Importance of relationships

Relationships with family and friends are important and essential to quality of life. Participants described the importance of love, caring, listening, giving, sharing, understanding, having others' attention, having a laugh, stirring things up, a good talk, singing together, community, church, and meeting new people. One man said that when someone listens and understands him, "it is a great and wonderful feeling. It makes you, ah, makes you feel that life is alright." Another man confirmed the importance of family and being with others, which broke the dullness or boredom in a day,

I like people . . . I have my family and ah, what else do I need? I'm ah, I'm 89 or 90 years, something in that ah, age group. So, I'm still going, so I'm not complaining . . . I am alone a lot. It's like this is a break for me, somebody come and get me, we're gonna do this and that, perfect. Well I am not hard to please. I'm ah, it interests if you know people pay attention to you . . . to stir things up a bit and enjoy a laugh, and like the people that you're working with. It's a change that we need. We can't sit around all the—all the time.

Another participant said, "My memory on names is zero, but not the faces and the meetings . . . I like that. It's another world for me." One participant spoke of the importance of people in his life, he said, "these people who I consider important . . . ahm, helped to mold me . . . they have inspired me with confidence." One participant spoke of the importance of a group of people he enjoyed, "I loved to sing and I enjoyed the people that were around me, men and women, and I enjoyed all those people and I enjoyed their company. And that makes life. You get the most out of it—something like that that makes your life so happy."

### Choosing an attitude for living on

Many participants described choosing an attitude to live by, be it choosing to keep going, seeing the best in things, or by being resigned to things, or by letting things go so you can get by day by day. Some described attitudes using the following words and phrases: "look on the positive side of life," "making the most," "doing things that keep you going," "living day-to-day," "not weeping my life away," "becoming used to things," "take life as it comes," "getting along," "what will be will be," "making the best of a bad situation," "having enough money to get by," "letting things go," "forgiving," and "learning." Participants described how they viewed life. One man said, "there is a lot of give and take in this world. And if you put them together, you have a good life." Another said, "You've got to make the best of it." And one man offered, "life cannot be a bed of roses but you can make it pretty good if you think the right way." One participant who spoke a few words said, "it [life] is nice, yes it is now. To give you the now I don't think is not as nice . . . I get along myself. It is good." Another participant spoke of what he hoped for: "I'm hoping that ah, my life will be made richer. That the people I meet with contribute to my wholesome life." And one other said he wanted to "learn to play the guitar." Participants who created the song of quality of life stated the following, "a positive attitude is important," "a forgiving nature is important . . . a forgiving nature goes a long way to bring happiness," "[Life is] beautiful, beautiful. You just got to live it. Life is what you make it!"

### Feeling worthy

Participants described the importance of feeling wanted, feeling worthy, contributing to the world and others, inspiring others, believing in yourself, and giving to others. One participant spoke of the importance of respecting others as a way of getting along. He said it was important, "To get to know and understand the people here I'm with. Don't say, 'oh, he's a this or he's a that' . . . I figure people are all the same when they come on this earth. I don't know about that, but don't think of yourself as who you are, think of the person you are . . . who you are because they have a life to live too." Another participant spoke of giving to others as a way of feeling worthy which links to feeling content, "giving makes you happy, even if it is only amusing them. Helping other people makes you happy." One participant expressed the importance of feeling worthy, "They treat me pretty well

here . . . I'm made to feel that I am needed. I'm made to feel that I am working with people who are, who are appreciating . . . my contribution to their, to their, their life." Another stated that it is important to, "believe in yourself."

### Living with loss

Participants spoke of living with the losses in their life. Losses comprised of siblings, parents, spouses, comrades in the war, homes, another day of life, time, abilities, energy, occupation, and meaningful work. Many times the losses were described in the present moment as if they just occurred and then intermingled with the past tense of the experience. Participants described their life stories with a fluidity between past and present and thus feeling and revisiting the grief and loss of a brother, mother or father very deeply in the moment. Interestingly most of the losses described were of the participants' first family members with their parents and siblings. One participant also described the loss of time, she said that, "time is most important; it is just slipping away so we have to keep up with it."

### Wishes for freedom amid the frustrations with restrictions

Some participants described the importance of being free and others wished to be free—to move around, to walk, to be outdoors, to say what you want. They identified living with opportunities amid the restrictions that come with the routines and safety measures of institutional life. One participant exclaimed that he went to war to free Canada and now he is locked up in Canada. He described the importance of freedom to him, "The most important thing is—I want to be free. I was never tied up and I hate people who lock me up . . . I lose a day every day that I am held in here; I lose a day of my life . . . I want freedom." This same participant described how frustrated he was being expected to go to bed at seven o'clock, "now imagine, a soldier going to bed at 7 o'clock." One participant said his life was more free. When asked by a researcher how it was more free he said, "because when you go into something, you think different to anything you've done in your life. It takes more getting used to." Another participant stated, "I love being outside . . . because I feel different, I feel free . . . 'course inside you got to make the best of it." The participant who created the painting of the Arabian sea and sand requested pink paint, which he brushed across the

middle of his painting. When asked what the pink color meant he said, "opportunity."

### Struggles with thinking and communicating

Some participants described having trouble with memory, and with getting their points across. One participant said, "My memory on names is zero, but not the faces and the meetings . . . I like that. It's another world for me." Another participant prefaced his answer to one of the research questions by saying, "I would say, just from what I can get together, and there's a coconut up there," as he thumped his head with his fist and laughed.

### Persisting life patterns

Some participants spoke of how continuing with certain life patterns such as walking every day, singing, playing the piano, and going to church, enhanced their quality of life. One participant said, "walking is a big plus in my life, because if I'm not satisfied, nothing to do with something, I just dress up and go for a walk." Another participant described how he loved to hear hymns when he was younger and how he still loved to sing hymns. After the interview the participant, the researcher, and the music therapist sang a hymn together.

### Song of quality of life

The following song was created out of the transcript from the song-writing group by the music therapist. This song, which captures the key messages, is sung to the tune of *Side by Side*.

#### *Song of quality of life: Happiness*

vs.1 When asked, "what is life like for us now,"  
We enjoy life and make it the best we can,  
And happiness is,  
Being with others,  
Side by side.

vs.2 The most important things for us, now  
Include some of life's simple pleasures—  
Whether singing a song,  
Having a good pair of shoes on,  
Or sitting in a comfortable chair.

Chorus:  
For us, time is important,  
And life is important, too.  
We enjoy doing things for others—  
While valuing ourselves too.

vs.3 As for any of our hopes and dreams,  
Money sure can help with these things,  
We take life one day at a time—  
Make the most of what we've got—  
Keep smiling and be happy.

When the group heard and sang their song, participants recognized their words. One participant said, "those are my shoes." Others said it was wonderful and the group decided to name their song *Happiness*. One participant stated, "It is good to sing about happiness. Songs help remind me of my blessings." When asked what it was like to be involved in this study, this same participant said she liked participating and added, "I have learned something more about myself."

### DISCUSSION

What brings quality to your life? Consider your answer to this question and record your thoughts on a piece of paper. Now consider your answer in the light of our findings. In creating a research-based drama about living with dementia based on this study and others by the researchers, playwright Vrenia Ivonoffski, asked the actors and researchers this question. Persons described the following as bringing quality to their lives: time with children or grandchildren, loving relationships, a sunset, listening to music while sipping a glass of wine, watching the sunset, gardening, biting into a ripe sweet tomato, reading, and walking, as examples. The playwright then asked us, "What of these things could we *not* do if we lived with dementia?" Not one thing! We realized *how* quality of life was possible when living with dementia after experiencing this exercise. This discovery was particularly important to one of the actors whose mother lived and died with dementia and she could not imagine how she could have had any quality of life until that moment. To truly understand this possibility will better help understand our findings.

Key findings from this study are evident in some of the literature to date, however, the predominate theme of *feeling content* is not often described. The finding of contentment was reported in two studies exploring quality of life for persons living with dementia<sup>23,31,36</sup> In Parse's<sup>23</sup> study, contentment was described as being experienced by persons living with dementia amid the tedium of the day-to-day. Having the ability to experience joy and peace amid realities of loss and sorrow, restrictions and freedoms that frustrate and liberate were also described by Mitchell<sup>36</sup> and in Mitchell and Kolodny's<sup>31</sup> research findings. Similarly

the finding regarding the *importance of relationships* emerged in Parse<sup>23</sup> and Mitchell and Kolodny's<sup>31</sup> findings. Mitchell and Kolodny<sup>31</sup> described the connection with friends and family as "affirming continuity of life and sustaining a sense of connectedness with the world."<sup>(p10)</sup> In this study<sup>31</sup> the importance of the relationship with staff, as well as family and friends, was described as it was by some of the participants in this current study. Parse<sup>23</sup> also found that participants described the desire for *cherished intimacies* with others. Our key findings, *choosing an attitude for living on and feeling worthy*, were similar to Harris and Durkin's<sup>27</sup> finding that a *positive attitude and self-acceptance* was important to enabling persons with dementia to continue on. The notion of *choosing an attitude for living on* may also be linked with persons who were confined and who chose to *seek respite* to shift their thoughts from being confined.<sup>32</sup> *Living with loss* was spoken about by a few participants in this study, however, it was the predominate theme in Oswald et al's<sup>26</sup> study. *Wishes for freedom amid restriction* was also evident in 3 studies.<sup>23,32,31</sup> The key finding, *struggles with thinking and communicating* was evident in the findings of Phinney et al<sup>28</sup> for those who were considered to have mixed awareness of their dementia, which was described as, "it doesn't stick in the brain." Last, the finding, *persisting with life patterns* was evident in the finding that persons with dementia experienced *trying to be normal*.<sup>25</sup>

#### IMPLICATIONS FOR PRACTICE AND RESEARCH

1. Listen to persons with dementia with the intent to understand even when you do not understand.
2. Believe that persons with dementia can express their meanings, concerns, and wishes through their movements—being still, speaking, and being silent.
3. Ask persons with dementia about their life, their meanings, concerns, and wishes.
  - What is life like for you now?
  - What is most important to you?
  - Who is most important to you?
  - What does (person or thing, event, life situation) mean to you?
  - What do you like doing day-to-day?
  - What are your concerns?
  - What are your hopes and dreams?

More studies exploring the perspectives of persons living with dementia are required to better understand

their lived experiences as well as to better understand dementia itself. Studies in the community, long-term care facilities, and on locked units are required to continue to give voice to the persons living the life. Although our interview questions could be used in future research, these questions could also be used in health-care practices. Beliefs that persons living with dementia, with moderate to severe impairment cannot answer questions about their life have been challenged by persons in this study as well as other studies and healthcare professionals practices.<sup>9,21,23,31,36-38</sup> While it may be difficult to recall what was eaten at breakfast or what medications were taken and when, questions about life, and how it is experienced, the concerns that people have, their joys and sorrows can be talked about. One woman with dementia explained that she may not remember the details of a movie she saw or a walk in the park, but she remembers the feelings and this is what she wants her family and friends to ask her about, not recalling the details.

Just reading and reflecting on many of the inspirational quotes from the research participants' voices alone can change attitudes about persons living with dementia, what it means to be human and about the meaning of life. These findings contribute to seeing persons with dementia, beyond the disease. New understandings can change or affirm beliefs, thoughts, and actions toward persons living with dementia and eliminate any unnecessary suffering that comes with the lack of understanding. Ultimately, what becomes possible is enhanced quality of care and thus quality of life experienced by persons with dementia and their families.

**Christine Jonas-Simpson, PhD, RN**, is a nurse researcher, and the Director of Nursing Research at Sunnybrook and Women's College Health Sciences Centre in Toronto, Ontario, Canada.

**Gail J. Mitchell, PhD, RN**, is an assistant professor at York University, Toronto, Canada.

This study was funded by the Collaborative Research Program: Rehabilitation and Long-Term Care, Toronto, Canada. The researchers gratefully acknowledge the music and art therapists who assisted with this study.

Address correspondence to: Christine Jonas-Simpson, PhD, RN, Sunnybrook and Women's College Health Sciences Centre, Toronto, Ontario, Canada. E-mail: christine.jonas-simpson@sw.ca

## REFERENCES

1. Kitwood T. Discover the person, not the disease. *J Dement Care*. 1993;1:1.
2. Kitwood T. *Dementia Reconsidered: The Person Comes First*. Philadelphia: Open University Press; 1997.
3. Cottrell V, R Schulz. The perspective of the patient with AD: A neglected dimension of dementia research. *The Gerontologist*. 1993;33(2):205-211.
4. Goldsmith M. *Hearing The Voice of People With Dementia: Opportunities and Obstacles*. London: Jessica Kingsley Publishers; 1996.
5. Gwyther LP. The perspective of the person with Alzheimer's disease: Which outcomes matter in early to middle stages of dementia? *Alzheimer Dis Assoc Disord*. 1997;11:18-24.
6. Harris PB. *The Person With Alzheimer Disease: Pathways to Understanding the Experience*. Baltimore, MD: Johns Hopkins University Press; 2002.
7. Keane WL. The patient's perspective: the Alzheimer's Association. *Alzheimer Dis Assoc Disord*. 1994;8:151-155.
8. Lyman KA. Living with Alzheimer's disease: The creation of meaning among persons with dementia. *J Clin Ethics*. 1998;9:49-57.
9. Sabat SR. Voices of Alzheimer's disease sufferers: a call for treatment based on personhood. *J Clin Ethics*. 1998;9:35-48.
10. Boden CA. *Who Will I Be When I Die*. Pymble, Australia: HarperCollins Publishers; 1998.
11. Friedell M. Dementia survival: A new vision. *Alzheimer Care Q*. 2003;4(2):79-84.
12. Lee J. *Just Love Me: A Life Turned Upside-Down by Alzheimer's*. West Lafayette: Purdue University Press; 2003.
13. McGowan DE. *Living in the Labyrinth*. San Francisco: Elder Books; 1993.
14. Raushi T. *A View From Within: Living with Early Onset Alzheimer's*. New York: Northeastern New York Chapter Alzheimer's Association; 2000.
15. Rose L. *Larry's Way: Another Look at Alzheimer's from the Inside*. iUniverse; 2003.
16. Snyder L. *Speaking Our Minds: Personal Reflections from Individuals with Alzheimer's Disease*. New York: W.H. Freeman & Co; 1999.
17. Truscott M. Life in the slow lane. *Alzheimer Care Q*. 2003;4(1):11-17.
18. Killick J. Memorializing dementia. *Alzheimer Care Q*. 2003;4(1):18-25.
19. Mayhew PA, Acton GJ, Yauk S, Hopkins BA. Communication from individuals with advanced DAT: Can it provide clues to their sense of self-awareness and well-being? *Geriatr Nurs*. 2001;22:106-109.
20. Sabat SR, Harre R. The construction and deconstruction of self in Alzheimer's disease. *Aging Soc*. 1992;12:443-461.
21. Tappen RM, Williams-Burgess C, Edelstein J, Touhy T, Fishman S. Communicating with individuals with Alzheimer's disease: Examination of recommended strategies. *Arch Psychiatr Nurs*. 1997;11(5):249-256.
22. Ward R. Dementia communication and care: Communication in context. *J Dement Care*. 2002; Nov/Dec: 33-37.
23. Parse RR. Quality of life for persons living with Alzheimer's disease: The human becoming perspective. *Nurs Sci Q*. 1996;9(3):126-133.
24. Norman HK, Asplund K, Norberg A. Episodes of lucidity in people with severe dementia as narrated by formal carers. *J Adv Nurs*. 1998;28:1295-1300.
25. Phinney A. Living with dementia: From the patient's perspective. *J Gerontol Nurs*. 1998;24(6):8-15.
26. Ostwald SK, Duggleby W, Hepburn KW. Stress of dementia: View from inside. *Am J AD Other Dement*. 2002;17(5):303-312.
27. Harris PB, Durkin C. Building resilience through coping and adapting. In: Harris PB, ed. *The Person with Alzheimer Disease: Pathways to Understanding the Experience*. Baltimore, MD: Johns Hopkins University Press; 2002.
28. Phinney A, Wallhagen M, Sands LP. Exploring the meaning of symptom awareness and unawareness in dementia. *J Neurosci Nurs*. 2002;34(2):79-81, 85-90.
29. Gilles BA. A memory like clockwork: Accounts of living through dementia. *Aging Ment Health*. 2000;4(4):366-374.
30. Harris PB, Keady J. Living with early onset dementia: Exploring the experience and developing evidence-based guidelines for practice. *Alzheimer Care Q*. 2004;5(2):111-122.
31. Mitchell GJ, Kolodny V. Quality of life: Residents of long-term care facilities speak out. *The Picker Rep*. 1996; Spring/Summer:10-11.
32. Moore T, Hollett J, Pilkington B, Jonas-Simpson C. The experience of feeling confined. *Perspectives*. 2004; 27(2):5-12.

33. Parse RR. *The Human Becoming School of Thought: A Perspective for Nurses and Other Health Professionals*. Thousand Oaks, CA: Sage; 1998.
34. Parse RR. Quality of life: Sciencing and living the art of human becoming. *Nurs Sci Q* 1994;7:16-21.
35. Parse RR. *Qualitative Inquiry: The Path of Sciencing*. Toronto: NLN; 2001.
36. Mitchell GJ. Look beyond the disease to see the person. *Alzheimer Alert*. 1994;10(3):1-2.
37. Jonas-Simpson C. From silence to voice: Values and beliefs that guide healthcare practices with persons living with dementia. *Nurs Sci Q*. 2001;14(4):304-310.
38. Mozley CG, Huxley P, Sutcliffe C, Bagley H, Burns A. 'Not knowing where I am doesn't mean I don't know what I like': Cognitive impairment and quality of life responses in elderly people. *Int J Geriatr Psychiatry*. 1999;14:776-783.