Occupation and Well-Being in Dementia: The Experience of Day-Care Staff

Betty R. Hasselkus

Key Words: Alzheimer's disease • quality of life • therapeutic activities

Objective. The purpose of this study was to gain understanding of the staff experience of occupation in the context of day care for persons with dementia.

Method. Narratives of especially satisfying and dissatisfying experiences of care were elicited from a random state-wide sample of day-care staff members. Qualitative methods were used to analyze the phenomenological data.

Results. The core meaning of occupation derived from these data was Occupation as the Gateway to Relative Well-Being. A model of the experience of occupation for staff members is proposed that is composed of three phases: the meeting of minds, engagement in occupation, and relative well-being. The skills of the staff informants that bring about the meeting of minds, the many levels of client engagement in occupation, and the indicators of well-being for clients and for staff members are described. The three phases together constitute an occupational space—created by the staff person—and the engagement in occupation itself constitutes an occupational place within that space.

Conclusions. Bringing about indicators of well-being through occupation was a primary source of satisfaction for the day-care staff informants in this study. The model of the staff experience of occupation proposed in this study has application to all areas of occupational therapy practice.

It is a founding premise of occupational therapy that health is related to occupation. It follows from this premise that occupation, defined as "the ordinary and familiar things that people do every day" (American Occupational Therapy Association, 1995, p. 1015), can be used as therapy to promote and support health (Kielhofner, 1992; Nelson, 1996; Reilly, 1962; Trombly, 1995; Wood, 1995; Yerxa et al., 1990).

The implications of this basic premise have been deepened by conceptualizations of humans as occupational beings (Clark et al., 1991; Kielhofner, 1992; Wilcock, 1993; Yerxa et al., 1990). Zemke and Clark (1996) and Wilcock (1993) depicted occupation as central to understanding the framework of human experience. Wilcock further declared that "the need to engage in purposeful occupation is innate and related to health and survival" (p. 17). In the Model of Human Occupation, the occupational nature of human beings is seen as the organism's driving force for health and life-span development (Kielhofner, 1992). In Matheson and Bohr's (1997) model of occupational competence, occupational roles are also conceptualized as an organizing focus in people's lives across the life span.

This article draws on narratives from a state-wide sample of day-care staff informants to examine the na-
ture of occupation and its relation to health in the context of day care for persons with dementia. Dementia is an illness syndrome manifested by progressive cognitive and functional decline. Ultimately, the decline leads to the loss of the person's ability to engage in ordinary daily activities in a meaningful way. Teri and Logsdon (1991) described this loss as one of the most debilitating consequences of dementia. In occupational terms, if daily activity fills our basic innate need as occupational beings and supports our health and well-being, then it follows that the loss of the ability to engage in occupation, as occurs in progressive dementia, is a powerful sign of unmet human needs and a major threat to the health and well-being of persons with dementia (Perrin, 1997).

Once the capacity for engagement in activity has declined, it is accepted practice that the others in the person's world have the responsibility to help him or her continue to lead an active daily life (Zgola, 1987). This practice reflects assumptions about the relationship of occupation to health and well-being and forms the basis and rationale for planned activity programming in care for persons with dementia. Yet, the nature of occupation in the life of a person with dementia is not well defined, nor is it fully understood how a state of well-being manifests itself in the presence of cognitive impairment.

A body of literature exists that describes guidelines for therapeutic activity for persons with dementia (Borell, Sandman, & Winblad, 1991; Dowling, 1995; Griffin & Matthews, 1986; Hellen, 1992; Mace, 1987; Maloney & Daily, 1986; Teri & Logsdon, 1991; Zgola, 1987, 1990), such as using activities that are familiar, that incorporate repetition and rhythm, and that ensure some degree of success. Further, the meaning of occupation in day care for persons with dementia has been examined in three studies. Josephsson (1994) used the term meeting-places to describe the meaning of activity, referring to the potency of activity to enable persons with dementia to experience social connectedness. Hasselkuss's (1992) participant observation revealed patterns of activity programming that served two primary purposes: preventing harm and providing purposefulness. In Borell, Gustavsson, Sandman, and Kielhofner's (1994) ethnographic study, a major theme of using activities to keep order was derived from the data; the authors interpreted this to reflect an emphasis on using occupation for "crowd control" (p. 231).

Attempts to understand and define the concept of well-being in persons with dementia are limited. Kitwood and Bredin (1992) used the term relative well-being to describe the wellness state of a person with dementia. They proposed 12 indicators of relative well-being, such as evidence of humor, expressions of affectional warmth, initiation of social contacts, and helpfulness. In other research, the frequency of participation in activity programming (Albert et al., 1996) and the amount of initiative shown during activities (Borell et al., 1994) have been used as indicators of well-being. Zgola (1990) referred to participation in activities as one way in which persons with dementia define themselves as individuals, demonstrate independence, satisfy their need for control over their environments, and develop satisfying relationships with others. These assertions were at least partially supported by Nygard and Borell (in press) in a study in which they followed the daily occupation of two women with dementia over a period of 3 years. The women came to view their daily activities and routines as the source of existential meaning in their lives, using familiar tasks and objects to hold on to their personal identities and to maintain some control over their worlds.

The purpose of this study was to gain understanding of the nature of occupation in the context of day care for persons with dementia. Narratives of especially satisfying and dissatisfying experiences of care were elicited from a random state-wide sample of day-care staff persons. The use of narratives in qualitative research is based on a narrative theory of experience, that is, the theory that stories are a salient source for understanding the nature of an experience (Bruner, 1986, 1990; Coles, 1989; Good, 1994; Polkinghorne, 1988; Ricoeur, 1984). Informants in this study provided stories rich in occupational content as they described especially satisfying and dissatisfying experiences of their everyday practice. The analysis of the narratives aimed to understand the phenomenology of occupation as it was lived by the staff members in these experiences of day care. Greater understanding of occupation in this context of care will lead to more responsive and therapeutic activity programming, enable us to better articulate the meaning of practice in the care of persons with dementia, and contribute to our developing theory base of the relationship between occupation and health.

Method

A random sample of 50 day-care centers was generated from the membership list of the Wisconsin Adult Day-Care Association. Letters were sent to the directors of all centers in the sample, explaining the study and inviting each to designate a staff member to participate in a telephone interview. Interviews were successfully completed with staff members of 40 centers. Of the 10 nonparticipating centers in the original sample, 3 were no longer in operation, 3 did not have participants with dementia, and 3 were not yet fully operational. The contact person at the 10th nonparticipating center seemed hesitant to set up the interview and so was ultimately dropped from the list. Two staff members contributed to the interviews from each of two facilities, making a total of 42 staff members interviewed.
Forty-one of the 42 informants were women; ages of all informants ranged from 28 to 66 years (M = 44 years). Experience in caring for persons with dementia ranged from less than 1 year to 36 years. Twenty-five informants were program coordinators or directors, and six were activity directors. Professional backgrounds included occupational therapy, physical education, nursing, social work, music therapy, related art, and recreational therapy. Eight informants had no specialized training beyond high school except what they had pursued in continuing education.

**Data Collection**

Data collection was based on an interview method used in an earlier study by Hasselkus and Dickie (1994). The phenomenological question in the present study was, “Think back over your practice and describe an especially satisfying [dissatisfying] experience in your day care for persons with dementia.” The goal of the interviews was to obtain detailed narratives about the staff experiences as they were lived through. Probes were used to keep each informant “in” the experience or close to the plot, thereby minimizing an interpretive approach to the storytelling (Van Manen, 1990). Narrative theory holds that lived experiences and memories of experiences are typically framed in narrative form (Bruner, 1990; Mattingly, 1994; Ricoeur, 1984), and they are shaped with a coherence that embodies more than a linear sequence of events. By keeping the narrator “in” the experience, the essence of the experience is likely to be gradually revealed.

Each staff informant provided narratives of a satisfying and a dissatisfying experience. A graduate student assistant carried out all initial interviews by telephone during a 5-month period. Interviews lasted from 20 to 45 min and were taped recorded for transcription. Second callback interviews with 10 informants (chosen on the basis of their ability to articulate their experiences and the emerging themes in their narratives) were conducted by the author. The callback interviews served as member checks, providing an opportunity for staff informants to elaborate on narrative details and to give feedback on understandings that were emerging during the early analysis.

As Bruner (1990) declared, narratives unfold in such a way as to justify the actions and attitudes of the narrator. The stories related by the staff informants are “loaded” in this way. Because the graduate student assistant and author were both occupational therapists with professional experience in geriatric practice and research, the interview process was inevitably also shaped by their views of occupation and health. Thus, interviews yielded co-created knowledge of a certain kind (Beer, 1997; Hasselkus, 1997). This process of co-creation does not negate the power of the data and analysis; recognizing it simply helps clarify their grounding.

**Data Analysis**

The analysis began with a search for the structures of the satisfying and dissatisfying experiences that constituted the phenomenon of providing day care to persons with dementia. The graduate student assistant and author carried out parallel reading and preliminary coding of the first six interviews. For example, one early unit of experience was “things that worked.” Initially, this code referred to informants’ descriptions of activities that “worked” to redirect difficult behaviors.

After consensus was reached on the early parallel coding, the remaining interviews were conducted; the early coding decisions were continuously challenged, expanded, and enriched by subsequent data. To continue with the same example, the coded category “things that worked” was expanded to include bringing about pleasure and enabling a day-care client to accomplish an activity independently. “Things that did not work” became another part of this code. Additionally, the concept of “skill” emerged in these data; that is, some informants described the ability to find things that worked as a skill that they were “good at” or “not good at.” At this point, the label for this category was broadened to “techniques,” and subcategories were created.

During the callback interviews, probes were used to further challenge, expand, and elucidate the emerging themes and interpretations. The iterative cycle of reflective analysis, consensus building, and data collection is a process that helps the researcher stay as close as possible to the actual text, maximizing the authenticity of the interpretations that are emerging (Lincoln & Guba, 1986; Van Manen, 1990). The results of this analysis are presented in the next section, followed by a discussion of the findings as they relate to theories of occupation and occupational therapy practice.

**Occupation: A Gateway to Relative Well-Being**

The core meaning of occupation in this context of care for persons with dementia was Occupation as the Gateway to Relative Well-Being. In these narratives, occupation stood as a dynamic centerpiece of the experiences that were shared. Engaging in occupation depended on the staff informant’s connecting in some way with the day-care clients. As one informant said, “It’s basically being able to tune in on the person…. There’s one part of the mind that you can still reach, you know.” The narratives were stories of the informants trying to bring about a connection, that is, a meeting of minds, with the day-care clients. Engagement in occupation could then take place, and a state of relative well-being was facilitated.

A narrative from one interview illustrates the nature
of occupation revealed in the analysis of these data. In this narrative, the staff informant described a client (pseudonym “Lottie”) who had been resistant to any involvement in activity at the day-care center and unresponsive to verbal and nonverbal interaction attempts by staff members. The informant told a satisfying story about successfully getting Lottie involved in a flower arranging project:

After talking with the family a little bit about what’s her history, what did she like to do, what kind of lady was she, that sort of thing, we picked up on a few cues, one being that she was a farmer’s wife….and that she had won blue ribbons with her flower-arranging skills and picking garden flowers, that sort of thing. And knowing that, we thought maybe we can draw this lady out in a one-on-one situation where she will not feel put on the spot; we can draw her out in maybe doing some flower arranging. So the next time that a funeral home was going to bring a funeral spray, that was what we were going to target with Lottie, to have her rearrange these flowers for us. And so we did just that. I sat down with her, I brought the whole spray in at the table, and the vase, with water, and I said, “Lottie, I need your help.” And she just kind-a looked at me; she barely opened her eyes….And her one hand was up to her mouth and her other hand was clutched in a fist in her lap, and she just kind of gave me a grunt. And I said, “I’ve got all these flowers that I need to have in the vase, can you help me put these flowers into the vase?” And I just let that set in for a minute, and I said, “I’ve got carnations here,” and then I’d let it be quiet; and I said, “I’ve got some glads here,” and just kind of gave her some time to get used to the fact that I wasn’t going to go away, that her just trying to be quiet and kind of grunt at me a little bit wasn’t going to shoo me away. And she did open her eyes, and she did reach out and start to touch the flowers….And I took a flower out and I put it down on the table, and with that she picked it up, and she started putting them into the vase. And before long, she was sitting up in the wheelchair instead of slouching back, and she started to pull the flowers out [of the spray] herself. And so it was very satisfying to have found the key that opened her up and let her know that someone cared about her and showed her that she could do something….I think she felt good about herself because she was able to accomplish something.

From this narrative, a model of the experience of occupation for staff in day care for persons with dementia can be generated (see Figure 1). In Phase I of the model, and as a necessary first step, a meeting of minds takes place, that is, a cognitive connection is made between the staff person and the client. Staff members use a variety of skills and strategies to bring about this meeting of minds. In this experience, the staff informant described a repertoire of skills that she used until she “found the key that opened her up.”

Once the meeting of minds takes place, the potential for engagement in occupation (Phase II) is created. In the narrative, Lottie opened her eyes, demonstrating the first level of engagement. Then she reached out and touched the flowers. Next, Lottie picked up a flower from the table and put it into the vase. And finally, she sat up straighter and started to take the flowers out of the spray herself. For Lottie, even the first engagement of opening her eyes represented changed behavior; that she progressed all the way to taking initiative and completing a task is truly remarkable.

The behaviors that Lottie demonstrated were clearly signs of well-being (Phase III) to the informant. The visual tracking, attentive body posture, purposeful movement, and initiative are all behaviors that we attach to meaningfulness and orientation to place. The informant described this occupational scenario as very satisfying. She expressed her strong valuing of Lottie being able to “do something” and “accomplish something.” She transferred her own satisfaction about the incident to Lottie, stating that she thought Lottie felt good about it too. In other words, she believed that she helped Lottie experience a sense of well-being by getting her involved in the flower-arranging activity. This is the theory of the relationship between health and occupation played out in a real-life example in the context of dementia.

Phase I: The Meeting of Minds

In the first phase of the staff experience with occupation, staff members are striving to connect with persons with dementia and to bring about shared meanings of the proposed activities. Bringing about the meeting of minds draws strongly on the skills of the staff members. They use various strategies, including persuading, redirecting, teaching, enabling, and searching for the key.

Persuading. Persuasion was perhaps the least effective means of bringing about the meeting of minds. Persuasion is a technique that relies on reasoning and logic, the very cognitive capacities that are missing in the person with dementia. Being able to persuade someone of something actually presumes that a shared meaning already exists; it does not serve as an effective strategy for bringing about a shared meaning. One informant described the unsuccessful use of this strategy in a narrative about a female client who kept wanting to go out the door:

We had such a hard time, or I did, trying to get her back in, to reason with her that she could not be outside, that it was dangerous, that you know, that it was for her own protection that she stay in...
These tactics demonstrate attempts to redirect a client's thinking and action toward an idea or activity that is safer, more constructive, less stressful, or more calming than what the person is currently engaged in doing (here, going out the door). Redirecting is a widely used strategy for managing behaviors; it acts as a substitute for reasoning and persuasion.

**Teaching.** For persons with dementia, it is axiomatic that little or no learning can occur. Nevertheless, the informants believed that providing a daily routine that had structure and predictability would help new clients to gradually get comfortable and accustomed to their stay at the center. An element of trying to reach clients about what to expect is present in these strategies, illustrating another kind of meeting of minds. The following narrative describes a situation with "a man in the middle stages of Alzheimer's" with whom it was difficult to communicate. The staff informant described an incident of teaching a new client to pace himself when bringing himself back to the program, that he "had to talk" and with whom it "took a lot of encouraging to get him to participate in any activity at all":

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We would always take him to the bathroom at a certain time, and our activities are pretty much set at certain times during the day... and we always do our hallway walking right after he's done with his bathroom routine. Normally, we'd have to get him out of the door of the bathroom and then explain to him again that we need to do some walking in the hallway... But then we got to the point where he would actually come out of that bathroom door and he'd tell me that we were going to go walking now! I thought that was pretty neat. So we could tell that he was getting real used to our program, and getting in the swing of things, and feeling more comfortable.
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**Enabling.** Enabling strategies are those that often required inventiveness on the part of the staff members to help the person with dementia engage successfully in an activity. These are sometimes simple strategies such as putting a large black-line drawing of a toilet near the entrance to the restroom as a visual cue for toileting. Cuing, breaking tasks down into single steps, eliminating or simplifying environmental stimuli, and relying on already familiar routines and activities were enabling strategies described most often.

In an exception to these rather simple strategies, one informant devised a relatively elaborate system of cues and routines in an effort to enable a client to manage his medication regimen accurately. The system included a medication chart ("It tells him what the pill is, with one of the original pills taped to this chart—so he knows what it is and how many times a day he should take it") and pill boxes in different colors ("One for morning, one for evening"). The informant ended the narrative with these remarks:

This is something that is really rewarding with this gentleman because he's grasped this over the past several weeks of setting up his meds, to the point that he's even tried to set them up himself now. This is absolutely wonderful. Just going back over some of his medical history and looking at some of his lab results, he is now in compliance with what he has been in years. And it is absolutely wonderful that this is the end result... It has been more rewarding to me than anybody will ever be able to know.

As is evident in the above narrative, adaptations often require a certain amount of learning to take place in order for them to be effective. To accomplish this, the staff member tries to think like the person with dementia—to meet his or her mind—and then to create circumstances that match that thinking. Because learning is so difficult for the person with dementia, the staff members react with deep satisfaction to success with this strategy.

**Searching for the key.** In the narrative about Lottie and the flower-arranging activity, the staff informant described the situation as one in which she "found the key." Finding the key is a metaphor for bringing about a meeting of minds; it is a way to describe the experience of unlocking the mind to understand and opening up that "one part of the mind you can still reach." In the example below, the informant described an incident of finding the key with a client who "just didn't really talk" and with whom it "took a lot of encouragement to get him to participate in any activity at all":

One day we had a program on Chicago, a whole program centered on Chicago and the past bringing up to the present. And I knew that he had lived in Chicago and brought him in, and he'd only go in if I would walk him into the program and stay with him a little bit. And [after a short while] he was contributing to the program, I mean, in such an alert manner you wouldn't know that he had Alzheimer's! I mean, he was just remarkable. And I was able to go away and do my work, and he stayed in the program for an hour and just watched the slides; and then he was giving, you know, play-by-play what this slide was, where this was, and could remember those things. His family found that very difficult to believe!

The complexity of the thinking needed to find the key for some participants was evident in many narratives. The social demands of an activity, its physical characteristics, the way the task was introduced and explained, where the task took place, the visual cues it offered, the finished product it led to, how it was integrated into other naturally occurring routines and activities—these

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were all important to successful engagement in occupation. The search for the key to engagement in occupation was not like following a logical sequence; it was more like knitting together an intricate network of related elements.

One other strategy for bringing about a meeting of minds was present in these narratives, and that was the strategy of trial and error. In general, the staff person probably brought more skill to bear to the situation than he or she realized, but the engagement in occupation sometimes seemed to be the result of pure chance, as in the following narrative:

...she was not participating in much. I couldn’t even get her—[pause]—I gave her a deck of cards and she would just do absolutely nothing with them, she wouldn’t pick them up, she wouldn’t just play with the cards or set them anywhere...Then one day I gave her a piece of paper and pencil. I just set it in front of her, I didn’t even give her any instructions what to do with it. And all of a sudden she just picked it up and started writing. She wrote her name! She did spell it wrong, but she wrote her name!

In a way, trial and error is another way of searching for the key.

Phase II: Engagement in Occupation

The second phase of the staff experience of occupation in dementia care is that of engaging the client in occupation. Engagement in occupation represents the behavioral sequelae to the meeting of minds. Descriptions of occupational involvement in this context of care were rich in detail, leading to a conceptualization of multiple levels of occupational engagement. To the informants, the clients’ levels of engagement represented levels of connection with the real time, place, persons, and activities of the day-care center. The following quotation helps to convey this concept of levels of occupation:

This particular client would become very agitated being with the group, especially at mealtime. And he was not eating well. What we had suggested doing was to bring him back into the office area where it’s somewhat more quiet....And when he would be in a quiet, more controlled situation, he just did very well....He would actually sit down with his meal and bless himself and his food...he ate much better and he was even concerned, you know, if he would spill something, and just seemed to be much more in touch with reality....[This] was very satisfying, you know...he was very much in contact with his past and the real situation of sitting down to eat a meal.

To the informant, this man’s engagement in the mealtime occupation under the changed conditions led to deep connections to his past and to his present. The client’s levels of spontaneity, rational communication, capability, and affect were embedded in the engagement in occupation.

Levels of spontaneous occupation. The spontaneity of a client’s occupational engagement was an oft-noted part of an occupational narrative. In preceding story, the man spontaneously blessed himself and responded to spilled food during his meal. In the story of Lottie and the flower-arranging activity, spontaneous occupation was represented by activities ranging from the simple act of opening her eyes or reaching out to touch an object to the more complex behaviors of initiating and completing a task. Spontaneity often encompassed elements of “independence,” and informants clearly found satisfaction in such demonstrations. As the informant said regarding the adaptations of the medication regimen, the client “even tried to set them up himself.” In reference to the bowling ability of another client, an informant said:

He can negotiate the whole thing himself....You can tell he must have bowled in his time. He has the form, and he knows how to knock the pins down, and then he goes and he resets them up. To me it is satisfying because he’s doing this on his own. I’m not doing it for him, he’s doing it.

Levels of rational communication. At the simplest level, communication by clients occurs nonverbally through eye contact, a smile, or a “twinkle” in the eyes. Verbally, communication ranges from the pretense of socializing that sometimes takes place between participants to moments of rational, sentient conversations between staff members and day-care clients. Either experience could be very satisfying. In one narrative about conversations between two clients, the informant said, “Neither was connected with reality or with each other...[but] those two ladies would sit for an hour and a half and just enjoy each other. And that’s incredible, you know, but they would do it.” At a somewhat more cognitively demanding level, it was satisfying to informants when clients talked about their past interests and life histories. The highest level of communication is represented by those rare occasions when a client actually takes part in a rational exchange, contributing in a natural, reciprocal manner to the interaction. It was in narratives about this kind of social interaction that an informant sometimes described the person with dementia as “like normal,” or, as in the narrative about the client and the Chicago slide show, the informant said, “He was contributing to the program, I mean, in such an alert manner you wouldn’t know that he had Alzheimer’s.” The informant’s sense of satisfaction with this high level of engagement in occupation is evident.

Levels of capability. Staff members’ satisfaction with even minimal levels of client capability was illustrated many times in the data; Lottie’s successful engagement in flower arranging and the former bowler who “knows how to knock the pins down” are two examples. In a few incidents in the data, staff informants shared stories in which a client not only successfully engaged in an occupation, but actually far surpassed staff expectations for capability, such as the woman who “wrote her name” after being handed a pencil and a piece of paper. In another narra-
tive, a client who was “very, very demented” unexpectedly, but correctly, hollered out, “It’s Truman! Who else could it be?” in answer to a question during a group discussion about former presidents. The informant said that at the end of the day, “That’s all we could talk about: ‘It’s Tru­
man’” [laughs]. She even had eye contact with the leader of the group. It was just for a split second, but it was there.”

Levels of affect. Finally, clients’ engagement in occupation was almost always described to some extent in affective terms. A client “looked relaxed,” “looked more alert,” or “was delighted” were informant expressions of client affect. In some stories, the intensity of the engagement was beautifully described by one informant as follows:

We would set her up with a cooking group... She couldn’t get the supplies ready herself, but if we would have the supplies sitting out for her—like the half a cup of butter, and the two cups of flour, and the brown sugar—she could mix that up. I mean, she just—she glowed. And she would talk about it and then she would reminisce about her cooking days. And she could take teaspoons of the cookie dough and drop them on the cookie sheet and just talk. And she would just smile. She would just become radiant [emphasis added].

In summary, the engagement of clients with dementia in occupation occurred on many levels and represented dimensions of occupation, including levels of spontaneity, rational communication, functional capability, and emotional investment. To the staff informants, the levels of occupation represent the clients’ levels of connectedness with the realities of their lives and surroundings, with the deepest and most complex occupational engagement reflecting the most profound connectedness.

Phase III: Well-Being

The third phase of the model of occupation and dementia care is the phase of well-being for both day-care clients and staff members. Many observable indicators of well-being for the day-care clients were named by the staff informants in the narratives. In addition, informants used these observable indicators to draw inferences about inner states of well-being in the persons with dementia, such as happiness or comfort or peace. Beliefs about the theoretical relationship between occupation and health were expressed to support these inferences. Finally, informants expressed their own well-being in statements of satisfaction, inspired by their observations and beliefs about the well-being brought about in the clients.

Indicators of well-being: Clients. The smile, the laugh, the “big toothy grin,” the pleasant look on the face of the client—these were all indicators of well-being as seen by the staff informants. Other indicators were clients being friendly, showing affection, not getting up all the time, not asking questions all the time, socializing with others, singing with “gusto,” and talking a lot. One informant said, “We play a lot of music; it keeps them all very up. They all sing the words, they all smile, they love it.” Clients’ body language, often evoked by music (foot tapping, body swaying, head nodding), signified well-being to staff informants.

The ability of a person with dementia to attend to a task for any length of time was clearly a sign of well-being to the staff informants; the story about the two ladies who socialized for an hour and a half was one example. As was evident in other narratives, lesser signs of attentiveness could be considered very positive, such as simply getting eye contact for a “split second” or visually tracking a visiting pet as it crossed the room. It was a strong sign of well-being when one client started paying attention to us every day... he’s complimenting people, and he’s friendly. He joined in a sing-a-long one day this week, he talks to other clients, and he smiles willingly. And this has just been one of the greatest things about being in day care is to see this change in a few weeks.

Moments of remembering were regarded as moments of well-being by the informants. In general, the more clients talked about their past, the more pleased are staff members about the client’s state of well-being. Activities that stimulated reminiscing were viewed as positive. Laughter was sparked for one informant and a usually quiet client at a day-care dance when the woman suddenly said, “I used to sing in a piano bar... and I ran a massage parlor.” The informant described her own somewhat startled response and then continued: “She started laughing and she kind of knew what that innuendo kind of thing was, and she was having a really good time.”

Remembering events and persons from the present was also considered a strong sign of well-being; an example is the client who remembered the daily routine of walking the hallway after using the bathroom. In describing a man who was very good at a parachute-like game with bed sheets and a beach ball, an informant said:

[He] remembers it, day to day. ’Cause when we put it away and bring it out the next day, or whenever, he’s, “Oh, that one. That goes way up in the sky.” I told the other staff people here that we can definitely put ourselves on the back for that one because this gentleman is really getting a lot of benefit out of it.

Finally, signs of independence in carrying out activities are regarded as signs of well-being by staff members. The fact that the bowler could “negotiate the whole thing by himself” was very satisfying to the staff informant. When the client was able to learn to use the new medication regime independently, the informant found the feat
was good; to be uninvolved was not good. 

"absolutely wonderful."

The informants' beliefs about the relationship between occupation and relative well-being in the day-care clients were evident. Basically, to be involved in activity was good; to be uninvolved was not good.

On the basis of the value they placed on occupation and the indicators of well-being they observed, informants projected other conditions and feelings on the clients with dementia. For example, in reference to Lottie's successful engagement in the flower arranging, the staff informant said that she thought that the activity showed Lottie "that she could do something... that she was still of value, that she was important enough to us to spend time with her. I think she felt good about herself because she was able to accomplish something." According to another informant, the bowler who was "doing this on his own" felt "some inner satisfaction, some inner accomplishments." The man who gave the monologue with the Chicago slides "had a look about him that he was very satisfied with himself because he was able to contribute." Being so good at the parachute game gave the client a "sense of belonging to the group." Thus, staff members use the behavioral indicators to make inferences about the inner feelings of the persons with dementia, projecting onto them their own beliefs and values about occupation.

Staff well-being. The model includes staff well-being as the other major component of the third phase of the experience of occupation in dementia care. When the meeting of minds had been successfully brought about, when engagement in occupation and indicators of client well-being were present, staff informants expressed their own well-being in phrases such as "I find that very rewarding" or "that's really satisfying" or "I was really pleased by that."

Staff informants spoke with pleasure of their own skills. As one informant said about the day-care clients' arrival time in the mornings, "I can get them to walk in the room and forget about their problems, you know, and I just love that." Exultation over bringing about changes in an unresponsive client was declared by one informant as follows:

God, I loved that woman. She could sit and laugh and talk, where at the beginning she was agitated, sulky; so there was a real definite, good gain and, you know, a feeling that I had a little something to do with her calming down and being able to function the way she did for a while.

In Figure 1, the feedback from Phase III to Phase I is depicted as a broken line. This "brokenness" is intended to represent the disruption in feedback experienced by the day-care clients. The cognitive losses of dementia prevent the clients from retaining or learning from their daily occupations. For the staff members, however, feedback is present in the intact memories of their daily experiences; new skills and understandings emerge to affect the next creation of an occupational space.

The sense of personal satisfaction derived from her practice in dementia day care was summed up by one informant in this way:

This [dementia day care] opened up a whole new world for me, and an interesting one, and I am able, as an individual, to do something for them, whether it's just to give them a hug, to reassure them, or to listen to what they're babbling about... I would say every day, if you can get a smile out of somebody so deep into dementia that they no longer talk or can feed themselves, I mean, they're just there; but there must still be something within them that as you speak to them and touch them, you see it in their eyes. There is a response, and an occasional smile; and that, to me, is very satisfying.

Discussion

On the basis of the narrative data analysis in this study of dementia day care, a model of the staff members' experience of occupation in this setting has been proposed. The phases of the model—bringing about a meeting of minds, actively engaging in occupation, and observing and experiencing well-being—can be conceptualized as comprising a whole to which the term occupational space is applied (see Figure 1). The occupation itself, that is, the activity that takes place within that space is the occupational place. The use of these terms is borrowed from Tuan's (1977) writing on experiential space and place and from Josephsson's (1994) use of the term meeting-places to describe the social connectedness found through occupation by persons with dementia.

Occupational Space and Place

Tuan (1977), in his discussion of the creation of a space, used the example of architectural space to illustrate the process:

What is the builder conscious of as he first creates a space...? The answer is complex because several kinds of experience and awareness are involved. At the start, the builder needs to know where to build, with what materials, and in what form. Next comes physical effort. Muscles and the senses of sight and touch are activated in the process of raising structures against the pull of gravity. A worker modifies his own body as well as external nature when he creates a world. Completed, the building or architectural complex now stands as an environment capable of affecting the people who live in it. (p. 102)

Tuan's description of the creation of architectural space can serve as a metaphor for the parallel process of creating an occupational space. What are day-care staff members conscious of as they create an occupational space? At the start, the staff member needs to know where, how, and with what an occupational space can be created; the various strategies for bringing about a meeting of minds are brought into play to gain this information and understanding. Next comes the activity itself, the engagement of mind and body in an occupational endeavor. The staff member and the day-care client come together in a modified version of themselves and their environment, carry-
ing out occupation in a way that is adapted to their needs and circumstances. Finally, during the activity and on its completion, the occupation affects the feelings and sense of well-being of the staff members and day-care clients who experience it.

Space is transformed into place as it takes on definition and meaning (Tuan, 1977). In this proposed model of occupational space, it is in the second phase of the model, during the engagement in occupation, that occupational place is created. The staff member and client meet and carry out an occupation that has definition and meaning. In Josephsson’s (1994) terms, a meeting-place is created for social interaction, fellowship, and doing things with the client.

In the care of persons with dementia, the occupational place is one of intimacy. An intimate experience of place is an experience of the here and now; the experience is fleeting, momentary (Tuan, 1977). Yet, intimate places are nurturing, attending to and caring for our most fundamental needs. Reminiscent of the radiance seen on the face of the client while she baked cookies is Tuan’s (1977) description of intimacy of place:

It glows in moments of true awareness and exchange. Each intimate exchange has a locale that partakes in the quality of the human encounter. There are as many intimate places as there are occasions when human beings truly connect. What are such places like? They are elusive and personal. (p. 141)

The occupational place in dementia care is fleeting, sometimes just a “split second.” Two women socializing for an hour and a half is viewed as “incredible.” Rarely does a client actually remember an occupation from hour to hour or from day to day, and it is a source of special satisfaction when he or she does. The experience of occupational place is simply a moment of “true awareness and exchange”—nothing more but, also, nothing less. For in that moment, the person with dementia experiences once again a brief sense of self and identity (flower arranger, resident of Chicago)—images of his or her being. As Tuan (1977) said, “To strengthen our sense of self the past needs to be rescued and made accessible” (p. 187). In the care of persons with dementia, occupation helps rescue the past and make it accessible.

Narrative Reasoning

Bringing about a meeting of minds is akin to the process of narrative reasoning described by Mattingly (1991). Thinking narratively means trying to understand a particular person’s experience; it is our primary way of “making sense of human experience” (p. 999). In the narratives of day care for persons with dementia, staff informants described the process of trying to make sense of clients’ unique illness experiences. Mattingly included images of the client’s possible and desirable future in her concept of narrative reasoning—what she calls the prospective treatment story. This dimension of narrative reasoning does not fit well with the therapeutic concept of activity programming for persons with dementia. In this context of care, narrative reasoning helps bring about the meeting of minds and, thence, engagement in occupation and relative well-being. But the emphasis is on the here and now, not the future; staff members do not expect nor even wish for long-term effects. Mattingly also stated that in therapeutic experiences, the “therapist and patient must come to share a story about the therapeutic process; they must come to see themselves as in the same story” (p. 1002). This mandate also does not fit well into the context of dementia care. In creating the occupational space, staff members are trying to create an occupational story to share with the day-care client—in that moment. The capacity of the person with dementia to share beyond the moment is limited; the staff person cannot create with the client shared images of the future. Satisfaction can be gained, however, by creating meaningful “short stories” with the day-care clients while “in” the occupational space created by staff members.

Levels of Engagement

The concept of levels of engagement in occupation has been broached by others. Christiansen (1994) and Trombly (1995) both addressed levels of occupation as represented by progressively larger units of time in activity and by the concept of nesting in which simple units of behavior are nested within more complex occupations (e.g., hanging up clothes is nested within doing the laundry, and doing the laundry is nested within being a home manager). Nelson (1988) conceptualized the nesting of occupation in terms of low, intermediate, and high levels, reflecting both the immediacy and the expansiveness of the occupation; steering the car would be an immediate, low-level occupation nested within the more long-range, higher level occupation of taking a trip. In the study reported here, the levels of spontaneity and capability reflect similar concepts.

In Allen’s (1985) cognitive model of occupation, each of six levels is defined by the person’s cognitive capabilities as they relate to the environment and purposeful activity. For example, activities at Level 2 are restricted to imitation of simple one-step movements that are already very familiar; at Level 4, activities may include two-step to three-step actions that lead to familiar goals. In this study, parallels may be drawn between Allen’s cognitive levels and the levels of spontaneous behavior, capability, and rational communication.

In other occupational therapy literature, Borell et al. (1994), in their study of occupational programming in
dementia day care in Sweden, generated levels of spontaneous behavior representing degrees of clients' personal initiative in activities. The five levels of spontaneous behavior ranged from spontaneous action (not cued by another person or by the routine) to unresponsiveness (disregard of personally directed questions). Interpretations in our study are drawn more from the process of occupational engagement itself, yielding understandings of the unfolding levels (complexity) of the spontaneous behaviors as part of that process.

**Well-Being and Dementia**

Buber (1958), a German philosopher, stated that “all real living is meeting” (p. 11). Further, “the real, filled present, exists only in so far as actual presentness, meeting, and relation exist” (p. 12). These are statements about the meaning of life, that it is in relating to (meeting) one’s world that the only real meaning of living is found. It is obvious that persons with dementia have diminished abilities to relate to the people and objects in their surroundings. Findings from our study support the value of occupation in enabling persons with dementia to continue to relate to their worlds—to engage in “real living.”

The indicators of relative well-being brought about by engagement in occupation closely parallel the list of indicators offered by Kitwood and Bredin (1992). Included on their list are the following behaviors: the assertion of desire or will, the ability to express a range of emotions, initiation of social contact, affectional warmth, social sensitivity, self-respect, acceptance of other persons with dementia, humor, creativity and self-expression, ability to show evident pleasure, helpfulness, and relaxation. Kitwood and Bredin proposed that the indicators reflect four global states of being: a sense of personal worth, a sense of agency, social confidence, and hope. They recognized that the presence or absence of indicators of well-being is partly the result of both the nature of the disease pathology and fundamental personality of the person with dementia. They asserted, however, that the social environment is a third major influence on well-being: “There can be little doubt that a considerable part of the variability of well-being must be attributed to the quality of care” (p. 284).

Occupation in the day-care setting is part of the social environment and care of the person with dementia. To the staff informants, the indicators of client well-being that accompanied engagement in occupation were behaviors that unquestionably reflect the ability to show pleasure, experience affectional warmth, initiate social contacts, and so forth. Similar to Kitwood and Bredin (1992), the day-care staff members also use their indicators as a step toward making assumptions about the clients' more global inner states of self-confidence, pride, and sense of accomplishment.

Occupational therapy practitioners are especially well qualified to use occupation therapeutically in the care of persons with dementia. The study of the nature of occupation and its relationship to health and well-being provides a strong background and deep understanding of the meaning of occupation in the daily life stories of persons with dementia. Further, the model of the dementia day-care staff experience of occupation and the concept of occupational space and place can be applied to all occupational therapy contexts. Therapists try with all clients to bring about a meeting of minds. In many settings, the clients are not cognitively impaired, but, still, therapists invest time and skills in an effort to establish a connection and shared meanings with the persons with whom they work (Crepeau, 1991; Rosa & Hasselkus, 1997). Engagement in occupation occurs on many levels. The extent of the clients' investment of time, energy, and ideas and his or her physical and mental capability yield corresponding levels of expectation and therapeutic activity within the therapy context. Finally, in the broader therapeutic context, the outcomes of therapeutic occupation represent a wide range of well-being indicators, from the flicker of eye contact and recognition by the client who has been comatose to the independent homemaking skills of the person who is discharged home after a stroke. In every therapeutic session, the therapist works to create an occupational space within which to relate to the client through occupation. Within that space, engagement in occupation per se creates a place, a focal point that provides meaning and definition to what is occurring. The three phases contained within the occupational space embody the nature of the therapist's experience of occupation in occupational therapy. The model represents a gestalt of the relationship between occupation and health as it is experienced in the lived world of occupational therapy.

**Conclusion**

A model of the staff members' lived experiences of occupation in day care for persons with dementia has been generated from staff narratives of satisfying and dissatisfying experiences. The stories reflect the staff members' strong beliefs in the connection between occupation and relative well-being in this context of day care. The strategies staff members use to connect therapeutically with day-care clients reveal the skills needed to bring about successful engagement in occupation by persons with dementia. The indicators of relative well-being in the clients are behaviors that reflect their personhood, such as humor, helpfulness, and initiative in social contacts. Bringing about these indicators of client well-being through occupation is a primary source of satisfaction and reward for staff mem-
bers. As a variant to Tuan's (1977) concept of experiential space and place, the term occupational space has been proposed to describe the three-phase phenomenon of bringing about engagement in occupation and relative well-being. The term occupational place is suggested to name the actual engagement in occupation. The concepts of occupational space and place are applicable to occupational therapy in all areas of practice.

Acknowledgment

This study was supported by the Helen and Philip Brody Pilot Research Grant from the Alzheimer's Association, Inc.

References


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