Doing-Being-Becoming: Occupational Experiences of Persons With Life-Threatening Illnesses

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KEY WORDS
• day hospice
• palliative care
• terminal illness

OBJECTIVE. Life-threatening illness profoundly affects people’s occupational functioning, yet continuing occupational engagement seems vital to their well-being. This qualitative study used a doing-being-becoming framework to explore the place of occupation in human lives threatened by illness.

METHOD. The experiences of 13 male and 10 female day hospice participants were investigated through a combination of focus groups, individual interviews, and participant observation. These data were interpreted by a process of constant comparison, coding, and theme building.

RESULTS. Experiences of doing were evident in accounts of losing and maintaining valued occupations and striving to preserve physical and mental functioning. A sense of being through occupational engagement arose in social relationships and self-exploration that enhanced feelings of self-worth. Occupation promoted the experience of becoming by providing fresh learning opportunities and a sense of contributing to others’ welfare.

CONCLUSION. The data offer new insights into the potential benefits of occupational engagement for persons dealing with life-threatening illnesses. Use of the doing-being-becoming framework enriched analysis of these data, which, in turn, have contributed to the understanding of the framework’s theoretical concepts.


The term life-threatening illness refers to any illness that “because of its nature can be expected to cause the patient to die...[and generally the person has a] prognosis of 6 months or less to live” (Hospice Task Force, 1987, p. 9). A wide range of life-threatening illnesses exist, including cancer, AIDS, motor neurone disease, and “allied degenerative neurological disorders” (Doyle, Hanks, & McDonald, 1993, p. 3). However, cancer is the primary condition of the persons whose occupational experiences are discussed in this article. These persons preferred to describe their condition as life-threatening rather than as terminal; hence, the former term is used throughout this article in deference to their wishes.

The imagery commonly associated with persons who have life-threatening illnesses is powerfully negative: images of incapacity, loss, decline, and death. An unlikely image of such persons is that of proactive, occupational beings: individuals who engage purposefully in occupations as part of living with a life-threatening illness. This article reports on data from a study of the experiences of a group of persons with life-threatening illnesses who were attending a day hospice program. One important aspect of their experiences was their continued functioning as occupational beings and the ongoing significance of occupation in maintaining and shaping their lives.

Our fundamental interest in the occupational nature of the persons we serve as occupational therapists and our growing interest in the fledgling science of occupation expressed in the work of Wilcock (1998), Zemke and Clark (1996), and...
their colleagues has led us to write this article. What follows is, first, a background discussion of literature about the concept of day hospice, the doing-being-becoming framework, and the impact of life-threatening illness on occupation. Second, the occupationally related experiences of a group of persons with life-threatening illnesses are analyzed and discussed in relation to the literature, with particular reference to Wilcock’s conceptualization of occupation in terms of doing, being, and becoming. Finally, implications of this occupationally focused understanding of persons with life-threatening illnesses are considered.

Day Hospice

Although life expectancy for persons with life-threatening illnesses such as cancer has been extended in recent years with biomedical advances, it is well recognized that the totality of needs of such persons cannot be met solely through biomedical means (Bye, 1998; Tigges & Marcil, 1988). This recognition has led to an expansion in the range of palliative care services offered to persons with life-threatening illnesses, including the development of hospices.

Although the existence of hospices can be traced back to medieval times, their “coming of age,” particularly in countries such as the United Kingdom and Australia, has occurred over the past 30 years in line with other developments in palliative care (Bray, 1997). In contrast with a biomedical focus on curative intervention, the hospice philosophy focuses on enhancing the quality of remaining life for persons with life-threatening illnesses (Spencer & Daniels, 1998). Life quality enhancement is achieved through attending to the control of pain and other symptoms, providing pastoral care, addressing physical and psychosocial needs, and assisting the family to support the patient at home for as long as possible (Rose, 1999; Tigges & Marcil, 1988). Hospice and other palliative care services, therefore, are increasingly being used by persons with life-threatening illnesses. One component of these services is day hospice programs.

Within the broad aim of maintaining or improving quality of life, day hospices may provide a breadth of services, including social and diversional activities, respite and nursing care, multiprofessional rehabilitation within disease constraints, and an array of complementary therapies (Spencer & Daniels, 1998). Corr and Corr (1992) coined the description of the day hospice as a day out and a day off: a day out for the person with a life-threatening illness and a day off for his or her caring relatives and friends. Furthermore, they proposed that day hospice programs bridge inpatient and home care, which is of great practical and emotional importance to both patients and caregivers. Occupational therapists, as part of the hospice team, assist each individual “to attain the occupational roles that are perceived by the individual and the caregivers to be important, given the limitations of time and physical ability” (Dawson, 1993b, p. 13).

Occupation as Doing-Being-Becoming

Among many conceptualizations of human occupation in the literature, Wilcock (1998) described occupation as “a synthesis of doing, being and becoming” (p. 249). Wilcock encouraged occupational therapists to acquaint themselves more fully with the occupational nature of the persons they serve in order to better respond to their needs. Drawing on the work of theorists both in occupational therapy (e.g., Fidler & Fidler, 1983) and in other disciplines such as psychology (e.g., Maslow, 1968), Wilcock offered the doing-being-becoming framework as a mechanism to better understand the complexities of occupation and, in so doing, to move therapists outside the “comfortable rut” (p. 253) of their thinking about their professional mandate.

Stated in simple terms, the first dimension, doing (the active part of occupation that is most readily observable), is the one with which people are understandably most familiar. Less readily appreciated, however, are the occupational dimensions of being (as in “being within self” whereby the doer experiences an enhanced sense of self manifested, perhaps, in a sense of inner peace or in self-discovery) and becoming (the transformative element whereby the doer strives to develop, change, grow, and be better). Wilcock’s (1998) proposition was that to fulfill their professional mandate to enable health through occupation, occupational therapists must attend to persons’ need for a dynamic balance among these three dimensions in their occupational lives. This proposition offers an interesting reworking of the more familiar notions in occupational therapy of a balance of occupations and its effects on human health and well-being.

Occupation and Life-Threatening Illness

Persons with life-threatening illnesses are likely to experience progressive loss of occupation as they become ill. The resulting state of occupational deprivation (Whiteford, Townsend, & Hocking, 2000; Wilcock, 1998) will have a significant impact on a person’s perceived health and well-being (Yerxa, 1998).

Unruh, Smith, and Scammell (2000) described the powerful restorative properties of occupational engagement for persons with life-threatening illnesses. Their research
focused on the occupation of gardening, which, for their participants with cancer, met such needs as “creativity and challenge, preserving memories, and feeling satisfaction in accomplishment” (p. 74). They reported that gardening also provided them with a means of coping with their illnesses through relaxation, sense of control, and diversion from worries. Day hospice programs seek to enable such restorative experiences for persons with life-threatening illnesses.

Within an interpretive framework of doing-being-becoming, the data reported in this article address the following question: What are the occupational experiences of the men and women with life-threatening illnesses attending a day hospice program? We chose this framework to represent these data because of our desire to stimulate and possibly extend our thinking about the layers of meaning of occupation for these persons.

Method
Setting
The hospice where the study took place is a 20-bed facility attached to a general hospital. The hospital, affiliated with the Catholic church, is located in a regional city on the eastern seaboard of Australia. The hospice is the base for a range of inpatient and outreach palliative care services for persons with life-threatening illnesses. At the time of this study, the day hospice program had been operating for approximately 3 years. The program ran 3 days per week, with an average of 20 participants attending weekly. Each participant normally attended only 1 day per week. The primary condition of the program participants was cancer.

One full-time and one part-time occupational therapist coordinated the program. Other day hospice staff members were an occupational therapy assistant, a nurse, and volunteers.

Participants
The experiences of 13 men and 10 women with life-threatening illnesses who were attending the program regularly were investigated over a 5-month period. All participants were middle-aged or older. Most lived in their own homes, receiving daily living support from a family member. The length of time participants had been attending the program (at the time of data collection) ranged from 1 week to 2.5 years.

Procedure
Data were collected through focus groups; participant observation; and individual, semistructured interviews. Although most participants were interviewed both in a group and individually, this procedure was not possible with all because of ill health or death. The first two authors gathered the data because the third and fourth authors were actively involved in the day-to-day running of the program.

Data collection commenced with three focus groups (one for each of the program days), involving 15 participants. Each focus group began with all participants responding to the following question: How long have you been attending the day hospice, and why did you start attending? The discussion then explored such issues as what participants did while at the day hospice, their relationships with day hospice staff members on days when they were not attending, and their views on the day hospice program’s strengths and weaknesses.

Commencing with focus groups enabled us to obtain an overview of the participants’ day hospice experiences in circumstances akin to the social context of the program itself (Hurworth, 1999). Focus groups also were used as a starting point for data gathering to facilitate researcher rapport with each group of participants, most of whom were well acquainted with each other. Each focus group ran for approximately 1 hr and was audi-taped.

An acknowledged limitation of focus groups is that they may constrain participants’ comments on sensitive issues that they may not wish to discuss in front of other group members (Hurworth, 1999). For the program participants, sensitive issues could have included their fears about the future or dissatisfaction with program staff and activities. Therefore, at the conclusion of each group, participants were invited to participate in an audiotaped, individual interview of approximately .5 hr to 1 hr duration. Eight participants were interviewed individually along with another 8 who were not present at a focus group. Discussion within these interviews opened with participants responding to questions about their personal lives, including their health, family supports, and interests. Then participants were encouraged to speak openly about their day hospice experiences. Finally, they were questioned about their wishes and needs for the future.

Data also were gathered through participant observation of the program. The observation sessions ranged from 1.25 hr to 4 hr each (20.5 hr total). Observation sessions were scheduled to include different aspects of the program (e.g., participants’ arrival in the morning, the morning activity sessions, lunch time, the afternoon activity sessions, participants leaving at the end of the day) as recommended by Krefting (1991) to increase the study’s credibility. A participatory approach was adopted to make our presence as researchers less obtrusive and to facilitate understanding of participants’ experiences through personal involvement.
(Lincoln & Guba, 1985; Maykut & Morehouse, 1994). The resulting field notes included both descriptive and reflective components, including notes about our thoughts and feelings prompted by the data collection.

Data Analysis

Data from the focus groups, individual interviews, and field notes were transcribed. Pseudonyms were used in place of participants’ names, and other identifying details were altered. Analysis began while data were being collected, using a process of constant comparison (Bogdan & Biklen, 1998). From this preliminary analysis, issues were identified and then explored in subsequent interviews to clarify and extend our interpretation, thereby bringing greater rigor to the interpretative process (Krefting, 1991). At the conclusion of data collection, a full-scale thematic analysis began with systematic coding of the data.

The rigor of our interpretive process was strengthened through triangulation of data-gathering methods. The individual interviews enabled preliminary interpretations of focus group data to be subjected to further scrutiny. The use of reflexive analysis throughout data collection and analysis phases enabled us to appraise critically our relationship with the data and the study context, taking account of our own preconceptions (Krefting, 1991; Lincoln & Guba, 1985). The preliminary thematic interpretation of data was also subjected to participant scrutiny through member checking (Krefting, 1991). Participants’ comments were sought in response to our oral and written accounts of data interpretation.

Among the 28 coding categories developed in the analysis, 7 addressed the occupationally related experiences of day hospice participants. Frank (1997) posed the question, “Is there life after categories?” (p. 84) and, in turn, observed that after categorization of qualitative data, the researcher’s further analysis based on “theoretic concerns” (p. 85) enables the data to be “recontextualized in the world of social thought” (p. 85). In sifting through our data and considering their representation, we were drawn to the doing-being-becoming framework for its simple, but compelling analysis of various dimensions of occupation. On closer inspection, this framework offered sufficient latitude to encompass the breadth of participants’ occupational experiences without compromise. At the same time, it presented us with the stimulus to consider additional interpretive possibilities in relation to these experiences. Wilcock’s (1998) discussion of being and becoming, in particular, was for us akin to the changing “slant of light” (Beer, 1997, p. 111) that enabled us to subject these data to fresh scrutiny and to produce what we believe is a consequently greater richness of interpretation. Table 1 provides details of the codes delin-

<table>
<thead>
<tr>
<th>Code</th>
<th>Descriptors</th>
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<tbody>
<tr>
<td>PROD</td>
<td>Productivity, feeling resulting from doing and participating</td>
</tr>
<tr>
<td>GO</td>
<td>Having a go, attempting things</td>
</tr>
<tr>
<td>MND</td>
<td>Mind being active</td>
</tr>
<tr>
<td>ACT</td>
<td>Activities, types of and variations in program activities</td>
</tr>
<tr>
<td>LNG</td>
<td>Learning new things</td>
</tr>
<tr>
<td>FGT</td>
<td>Fight illness, not curl up and die</td>
</tr>
<tr>
<td>PP</td>
<td>Personal profiles of participants</td>
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Table 1. Occupationally Related Codes and Descriptors: Their Links With the Occupational Dimensions of Wilcock’s (1998) Framework


eating participants’ occupationally related experiences and indicates how these were subsequently linked with Wilcock’s theoretical framework.

Three Dimensions of Occupational Experience

Wilcock (1998) conceptualized occupation in terms of the dynamic relationship among all the things that people do, who they are as human beings, and their constantly becoming different (p. 248). This interplay of observable actions, inner meanings, and sense of growth and change was present in the data on participants’ occupational experiences. While bearing in mind this interdependence of doing, being, and becoming, the results are discussed under the three separate headings, as Wilcock has done, as an artifact of our intention to explore and represent each of these linked, but distinct dimensions of occupational experience.

Doing

Occupational therapy practice is grounded in beliefs about the importance of doing for health. At the same time, there is a realization that many people in postindustrial societies not only are busy doing, but also, in fact, feel that they are doing too much (Wilcock, 1998). In contrast, persons with life-threatening illnesses may cease doing many of their life’s occupations. What the two groups share is that too much or too little occupation can be detrimental to “well-beingness” (Yerxa, 1998, p. 414). From this study, it was apparent that participants struggled with actual and threatened losses of occupation and that the day hospice program played a role in their striving to maintain their sense of well-being through doing. These issues are addressed in the subthemes of losing and maintaining occupations and preserving physical and mental function.

Losing and maintaining occupations. In their stories, participants told of their varied histories of occupational engagement. All reported difficulties in undertaking tasks
that were previously manageable, as their illness progressed. Substantial variation was found among the participants in the degree of difficulty experienced, their current level of occupational engagement, and the types and ranges of activities performed regularly. Most had become increasingly dependent on others to meet their needs; for some, to perform even the most fundamental and personal of daily occupations was difficult. Under such circumstances, participants seemed determined to do what they could for themselves no matter how little that was. For example,

My newest thing is now my daughter pushes [my wheelchair] into the bathroom, and I can stand up and clean my own teeth. Usually, she used to bring me a bowl; but now, I can stand up and clean my teeth. And to me that’s an achievement.” (Bea)

Participants expressed considerable regret about having to relinquish activities that were valued for the sense of independence they gave (e.g., driving) or treasured for the pleasure they generated (e.g., playing the piano). One participant, a former electrician, spoke of his intense disappointment at now having to pay someone else to do something as simple as changing a light bulb in his house. Several participants who were largely confined to home spoke of the crushing boredom and isolation of their daily lives, from which the day hospice program provided a welcome reprieve. For example,

And just sitting at home, I got very depressed, and I’ll just sit and think, “Well, what’s life all about?” you know. Day after day, it’s the same old grind, you know. So actually, it’s a godsend, I suppose in a way, that I’ve got to this stage where at least I can come in [to the hospice] and have somebody to talk to. (Jim)

Participants spoke with enthusiasm of attending the day hospice and joining in the activities. What were they looking for? As a day away from home and an escape from boredom and loneliness, the day hospice offered a place of refuge and comfort. These aspects of the day hospice experience seemed to be of great importance to participants. However, the activities themselves also seemed integral to the meaning of the day hospice to participants.

Activities ranged from arts and crafts, such as card making, mosaic tiling, and silk-screen printing, to outings to the shops, the beach, or a local vineyard and from gentle exercises for the body or the mind to activities allowing for reflection and discussion of thoughts and feelings. The ethos of the day hospice program was one of participants deciding for themselves whether and to what level they participated in the day’s activities. For example,

As everybody says, you learn to do things—you don’t just sit here and be a blob in the chair—and you do. And it’s lovely to see Tom [another participant] doing something [during the group discussion, Tom was sewing together a small stuffed bear], even though we’re all just sitting watching him. (Sophie)

Yes, that’s right. (Several other participants)

And this is it. Even though you don’t participate, you do participate—even though you think you’re not. (Sue)

Kielhofner and Forsyth (1997) described participation in terms of an individual’s capacity to alter the external world through his or her actions. The participants seemed to consider that their day hospice participation was not confined to the world of tangible objects and overt actions. They could legitimately do by sitting and watching others in action; they regularly commented on the importance to them of having this choice over what they did, which was respected by day hospice staff members. Dawson’s (1993b) day hospice study similarly identified the importance of occupational therapy intervention that responds to patients’ need to exercise choice and experience a sense of control in the face of a life-threatening illness.

Preserving physical and mental function. Dawson’s (1993a) single-case study of a man attending a day hospice program identified his desire to maintain as much independent functioning as possible in the face of declining ability. For several participants in this study, the craft activities were accorded value (akin to a “maintenance therapy”) for keeping their hands moving and their muscles from wasting. For example,

I mean I can’t use my hands that much really, but I use them for what I can do. Like we did those paintings—hand paintings—and different things and wooden boxes. We were going to make jewelry boxes, you know…and painting them. I’ve used my hands a little bit doing that sort of thing, which has given me a little bit more use in my hands than what I thought I had, you know. (Ray)

Like the craft activities, a morning exercise session was identified by several participants as important for their maintenance of physical capacities, an issue Bray (1997) also identified as important in her discussion of occupational therapy hospice services. A different “physical therapy” for some individuals, however, was the pleasure of having their bodies pampered with spa baths and massages for pain relief and relaxation, remedies also valued by Dawson’s (1993b) study participants.

More “cerebral” activities had a special significance for a number of participants as “mind games” in the sense that they engaged participants to keep their minds active. They feared that without this conscious effort to use their minds, their mental agility would diminish. For example, participants in one focus group commented,

I work on my crosswords for brain exercises ’cause if it’s not used, it will curl up and die also. (Tom)

We do different sorts of things like “words”…make quotations or whatever you call it. Because I mean we might be
disabled in one way, but we've still got brains, and you can't let that go to sleep, can you! (Bea)

Bray (1997) identified the importance of attending to day hospice participants' cognitive skills as part of maintaining their occupational functioning. In discussing the occupational nature of humans, Wilcock (1995) stated that “the brain's many systems drive, motivate, facilitate, support or influence the need to engage in occupation which in itself forms an integral part of inborn biological systems aimed at survival and health” (p. 69). Although the day hospice activities were not necessarily designed and prescribed specifically for the achievement of such therapeutic goals as improvement of hand function or maintenance of cognitive skills, some participants apparently valued them for such therapeutic properties that were highly meaningful to them.

Thus, two manifestations of the experience of doing were found for the study participants. These manifestations related to their concerns about losing and maintaining occupations and to their efforts to preserve physical and mental functioning. With regard to the former, just as Wilcock (1998) identified doing as a fundamentally human enterprise of the mind and body and as a means of fostering social interaction and a sense of community among individuals, so these participants described the significance of the day hospice program for them as a refuge from boredom and isolation. With regard to preserving function, participants attributed meaning to doing that fostered their exercising of mind and body, which echoes Wilcock’s identification of occupation “as the natural biological mechanism for health” (p. 248).

Through the doing of occupation, participants strove to maintain a sense of well-being in the face of illness. A notable feature of some participants’ experience of doing, though, is their sense that participation was not restricted to observable actions and tangible outcomes but extended to watching others in action. This notion of “observing from the sidelines” as a legitimate form of participation represents an interesting expansion of the typical understanding of doing discussed by Wilcock (1998).

### Being

Beyond the more visible (and, thus, more easily understood) actions of doing an occupation lies the experience of being. According to Wilcock (1998), being is concerned with the “self” and the “essence” of the person. The notion of being ranges from our sensuous savoring of the moment to the deeper experiencing of our inner selves, all of which can be facilitated through occupational engagement. For many people in postindustrial societies, the busy-ness of doing may largely preclude the experience of being. Like an antidote to the pent-up pressures of doing, people may seek out doses of overtly being-centered activities, like meditation and yoga, while at the same time rationing “quality time” to human relationships that underpin their being. Interestingly, facing death may provide people with the stimulus to pursue and experience a greater sense of being than they might have ordinarily sought to do. Within the occupationally related experiences of the study participants, various elements of being were represented in their narratives, ranging from their descriptions of the simple pleasures of day hospice involvement to their revelations of an enhanced sense of self that was stimulated through program activities. These elements are discussed as the two subthemes of relationships for pleasure and worth and a voyage into the self.

**Relationships for pleasure and worth.** Within the overarching occupation of being a day hospice participant, many small but important manifestations of the humanness and worth of these persons with life-threatening illnesses were found. These manifestations were an integral, yet subtle element of occupational engagement in program activities (e.g., the welcome greeting they received when they arrived in the morning, the attention given to making people comfortable as they sat in a chair during an activity, the gentle use of touch, the caring tone of voice staff members used when communicating).

It was apparent from participants’ comments that relationships were central to the functioning of the day hospice. They spoke appreciatively of their relationships with day hospice staff. For example,

> They treat you as an individual but also as part of the team. Like Lena [another focus group participant] was saying: You're like a family, like one happy family—and that's how they treat you. They treat you as an individual, though—but you're all in together, which I think is important. (Ray)

Staff members were consistently identified as being helpful, kind, and compassionate. In addition to paid staff, a team of volunteers was attached to the day hospice, some of whom participants came to regard as friends. Several of the volunteers helped with the activity program, while others transported participants to and from the day hospice. During the interviews, participants regularly described the enjoyment they derived—and alluded to the sense of dignity and worth they gained—from their relationships with day hospice staff.

Equally importantly, fellow day hospice participants were valued for the friendship they offered and the sense of belonging they shared. For example,

> [Coming to the day hospice] is one of the best things I've ever done. I have met so many friends. We've had outings, sort of picnic-type things. Well, it's altered the whole course of my life, you know. I've always sort of—I reckon I'd just...
become a vegetable and nothing else. I think the main thing is the friends I've made. I've made some lovely friends here. (Frank)

The importance of the socialization and mutual support among persons with life-threatening illnesses has been identified in other studies of day hospice programs (e.g., Dawson, 1993a; Holland, 1984). Relationships among participants and between participants and staff members, which were fostered through the program activities, in turn facilitated activity participation and enjoyment—a reciprocal relationship. As Egan and DeLaat (1997) stated in their discussion of spirituality, “It is through our occupations that we live out the relationships that bring meaning to our lives” (p. 116).

The sense of being experienced through day hospice participation extended beyond the experiences of compassion and support in relationships to humor and laughter. For example,

And we laugh a lot. (Tom)  
Of course we laugh a lot. (Sophie)  
Yes. (Pam, Frank)  
That’s what we’re sent here for. And if we can’t make fun and enjoy our life now, then we never ever will. And that’s what we’re going to do: enjoy what we’ve got left. (Sophie)  
That’s right. (Pam)

Among the characteristics of occupation identified by Yerxa (1998) are that occupation be self-initiated, self-directed, productive for the person, and contributing to others. Yerxa noted that productivity extends beyond the visible product to the intangible outcome of enjoyment. More than any other characteristic of the day hospice program, a sense of enjoyment was the feature that participants consistently identified as integral to the day hospice experience. The irony of persons with life-threatening illnesses having fun while society construes them and their situation in overwhelmingly negative terms was not lost on these individuals who identified their own initial reservations about coming to a place they imagined only as a repository of people’s pain and despair.

The social climate created by staff members and participants—particularly the sense of support, belonging, and overall enjoyment—was a vital ingredient of the day hospice program. Just as the social environment is recognized in occupational therapy practice models as a key determinant of occupational behavior (e.g., Kielhofner, 1997), so the social context of the day hospice program was clearly pivotal to the sense of being participants experienced in their occupational engagement. It was clear that their willingness to try unaccustomed activities and the ensuing pleasure were entwined with the “therapeutic milieu” created by staff members and fellow participants.

A voyage into the self. Among the many activities within the day hospice program, some were designed to enable participants to reflect on aspects of their lives and, if they wished, to give voice to their feelings about them. At the very least, such reflective activities could offer participants a novel experience and a pleasurable affirmation of themselves as persons. For example,

What have you done since you came here [to the day hospice] that you wouldn’t otherwise be doing? (Interviewer)  
Well, like having a bit of a talk and a drawing about my past history—of the main things that’s happened to me in my life. We cut out drawings and all those sort of things: pasting things and all that sort of thing. But you use your imagination; and I just went back to my teenage years—what I enjoyed most—and I just put it on my drawing, all that type of thing. It seemed to come out you know after a while. When they first put it in front of me, I said, “Oh, I couldn’t do that!” Gradually, these things seem to come together, you know. (Chris)

Unruh (1997) offered an interpretation of spirituality as “an internal state of being that permits the individual to stand apart from everyday life to reflect on one’s place in that life. Engagement in some occupations may facilitate this internal state” (p. 157). The potential of expressive media to facilitate a process of self-exploration; discovery; and, possibly, healing has been well described elsewhere (e.g., Wilson, 1996). It was clear that the program activities gave participants opportunities to reflect on their past, present, and future in order to place their current experiences of illness within the broader context of their lives. Sometimes, though, people may just have wanted to savor the moment, reliving happy life events without dwelling on deeper feelings.

Beyond this savoring of the moment, Yerxa (1998) identified other spiritually nurturing elements of occupational engagement, including the pleasure derived from a sense of achievement. The importance of this sense of achievement to some participants’ sense of well-being was readily apparent. For example,

Well, I’ve got no feeling in me hands, and it helps me a bit to try to do all of this [craft activities] because I didn’t think I’d be able to do anything really. I only do what I can do. But it does help me a fair bit; I wouldn’t use my hands. Even if it looks shocking at the finish, I’m still using me hands, which helps me within myself too, which is good. (Ray)

The sense of achievement? (Interviewer)  
Yeah. Whether it looks good, bad, or indifferent, at least I’ve tried to do something, or I have done something I didn’t think I’d be able to do. (Ray)

As identified earlier in this article, many of the study participants struggled with their loss of independence and
an associated loss of self-worth as their illnesses progressed. This struggle was poignantly illustrated by two participants who talked about having to surrender their driver’s licenses, acts which seemed to erode the very core of their being: “It drove it home again that I’m not a real person.” This experience of loss seemed to be lessened by the meaning derived from engaging in the various day hospice activities. For example, with Ray, the meaning of the craft activities lay both within their physical requirements and the sense of accomplishment he felt, regardless of the quality of the product; both contributed to his sense of self as still possessing competencies in spite of declining function.

Although Wilcock’s (1998) conceptualization of being acknowledges its contribution to human relationships, her view of the concept is focused more on an individualistic sense of self than on a collective one. For study participants, however, the experience of being through occupation appears strongly linked with the social milieu in which the occupational engagement occurs—in this case, the social climate of the day hospice created by other persons with life-threatening illnesses and by day hospice staff.

In addition to the part of the experience of being that is stimulated through pleasurable, valued relationships, several of the study participants described how the various day hospice activities provided opportunities to reflect on their current circumstances within the broader context of their lives. At other times, activity participation gave rise to a sense of achievement that helped to counter their sense of loss of self associated with their functional deterioration. Wilcock (1998) described the fundamental importance of reflection and self-discovery to individuals’ enhanced sense of their own being. At the same time, she cautioned against an overemphasis on achievement at the expense of being at peace with our inner selves, a question of moderation in our expectations of ourselves.

Wilcock’s (1998) representation of being through occupation is closely related to the concept of spirituality discussed in the occupational therapy literature. Both seek to give expression to the inner person and the making of meaning that were apparent in the study participants’ experiences, particularly through the relationships between day hospice staff members and participants and through the reflective processes fostered by program activities.

Becoming

Wilcock (1998), Townsend (1997), and others described the transformative potential of occupation whereby people develop and change through occupational engagement. This ongoing process of becoming through action is regarded as essential for health. For persons with life-threatening illnesses, the sense of a future (which, of course, is unavoid-
A foundational belief of occupational therapy is that of the beneficial effects of occupational engagement on people's health through the sense of meaning, discovery, and creative contribution they can experience in occupation (Yerxa, 1998). However, a healthy state of wholeness and adaptation “does not require freedom from pathology” (Yerxa, 1998, p. 414). This group of persons with life-threatening illnesses not only acquired new skills and ideas in some of these activities, but also uncovered a renewed and exhilarating sense of their capacity and usefulness in the midst of their illness. As Yerxa (1998) noted, through engagement in meaningful, satisfying occupation, people are able to transcend very difficult circumstances in which they may find themselves.

Making a contribution. Many participants expressed appreciation of family members, friends, volunteers, and others who supported them throughout their illness. The very act of coming to the day hospice was often represented as their gesture to caregivers, the gift of “time out” from the constant demands of caregiving.

However, the participants viewed the day hospice activities themselves as a vehicle for giving something of themselves to others. For example, one participant drew on her history of experience with crafts to find activity ideas and items from her home that might be used in the day hospice program:

Like it’s coming back that I can contribute. Yeah, I mean even just bringing that page of that [craft] book for [a day hospice staff member]. It’s a little bit of being able to contribute to...you know, they might not use it for 3 months. It doesn’t matter. People have to program and things like what they are going to do. Yeah. And it’s just that when I see them like today doing the mask-making, there’s probably quite a bit I can contribute. (Sarah)

Sarah seemed to place great value on her capacity to contribute to others’ enjoyment and well-being. Her rediscovery of this capacity, which had been severely curbed with her progressive loss of functioning, appeared to offer fresh purpose and meaning in her life: a renewed sense of becoming stimulated by profoundly simple acts of doing.

As previously discussed, a consistent thread through the fabric of participants’ stories was their strong identification with the group of people with whom they attended the day hospice regularly. Among the many manifestations of this group identity was the sense of responsibility expressed by some participants such that they joined in day hospice activities out of a desire to be “good corporate citizens” by responding to other group members’ needs. For example,

Like I feel if you weren’t supportive, it [the day hospice program] could fold up, and there would be so many unhappy people. (Bob)
You mean supportive in what way? (Interviewer)
Attendance, and I take part in so many activities, if possible. (Bob)

To Bob, his attendance and participation in the day hospice program contributed substantially to the well-being of the group. Holland (1984), a clinician working in a day hospice program, observed that participants “progressively begin to look to the needs of each other and to achieve a sense of belonging” (p. 347). Other participants described contributions that took the form of items they made (e.g., mosaic pots, decoupage) as gifts to give to family and friends or as small mementos (e.g., teddy bears, greeting cards) to be left behind after they died. These contributions were identified as important reasons for their activity participation.

Occupational behaviors such as these can transform a person’s self-concept and social identity (Kielhofner & Forsyth, 1997), helping to counteract the psychosocial effects from loss of other occupational roles with the onset of serious illness (Cusick, Lawler, & Swain, 1987). Wilcock (1998) identified the importance of our becoming aware of our own strengths and talents if we are to realize our potential. This aspect of becoming was apparent in our study participants’ experiences not only with discovering new and satisfying occupations to engage in, but also in exploring what they might still “do for others” (Wilcock, 1998, p. 252) in spite of their illness. Thus, the day hospice program activities (and the actions of the occupational therapy staff members facilitating them) appeared to be an important part of the process of becoming for these persons with life-threatening illnesses.

Conclusion

Although a desire to grasp the complexities of human occupation and a mission to harness its restorative powers have been at the core of occupational therapy practice since its inception, recently there has been a renaissance (Whiteford et al., 2000) of enthusiasm for critically exploring occupation. This study arose from the authors’ interest in the occupational nature of a group of persons with life-threatening illnesses, couched within the group’s experiences as day hospice program participants. We have framed our discussion...
around a doing-being-becoming conceptualization of occupation by Wilcock (1998), who as one of the new generation of occupational scientists is striving to breathe new life into the profession’s occupational gaze.

Our data offer fresh insights into the potential benefits of occupational engagement for people dealing with life-threatening illnesses and suggest the importance of day hospice occupational therapy services to palliative health care. First, life-threatening illness and others’ responses to it may cause people to cease doing many of their life’s occupations. Major issues for the study participants concerned losing and maintaining occupations and preserving physical and mental functioning. Through the doing experience of occupation, they strove to maintain a sense of well-being in the face of illness. Second, participants’ experiences of being ranged from the simple pleasures of day hospice involvement to the enhanced sense of themselves stimulated by program activities. Their varied expressions of a desire to be as fully as possible indicated the importance of attending to the spiritual domain within the day hospice program. Finally, occupational engagement provided participants with a sense of becoming through unexpected learning experiences and opportunities to contribute to the welfare of others. As Wilcock (1998) stated, “Occupational therapists are in the business of helping people transform their lives by facilitating talents and abilities not yet in full use through enabling them to do and to be” (p. 251).

We recognize that our use of Wilcock’s (1998) doing-being-becoming framework (in a deductive fashion) to represent these occupationally related data (which were initially analyzed inductively) is contentious. It is reasonable for readers to ask, “Have these data been manipulated to fit within Wilcock’s structure (akin to the ugly sister squeezing her foot into Cinderella’s glass slipper) at the expense of the ‘truth value’ of the data (Krefting, 1991)?” We believe that rather than compromising the data interpretation, use of this framework “as a focus for more intense insight” (Frank, 1997, p. 89) has enriched our analysis.

Like the changing slant of light from a window into a darkened room alters the observer’s appreciation of the form and substance of the room and its contents (Beer, 1997, p. 123), so our use of this framework extends our analytical “eye of the beholder” (Hasellkus, 1997, p. 82) in exploring possible meanings of the study participants’ day hospice experiences. This extended analytical gaze was particularly apparent with our consideration of the more existential dimensions of their occupational experiences, namely, those related to being and becoming through occupation.

However, our analysis not only has been aided by Wilcock’s (1998) framework, but also has contributed to it. Our study puts empirical data on the “skeleton” of her theoretical framework while also adding to her description of various concepts. For example, in relation to doing, participation for these persons with life-threatening illnesses moved beyond observable actions and tangible outcomes to include “observing from the sidelines” as a legitimate form of participation. Furthermore, our study participants’ occupational experiences extended the more individualistic focus of Wilcock’s conceptualization of being to a collective sense of self linked with the social climate of the day hospice.

Although we recognize the inherent risks of the analytical approach we have taken and acknowledge the fallibility of any such exercise in human reasoning, we believe the end more than justifies the means. Stimulated by Wilcock’s (1998) vibrant account of fundamental occupational therapy principles, our analysis adds substantive evidence of the contribution of occupational engagement to human health and well-being, particularly in affirming life while people prepare for death (Bye, 1998).

References


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