Occupations and Signs of Reduced Hope: An Explorative Study of Older Adults With Functional Impairments

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Objective. The purpose of this explorative study was to uncover and interpret the experiences, values, and meaning of being in daily occupations of older adults with functional impairments.

Method. Interviews were conducted with 21 older adults with disabilities who were between 70 and 92 years of age. The interviews occurred in their home environments; 18 of the 21 participants lived alone. The interviews were analyzed using a constant comparative approach.

Findings. Occupational themes related to participation against the odds, retreat from occupation, the need for an invitation from others, and personal meanings related to capacities for occupation were uncovered.

Conclusions. The findings suggest that the loss of positive belief in enjoyable occupations can be a sign of reduced hope in late life. For occupational therapists, whether an older adult has made a conscious choice to withdraw from occupational life or has too few occupational choices is important to distinguish.

We can understand more about how people experience occupations by studying how they engage in them daily (Clark, 1993; Kielhofner, 1995; Larson & Fanchiang, 1996, Mattingly & Fleming, 1994; Spencer, 1993; Zemke & Clark, 1996). Clark (1993) demonstrated how occupations provide a positive influence on a person's self-image, whereas Primeau (1996) showed how running as an occupation has multiple meanings and therapeutic outcomes for a person. Occupations have the potential to provide increased self-knowledge of capacity and sense of efficacy, which may, in turn, lead to an increase in confidence and pleasurable participation (Clark, 1993; Hasselkus 1998; Kielhofner, 1995).

Naturally, a strong relationship exists between disability and what a person does in terms of occupational engagement. Tham, Borell, and Gustavsson’s (2000) study of persons with unilateral neglect provided examples of how occupations serve as important means for some clients to come to grips with impairment and how occupations aided these clients both in their recovery and in their ability to handle everyday living situations. Nygård, Borell, and Gustavsson (1996) found that for two women with dementia, performance of chosen occupations afforded relief from experiences of incompetence. Still, exploration through empirical research of the concept of occupation in relation to people's sense of well-being has just begun.
The purpose of this explorative study was to uncover and interpret the experiences, values, and meaning of being in daily occupations among a small number of older adults with functional impairments. Occupational behavior, or human occupation, can signify meaning in daily life (Borell, Gustavsson, Sandman, & Kielhofner, 1994; Nygård et al., 1996; Rowles, 1991). Ricoeur (1991) argued that humans use symbols, signs, letters, and texts as a way to communicate meanings. Hermeneutics provides an approach for interpreting a person’s experiences of his or her daily life in which the person is regarded as a subject with intentions to act and grasp the life world. In this study, we sought to uncover and comprehend what is of importance in the occupations of 21 older adults with disabilities living in Stockholm, Sweden.

Method

Design

As a part of a larger study of occupational therapy for older adults living in the community, the interviews reported here were conducted with 21 participants. All persons who were more than 65 years of age and had been inpatients in a geriatric clinic in Stockholm sometime during a period of 3 months before the study were invited to participate. Persons observed by the clinical occupational therapist as having symptoms of dementia, those who had been hospitalized, and those who were currently unwell at home were not included. Seventeen women and four men gave informed consent to participate in an interview study in their own homes after the study was approved by the hospital ethics committee. The focus of the interviews was on how the participants spent and experienced time in everyday life. All interviews were tape recorded. The 60-min to 90-min interviews were sometimes supplemented by a tour of the participants’ homes, if offered, to facilitate rapport. Thus, the total amount of time spent in each participant’s home ranged from 2 hr to 2.5 hr.

Participants

The participants ranged in age from 70 years to 92 years ($M = 83$ years). They lived in one area of Stockholm in independent or “service block” apartments. In Sweden, an apartment in a service block is part of the differentiated care for older adults and persons with disabilities that is provided by the local community or run by a private company. A service block typically includes small apartments, a restaurant, and an activity center. Organized activities (e.g., bingo, physical exercise) often take place in the activity center. Older adults who need domestic support can get it from service block home-help aides as well as from nurses and occupational therapists; sometimes physical therapists are also available.

The occupational therapists in the clinic from which all study participants had been discharged reported the circumstances of each person’s last hospitalization to the researchers. Stroke, rheumatoid arthritis, and fractures were the most commonly experienced conditions. One participant (Elsa) had symptoms of depression. Most participants lived alone, but three lived with a spouse. Fifteen received home-help services, whereas most of the other participants occasionally received help from relatives. Nine participants needed wheelchairs for mobility outside the home.

Data Analysis

The interviews were transcribed verbatim and analyzed using a constant comparative approach (Bogdan & Biklen, 1992). The transcripts included more than 600 pages of text. We first read all transcripts several times to obtain a good overall understanding of each participant’s situation. We then coded all data identified as containing meaning about occupation. Data irrelevant to the purpose of the study (e.g., statements about a stay in the hospital, personal opinions on the cost of living or political issues) were deleted. Using a constant comparative approach, codes with the same meaning “units” were grouped together into themes. These themes were (a) participation against the odds, (b) retreat from occupations, (c) the need for an invitation by others, and (d) capacities as occupations.

The themes led us to make further comparisons and to repeat searching for similarities and differences among the participants. The differences led to questions and a return to the transcribed interviews for possible explanations. For example, we asked whether the participant differences in interests in occupations and how time was spent were related to physical capacity.

After formulating the interpretations in writing, we met with colleagues familiar with qualitative analysis and the constant comparative approach to data analysis to discuss the findings and examine their consistency by rechecking all data against the interpretations. We discussed the findings and interpretations several times before the most fruitful interpretations for understanding the data were identified and accepted.

Findings

In a first attempt to compare the data, a figure of four quadrants was developed (see Figure 1) that was based on all the participants’ interests in occupations and where these occupations took place. The four groups led us to repeated searching for similarities and differences across the participants and groups and finally to identifying the themes presented here.

Participation Against the Odds

Some participants described occupations that were still meaningful for them and in which they participated regularly in spite of physical limitations (see Figure 1). For example, Greta, who had experienced a stroke, said, “I
enjoy making bread so much that I have to do it almost every day, even if it takes me some time.” These participants were regularly occupied with leisure activities that they enjoyed with others, such as group activities, bingo, and gymnastics. They also took walks and visited shops in the neighborhood. All of these participants reported that they could still “do” activities they liked.

Some participants with serious medical conditions, such as stroke and rheumatoid arthritis, initiated and participated in leisure occupations as if doing such was against all the odds. Astrid, Olga, Lars, and Stina occupied themselves in various meaningful ways every day, despite the fact that they had physical impairments. Astrid, who highly depended on home-help and spent most of her time in a wheelchair, actively asked about the possibility of doing enjoyable things. For example, she asked for help to visit a restaurant and the local library.

Astrid, Olga, Lars, Stina, and Greta all kept positive interest in occupations. Greta participated in organized physical exercises once a week and liked them a lot. She had arranged for herself to get more training in another place close to her home. At home, she was fully occupied in making all the bread she needed. Lars, who could only use one side of his body, cleaned his apartment twice a week by himself. Stina had severely restricted joint range, but she participated in and enjoyed bingo as an outside venue twice a week.

In spite of loss of functional abilities, these participants were driven by and maintained the positive expectations that were needed for continuing the occupations they liked and wanted to do. The diagnosis or the physical incapacity was not the main factor that determined their involvement in “doing.” Physical impairments were not handicapping their participation in chosen occupations. The findings revealed, however, that this was not the case for all of the participants. As might be expected, some of the participants who experienced functional limitations withdrew from occupations that were hard to perform independently.

Retreat From Occupations

Some participants demonstrated no sign of an interest to take part in or to initiate occupations. Even when asked, Florence, Ingrid, Nanna, Kurt, and Ulla were all unable to mention any interesting or pleasurable occupation in which they engaged (see Figure 1). These participants showed no sign of positive expectations from occupations. For example, when asked about what a really nice day would include, none of these participants expressed belief that they could have a nice day anymore, nor did they give any examples of what a nice day could include or of an occupation that was meaningful to them. We then started to wonder how these participants, who stated that they had no interests and that each day was spent mostly without any type of active occupation, could be best understood.

Some answers were found in what Martin, Vera, and Rut reported (see Figure 1). Watching or listening to television was the only occupation mentioned in relation to what occupations an ordinary day would include, apart from activities related to meals and personal care. Watching television can be a very meaningful occupation for persons who favor it; however, Vera and Rut did not much appreciate television, even if they spent many hours in front of it. Rut’s way of formulating this was, “TV is just a way of letting the time pass by.” To “just let time pass by” can be interpreted to mean passively filling time rather than choosing to actively do so. This statement was also significant for those participants who gave no examples of positive belief or pleasure related to participation in occupations, such as Kurt who said, “I have totally lost the feeling of pleasure, it’s not there any more.” Rut stated, “It’s a long time since I wished for something pleasurable to do. I do not have a desire for anything.” Such negative state-
ments where the outlook for the future was colored by an absence of delight and interest in doing things were typical of these participants.

The Need for an Invitation From Others

Some participants still desired to do “nice” things, yet we discovered that many never actually acted on their desires. Nanna, who was accustomed to managing her own occupations, said, “The worst thing is that I cannot go shopping, and I love shopping.” To our surprise, she never asked for help to go shopping; her statements appeared to be simply wishful thinking rather than actually trying hard to bring her desire about. We found several examples of the same phenomenon where the participants who mostly lived by themselves seemed to wait for someone, a relative or a professional caregiver, to invite them in order for meaningful occupations to take place in their daily lives. However, this proactive form of support from caregivers and professionals was not apparent.

Most of these participants also stated that they often felt lonely. Not even the adapted environment (the service block) with its professional staff appeared to be an adequate or accepted support to these participants. We also found that those participants who had not expressed positive beliefs about occupations and who felt lonely almost never spent time outside of their own apartment. They did not participate at all in activities that took place in the service block, which were easily accessible to persons with mobility problems. In contrast, the participants with a more positive view were able to leave their apartments to participate in activities by asking for help.

Capacities Are Occupations

Participants often described and related the experience of capacity and different types of physical body experiences to the performance of occupations. One might predict that a body sensation such as pain or impaired vision would be described in bodily terms, but instead, the participants linked experiences of both well and impaired body functions directly to occupational performance. Experiences of physical impairment were embedded with occupational meaning; in other words, bodily complaints were described in relation to an occupation—the doing of things. For example, Cecilia, who experienced impaired vision, described the extent of her impairment as, “I cannot see enough to clean my apartment.”

Although all of the participants had medical problems, their descriptions of their illness experiences were not couched in medical terms. On the contrary, they referred to occupations when they wanted to explain how well and independently functioning they were. Beda, who was recovering from a fracture, said, “I can take the ferryboat to the museum by myself,” and Dagmar, who had broken her left arm some months earlier, said, “When it gets warmer, I am going to take the bus by myself.” Occupations served as a unique personal construct for the meaning of the physical limitation or for the enhanced ability experienced by the participant in recovery. When asked why she chose caring for her apartment as a point of reference for the meaning of her limitation, Cecilia said that she felt very bad about not being able to clean and that the apartment’s tidy appearance was important to her. The references made to occupations seemed to reflect concern for the occupations that were significant or enjoyable to the participant.

Paula stated, “Sometimes I feel so much pain that I am unable to take a walk.” When we compared this to Rut’s statement of her pain, “Sometimes I feel so bad that I am unable to raise my head from the pillow,” we discovered differences in how these women expressed their pain in relation to their occupations in daily life. Paula’s life world included such occupations as taking walks, spending time outside of her own apartment, and participating in bingo in the local community (see Figure 1). Rut never left her apartment and spent most of the day in bed. We needed then to explore whether there were differences in how the participants who seemed to have reduced positive beliefs described their physical capacity compared with those who demonstrated more positive beliefs in occupations.

Among the participants who could not find anything interesting or meaningful with which to occupy themselves, physical incapacity played an important part in their daily experiences. Moreover, we found that these participants demonstrated grief and sadness related to experiences from the incapacitation of their bodies, but the grief was related not only to loss of physical capacity, but also to bereavement for the important occupations that had become hard or impossible. For example, Florence, who really “loved” reading, experienced a significant loss of an important occupation when she was prevented from reading because of pain. She said, “I feel so much pain that I am unable to hold even a book.” It is easy to understand what this meant to Florence because she had experienced many losses, including the death of all her old friends. She said about reading books, “This [reading] is what was left for me, but now I cannot even do that.” Vera also experienced a loss of physical capacity. She lost the use of her hands from the effects of rheumatoid arthritis and spoke of her hands as “dead parts of the body,” stating that now, “I just wait for the Lord to take me home.” Such statements as it was “no use any more” indicated that Vera perhaps felt useless, as if she had no hands.

Summary

Thus, some participants continued to participate in occupations they enjoyed and were so determined that they asked for help to do them. Others seemed to have lost enthusiasm or pleasure for their occupations which, combined with lack of offer from professionals to help, led to
the passive filling of days and the reduction in pleasure. All participants interpreted their capacities in terms of occupations they could or could not do.

Discussion

Four themes of meaning were uncovered in this study. The occupational themes were related to participation against the odds, retreat from occupation, the need for an invitation from others, and personal meanings related to capacities for occupation. Participants reacted toward occupations in essentially two different ways. Some continued their occupations in spite of their disabilities, maintaining a positive sense of drive for, or hope in, continuing the occupations they liked and wanted to do. Others seemed to retreat from their occupations.

The participants who could not identify any interests and who did not initiate activities even when they wished to suggests that the loss of determination and positive belief in enjoyable occupations may be a signal of reduced hope in late life. Hope is defined here as a general state of positive belief about the future. Hope is based on the past, present, and future and helps an older adult manage daily life (Spencer, Davidson, & White, 1997). Because this study concerned older adults with functional impairments, creating a positive illusion of life in order to endure and enjoy it might be a part of having hope. Hope can be seen in the context of an older adult’s doing in everyday life or seen as the will to try within, or even beyond, the limits of his or her own possibilities.

Hope has been previously explored in occupational therapy research. Spencer et al. (1997) described the cognitive and emotional dimensions of hope, including the ability to imagine possibilities, to establish goals, and to demonstrate intentions and will. According to these criteria, some of the participants in this study could be seen as having reduced hope. They lacked intentions and will for occupations. Hope can be seen as a part of will, which helps in the present and directs to the future.

In research related to health care for older adults in general, hope has been found to be influenced by age, energy level, place of residence, functional ability, and health status (Herth, 1993). In a study of hope among older persons after stroke, Bays (1996) found that active participation in occupations, inner strength, previous abilities, and mobility were manifestations of hope. The participants in the present study who demonstrated signs of reduced hope suffered negative experiences of the impaired body and what that meant in terms of enjoyable occupations they had to give up. The loss of both physical capacity and occupations seemed to contribute to the experience of reduced hope. Empirical studies on hope and older adults with disabilities are frequent in cancer research. McGill (1992) investigated how functional status related to hope in older adults with and without cancer and demonstrated that declining physical health (which may be seen as declining occupational capacity) was the major threat to hope in these persons.

We discovered that several participants in the present study waited for someone (a relative or caregiver) to offer help or invite them to participate in order for meaningful occupations to take place in daily life. Such invitations rarely occurred. This reluctance to seek assistance is of importance to occupational therapy because it implies that many older adults may never initiate or ask for services unless they are invited to do so. This finding also suggests that occupational therapists need to be aware of and sensitive to undertones in statements from older adults. Occupational therapists have long held assumptions that the ability to engage in pleasurable occupations affects a person’s hope for the future. For example, Gray (1998) described how occupations performed with purpose and meaning have positive psychological and emotional effects. A discussion within occupational therapy on how to support persons who experience lack of or reduced hope may generate understanding of ways to enhance hope in older adults with disabilities.

Occupational therapists can also learn from Hasselkus, Dickie, and Gregory (1997) who stressed that therapists in the care of very old persons need to value the here and now and to accept the older person’s move toward death. Occupational therapists need to be cautious in both research and practice that the view of an active lifestyle filled with lots of daily occupations does not become an ideal that we try to impose on older adults generally (Tornstam, 1992). We also need to accept the presence of death and grief and reduced hope in older adults’ daily experiences, providing time and space in practice for sorrows and sadness (Spencer et al., 1997).

Spencer et al. (1997) showed that providing hope must be seen as a complex and collaborative process in occupational therapy. Perhaps occupational therapists need to incorporate the two constructs of hope and occupation to a larger extent into everyday practice with older adults, especially if the loss of hope is a major threat to well-being (Herth, 1993). It might be important for therapists to learn more about how the loss of hope is experienced, manifested, and demonstrated in occupations among older adults with decreased functional abilities. For occupational therapists, distinguishing when a person has made a conscious choice to withdraw from some aspects of an occupational life and when a person feels a sense of loss related to having too few occupational choices is important. In the latter case, therapists might need to help create new opportunities for the person to widen the choices in his or her life.

A limitation in this study is that the researchers met the participants only once, whereas a second interview might have provided more details about contacts with family and
friends and about the context of support from community services. A clearer picture might have emerged regarding the feelings of loneliness that the participants briefly mentioned. The social dimensions could be further explored in new studies of hope among older adults. The length of time since the onset of participants’ disabilities might also have affected the results. Perhaps the participants who seemed to have positive belief in their occupational possibilities had had a longer time to restore hope. These interpretations need further study. Additional interviews following analysis of the first ones might have helped explain the participants’ different experiences and beliefs about their participation in enjoyable occupations.

Conclusion

Occupations provided a fruitful reference for both the experience of impaired body function and the experience of well functioning among the participants in this study. The common reference made to occupations led to a search for new understanding about why some of the participants initiated doing, whereas others did not. In seeking to understand why the participants chose to occupy themselves the way they did, we discovered that occupations served as personal, unique constructs for both the meaning of physical limitations and the enhanced abilities of the participants. The descriptions of how and where the participants spent time in daily living helped us to see that these behaviors related to occupations had special meaning for each individual. As Ricoeur (1991) has stressed, it is only possible to fully understand a person when the spoken word can be related to something (i.e., when the text has a reference or a context). In this study, occupations served as the context, the reference for understanding the illness experiences of these older adults. ▲

References


