

Research Report

Adaptation of daily life functioning after disability

— the case of Dutch older persons —

Peter BONTJE *Department of Occupational Therapy, Faculty of Nursing and Rehabilitation, Aino University*

Abstract

An extensive geriatric and medical body of knowledge exists to inform occupational therapy practice about possible adaptive strategies used by older people. Usually the focus is on specific disabling conditions, without taking other characteristics of the individuals' situations into account. The purpose of this study was to explore adaptation of functioning in daily life activities from the point of view of older persons with disabilities. For this study, adaptation was defined as "overcoming disabling influences on functioning in daily life activities". **Method:** Phenomenological (open in-depth) interviews. The informants were eight older Dutch persons with physical disabilities, who were receiving occupational therapy at home or in day-care). **Results:** 1) Descriptions of adaptation as a process that required these clients' active engagement: The clients used problem-solving strategies familiar from their past and personal resources as well as resources in their social and physical environments. Adaptation started with identifying prospects of potential solutions, followed by creating solutions to overcome constraints on occupational functioning. 2) The phenomenological analysis also resulted in descriptions of outcomes of adaptation. Adaptation was aimed at finding satisfaction through occupations. Satisfaction through occupations was found in maintaining daily routines and engaging in fulfilling occupations. 3) Finally, the analysis produced four meaning-dimensions that express how personal values influenced the adaptive processes. These were: "quite an endeavor", "that's the way I do things", "to lose a part of oneself", and "maintaining directorship". Recommendations for supporting older persons with disabilities were formulated, such as fulfillment as outcome-indicator, instilling hope and expectations, practice-situations that include family or other relevant persons, building on familiar problem-solving strategies, and the utility of narrative approaches.

Key words: adaptation, occupation, phenomenology, older people, the Netherlands

Introduction

Since its inception as a medical profession, occupational therapy has embraced adaptation as a central concern (Schultz & Schkade, 1997). A single definition or conceptualization has never been produced, but Schultz and Schkade theorized that adaptation refers to processes of how people overcome the consequences of disease and disability to their occupational¹ lives. The current discourse on

adaptation, as outlined below, suggests that adaptation is a multi-faceted phenomenon, namely:

- Adaptation refers to a process of reconciling (constricted) abilities with the demands of a given task/occupation. According to this line of thought adaptation is regarded as a phenomenon that concerns all people, whether they are disabled or not (Kielhofner, 2002; Schkade & Schulz, 1992; Schultz & Schkade, 1992). How-

1 There is no equivalent in the Japanese language to the term occupation. Given the current discourse that stresses the importance of ↗

↙ meaningful living, I will use the term occupation in this paper as meaning activities that people perform in their everyday life to sustain themselves and live a meaningful life.

ever, in the case of disabled people disabilities pose special problems and occupational therapy assists clients in closing the gap between demands and limited abilities.

- Adaptation is not a pure individual process. Research findings (Jongbloed, 1994) and theoretical propositions (Fine 1991; Kinébanian, 1999) have stressed that adaptation also depends on material and financial resources, reliance on other persons and support systems, and adaptation of the physical and human environment.
- Frank (1992) proposed that adaptive strategies are embedded in personal styles of coping and problem-solving. Such is supported by various researches into adaptation by older persons (Carlson, Clark, & Young, 1998; Jackson, 1996; Nygård & Öhman, 2002; Spencer, Hersch, Eschenfelder, Fournet, & Murray-Gerzik, 1999; Tham, Borell & Gustavsson, 1998). Cardol and Dedding (2000) found that it was beneficial to include clients' strengths and strategies to facilitate overcoming problems.
- An extensive geriatric and medical body of knowledge exists to inform occupational therapy practice about possible adaptive strategies that may be beneficial to overcome constraints to occupational functioning of older people (for example, Bonder and Goodman, 1995; Briggs, 1997; Burton, 1987; Oostelaar & Wolfswinkel, 1998). These adaptive strategies generally depend on specific disabling conditions and, therefore, can be critiqued for not taking into account the contexts/conditions of an individual's life.
- Adaptation is aimed at something. Researches into adaptation (Carlson, et al, 1998; Jackson, 1996; Nygård & Öhman, 2002; Spencer, et al,

1999; Tham, et al, 1998) identified that older persons strive to uphold values such as retaining independence, being in control of one's own affairs, maintaining social relationships, having basic needs met, and engagement in meaningful and fulfilling occupations.

In conclusions, although much is known about adaptation, hitherto no attempts have been made to describe the structure of adaptation, such as in older persons with disabilities.

Research design

Theory derived from the perspectives of persons who experienced a given phenomenon (here: adaptation) may better prepare occupational therapists to offer their services in ways that match clients' unique situations (Clark, 1993; Depoy & Gitlin, 1998; Yerxa, 1991). This research aimed to explore informants' experiences and the research question was: How is occupational adaptation experienced by some older Dutch persons with physical disabilities? Phenomenology is a research approach sensitive to revealing persons' life experiences and was selected for this study to reveal the structure and essences of informants' experiences of adaptation (Giorgi, 1985; van Manen, 1990; Yerxa, 1991). Open in-depth (phenomenological) interviews with eight occupational therapy clients provided the data. The informants were living in the city of Vlaardingen, the Netherlands, and were receiving occupational therapy at home or in day-treatment (see table 1). The data were

Table 1 Background information on informants

Informants	social status	workingage trade	main diagnosis/conditions	time since onset
Mr. A	76, widower	tax office manager	left hemiplegia, pre-morbid : asthma	onset : 7 months, 3 months post-discharge
Mr. B	72, married	head graphic designer	above right knee amputation, pre-morbid : heart condition	onset : 10 months, 2,5 months post-discharge
Mrs. C	88, married	housewife	chronic low back pain, pre-morbid : dupuytren right hand, polio in childhood	gradually worsened over many years
Mrs. D	77, married	housewife	above right knee amputation	onset : 2 years, prosthesis for 14 months
Ms. E	74, single	head domestic services hospital	tetraplegia due to multiple sclerosis	unable to stand for 12 months (last exacerbation)
Mrs. F	80, widow	teacher (fashion, home-helping)	rheumatoid arthritis, incomplete tetraplegia	onset of rheumatoid arthritis : more than 3 decades ago
Mr. G	74, widower	biochemical researcher	right hemiplegia, pre-morbid : partial amputation right hand in 1950s	onset : 4 months, 1,5 months post-discharge
Mrs. H	?, widow	housewife	left hemiplegia	?

The data were not purposefully collected, but were revealed by informants and thus deemed relevant to their experience of adaptation

analyzed using phenomenological analyses following Giorgi (1985) and Finlay (1999) and trustworthiness was enhanced using reflexivity, peer review and member checks (Depoy & Gitlin, 1998 ; Krefling, 1991).

For a fuller account of the research methodologies readers are advised to refer to : Bontje, Kinébanian, Josephsson, Tamura (2004) Occupational Adaptation : The experience of older persons with physical disabilities. American Journal of Occupational Therapy : pp. 140 to 149.

Findings

The analysis resulted in descriptions of adaptation to constraints of functioning in daily life activities as a process **requiring individuals' active engagement**. The analysis also revealed that adaptation aimed at **finding satisfaction through occupations**. These two main themes were further subdivided (see table 2). Furthermore, the informants indicated that adaptation had implications to their being in this world. The following four **meaning-dimensions** express how personal values influenced the adaptive processes: "quite an endeavor", "that's the way I do things", "to lose a part of oneself", and "maintaining directorship".

A process requiring individual's active engagement.

The informants' efforts were essential to adaptation. They used expressions such as "I've figured that out myself", and "I'm blessed with an enormous will to persist".

Identifying prospects for potential solutions: The adaptation process was triggered by informants developing expectations that they could identify solutions to constraints on their occupational functioning. **Utilizing personal resources** instilled informants with a belief that a solution to problems with occupational functioning could be found. Mrs. C

told how she would think through problems before falling asleep at night. Mr. G reflected on how he searched for adaptive equipment from a catalogue, referring to his work as a researcher, "That's how I do it. I've spent half my life in the library searching for solutions." Additionally, informants emphasized the importance of intact intellectual functioning towards identifying potential solutions; as Mrs. F stressed after talking about some self-designed adaptive strategies, "I'm rich in thoughts. I think that's an advantage." On the other hand, informants also described that they were **being made aware** (by other persons or pure chance) of prospects for solutions. Mr. B credited his wife for bringing time-saving techniques to his attention, when he struggled to perform his personal hygiene tasks in time for the transportation to the day-treatment center in the morning. Potential means by which to get around a problem, however, sometimes emerged by chance, for example when seeing other disabled persons in public, in the day-treatment center, or on television performing occupations that the informants hitherto had experienced as problematic.

Recognition of constraints to occupational functioning did not automatically lead to the identification of potential solutions to those constraints. For example, Mrs. H had been unable to develop any prospects towards overcoming constraints on performance of cherished occupations such as sewing and going to museums and concerts. She said, "That just won't go anymore." When asked if she had thought of any solutions, she threw her arms up in despair and replied, "What solutions could there be?"

Creating solutions to overcome constraints: Creating solutions to overcome constraints on occupational functioning ranged from fairly simple actions to careful thinking through of and experimenting with the proposed solution. Informants' **mental and physical efforts** were

Table 2 Adaptation : Main themes, their sub themes, and sub-sub themes

Adaptation as a process :	Outcomes of adaptation :
Requiring Individuals' Active Engagement	Finding Satisfaction through Occupations
Identifying prospects of potential solutions	Engaging in fulfilling occupations
Utilizing personal resources	Maintaining daily routines
Being made aware	
Creating solutions to overcome constraints	
Informants' mental and physical efforts	
Giving a role to other persons	
Technological adaptation enhancing functioning	

evident in their pondering over problems and trying out solutions. Furthermore, these were often correlated, as the following example demonstrates. Mrs. C told how she had figured out in her mind how she might be able to put on her brace and shoe while having one hand bandaged after wrist-surgery. After convincing herself that she had identified a feasible method, Mrs. C successfully applied it (after requesting a nurse to stand by and supervise). Trying out could also function to overcome resistance to a solution. For example, Mrs. C told how she overcame her resistance to using a wheelchair when experiencing its benefits during a shopping-outing, "I wasn't tired when I got home; I'd managed to have a look in all the shops. . . . Wonderful! That's when I sort of got over it [the idea of using a wheelchair in public]." On the other hand, factors associated with disability imposed restrictions on achieving adaptation. For example, Mrs. D explained how a lack of motivation and energy prevented her from making full use of her leg-prosthesis. She said, "I know what I've got to do [how to function with a leg-prosthesis] . . . but then I feel tired and think 'Oh well, it'll go like this [using a wheelchair instead of walking with her prosthesis]."

Creating solutions to overcome constraints often required **giving a role to other persons** (support, advice, and encouragement). Mrs. D made an explicit point of needing encouragement to use her abilities to their full potential, such as not to use a wheelchair but walk with her walker. Mrs. F told how relatives and friends would help her out with such daily tasks as opening milk-packs or tinned food, polishing her shoes and so forth. Informants also noted how professionals' exercises and encouragement had enhanced their ability to function. Mr. F said, "Undressing, they show you rather soon, they teach you tricks." Informants also told of occasions where they had sought out suggestions, for example by simply asking, "Isn't there something that can be done?" On the other hand, informants quite often told of asserting themselves by demanding that family, close friends and formal assistants adapt to their wishes and demands. For example, Mrs. E had negotiated hard for her right to call for assistance to come to her flat for going to the toilet at irregular times, if need be. However, sometimes informants could not create a solution and were forced to adjust their standards. Mrs. F reflected, "There

are so many things that are not done [by the home-helper] the way you'd like them to be done . . . So each time [that declining functions makes another aspect of independent performance impossible] you have to let go . . . take a step down in your standards."

Finally, all informants told of using home-adaptations, mobility aids and so forth and considered these beneficial because **technological adaptation enhanced functioning**. As Mrs. C put it, "because of those [bathroom] adaptations, I function so much better."

Finding satisfaction through occupations.

Informants' stories revealed that their adaptation aimed at finding satisfaction through occupations. For the informants daily routines provided the basic time-structure within which they engaged in fulfilling occupations.

Engaging in fulfilling occupations: All informants told that they engaged in occupations for their enjoyment or to satisfy values such as contributing to other persons and the community. This was highlighted in statements such as, "I can't sit still" (Mr. A), and "I need to do something" (Mrs. C, Mr. F), and "Doing something for other people" (Mr. A and Mr. B). Health-promoting activities (including therapy) also played an important role,

Maintaining daily routines: All informants lived according to daily routines of personal hygiene activities (morning routines such as taking a shower, getting dressed, etc), three meals a day (breakfast, lunch and evening meal), and sleeping/resting. Furthermore, there was a weekly rhythm in which the weekends were more for family and other social events, such as going to church. The informants strived to uphold this basic time-structure. The importance of a normal daily rhythm was clearly highlighted by Mrs. F and Mrs. H who both developed their own solutions for taking a shower, because the formal assistance was provided too late in the morning. These daily routines provided the basic time-structure within which the fulfilling occupations could be engaged in.

Four meaning dimensions.

The following four meaning-dimensions express how personal values influenced the adaptive processes.

"Quite an endeavor": The term endeavor indicates that adaptation required an active attitude and adaptation was not at all a pas-

sive experience. "Don't give up", "Persevere", and "That's what I do in such cases" voiced that efforts were needed. Mr. A told how his intact mental functions enabled him to function, for example when preparing the breakfast table, "... with each step you must think. In the past everything went automatic." Furthermore, adaptation was a continuous process and successful experiences with adaptation contributed to the creation of solutions for other problems. Reflecting on 30 years living with rheumatoid arthritis, Mrs. F concluded, "You get more and more creative." The term endeavor, therefore, also indicates that adaptation is not a single event, but a continuous process.

"That's the way I do things": It was apparent that the informants carried with them a life-time of experiences with overcoming adversity and problem-solving. The ways in which informants adapted varied, but continuity of familiar problem-solving strategies dominated. Mrs. C told how her husband time and again created situations that enabled her to adapt, from the time when they were 16 and he had taught her to swim, up to the present day (as in the aforementioned example of her learning about the benefits of using a wheelchair while shopping). Mr. G explained his ability to persevere from his experience as amateur mountain-climber, "... to the top. But then you have to come down ... then you have to again."

One's life-course provided a powerful instigator for the kind of occupations informants engaged in. Mrs. C continued to be meaningful to other people, in spite of an advanced stage of multiple sclerosis. She said, "I always worked in care, so yeah, I am used to do things for other people ... not much more is left than to be the listening ear."

"To lose a part of oneself": Dependence was problematic when other persons did not execute tasks to the standards of the informants. For example various stories related to home helpers executing household chores, such as cleaning, below the standards of the informants. Thus, informants were forced to lower their standards. Furthermore, some informants commented that their disability affected their appearances. Mrs. F stated that she sometimes felt miserable because her way of standing up and walking gave her an "old appearance."

Not being able was not always easy to accept, as Mr. A said, "inside I sometimes swear."

However, on the other hand, reduced expectations towards functioning and privileges associated with older age resulted in a certain acceptance, "that time has passed."

"Maintaining directorship": It was often assistance from family and friends that contributed to the informants functioning. However, that is not to say that informants became passive and grateful recipients of assistance. Often the informants were the directors of whatever had to be done, such as Mrs. F who would instruct or ask her home helper, relatives or friends when they arrived at her house. Mr. G and Mrs. H now had their children come to them instead of them visiting their children as what was usual before they had their strokes. However, stories of informants asserting their needs most often pertained to professionals' paternalistic attitudes and home helpers not working to informants' standards. Assertiveness towards social services pertained mostly to waiting times, such as Mr. A who ordered his home-adaptations himself so he could be discharged from hospital.

Conclusion

It must be considered that the informants were all Dutch informants. Nevertheless, the following discussion may inspire reflections about adaptation of people belonging to other groups (e. g. Japanese), and how such persons may be better supported.

- Although identifying potential solutions logically depends on awareness of a problem, in this study awareness alone did not necessarily lead to adaptation. This finding suggests that patients may benefit from situations that instill hope and expectations.
- The findings lend further support that adaptation is something that takes place in the individual as well as in the human, physical and societal environments. It seems well-advised to include family or other relevant people in situations where disabled older persons experiment or practice with potential solutions. Furthermore, it must be taken into account that the informants relied on familiar problem-solving strategies. Thus, support must match patient's personal problem-solving strategies and resources.
- The findings suggest that support should aim for a balance of fulfilling occupations and recovery of daily routines. Fulfillment may be gained from recreational activities, but more so from occupa-

tions that contribute to other people or the community.

- Independence and mastery were not that important and the subjective terms satisfaction or fulfillment may be better benchmarks for evaluating occupational functioning.
- Careful attention should be paid to the downsides of dependence. It was found that assistance may result in diminished control over one's affair. Assistance may also not meet person's personal standards, giving rise to more suffering.
- One's being (identity) determined how people experienced their adaptation-process as well as the desired outcomes of adaptation. Hence, it appears beneficial to use approaches that build on a person's life-story.

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