

Original Paper

Returning to participation in everyday life after disability

— A discussion of adaptation, transition and occupation —

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Abstract

The aim of this article is to explore the concepts of adaptation and transition as concepts to be used when thinking about recovery processes of occupational lives of persons with disabilities. It posits that the term transition denotes the overarching idea that people strive towards getting their occupational life back on track and that adaptation refers to the redressive and remedial procedures of mitigating the effects of impairments to occupational functioning. This article argues that these concepts grasp the efforts made for people to overcome specific difficulties as well as the longitudinal aspects of revitalizing participation in everyday activities. Furthermore, the importance of this article is that this kind of knowledge, which generally is reflective of the perspectives of the person(s) involved in these processes, is likely to inform more effective client-centered occupational therapy services.

Key words: occupational science, occupational adaptation, philosophy

Introduction

Several factors, such as a renaissance of occupation-centered occupational therapy practice, trends towards enabling persons with disabilities to live in the familiar surroundings of their homes and communities, and calls for disabled persons' full participation in the gamut of everyday life, have coincided to raise the interest in recovery processes after disability from an occupational perspective. In the light of these trends it can be questioned whether current models and theories that inform occupational therapy suffice to produce the best possible services to clients. We propose there is a need to evaluate the types of theoretical tools used by the profession. For example, we[†] identified that what is particu-

larly lacking is knowledge of recovery processes in terms of participation in everyday activities and how people's occupational lives get back on track after disability.

This article aims to explore adaptation and transition as concepts that may be used when thinking of rehabilitation processes for persons with disabilities. The concept of adaptation pertains to the process of using new or different strategies to mediate problems in the person-occupation fit (Frank, 1996; Schkade et al., 2001). The concept of transition denotes

[†] first authors' doctoral research (at Karolinska Institute). The concepts discussed in this article form two of the perspectives that will be used when researching how older persons in Japan return to participation in everyday activities after physical disabilities. To further understandings of these concepts and their relevance to Japanese situations readers are invited to contact him and share their reflections on adaptation and transition.

[†] The present article is based on the literature review for the ↗

the idea that people undergo fundamental change, including a changed self and new ways of living one's life (Meleis et al., 2000; Turner, 1988). There are many theoretical concepts that can be explored; however we choose adaptation and transition here because these grasp the efforts made for people to overcome constraints as well as the longitudinal aspects of returning to participating in everyday activities. Furthermore, our reasoning is inspired by the idea that this kind of knowledge, which generally is reflective of the perspectives of the person(s) involved in these processes, is likely to inform more effective client-centered occupational therapy services (Bontje et al., 2005; Fine, 1991; Saenger et al., 2005).

In order to explore the conceptual nature of these terms this article reviews interdisciplinary literature of adaptation and transition. (Please note that the frequent illustrations on aspects of adaptation and the lack of illustrations on aspects of transition are reflective of the current progress of research related to these concepts from an occupational perspective.) The discussion at the end of this article will discuss what adaptation and transition contribute to thinking about processes of returning to participation in everyday activities.

Adaptation

In the occupational therapy and occupational science literature, adaptation is typically described as processes of *adaptive strategies* that work towards closing the gap between abilities and the demands of the task(s) (Clark et al., 1996; Frank, 1996; Kielhofner, 2003; Schkade et al., 2001). These strategies may be used to enhance impaired occupational functioning (i.e. drinking from a cup held with both hands to compensate for weakness in either of the hands) or they may pertain to selecting and organizing occupations (i.e. occupying oneself with jobs in and around one's house instead of farming a field). This occupational therapy literature also describes adaptation as a process that not only functions towards overcoming disabilities (as described above), but one that is present in all human beings to contribute towards growth and development (i.e. develop one's artistic skills in calligraphy and drawing). Here, the focus of adaptation is situated in the individual. However, altering the task-demands (i.e. use a

spoon instead of chopsticks) is one example of matching the demands of a task to the available abilities of a person. An extensive body of knowledge exists that informs us about how people may mitigate the effects of disability to occupational functioning by altering the demands of the task(s). Geriatrics, for example, provides an extensive body of knowledge about adaptive strategies that professionals may introduce to their clients (for example: Bonder et al., 1995; Briggs, 1997; Burton, 1987). These adaptive strategies are usually matched for impairments that older clients might use to overcome constraints in occupational functioning (i.e. to fix carpets to the floor so people's feet do not get stuck under them, using ADL-aids to compensate for limitation in joint mobility and muscle strength, using contrasting colors to compensate for reduced vision).

However, qualitative research concerning adaptation from an occupational perspective has put these problem-solution sets under a critical lens (Bontje et al., 2004 and 2005; Carlson et al., 1998; Jackson, 1996; Nygård et al., 2002; Spencer et al., 1999; Tham et al., 1998). From these researches it can be understood that adaptive strategies are embedded in, what Frank (1996) called, personal styles of overcoming problems and in these research studies older individuals reported that they relied on personalized well-familiar problem-solving strategies (for example, older women reported to make do with whatever was still possible because that was how they had lived after the war; others referred to working life strategies, such as a researcher who always sought for solutions in literature). Furthermore, according to these studies adaptation in the experience of older persons was aimed at certain concerns, but not so much on specific medical conditions, as the aforementioned geriatric literature suggests. Some of the concerns that were found by these researches illustrate that older informants strive for health maintenance, strive to maintain a sense of (occupational) self through engagement in well-familiar occupation (such as household chores, long-time hobbies). Furthermore, research found that older persons life-satisfaction is linked to daily routines (i.e. three meals per day and regularly scheduled occupations such as household chores) and engaging in fulfilling occupations, characterized as personal enjoyment (i.e. some hobby),

maintaining relationships with others (i.e. joining club activities) and being meaningful to other people (i.e. helping other people) (Bontje et al., 2004 and 2005; Carlson et al., 1998; Clark et al., 1996; Spencer et al., 1998). Japanese qualitative researches identified similar concerns, but also identified concerns such as feasibility of occupations, facing death, time-use, financing for the future, and going outdoors (Mukai et al., 2004; Sakaue et al., 2002; Sakaue, 2004a and 2004b).

The above review has identified a number of features of human adaptation and the cited literature and studies generally have a strong focus on the individual. Yet, emerging research findings suggest that adaptation transcends the individual with a disability, and add the perspective that adaptation unfolds in the interaction between the person with disability and other persons in the individual's environment. For example, from a study by Tham et al. (1999) we learned how other people's actions and deliberate strategies were instrumental to four women's adaptation of occupational functioning to unilateral neglect. These other people helped these women to return to participation in everyday life in several ways, namely made the women aware of the left side of their worlds that they no longer perceived, provided security and order in for the women confusing worlds, compensated for the women's impairments, as well as assisted them in finding ways to recover from the neglect. Skold et al. (2004) studied how youngsters with hemiplegic cerebral palsy coped with bimanual tasks. This study demonstrated how persons plan, weigh options, and employ a variety of adaptive strategies in order to perform tasks as competent as possible. Furthermore, these researches also describe a struggle with social ideals and adaptation also confronts people with issues of self-images and social endorsement of who they are or may be (Luborsky, 1994). Other researches demonstrated that adaptation also occurs in persons other than but close to the individual, either of those other person's own accord (i.e. offer to provide transportation outdoors) or because of assertive action by the individual with disabilities (i.e. demanding assistance according one's preferences; Bontje et al., 2004 and 2005; Jongbloed, 1994; Larson, 1996; Spencer et al., 1999). The above social dimensions also feature in the Japanese *Kawa*

(*river*) *model* (Kawa-model.org, 2003) through the mutual influence of the flow of the water (that stands for vigor, zest for life, abilities for doing) and the river bed and river walls (that represents the social and human environment). Frank (1996) and Kinébanian (1999) argued that social change also offers opportunities towards adaptation (i.e. the introduction of the long-term care insurance system 'kaigo-hoken' has enabled many older people to sustain themselves in their own homes and participate in social occupations).

In conclusion, the discussion thus far puts forth the concept of adaptation as something that is more than just closing of gaps between personal capacities and the demands of an occupation. Adaptation is a social process too and involves issues of continuity and meaning-making. Moreover, adaptation has been presented as an essential aspect of returning to participation in everyday activities. It is purported that adaptation is linked to longitudinal processes that occur over time, which has implications for (re)crafting one's occupational life. Although the literature on adaptation offers some glimpses into such longitudinal processes, it is proposed here that the concept of transition offers a more suitable perspective for understanding the dynamics and processes of 'getting one's occupational life back on track'.

Transition

This section deals with transition. Work by nursing scholars (de Lange et al., 2003; Meleis et al., 2000; Schumacher et al., 1999) point out that (older) clients experience transitions. These emerging theories propose that many health conditions trigger person-altering processes, called transitions, that occur over time and that are processes that replace a lost state of certainty with a (re)new(ed) sense of certainty. These scholars derived their work from the work on 'rites of passages' by anthropologist Arnold van Gennip. However, whereas van Gennip's work is based on rites, for the purposes of the discussion here we will draw on the work of anthropologist Victor Turner (1988), because he studied how transitions are enacted in social life, specifically as depicted in the performing arts. Thus, we concluded that Turner's work is more appropriate to consider transitions from an occupa-

tional perspective.

Following Turner (1988) it is proposed here that transitions are enacted on four stages. First of all, transitions are triggered by a breach of normal functioning, such as a disease or accident, that causes separation between a person from his/her social and psychological selves and life becomes sub-junctive. Put more simply, life as it was, more often than not a taken-for-granted life at that, is suddenly not possible anymore, on hold. This separation is characterized as a crisis; a period of confusion, uncertainty and disconnection. Chaos reigns and emotion tends to rule over reason, especially in the person(s) with the disability but the crisis may envelop other persons, i.e. a spouse, siblings, close friends, too.

However, human beings will attempt to mitigate the effects of the initial breach and its consequences, the constraints to occupational functioning, and seek resolution to reduced health and well-being. Thus the next stage is one where people engage in remedial and redressive procedures. The person with the disability usually will receive treatment and rehabilitation to recover lost function, adapt the methods of performing everyday activities, which may or may not include relying partly or wholly on adaptive equipment and/or other persons. Furthermore, they may endeavor to discover or be introduced to new possibilities to replace lost participation in everyday activities and to (re)craft (new) identities, which in fact is a central tenet within occupational therapy and occupational science (Asaba, 2005; Josephsson et al., 2006). Transitional processes are propelled by engagement in everyday activities and special projects, another central tenet within occupational therapy and occupational science (Asaba, 2005; Blair, 2000; Clark et al., 1996; Josephsson et al., 2006; Kielhofner, 2002).

Turner's (1988) exposés on transition demonstrate that the involved processes transcend the individual to include the social environment. As was also found for adaptation, other people are also instrumental to the progress of transitions. The changes and achievements of individuals on the stage of redressive and remedial procedures are not only supported by other persons, but informed by social-cultural values and indeed endorsed by other persons. This is perhaps most evident in mechanisms such as stock-taking and mean-

ing-making around questions as to who one was and who one wants to be, what one finds important in life, and so on. Similar to how adaptive strategies may be judged against social norms, as was seen in the adaptation section, questions of 'who one was and may want to be' are not answered at the individual level, but informed by social cultural values and bestowed upon by others as well (Luborsky, 1994; Turner, 1988). Thus, in addition to a need to adapt to changing abilities, this stage for transition is characterized by giving meaning to the transition, coming to terms with a person's new life-situation with restricted abilities (Turner, 1988) and repair the biographical disruption by fitting the disease or disability in the life-story (de Lange et al., 2003; Luborsky, 1998). Rephrasing the above from an occupational perspective, we argue with Blair (2000) for the central place of occupations and highlights how 'doing in daily life activities' functions to facilitate change (i.e. develop new skills, recover lost function), maintain a sense of self (i.e. a former farmer who directs someone else in potting plants and thus demonstrates competency), and to generate a sense of managing the transition (i.e. trying out things without asking for help).

On the final stage of transitional processes we find the outcomes. All theories suggest that by the end of the process a changed person has emerged. From an occupational perspective we might say that transitions result in a new occupational existence (the word 'being' is deliberately not used here to express that there most likely will be continuity as well as changes). Turner (1988) characterizes the outcomes as reintegration, which de Lange et al. (2003), Meleis et al. (2000) and Schumacher et al. (1999) propose to be made up of from such things as changed habits and behavior, new equilibrium, connectedness, retaining continuity and regaining of new selves. Transition theory according to Turner has it that redressive and remedial procedures turn the chaos and disconnection from the crisis into significant process and reason is restored. From an occupational perspective we may say that persons once more participate in everyday activities and have their occupational lives back on track.

Finally, the presentation of transition theory above may give the impression of transitions being a linear process, but pays little

attention to how desired short- and long-term outcomes may shift, how short-term issues are linked to long-term aspirations, and the recurrent character of transitions (i. e. an older woman might first adjust to the new reality of requiring assistance with self-care during hospitalization after a stroke and after discharge home be confronted with the inability to do household chores). It is beneficial to think of the transitional stages as places where things happen (as in 'on-stage'), rather than phases in time. Be that as it may be, success cannot be guaranteed and the outcome may be a legitimization of a schism with social-cultural values and norms (Luborsky, 1994). Scheer (explained in Luborsky, 1994) called this a situation of being 'betwixt and between', a situation in which a person is not a patient anymore, but also not a person who fully participates in social life and who can fulfill the requirements of the norm-bound life of 'full adult personhood'.

In conclusion, it appears that by incorporation a transitional perspective into our thinking of recovery processes for persons with disabilities we will be better able to understand the involved dynamics. Transition theory sensitizes us to the longitudinal and recurrent aspects of returning to participation in everyday life as well as issues of meaning-making and stock-taking. Furthermore, as transition theory was developed from anthropological research it is particularly powerful in facilitating understandings of social perspectives and the person-perspective.

Discussion and conclusion

The aim of this article was to explore the concepts of adaptation and transition as concepts to be used when thinking about recovery processes of occupational lives of persons with disabilities. Adaptation, defined here as repairing the person-occupation fit, has a long history in occupational therapy. However, likewise to the critique of the limitations of the medical model, we found that adaptation was predominantly understood as a mechanism located in the individual. This view has been challenged and expanded by more recent (qualitative) research, yet still important aspects remain hidden. The exploration of theories of transition demonstrated that that concept brings those hidden aspects to the

fore. Using the concept of transition sensitizes us particularly to mechanisms and dynamics such as the longitudinal and recurrent characteristics, issues of meaning-making and stock-taking, and regaining new selves (social and psychological status) and reorganization of one's life. From an occupational perspective it can be said that both adaptation and transition acknowledges that engagement in everyday activities and special projects conjointly function to propel adaptive and transitional processes. On the basis of this reasoning it is proposed here that the term transition denotes the overarching idea that people strive towards getting their occupational life back on track. Following this line of thought, adaptation then refers to the redressive and remedial procedures of mitigating the effects of impairments to occupational functioning.

Furthermore, expanding our understandings by linking adaptation and transition theories to processes of returning to participation in everyday life from an occupational perspective has given voice to these processes social dimensions. Another conclusion is that it may be beneficial to speak of 'overcoming constraints to occupational functioning *by, for and together with* persons with disabilities'. Finally, the theoretical material and reflections presented above can serve as a resource for developing more holistic understandings, which includes social perspectives, in tune with how people recover from disabilities in terms of participation in everyday activities and in tune with how people get their occupational lives back on track.

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