Re-creating self-identity and meaning through occupations during expected and unexpected transitions in life

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Abstract

The present study aims to explore occupational engagement during expected and unexpected transitions in life, as well as to understand how self-identity and meaning, situated in the context, is created and re-created through the daily occupations. We use case examples of children with disabilities, adults with acquired brain injury, older adults with stroke and people with serious somatic illness, undergoing rehabilitation. The cases are drawn from previously performed studies by each of the authors. In the present study, a secondary analysis of data was conducted based on an abductive approach and theories of self-identity and transaction, to illustrate how changes in everyday life occupations made sense. Three themes emerged that structure the discussion; *Disruption of a former self, Pursuing normality*, and *Re-constructing daily occupations and routines*. Our discussion illustrates how different life transitions can be demanding and how people, situated in the context, revise and create new meaning and self-identity through their occupations. This discussion is relevant to occupational science and occupational therapy as well as to health promotional work more generally.

Introduction

Life transitions usually describe changes through phases and events of life, that have implications for established ways of doing things and are related to how people perceive their roles, relationships and who they are (Anderson, Goodman, & Schlossberg, 2012). The term "transition" covers both positive and negative changes during the life-course (Anderson et al., 2012). Transitions can also be grouped according to whether the events are expected and can be planned, such as starting a new school or retiring, or occur unexpected, sudden and not planned, such as an accident or an acquired illness. Transitions can also describe cases where something that is expected in life does not occur, such as expecting to have a child that does not come (Anderson et al., 2012). Whether transitions are or are not expected and whether they are or are not wanted, they can create emotional reactions, such as frustration, confusion, fear, anxiety and grief (Crider, Calder, Bunting, & Forwell, 2015).

The significance of what people do during a transition to master the related changes has been noted previously (Anderson et al., 2012). However, how this process occurs, that is the role that occupations may play, and how meaning is created in the new situation through occupation is not well understood. The literature within occupational science and occupational therapy highlights the role of meaningful engagement in occupations to cope with, and live through transition in people who have experienced an unexpected health-related illness or trauma (Scalzo, Forwell, & Suto, 2016). This focus differs from findings in psychology, sociology and social anthropology, which focus more on internal processes and identity issues (Scalzo et al., 2016). In the present paper, we want to integrate these two different perspectives i.e. we want to explore both the role of the occupational engagement during transitions, as well as how meaning is created through the continuous shaping of self-identity (Giddens, 1991). We have chosen people in various life situations who have experienced expected or unexpected life transitions. Recognizing that the occupation occurs

in and is dependent on the specifics of a situation, we also aim to understand the situatedness of the occupation, that is how the situation and occupation work together (Madsen & Josephsson, 2017). Our research question is: *How is self-identity and meaning created and recreated through daily occupations and routines in people experiencing expected and unexpected life transitions?*

Self- identity and transaction

What people do through the course of life creates an "activity story" or biography that changes continuously in the cultural and social context. According to Giddens (1991), self-identity connects to the individual biography or the stories people create about themselves, which he described as an ongoing process where "new" identities are constantly being created and interpreted in interaction with the environment. Thus, individual stories and how people understand and develop their own self-identity are social and linked to everyday life experiences (Giddens, 1991). This viewpoint resonates with ideas expressed in occupational science, where occupational identity is conceptualized as not only individual, but constructed in socially and culturally oriented perspectives (Phelan & Kinsella, 2009). In the present study, the term self-identity is used according to Giddens' (1991 p 75-79) understanding, as a continuous reflexive project which is linked to everyday life experiences, and that forms a trajectory of development from the past to the anticipated future.

A second theoretical perspective that assist with understanding how transitions are conducted is the transactional perspective (Cutchin & Dickie, 2012), which is based on the pragmatic philosophy of John Dewey (Dickie, Cutchin, & Humphry, 2006). The idea of transaction, contributes to understandings of how occupations are always situated (Dickie et al., 2006; Madsen & Josephsson, 2017); the relationship between the individual, the environment and the action, which would typically be seen as 'separate from each other are really *part of* each other' (Dickie et al., 2006, p. 88). According to a transactional perspective,

it is essential to understand how situation and occupation work together and how engagement in occupations is an inquiring process (Madsen & Josephsson, 2017). This perspective can shed light on how meaning is created during transitions.

Design and methods

For the purpose of exploring how self-identity and meaning is created and re-created through daily occupations and routines in people experiencing expected and unexpected life-transitions, we conducted a secondary analysis of data obtained from four different studies, which were previously conducted by each of the four authors. The selection of studies was based on the fact that the four authors themselves had been involved in them and had access to raw data, and that the studies could illustrate various expected and unexpected transitions in people of varying age. Further, we used an abductive approach (Brinkmann & Kvale, 2015), and the theoretical frameworks of self-identity (Giddens, 1991) and transaction (Dickie et al., 2006; Madsen & Josephsson, 2017) to make sense of the data from the selected studies. Based on a transactional perspective, we tried to understand the particulars of occupations and how they are bound together as a whole within the context in which people go about in their everyday lives (Jones & Hocking, 2015).

The four primary studies used are described in Table 1. All studies were based on interpretive epistemology. Each of the primary studies was conducted in Norway, and were approved and supported by either the Norwegian Centre for Research Data (Asbjørnslett, Engelsrud, & Helseth, 2015; Raanaas, Patil, & Alve, 2015) or the Regional Committees for Medical and Health Research Ethics in Norway (Lund, Mangset, Wyller, & Sveen, 2015; Sveen, Soberg, & Ostensjo, 2016).

[Insert Table 1 approximately here.]

An abductive form of analysis was used, where the goal is not to arrive at fixed and universal knowledge, but rather to make sense of specific situations by trying to break down

the relationship between the specific situation and the inquiry of interest to come to a new understanding (Brinkmann, 2014; Brinkmann & Kvale, 2015). For the purpose of this study, the following steps were conducted in the analysis. First, we tried to make sense (Brinkmann, 2014) of how different people in our studies 'did' their transitions, from an understanding that a transactional perspective sees the occupation of the individual as being enacted in a context (Dickie et al., 2006). For example, in the case of children with disabilities' transitioning from primary to secondary school, we interpreted the occupations that they were involved in, from the context or situation that they first and foremost saw themselves as ordinary teenagers. As a second step, and based on common discussions where all the authors met, each author, outlined examples of transition within their own research, that could illustrate how occupations can create new meaning during transitions. The examples should make sense from perspectives of self-identity and transaction and illustrate how occupations are bound together as a whole within the particular situation in which the participants live. These case outlines used are described in the next section. Following an abductive approach (Brinkmann, 2014), in the third step, we discussed the cases from the perspective of the theory of selfidentity and transaction to highlight our main points. We broke down the particular main points in each example, and came up with three common themes across the examples that were useful to understanding the process of transition. These are described and discussed in the discussion section. Both the outline of the cases and the development of themes were part of the secondary analysis and were discussed in the whole group of authors. Some of the illustrating quotations used in the present study were already translated from Norwegian language into English as part of the publishing of the primary studies, and in some cases translated for the purpose of this study, by the primary authors.

Case outline

Case 1. Transitioning between main stream primary and secondary school for children with a disability

Using life-mode interviews (Gulbrandsen, 2012; Haavind, 1987), children with disabilities were interviewed about their everyday lives, related to the transition between mainstream primary and secondary school (Asbjørnslett et al., 2015). Oliver said that to meet the requirements at school, he had to spend more time on homework. He used to participate in wheelchair basketball but said that to be able to obtain sufficient time for schoolwork, he had decided to quit basketball because it was too far to drive to the training, and it was too timeconsuming. In Oliver's case, he also explained that he wanted to spend more time with local (and what he called *normal*) friends in his leisure time. Still, he wanted to be "sporty" and thus, he obtained a hand-driven bike that he could use in the neighbourhood as a sports occupation. While Oliver adapted his occupations from a more positive perspective of including himself in his local environment, Tobias, another participant, became more vulnerable in the process of creating new meaningful occupations. A progressive disease and consequent gradual loss of physical capacity hindered him from doing what he loved most: playing soccer. In addition, in the transition phase to secondary school, because he was not included in the same class, he lost daily classroom contact with his soccer mates. To Tobias, not being able to be with his soccer friends was experienced as a dramatic change because these children knew his 'history of illness' as well as his interests and resources.

When Tobias was in the transitional phase of needing more assistance, other children in the study said that in secondary school, it was important to be more independent. For example Oliver said that in primary school he could obtain help from his assistant in putting on orthopaedic aids to perform activities such as walking up and down the stairs with his mates, which he claimed was more 'normal' than using his wheelchair and the elevator to get to the classroom. Now, he claimed to be more independent by managing this task himself.

Oliver also said that in secondary school, his assistant was not present in the classroom anymore, as he had been in primary school. Instead, he could call with his cell phone if he needed assistance. According to Oliver, this was less disruptive and he felt that he could work more independently.

When Oliver transitioned to secondary school, girls also became more visible in his stories. For example, he said with a grin that during lunchtime, he was looking for a girl who had grabbed his cap, demonstrating that methods used by the boys and girls to get to know each other changed to more "teenage" occupational ways.

Case 2. Transitioning to a new everyday life after a traumatic brain injury

Using focus groups, people who had recently had a mild traumatic brain injury and were taking part in an out-patient work-rehabilitation programme, were asked about how everyday life and work-life had changed due to the brain injury (Sveen et al., 2016). A frequent topic shared by the participants concerned the sudden change from being active, working or studying full-time, spending leisure time with friends and pursuing hobbies to resting for most of the day and being unable to perform even simple everyday tasks. As Helga described, "I used to be very active, active at work, active doing sports...I went from that to suddenly not bearing to take a shower and getting dressed, not even bearing to talk to anyone. So, this is just a completely new me, I don't recognize myself." Despite a similar feeling, Ola explained that "I have such a bad conscience because I'm not able to work." The participants shared their transition experiences of becoming a 'new me,' like the fragile young man on 100% sick leave, lying on the couch most of the day, when the 'former me' was a successful medical student, even coping with working part-time in a hospital. Another story was shared by Liv, a former fulltime-working mother of a 10-year-old daughter, who now barely managed to work part-time. She used to spend much of her time with her daughter after work, but currently, she felt she neglected the daughter because she had to sleep several hours after work.

The participants stressed the importance of a good communication with employers and flexible opportunities to work, allowing for participation in vocational occupations as was still regarded as vital and meaningful to them. Not all the participants who returned to work after a few weeks on sick leave seemed to be ready for this. For some people, this had caused a feeling of failure and occasionally, anxiety, regarding this experience and being forced back to sick leave. The participants stressed the importance of workplace support and being met with an understanding of the consequences of the injury from work managers and colleagues. Tor's story illustrated this point: "I have a pretty good dialogue with my boss, he has been very supportive. He has told me to take breaks during the day, whenever I need it. And if I feel really unwell, then I'm allowed to go home." A strategy in returning to work, which was often successful, involved a gradual (step-wise) return to pre-injury working hours.

Choosing to take control over their lives, during the transition-process became a relief in many ways. To some people, the incident became a wake-up-call and an opportunity to reflect more about what is important in life. Per had a prestigious position, and his self-identity were closely linked to his position. In retrospect, he expressed: "Lots of work and little time for leisure. Actually, I had no real life...now I try to make my everyday life as rewarding as possible. Work shall never again fill my whole life."

In contrast with work and social life, which often were challenging, being outdoors, enjoying nature, and engaging in physical activities was described as occupations that gave energy to cope with other daily occupations, as well as preventing depression. When describing her course of recovery, Helga stated, "The one thing that has been good for me was to be physically active... yes, I really enjoy being outdoors; it gives me a lot of energy...I have wandered around in the woods, and this has kept the depression away. I noticed if I sit down one day and don't get out, then the sad thoughts come...I really want to get back to work, to see my friends, and to be quite normal."

Case 3. Transitioning to a new everyday life after stroke

Through six repeated focus group sessions, people who have experienced mild to moderate stroke were interviewed about how everyday life had changed after the stroke (Lund et al., 2015). The interviews revealed how the stroke was perceived as an 'occupational threat' in their everyday life. The participants described an experience of exclusion from performing activities that were important to them and expectations they had for themselves of being independent. As an example, Erna explained that she no longer managed to care for her three year old grandchild because the child ran so fast. This made her feel that she was no longer needed in society. Knut explained that he felt dependent on others when he could no longer drive a car. He had been driving for over 60 years and could not do it anymore. Emma and Evelyn were concerned with their housework that they had done for many years, and could no longer accomplish in the same way. Emma said, "I do not understand why I feel so tired. I did so many things before." Feeling redundant and not contributing to society the same way as before was addressed. However, at the same time, by performing occupations in new ways the participants constructed meaning in new ways. Knut, for example eventually sold his car and started to take the tram, which helped him feel more independent again. Erna chose to use a taxi instead of driving to the shopping mall. This was despite her daughter saying that she should not go to the store alone and that she (the daughter) could drive her. Erna maintained control and managed to reach the shopping centre alone, which contributed to an experience of independence. Evelyn and her husband had always been dancing once a week. After her husband died, and the occurrence of the stroke, she said, "Even though I cannot dance anymore, I go to the dance and listen to the music." Karl told that he had always taken long walks in the woods with his wife, but after the stroke, he took shorter walks to the local community centre instead. Anna used to go to church every Sunday. After the stroke, she found this to be difficult because she had to go with a walker, and it was too far. Therefore,

she made a change by staying home on Sundays and listening to the service on radio instead. Emma told that she was very fond of knitting and for many years, she had knitted beautiful sweaters with patterns for family members. After the stroke, she could no longer manage to knit advanced patterns, and started to knit socks for her children and grandchildren, which made her feel useful.

<u>Case 4. Transitioning to a new life with serious somatic illness in a residential rehabilitation</u> <u>centre.</u>

Using in-depth individual interviews and focus groups, patients diagnosed with pulmonary or cardiovascular diseases who were residing in a residential rehabilitation centre in Norway were interviewed about how the physical environment, such as a view from the windows to nature or living plants inside, could affect recovery and support the transition to a new life (Raanaas et al., 2015). The rehabilitation centre offered 4-week courses that consisted of different types of physical activity and lifestyle guidance. Participants resided in single rooms during their stay.

Although the informants greatly appreciated the programme at the centre, they also expressed that it was demanding and that they needed to retreat once in a while and do occupations in solitude. Referring to socializing in the common areas in the evenings, Per said, "I do not want to just sit there and listen to nonsense – so then I rather withdraw." Some of the patients said that they needed to rest in the room doing individual activities, and that these activities calmed them down. Astrid said, "In the night, I need to calm down. So then, I go down to the room. There I do crafts, I cut and paste postcards, I knit, and I read a lot. So, I need a couple of hours by myself before I go to bed."

At the same time, the physical appearance of the surroundings seemed to be relevant for the experience of coping with the transitional challenges. Those who had a view to nature from their bedrooms found that the room was a particularly suitable place to retreat and that it calmed them down to be able to watch the nice view. They expressed that they enjoyed looking at the landscape with the mountains, trees, birds and animals, as well as nature's shifts and the weather. One person said that the view from the room was significant even when he was not directly attending to it, and was engaging in an activity, such as reading. The participants expressed that to withdraw in a private and aesthetic environment allowed them to reflect and contemplate on their new life situation, and think more holistically about their lives.

Despite the need to withdraw and rest, the centre leaders encouraged them to participate in common activities and to socialize as much as possible and not withdraw to their own rooms. Accordingly, participants' requests for a vase for fresh flowers or to bring their own TV to watch in their rooms were not granted. Thus, the participants experienced that occupations that could have been meaningful to them, given their situation and the transition they were in, were not supported by the centre policy.

Discussion

The discussion is organized into three themes that are closely intertwined.

Disruption of a former self

The secondary analysis shows how people undergoing transitions perceive themselves as different from their former self. Socially and culturally constructed perspectives inform peoples' occupational self-identities that seem to be strongly connected to their experiences (Giddens, 1991; Phelan & Kinsella, 2009). Depending on the situation, transitions can be experienced as positive (Anderson et al., 2012), as for children transitioning to secondary school and thus becoming teenagers, which can indicate that they are a sufficiently clever student and important friend. On the other hand, for some children with disability, the transition may imply cumulative challenges related to the school and their social life, and the disruption of the former self may be negative and more pronounced. The participants having

had brain injury or stroke, described how the consequences of the injury challenged their preinjury self-identity in different ways. All informants expressed a sense of loss, the feeling of a
disruption of their former selves and their valued self-image, which is also referred to in other
studies (Bury, 1982; Hammell, 2004). They were not comfortable with how they experienced
themselves after the injury. At the same time, one of the informants reflected on not being
satisfied with his former self either, having worked too much, and that the brain injury
incidence opened up for new opportunities to redirect life. Findings among the residents in the
rehabilitation centre also indicated the need to calm down and think more holistically about
the new life situation, such as who they were and who they had become. The physical, as well
as the social and cultural environment seem to be of importance in this process.

Pursuing normality

Pursuing 'normality' seems to be another main issue, which concerns doing and being what is perceived as normal in the given situation. Children in transition to becoming teenagers enact their everyday occupations from an understanding of what teenagers usually do, which is embedded in a particular cultural context, and the situatedness of the occupation (Dickie et al., 2006; Madsen & Josephsson, 2017). Being more independent and responsible in making autonomous decisions for themselves seems to be a strong indicator of how they feel about themselves, which reflects values related to a Western cultural context (Kantartzis & Molineux, 2011), as well as the Norwegian Education Act (Government.no, 2014). Children with disabilities who have the right to be included in mainstream schools may have to work harder or find other forms of doing things in a similar manner as other children usually do, because their situation of attending regular school and activities in their local environments includes requirements of some form of 'normality' (Asbjørnslett, Helseth, & Engelsrud, 2014).

Also among the adults having faced unexpected transitions in life, the meaning people created in the new life-situation was situated in the context of cultural values which in this case was associated with being independent, caring for others and being of value to society (Kantartzis & Molineux, 2011; Lund et al., 2015). They demonstrated how they worked with roles and patterns of activity and how they pursued 'normality' of everyday life by doing things that they used to do in different or new ways to experience coping and self-respect and to build a new self-identity (Giddens, 1991; Hammell, 2004). The rehabilitation centre where data was taken from, not surprisingly had a strong focus on physical activity and fitness, as well as organized activities, and even organization of leisure time (HOD, 2005) (Kantartzis & Molineux, 2011). In this context the participants understood, and were willing to encounter what was expected, and regarded as normal, but did also express some degree of frustration of the narrow scope of normality.

Re-constructing daily occupations and routines

Although transitions can be difficult and demanding, the people interviewed in our studies found new ways of doing everyday occupations. Thus, the values of more independence and freedom described above, are likely to be seen 'in action' in different situations. For example, the way children with disabilities collaborate with school personnel and other students can be viewed as a transaction (Dickie et al., 2006). Their occupations can provide opportunities to succeed, as relations between people can maximize individuals' opportunities in life (Stone, 2013). In this context, disability can also be seen as enacted in context, where what they actually need and want help for is dependent on the context and continuously changes.

Likewise, transitions after a traumatic brain injury or stroke manifests itself as a dynamic and continuous process of reconstructing daily life routines and occupations. The process involves improving capacity through effortful activity, redefining values, and rethinking the meaning of daily occupations. Occupations such as dressing or taking a shower

may take on another meaning. Engaging in restorative activities, and enjoying a nice view from the window can also be seen as a meaningful occupation given the situation (Madsen & Josephsson, 2017). How daily activities are conducted and how meaning is created in collaboration with people in the environment can be understood from a transactional perspective (Cutchin & Dickie, 2012). Issues related to work participation became crucial for the participants of working age. This is obvious in our study, and seems to have become an issue of threatened self-respect and tension in individuals, when they did not manage to work as much as they felt was expected. The experience of a supportive environment at work and a gradual return to work among the participants is shown to contribute to a biographical reconstruction (Hammell, 2004). In this process, reconsideration of their occupational values and a re-orientation in life became imperative.

Limitations of the study

In the present study an abductive approach (Brinkmann, 2014) was used to make sense of previously collected data in the light of theories of self-identity and transaction. Several limitations to the quality of the study are of relevance (Tracy, 2010). The secondary analysis using an abductive approach may have led to a too narrow interpretation of the data, where the complexity of the situations have been lost. A limitation of secondary analysis might also create a distance to the empirical material. Although attempting to give thick descriptions of the various examples, the effort of including different kinds of transitions can be regarded as too ambitious and superficial. Rigor was realised through continuous face to face discussions among the authors through the whole process. The findings are not meant to be generalizable over populations, but rather work as illustrations of the inquiry of interest.

Conclusion and implications

In this paper we have illustrated how some people with disabilities, illness and diseases experience and enact expected and unexpected transitions in life. These examples illustrate

how their occupational biography is linked to the stories about their lives, where their changing self-identity is created and recreated (Giddens, 1991), and where the key values of society are highly reflected (Madsen & Josephsson, 2017). In occupational science and occupational therapy, as well as rehabilitation and health promoting work more generally, we recommend to draw more attention towards the complexity of how people, situated in the context, create new meaning during life transitions by performing the occupations in which they are involved. Future research should continue to explore occupational and transactional perspectives on peoples' life transitions.

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Table 1. Description of the primary studies

Case	Authors	Transition	Participants' age	Number of	Methods
ı			range in years	participants in	
				total	
				(males/females)	
1	Asbjørnslett et al.	Transition between	12-14	15 (9/6)	Life mode interviews
	2015	main stream primary			(1-4 interviews per
		and secondary			interviewee)
		school for children			,
		with disability			
2	Sveen et al. 2016	Transition to	22-60	20 (8/12)	Focus groups
		everyday life after			
		mild traumatic brain			
		injury			
3	Lund et al. 2015	Transition to	69-88	8 (5/3)	Six repeated focus
		everyday life after		, ,	group sessions
		stroke			
4	Raanaas et al. 2015	Transition to new	40-72	16 (9/7)	In-depth individual
		life with pulmonary		, ,	interviews and focus
		or cardiovascular			groups
		diseases in a			
		residential			
		rehabilitation centre			