

ORIGINAL REPORT

“I AM NOT LIVING MY LIFE”: LIVED EXPERIENCE OF PARTICIPATION IN EVERYDAY OCCUPATIONS AFTER STROKE IN TEHRAN

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Objective: To describe and understand the lived experience and to identify what characterizes the phenomenon of participation in everyday occupations after stroke, in Tehran, Iran.

Methods: Eight individuals with stroke, who had previously been admitted to a neurological hospital ward in Tehran, were interviewed in-depth on one occasion. Data were collected and analysed using the Empirical, Phenomenological, Psychological method.

Results: The findings identified 3 main characteristics of the phenomenon of participation in everyday occupations as being: (i) I cannot do activities as before; (ii) I am not the same person – discovery of a different self; (iii) I am not living my life.

Conclusion: Enabling participation after stroke within a client-centred paradigm in this socio-cultural context requires consideration of the essential meaning of this concept as characterized by the dynamic process between the characteristics of “doing”, “identity”, and “living life”. The study highlights how the provision of efficient rehabilitation services in this Eastern context requires attention to both “doing” and to “identity” in rehabilitation interventions, in order to enable individuals to adapt to their new lives after stroke and to “live their lives”.

Key words: participation; stroke; rehabilitation; adaptation; phenomenology.

J Rehabil Med 2013; 45: 528–534

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Accepted Dec 19, 2012; Epub ahead of print Apr 25, 2013

INTRODUCTION

Enabling individuals to participate in everyday occupations is an important goal for rehabilitation (1). Participation is a concept in the International Classification of Functioning,

Disability and Health (ICF), defined as “involvement in a life situation” (2). Although this definition concerns the subjective experience of the individual, this aspect is excluded in the operationalization of participation (3–5). Consequently, there is a lack of clarity regarding how participation should be addressed in rehabilitation programmes (5). To enhance our understanding of how to enable participation in everyday life it is essential to better understand individuals’ experiences of participation with the aim of exploring the nature and structure of the phenomenon.

Stroke is a leading cause of death and disability worldwide (6). Many persons with stroke perceive their participation as restricted (7–9). There are few studies exploring the lived experience of participation after stroke (5, 10–12). In order to meet the individuals’ desires and needs in rehabilitation, occupational therapists must understand each person’s life-world experience (13). Phenomenological research aims at better understanding the lived experiences and how a specific phenomenon is expressed and characterized (14, 15). Several studies have explored the lived experience of an altered everyday life situation after stroke, and found that stroke impacts considerably on individuals’ self or identity, and that engagement in activities, skills and roles before stroke were closely connected to their well-being after stroke (16–18). Only a few studies using a phenomenological approach have focused on the individual’s experiences in everyday occupations after stroke (19–24). A study by Eriksson & Tham (19) found that occupational gaps signified losing the possibility to recognize oneself in everyday occupations and to express one’s sense of self as a doer. The study stressed the importance of individuals’ engagement in desired occupations, defined as occupations developed from experiences throughout life and closely linked to a person’s self and identity. Other studies have focused on the experience and meaning of cognitive impairments, such as unilateral neglect (20, 21) and memory impairment in everyday occupations (22), and also the meaning of context (23) after acquired brain injury, such as stroke. These studies concluded that the experience of the individual’s everyday world changed dramatically into a different world; from a taken-for-granted

existence to a chaotic world that was difficult to understand (22, 24). By experiencing familiar occupations (20, 22) and enabling supportive contexts (23) individuals seem to discover how to handle everyday occupations and thereby recapture their occupations in everyday life.

Previous studies have contributed important knowledge about everyday life after stroke but their aim was not specifically to describe the phenomenon of participation, and the studies were all conducted in the Western world. In order to advance our knowledge about participation, it might be valuable to explore this phenomenon in non-Western contexts. The aim of this study was to describe and understand the lived experience, and to identify what characterizes the phenomenon of participation in everyday occupations after stroke, in Tehran, Iran.

METHODS

Participants and design

The study was approved by the National Ethical Committee at the Ministry of Health and Medical Education, Iran. The study design was qualitative, descriptive and interpretative using the Empirical Phenomenological Psychological Method (EPP) (25). The participants comprised 8 individuals with stroke who had previously been admitted to a neurological ward in a university hospital in Tehran. In order to collect rich and varied data, participants were selected based on different characteristics, such as age, gender, education, ethnicity, and financial status or family income. The inclusion criteria were: (i) ≤ 75 years of age; (ii) a first-time stroke occurring between 5 and 30 months prior to inclusion; (iii) living at home; (iv) sufficient cognitive function to share the experiences verified by Mini Mental State Examination (MMSE) scores greater than 22 (26); (v) able to respond and describe their experiences. The participants received information about the study orally and in writing and gave their informed consent to participate. The characteristics of the participants are shown in Table I.

Data collection

Data were collected through in-depth interviews by the first author between January and November 2009 in Tehran. Participants were

met twice in their homes. Each interview lasted approximately 90–120 min, and was tape-recorded and transcribed verbatim. The interview questions were informal and open-ended, based on an interview guide (27). The participants were invited to describe their ordinary day and their current experiences of participation in everyday occupations concretely and in detail compared with before their stroke and to give examples. Follow-up questions were asked about the occupations they valued and situations they perceived as problematic. Field notes were taken after the interviews.

Data analysis

The data were analysed using the EPP method (25). The EPP method is qualitative, descriptive, and interpretative and focuses on describing the meaning structure of the phenomenon based on the participants' concrete descriptions of their life-world experiences (25). Similar to previous studies (19–22, 24, 28), the psychological perspective in this analysis was replaced by an occupational perspective, focusing on the participants' daily occupational experiences. Theoretical knowledge outside phenomenology was bracketed during the analysis in order to be open for the phenomenon presenting itself in the participants' described experiences. The data were analysed and interpreted in 5 steps, as follows. Steps 1–4 were completed separately for each interview and all interviews were analysed together in Step 5.

- *Step 1:* Each interview was read thoroughly to get a good overall grasp of the interview and an empathetic understanding of individual's original experiences.
- *Step 2:* Each interview transcription was divided into smaller units (meaning units; MU) each time there was a shift in meaning in the text.
- *Step 3:* Each MU was interpreted and understood in the light of the whole interview from the participant and the phenomenon in the study. The focus was on describing the implicit and explicit meaning embedded in the facts in relation to the phenomenon.
- *Step 4:* The transformed meaning units from Step 3 were synthesized into a situated structure of the meaning and presented in the form of a synopsis with different themes describing the phenomenon. In this step the characteristics describing different aspects of the phenomenon and how they might be related to each other were identified.
- *Step 5:* Here there was a shift from a situated structure to a general structure of the phenomenon common to all the participants' interviews and describing the characteristics of the phenomenon.

All the interviews were conducted and transcribed in Persian by the first author. From Step 3, the analysis was performed in English.

Table I. Participants' characteristics in the study (n = 8)

	Participant							
	1	2	3	4	5	6	7	8
Age (years)	63	55	50	68	64	45	45	67
Gender	Female	Female	Female	Male	Male	Male	Male	Female
Education	Primary (5 years)	Secondary (12 years)	Secondary (8 years)	Academic (MSc)	Illiterate	Academic (BSc)	Secondary (12 years)	Primary (5 years)
Marital status	Married	Married	Married	Married	Married	Single	Married	Married
Employment history ^a	Homemaker	Retired but worked	Homemaker	Worked	Retired but worked	Worked	Worked	Homemaker
Living status	Family	Family	Family	Family	Family	Alone	Family	Family
Ethnicity	Azeri	Persian	Persian	Azeri	Gillak	Persian	Kurd	Arab
Financial status/family income	High	Moderate	Low	High	Low	Moderate	Low	Moderate
Hemisphere lesion	Right	Left	left	Right	Right	Left	Right	Left
Time after stroke (months)	5	22	26	10	22	7.5	7.5	20
Mobility	+ Cane with support	+ No aid	+ Cane	+ Cane with support	+ Cane	+ No aid	+ Cane with support	– Wheelchair
Rehabilitation, had/or not	Yes	Yes	No	Yes	No	Yes	No	Yes

^aParticipant's employment status before stroke.

+: can walk; -: cannot walk; MSc: Master of science; BSc: Bachelor of Science.

This strategy was applied because 2 of the co-authors were Swedish and 3 were Persian. Translation considerations were taken into account based on the literature (29). In regular meetings including the first and last authors each step in the analysis and the interpretations were examined and discussed until it was ascertained that the final interpretations best characterized the experience of each participant. The fourth author reviewed all the steps performed by the first and last authors and the translations. All the authors were involved in Step 5, challenging the interpretations and discussing alternative interpretations until the most plausible ones were identified. The analyses were discussed and refined several times until a horizontally consistent interpretation was reached.

RESULTS

The meaning structure of the phenomenon of participation in everyday occupations comprised 3 main characteristics (Table II). The first characteristic, “*I cannot do activities as before*” expressed change in their “doing” and interacted with their experiences of the second characteristic, “*I am not the same person – discovery of a different self*”. In this characteristic the participants expressed a changed experience of being in the world physically and socially. The third characteristic “*I am not living my life*” was identified and expressed as a result of changes in participants’ “doing” and their “self”, and the interactions between these first two characteristics. In the following sections the characteristics and sub-characteristics of the phenomenon will be described and exemplified in more detail as well as their interaction.

I cannot do activities as before

The participants described a tremendous change in doing and how their everyday life was characterized by “not being able to do” the way they did before stroke. They described their engagement as a continuum of “doing”; going from “doing nothing alone” (6 participants) to “doing something” (1 participant) to “can make it happen but differently” (1 participant). The participants described going from being a capable person to being a person who felt incapable, as one related:

“I did everything at home. If there were any problems with the plumbing, or anything else at home, I fixed them. I renovated different parts at home if it was needed as that was my job, but now I can’t do anything.”

One participant who experienced her engagement as “doing something”, described how she tried to do home management activities as much as she could and left the rest that she could

Table II. *The meaning structure, consisting of main characteristics and sub-characteristics*

I cannot do activities as before
Losing former everyday routines
Losing being a subject capable of acting and deciding
Losing former roles and authority in the family
I am not the same person – discovery of a different self
A senseless body – affected side as an object
Discovering “who they are” through “what they do”
Discovering a different “self” in communication with others
I am not living my life

not do to her family. She used simple ways to perform different activities, creating her own strategy to make engagement possible. This was also the strategy used by the participant who described the process after his stroke as going from doing nothing to making things happen.

Losing former everyday routines. This sub-characteristic describes experiences of losing former everyday routines and participants stressed how differently their daily routine is perceived after stroke. They experienced a painful loss of their old daily routines. They stressed how undesired and unpleasant their new daily routine is experienced. One participant said:

“I previously used to go walking in a park close to our place every morning at 7.15 am. Mornings make me cry. Mornings have been painful for me (after stroke). My daughter says that I would get better and go to the park again.”

This participant experienced her former pleasant everyday occupation as being replaced by unpleasant daily torture, which was her physical therapy exercise, her mandatory stressful new routine. She described how painful it has been for her to start the day after her stroke since mornings reminded her of her former enjoyable occupation for starting the day. She described losing her sense of time through losing her old daily routine so that she could not differentiate between mornings and evenings.

Two participants described their new daily routine as a temporary situation and hoped to perform their former routines in the future. For other participants this change seemed to be an obvious permanent “loss” creating a significant gap in their lives. They experienced saying goodbye to old, pleasant and meaningful occupations and habits. After stroke, desired former daily routines were lost and replaced by a daily routine experienced as meaningless. For example one participant used to be active and productive, earning money for the family, but after his stroke, he experienced his everyday tasks as doing nothing, killing time, with the day passing without a sense of engagement.

Losing being a subject capable of acting and deciding. This sub-characteristic describes the importance of being a subject. Participants stressed the importance of being a subject which meant being able to act and decide in order to experience engagement and satisfaction instead of being an object. To be a subject meant not only to act, but also to make their own choices and to be the centre of their own worlds. The participants’ loss of being a subject after stroke was described in different ways. Some participants experienced a total loss and felt that others treated them like objects. A few experienced that others respected their integrity and viewed them as subjects making their own decisions in everyday life. One participant described this loss:

“I am always placed here from the morning, just going to the toilet and then getting back here. My daughter does all my tasks (she does everything for me). My first daughter comes to do the cleaning. I can do nothing.”

Another participant described himself as being “*a piece of meat present there*”, a totally passive object not able to be an active subject doing different tasks. Although the participants

experienced satisfaction when they were active subjects, they described how the sense of being a subject could be preserved despite their not doing the activities by themselves. As for example, two participants described that they could do activities only by getting help from their partners. Although similar to the first example where help came from others, neither of these participants described themselves as being passive objects, despite being severely dependent. They described that they did daily activities together with their partners with their continuous and constant accompaniment. Their descriptions reveal that there were two subjects performing daily tasks together, showing an interaction and understanding between the two subjects and an inter-subjectivity.

The participants described how important it was for them to be able to make choices. One participant described how, after her stroke, she had lost the ability to make her own decision about inviting people to her place and instead was dependent on her two caregivers who were hired by her husband.

"I cannot invite anybody home now. When I tell them (the caregivers) to invite people, they say it's not possible. Well, they see it as difficult for them to take care of the tasks. I don't dare to invite anybody to my home. I say, this is my home; can't I invite anybody to my own home?"

Losing former roles and authority in the family. This sub-characteristic describes how participants experienced a dramatic change in various valued life roles that influenced the way they viewed themselves, their importance, competence, authority and value in the family. Female participants perceived their main important role as that of taking care of the family through various responsibilities, such as home management activities, having control of family relationships and family matters. One of these women said:

"In general, daily life tasks in the family are of greatest importance to me. It is important for me to perform those tasks as a woman at home (in the family), but when I can't, this hurts me a lot. I wish my hand could be fine to be able to take care of these tasks. This really hurts me."

All 4 male participants described their main valued life role as that of a productive person who worked full-time before stroke and the transition to being individuals who could not work anymore. They described how this loss created a significant gap in their life and influenced their position in the family, the way they viewed themselves after stroke and also how the family viewed them. One male participant described how not being able to do his different tasks made him experience himself as a dependent person who consequently lost his authority and former role as highest in the family hierarchy, from being somebody who was productive and head of the family to being a dependent consumer. He used a Persian saying to illustrate his feelings:

"I don't feel good when I say this sentence, but I say it nevertheless. You can understand how I feel when listening to my words in this saying. I hope the Lord doesn't take the kingdom away from any king."

I am not the same person – discovery of a different self

Participants described significant changes in their bodies, abilities, and engagement in different areas of everyday life. They discovered a new "body" and a different "self", reflected in their new ways of "engaging in different activities". They felt sad when comparing their unfamiliar and different "present self" with their "former self" who was pleasant, active, acceptable and able to do.

A senseless body – affected side as an object. Participants expressed how they experienced their bodies as different and unfamiliar, requiring new acquaintance and discovery of a new self. They were also connected differently to the world in everyday life due to this discovery. One participant said:

"There is a big difference compared with before my stroke... I basically wasn't like this (he points to his body) before stroke. I lost 18 kg in weight, I was an athlete. I used to exercise and do combat sports, swim and wrestle. I was a wrestling and swimming champion. Well, now it's never possible to compare (me) with that time. Now, when I walk, it's with difficult. My hand isn't what it should be; my foot isn't what it should be. When I want to speak, it isn't how I want it to be."

The participants described their bodies in the beginning after their stroke as absent senseless bodies. When making comparisons with their bodies before stroke, they talked about their affected side as a separate object that they had no control over, like a senseless object restricting them in doing tasks. They described their bodies as being present physically, but not present to do, move, or act – a senseless passive body, such as an object on the bed, not a physical and emotional subject.

Discovering "who they are" through "what they do". The participants described their self-images based on what they did before stroke (former self) differently from their current images based on what they could do after stroke (present self). Their descriptions of these changes varied; from a total loss of their former "self" in some participants, to a "changed self" in some others depending on what they could do. Those who had experienced a total loss of doing by "being able to do nothing", described a total loss of their former "self" – the one that they had known throughout their life – their familiar "self" as that self "doesn't exist anymore". The greater their gaps in "doing", the greater they experienced the difference compared with the present-former self.

The participants expressed their strong desire to get back to their familiar former self as an ideal, to do former activities.

"I'd like to have my former life back. (She cries and talks to God.) I say, my God please help me to get back to my former life. Please bring my former life back... I could sew, weave. I worked a lot. I worked at home. I took care of everything as a housewife. I cooked food, I invited guests to my home, I went to parties. But now I can't do anything."

Discovering a different self in communication with others. The participants also found themselves to be different when faced

with other people and the way others, especially the family, treated or viewed them was important in creating this new image and discovering their new self. The way the participants perceived this discovery in relation to others varied. Some of them perceived themselves as being an object due to how the family behaved. For example, one participant experienced that nobody listened to her pain. She felt scared of her painful everyday exercises and of not getting the attention she needed and being treated like a child.

"I feel my nail is hurting my toe. I tell him (her husband): if you really want to do something for me, make my toe better. He doesn't pay any attention to me, not at all. He sits there and just checks if I've done an exercise less than I'm supposed to... If I don't do an exercise, he gets mad at me and doesn't talk to me, I cry..."

One participant described how others did not view her the same way as before. This led her to discover her different "self" when communicating with others:

"I want to be who I was before. Now I feel that I do not exist, not at all. I mean, from other people's point of view, I do not exist. For example they (her family) asked for my views before when they wanted to do something, but now it's not the same. They must ask him (her husband). It feels like I don't exist as a person, not at all."

I am not living my life

The participants described their current situation as not living their life and this was influenced by their body, their doing, their self and the feedback they got from their family and environment. One participant described her life as being difficult to deal with:

"I talked to my friends on the phone; I also met my friends in their homes, and they also came to my place to visit me. I do not live my life. I feel sad since I've not been living my life. (She cries)... My husband has bought a new oven, and a dishwasher, I have never used them. My caregivers always use them. I can never use them. What does this mean? (She cries desperately.) I am not living, I have no life, not at all. This is my life. What life is this? I am never living my life."

The participants described their present lives as stressful, challenging and dissatisfying to deal with. One participant described how the feeling of being handicapped – meaning not being able to do anything – made his life mentally stressful and unsatisfying. Another participant described how nothing gave him pleasure or satisfaction in his life after stroke compared with his life before stroke when everything gave him pleasure.

"I have no fun, I mean nothing gives me pleasure. Nothing makes me satisfied now. Everything gave me pleasure before, for example visiting friends and talking to them and laughing, but not now. Nothing gives me pleasure and satisfaction because I am not satisfied with myself. Nothing gives me enjoyment and pleasure because I have to feel fine, that is the most important thing for me. Since I have no positive feelings about myself, I am not pleased with anything".

The participants experienced restrictions in their social interaction due to dissatisfaction with their current life. They

tried to avoid socializing, in order to decrease the stress, to control their lives, and to preserve their former image in the eyes of others, to stay close and connected to their former familiar self. By doing so, they have moved towards social isolation in this new current "life" after stroke.

DISCUSSION

This study aimed at advancing knowledge and understanding regarding experiences of participation in everyday occupations by applying a phenomenological perspective. Taken together, our findings describe how participation in everyday occupations had been profoundly disrupted after stroke, which was related to "what they could not do after stroke" and to "their discovery of a different self". These two aspects interacted with each other and made the participants experience "not living their life" in the way they had before stroke. Previous studies exploring participation have shown that participation is a complex and multidimensional phenomenon, encompassing not only the observed performance of activities, but also the subjective experience of participation. These studies have also described different areas of daily life as different aspects of participation (5, 10, 11, 30), as well as the barriers and environmental factors (12). The present study contributes new insights about this phenomenon, revealing that the meaning of participation in everyday occupations indicates something more than just different areas of everyday life; but rather how the changes in their doing were related to their identity/existence and their satisfaction in a dynamic process. In other words, *how the changes in their "doing"* were connected to *changes in their "self"*, resulting in experiences of "not living their life" rather than just describing various areas of everyday life. The findings could be seen as reflecting the experience of two dimensions of participation, one oriented towards doing and one towards how individuals experience themselves in the socio-cultural world, and demonstrate how important both dimensions are in contributing to how individuals live their lives. The two dimensions of participation are supported by our previous studies on persons with stroke in Iran (7, 31) and also Western studies on participation (30, 32, 33).

In this study participants' different experiences of themselves and their bodies led them to discover their different "self" or identity. The life world, as characterized by Merleau-Ponty, is also the lived world that individuals have access to through their bodies. It is the lived body that provides the connection to the world (34). The participants in the study experienced an altered body and a difference in what they could do, which was also viewed differently by others. The close association between occupation and identity has been discussed in the literature (35, 36). Kielhofner (37) conceptualized occupational identity as the primary means through which people express their sense of self, defined as the cumulative sense of who individuals are and wish to become as occupational beings generated from their history of occupational participation. Reframing self-identity was suggested to be an important aspect of rehabilitation after brain injury (38). Eriksson &

Tham (19) also found that by searching for a new sense of self through doing, individuals with stroke adapted to their new everyday life situation. However, the present study found that the “discovery of a different self” encompassing personal, social and occupational dimensions of identity characterised the phenomenon of participation in everyday occupations. The new finding in this study is that both “doing” and “self”, identified as the first two main characteristics, were essential in achieving the third characteristic, “being able to live life” and that their dynamic interaction defined the essential meaning of participation. The empirical findings of this study give support to how occupational adaptation is conceptualized in the Model of Human Occupation (MOHO) viewing occupational identity as a component interacting with occupational competence and arriving at occupational adaptation (37). The findings empirically support the view that when the participants experienced a loss of competence and identity after stroke, they had not yet adapted to the new life situation.

In line with previous literature (3–5, 10, 11), this study stresses the importance of subjective experiences of choice and control, autonomy and self-determination when assessing participation, and how important the “individual” is as a “*subject being*”, not only in acting, but also in making choices – in being a subject and the centre of his/her own world. The findings showed that the participants experienced satisfaction in their participation when they could be active subjects, which is in line with Cardol and colleagues (39), who stress the concept of autonomy as crucial to the operationalization of participation.

Comparing the findings from this Eastern-context study with similar phenomenological studies in the Western-contexts (19–24) reveals that the participants in this study, regardless of their gender or former roles, described how losing their main life role affected their importance, position and authority in the family, confirming the importance of their family role as their main concern regarding participation, which is not necessarily the case in Western contexts. From a gender perspective, although there are differences in the way they fulfil their roles, both genders stressed the role the person must fulfil in the family. One interpretation is that the socio-cultural importance of the family role in this family-oriented context can have coloured the participants’ experiences of losing their main life roles related to their participation, which is in line with our previous studies in this context (7, 31). Applying this comparative approach also reveals another socio-cultural aspect evident in the rather black-and-white picture that the participants painted to describe their experiences of changes after stroke. In contrast, studies in the Western world showed experiences of ongoing adjustments and positive future horizons in connection with participants’ engagement in everyday life after stroke, which indicates their adaptation to the new life situation (19–24). Lack of appropriate access to rehabilitation services and resources might have impacted the findings; however, socio-cultural issues could also impact on their participation. Future research is needed to study the role of the environment and especially the socio-cultural environment.

Implications for rehabilitation

This study highlights the importance of focusing on both “doing” and “self/identity” aspects in rehabilitation interventions to facilitate participation and satisfaction. This study also emphasizes the contribution of the family and caregivers to the rehabilitation process, both regarding the “doing” and “self” aspects in enabling individual’s participation. Rehabilitation interventions should pay attention to supporting the family in order to preserve the individual’s subjectivity, which seems to be a precondition for participation. Moreover, family support could be a worthwhile way of facilitating participation by creating opportunities to preserve the individual’s former important roles as much as possible, which seems to facilitate satisfaction with their identities.

Limitations

One limitation of the study could be that there was only one in-depth interview with each participant. However, the researcher and participants met twice to create and develop a relationship, which is of importance in acquiring rich data. Language can also be considered as a possible limitation. The analysis was performed in English from Step 3 to make it possible for authors from two different backgrounds to discuss the data analysis. When it was necessary, the first author went back to the Persian data and expressions were discussed to ensure that any important meaning did not get lost or changed in the translation process.

In conclusion, enabling participation after stroke within a client-centred paradigm in this socio-cultural context requires a return to the essential meaning of this concept, as characterized by the dynamic process between the characteristics of “doing”, “identity” and “living life”. The meaning of participation in everyday occupations is essentially connected to how individuals perceive “*living their life*” after stroke, as it is influenced by interaction between “*what they do*” and “*who they are*”. The study highlights how the provision of efficient rehabilitation services in this Eastern context requires attention to both “doing” and to “identity” in rehabilitation interventions, in order to enable individuals to adapt to their new lives after stroke and to “live their lives”. This study stresses the importance of both dimensions in facilitating adaptation and participation in everyday occupations in this socio-cultural context.

ACKNOWLEDGEMENTS

This study was supported by the University of Social Welfare and Rehabilitation Sciences. The authors thank the participants for their active participation and for sharing their experiences.

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