

ORIGINAL REPORT

LIVING WITH THE LONG-TERM CONSEQUENCES 11–13 YEARS AFTER STROKE: A PHENOMENOLOGICAL STUDY

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Objective: To follow up an original research project of persons 11–13 years after stroke, in order to describe and understand the impact of stroke on everyday life experienced during these years.

Design: Eleven persons who had had a stroke were interviewed 11–13 years after the original research project. Data were collected and analysed using the empirical phenomenological psychological method.

Results: Three main characteristics were identified from analysis of participants' experiences during the years after stroke: (i) going through the loss of the previous life; (ii) struggling to reclaim the former existence; (iii) finding meaning in a "new" and different world.

Conclusion: This study provides an understanding of the complexity of the lost connection between body and world occurring for a long time after stroke. This understanding provides support for the need for long-term and intermittent support and guidance to enable the re-creation of meaning and participation in everyday life in order to find a "new" self-identity after stroke, especially among persons with residual cognitive impairment.

Key words: occupational therapy; rehabilitation; stroke; qualitative research.

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INTRODUCTION

This is a long-term follow-up study of persons with stroke who have different types of cognitive impairments. Previous research (1) showed that the meaning of participants actions in different places was experienced as a desire for place integration in the home and workplace, which inspired engagement in rehabilitation (2–4). Most previous research has focused mainly on the first year after stroke and shows that people of working age often experience long-lasting cognitive impairments (5), activity limitations (6), and difficulties in using everyday technology (7). These impairments make it difficult to return to everyday life as it was before stroke, and the

goal of rehabilitation (8, 9) is therefore to enable integration and participation in everyday life. There are few studies of the long-term consequences of stroke and little longitudinal research that can guide the development of long-term support of people with cognitive impairment. However, there are a few longitudinal studies (6, 10, 11) (of which 2 are quantitative) that have concluded that participants with traumatic brain injury still experience considerable symptoms 10 years after injury (6). In one of these studies (11) most of the participants ($n = 145$) were retired and reported good overall health with frequent physical activity 10 years after stroke.

In other quantitative studies, activity limitations and participation restrictions have been shown to negatively influence everyday life among persons with stroke. Examples are: longstanding dissatisfaction with unfulfilled perceived needs for rehabilitation (12–14), dissatisfaction with social activities (15) and restrictions concerning recreation and leisure activities, fatigue and walking patterns (16). Even participants with mild stroke (87%) reported residual stroke-related changes, despite their independence in basic activities of daily life (17).

The results of these quantitative studies are supported by findings from qualitative longitudinal studies, mostly conducted during the first year after stroke. Several studies have shown that persons with cognitive impairment after stroke experience difficulties in everyday life, as well as changes in sense of self and self-identity (18–21) and self-body split (22). These impairments are commonly invisible (23, 24), which has consequences for recovery, continuing to work and engaging in occupations over time.

Phenomenological longitudinal studies of younger persons with stroke also show long-lasting difficulties in everyday life. A study 1–13 years after stroke showed a process of struggling to overcome tensions between the lived body, participation in everyday life, and sense of self during the process of ongoing change (10). Other phenomenological studies showed an embodied disorientation (25) and loss of identity (26). A study, 6 months–9 years after stroke, revealed challenges that varied with time from initial struggle for finding balance within the family to a more resigned attitude later on (27).

In order to develop better long-term support and rehabilitation for working-age people living with the consequences of stroke, qualitative and longitudinal studies are needed, with a specific focus on understanding the lived experiences (28) and needs of persons with cognitive impairment in everyday

life. The motive for this study was therefore to follow up the original research project 11–13 years after stroke, with the aim of describing and understanding the experienced impact of stroke in everyday life 11–13 years after stroke.

METHODS

This study is an 11–13-year follow-up of a qualitative research project (1). The design is longitudinal, qualitative, descriptive and interpretive. An in-depth interview was conducted with each participant, and analysed and interpreted using the Empirical Phenomenological Psychological method (EPP method) (28).

Participants

The participants in the present study were selected from a sample of 19 persons with acquired brain injury (stroke or traumatic brain injury) who had participated in a project (1) applying a qualitative phenomenological approach with repeated interviews during the first year after stroke. In the present study only the participants who had stroke were selected, comprising 11 individuals, (5 women and 6 men), age range 50–67 years. In the original research project all the participants were recruited from the same rehabilitation clinic in Stockholm, Sweden. The first and last author of the present study followed these participants during the first year after stroke; 4 interviews with each of the participants were then conducted. The first author carried out the interviews in the present study 11–13 years after stroke.

The inclusion criteria for the participants in the original research project were: first-time acquired brain injury less than one month prior to the study; working age; restrictions due to cognitive impairments in the performance of daily activities according to their occupational therapist; sufficient memory to retell events that had occurred during the past 24 h; sufficient verbal ability to understand the interview questions and to be able to recount daily experiences during the year.

In the present study 9 of the 11 participants described some form of cognitive impairment. The residual motor impairment as a consequence of stroke varied from an invisible impairment to wheelchair dependency.

All participants in the present study lived at home; 5 were married, 1 was in partnership but lived apart, and 5 lived alone (2 of the participants who lived alone had divorced after their stroke). Only 2 of the participants (with no described cognitive impairment) described satisfaction with their new lives or even added value, 11–13 years after stroke. One of these participants was working full-time in the same area but in a different workplace, and one participant worked 75% in her own business, mostly with the same tasks as before stroke. Four participants worked part-time at the same place as before stroke and all except one had modified duties. One person had sheltered employment and one person had been on sick leave since their stroke. The other participants had worked or trained at their workplaces for short periods of time, but were now on sick leave or retired, and some of them participated in union activities

Data collection

The participants gave verbal and written consent to participate after being contacted by the first author, who gave them both written and oral information regarding the study. A supplementary ethics application was submitted on the basis of the initial project's ethics application. The study was approved by the Regional Ethics Review Board in Stockholm.

The first author conducted an interview with each participant and the participants chose the location for the interviews. Eight participants chose to be interviewed in their homes, one at the first author's workplace, and 2 on other premises. An interview guide (29) was developed with areas of questioning focusing on the lived experiences of everyday life during the 11–13 years after stroke. Examples of general questioning included the participant's experiences and meaning of occupations, the

meaning of performing activities in different places, and the meaning of others, e.g. family, colleagues and friends, in the context of daily life. All interviews were digitally recorded and transcribed verbatim.

Field notes were taken in order to aid understanding of their described lived experiences during analysis.

Data analysis

The EPP method (28) was used to analyse the data. This method aims to describe the meaning structure of the phenomenon studied, as it presents itself, based upon the participants' descriptions of their experiences. This means that the researcher must be as open as possible to the original and immediate experience of phenomena studied to be analysed by way of bracketing (temporarily putting aside theoretical knowledge) (21). Using the EPP method (28), the analysis of these experiences can be described briefly in 5 steps.

Firstly, the first author examined the 11 interviews in order to acquire explicit and implicit meaning, which means the essential characteristics of the participants' described experiences of the years after stroke. Secondly, the data in each participant's interview transcript were divided into meaning units (MUs); for example, their experiences of performing activities at work or at home during these years. Thirdly, the meaning units in the transcribed interviews were interpreted. The researcher was moving from a particular fact towards examining its implicit and explicit meaning in relation to the studied phenomenon. For example, the fact that the participants had performed activities in everyday life during the years after stroke was not of interest *per se*, it was how they experienced the performance of activities. Fourthly, a summary was made of the interpreted MUs for each transcribed interview from step 3 into a "situated structure of meanings" (21, p. 106). This implies describing, in a phenomenologically significant way, the structure of the phenomenon and how the process of the phenomenon was lived through. Finally, in step 5, the researcher moved from the situated structure of meaning to an overall structure. The analyses of all the participants' experiences of occupations in daily life during the years after stroke were compared and interpreted in order to trace out a general meaning-structure of the phenomenon that was consistent for all participants.

In step 5 the researchers discussed alternative interpretations until those were identified. During this step the researchers also identified sub-characteristics as aspects of dimensions of the overall meaning structure in order to gain a deeper understanding of variations of the phenomenon studied. For example, the sub-characteristic "Finding new meaning through activity other than work" was an aspect of the main characteristic "Finding meaning in a "new" and different world". The researchers sought to ensure credibility by moving back and forth between the interpretations and the data. The researchers discussed and refined the dimensions of the overall meaning structure numerous times by applying a "horizontally consistent interpretation" (21, p. 131) to ensure that each aspect, first from each participant, then across all participants, was consistent with the other aspects that emerged in the analysis.

RESULTS

The analysis reflects the nature of the participants' lived experiences of everyday life during the years after stroke and is presented in the meaning structure below (Table I). The characteristics do not reflect discrete stages over the years. In fact, they overlapped and complemented the described lived experiences from each unique participant.

Going through the loss of the previous life

In some way, all the participants had gone through a loss after stroke; an ego capacity had been lost. They described a sense of alienation from their bodies. Those with both cognitive and

Table 1. *Meaning structure of participants 11–13 years after stroke, consisting of 3 main characteristics and sub-characteristics*

Meaning structure
<i>Going through the loss of the previous life</i>
Lost connection between body and world
Social loss
<i>Struggling to reclaim the former existence</i>
Struggling still dominates: longing for the familiar
Resigned acceptance
Need for others as an extension of the body
<i>Finding meaning in a "new" and different world</i>
Running one's own project and adapting to a new working world
Finding new meaning through activity other than work
Finding meaning through belonging
Finding a new profound dimension

physical impairments described a greater sense of alienation; it was more a cognitive function rather than a spontaneous non-reflected bodily action, which resulted in a lost connection between body and world. In situations of stress and excessive demands, the body felt limited.

Lost connection between body and world. Even 11–13 years after stroke the participants in many ways described their bodies as changed and described a decreased connection between body and world that seemed difficult to control. One of the participants gave an example describing a sense of enfeeblement in his changing body; "there is someone pulling out the plug and then the air goes out of me and I'm drained of energy, not brain power". When the goal and the body were not in harmony, he described it as the brain feeling diminished. An example was when he had worked late and he felt that his body was not sufficiently capable; it was both physical and cognitive fatigue; "My head and my brain hurt, it feels like someone hugs my head like a foam sponge and squish, squeezing it from the outside".

A world of constant frustration and a sense of inadequacy were also described; for example, a participant describing his changed body as a changed sense of self, he no longer trusted himself cognitively when sailing "a strong feeling of insecurity of the situation, reading the charts, translating them into reality, so to speak".

The participants with both cognitive and physical impairments still described a sense of fatigue and a greater sense of alienation, a barrier that over the years after stroke had limited their world, both in terms of activity and social participation. One participant described an "exhausted" brain in stressful situations, and another participant how fatigue had dominated over her resolve during all the years after stroke, her desire and her body were not in harmony "I've got into a bad habit of just going to bed". Another example of a sense of alienation was a participant (still in a wheelchair) who, in contrast to his former life, described a sense of being erased and useless and that he no longer had any direction in his life "I just float like a log in the water".

Social loss. A social loss of life compared with before stroke remained 11–13 years after stroke; life had slowed down.

Several of the participants described frictions in their close contacts, with traumatizing break-ups. Feelings of having been betrayed by relatives or friends who were no longer there for them were expressed. One of the participants gave an example of a traumatizing disruption, describing their divorce after stroke as a betrayal, becoming de-selected and being seen as a different person than he saw himself... "it's awful tough, it was she who saw me as a different person,... of course, you feel like the same person [as before]".

Social loss was also described; for example, as one of the participants described that his former world of community was no longer there, he felt ignored by his social network, both friends and colleagues: "...before I went out with the guys, took a sauna at my country house, had great fun and went boating." "...it feels a little bit bitter; it's always me who has to get in touch..."

Struggling to reclaim the former existence

During all the years after stroke the participants had been struggling to recreate their life-world as it was before their stroke.

Struggling still dominates: longing for the familiar. The ongoing struggle still dominated; the urge to find a way back to the familiar life before stroke. Above all it was a quest to regain the competence they had before stroke. It seemed important for the participants to be able to work to regain self-esteem and dignity in life. One participant expressed how he constantly sought, as it seemed, an unattainable "higher level" than the level he had before stroke. "The strong feeling is really annoying because I want my old life back, that's the strong feeling, I will do anything, I try to stay active a little bit, I do activities, I read, try to work, put pressure on myself at work to see if I can achieve a different level, so to speak".

Another participant exemplifies the strength of the struggle for coming back to work; it was still a battle that he was not going to give up before his goal was met, even if it not was realistic. "I have not got my job back yet, but I'm holding on and I will win, I'm close, close now".

Resigned acceptance. The participants who had let go and given up the fight to return to some form of work had to adapt to a new situation. There were different levels of acceptance; for example, one of the participants did not have any choice but to accept changes, to stop working, when his work was terminated. Another participant had accepted that she was not able to work full-time. It had taken 5 years after onset before even a sense of being on the right path had emerged. By being confronted with her limited capacity by her fellow workers when performing her work tasks she gradually realized her own restrictions "Yes, to some extent, it's better, but yeah, no, it's still there, even after 10 years; It's my memory, my balance".

Need for others as an extension of the body. For some of the participants when their body was not adequate they enlisted the assistance of others to extend their body. An example of accepting help, cognitively, from another person was when one of the participants described that his "brain power" came to an end when he performed tasks that required constructive

thinking at their summer home. He had then agreed to let his neighbour substitute for his body, as an extension of his own brain “I can’t handle constructive thinking, then I go over to my neighbour and he helps me to think”.

Finding meaning in a “new” and different world

It had been a demanding process for the participants to find meaning in their new world during the years after stroke.

Running one’s own project and adapting to a new working world. The only one of the participants who, after all the years, worked full-time, described the demanding processes he had undergone over the years to find meaning after stroke. He had driven his own rehabilitation project towards returning to work, adapted to a new work situation and processed his grief after stroke. He had required professional help to get through the grieving process of losing his job and understanding his new world, he said “and then there has been sadness along the way, I’ve been working quite a lot with myself, I contacted a psychologist by myself just to be able to go through and review why everything was as it was”. When initially in his rehabilitation he was not given any hope of returning to work this spurred him, through his obstinacy, to take up the fight. “I’m a very stubborn person. I started to work with myself in order to be more verbal, I began to communicate more and stand up for myself, speak in the company of others, I started over from the beginning”. He described the significance for him of not becoming stigmatized in a “stroke-role” and instead to succeed after some years in getting a new, less demanding job, although within the same area.

Finding new meaning through activity other than work. Several of the participants described that, during all the years after stroke, they had tried to find new meaning through activities that replaced their work. One participant described how he found meaning through his boat, like a lifeline that had replaced his former work both emotionally and economically, even if he was still fighting to get back to work, he said: “the boat has kept me alive as well, all of this engages me, renting out and booking and staying on with customers, it’s like a small business *per se*; you train for the job, you might say”. When the employer did not see him as competent enough to return to his former work, the boat gave him acknowledgement and a sense of still having work capacity.

Finding meaning through belonging. The key to finding meaning during the years after stroke was, in accordance with previous findings from the first year after stroke (4), still attributed to feelings of belonging. The social relations consisted of family, colleagues, friends or the meaning for the participants of contacts with organizations and non-profit associations when return to work was not possible.

They all described various processes they had gone through over the years. One example was a participant who described the importance of his family (wife and children) in contributing to his progress over the years and his feeling of security and continuity. The absence of deliberated demands from the

family seemed to support his progress. He had thus been able to mirror himself through safe and direct communication with his wife “she speaks honestly so that I know that I’m alive every day and that is what I think has lifted me, pretty much so that I’ve shaped up to be a real person at all times”.

Finding a new profound dimension. In contrast to most of the participants, two of them described their life after stroke not just as something negative, but also that life had gained a new meaning, an added value. One example was one of the participants who, in contrast to her former life, now described a sense of relief. Her life after stroke had progressed to a calmer pace, even if she still ran her own company, which had brought new meaning to her life. “The big change is that before I worked like a fool, it’s a big change and it was what was great about this”.

Another participant described that, thanks to his experience after stroke and his insight regarding his limitations, he had found a deeper meaning in life. The process of developing his new self after stroke had been demanding, adapting to a new reality through a process of grief that required professional help to understand and move forward. For him it meant an added value to have developed his self into what he felt was a more reflective, less prestigious and more empathetic person.

DISCUSSION

This study, 11–13 years after stroke, showed a lost connection between body and world, where most of the participants were still struggling to regain their former existence and find meaning. The results are also in accordance with other research, supporting the importance in rehabilitation of belonging and support (3, 4) to build upon everyday life with meaningful activities for each individual (30, 31).

Finding meaning in their “new” world after stroke was a big challenge for the participants. It seemed that they no longer had the same access to the world as before stroke through bodily experiences (32), such as work, which had given them positive experiences of belonging (4) and self-identity. This is in line with Merleau-Ponty (32, p. 94), who said “I am conscious of the world through the medium of my body”. No longer being automatically able to use their bodies seemed to reduce participants’ everyday life; they could no longer take their world for granted as before stroke (33). The major challenge during the years after stroke appears to have been to find meaning and a “new” self-identity, especially for participants with cognitive impairment. These persons described a greater sense of fatigue and alienation from their bodies, which had limited their world both in terms of activity and social participation. It seemed that the struggle to find meaning was linked to the possibility of finding activities that gave them positive bodily experiences in other places and with activities other than work. According to Merleau-Ponty (32), a person cannot step outside the body, since the body is always experienced from an internal perspective, as a fusion of soul and body when interacting with the environment. This can provide an understanding of the

participants' struggle over the years (especially for participants with cognitive impairment), to regain the habit-body, strongly connected with self-identity, as it was before stroke. Perhaps the participants could more easily have re-created habits they had before stroke that were connected with their self-identity if they had received longer-lasting support in finding and practicing familiar activities based upon the habit-body. These findings were in accordance with those of our previous study during the first year after stroke (2), showing that it was easier for persons with memory impairment to automatically perform activities they usually performed, which were thus integrated into the habit-body (32).

It seemed as if cognitive impairment influenced the lost connection between body and world for most of the participants, which is in line with research that identified a changed sense of self and self-identity among young persons with stroke (10, 20–24). For the participants in this study, when the body did not work, this was, above all, most apparent in working life. Even 11–13 years after stroke, work seemed to be the occupation most embedded with meaning and, furthermore, in agreement with other longitudinal studies, people achieved a sense of normality through work (34), which thereby enables the enhancement of quality of life (35). Only 2 of the participants in the present study described their return to work as successful after 11–13 years. One can reflect on the fact that these two persons did not describe any cognitive impairment that might have contributed to their ability to reorganize their lives. They seemed to have succeeded in re-creating “occupational engagement” (8) through their work and participation in their social life, which probably contributed to their described well-being and even added value, like a new existential dimension in life after stroke.

In contrast to these two participants, other participants (who, on the basis of their disability had not had the same ability to return to work successfully and still strived to find and create meaning) probably needed another kind of support or guidance. Since there is evidence of a changed self and self-identity among young persons after stroke (10, 20, 24), there is a need to focus on this in rehabilitation. By understanding the person's lived body and experienced self-identity, rehabilitation professionals can better support the persons with stroke in creating meaning and participation in everyday life. The challenge must be to find engaging activities/occupations and satisfactory activity patterns in everyday life that meant “something” to each person (36, 37). This is especially important for young persons with lasting cognitive impairment who can no longer handle work-related activities/occupations and contacts; this conclusion has also been reached in other research (38). Since this study shows a lost connection between body and world, and that self-identity, to a large extent, was also linked to the opportunity to perform meaning-bestowing activities, a daily occupation with engaging activities in interaction with others can be key to finding a “new” self-identity and meaning in the long-term after stroke.

Methodological considerations

By choosing a phenomenological method (21) in the present study, the goal was to describe the participants' lived experi-

ences of their life-world, 11–13 years after stroke, as reliably as possible. Eleven of 12 participants wanted to participate, which can be seen as a sign of strength, since they were motivated to share their life-world experiences during the years after stroke, and this provided rich data for analysis. In order to make this study as valid as possible, “horizontally consistent interpretation” (21, p. 131) was used. This means that the final interpretation for the participants was general and consistent with the data in all the analysed documents.

Conclusion

This study provides an understanding of the complexity of the lost connection between body and world occurring for a long period after stroke. This understanding supports the need for long-term and intermittent support and guidance after stroke, to enable the re-creation of meaning and participation in everyday life in order to help persons to find a “new” self-identity after stroke, especially among persons with residual cognitive impairment.

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