



## Integrating consequences of stroke into everyday life – Experiences from a long-term perspective

Charlotte Wassenius, Lisbeth Claesson, Christian Blomstrand, Katarina Jood & Gunnel Carlsson

To cite this article: Charlotte Wassenius, Lisbeth Claesson, Christian Blomstrand, Katarina Jood & Gunnel Carlsson (2020): Integrating consequences of stroke into everyday life – Experiences from a long-term perspective, Scandinavian Journal of Occupational Therapy, DOI: [10.1080/11038128.2020.1857433](https://doi.org/10.1080/11038128.2020.1857433)

To link to this article: <https://doi.org/10.1080/11038128.2020.1857433>



© 2020 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 12 Dec 2020.



Submit your article to this journal [↗](#)



Article views: 470




View related articles [↗](#)



View Crossmark data [↗](#)

## Integrating consequences of stroke into everyday life – Experiences from a long-term perspective

Charlotte Wassenius<sup>a,b</sup> , Lisbeth Claesson<sup>a</sup>, Christian Blomstrand<sup>c,d</sup>, Katarina Jood<sup>c,e</sup> and Gunnel Carlsson<sup>c</sup>

<sup>a</sup>Department of Health and Rehabilitation, Institute of Neuroscience and Physiology, The Sahlgrenska Academy at Gothenburg University, Gothenburg, Sweden; <sup>b</sup>Department of Occupational therapy and Department of Research, Education and Innovation, Södra Älvsborg Hospital, Region Västra Götaland, Borås, Sweden; <sup>c</sup>Department of Clinical Neuroscience, Institute of Neuroscience and Physiology, The Sahlgrenska Academy at Gothenburg University, Gothenburg, Sweden; <sup>d</sup>Stroke Centre West, The Sahlgrenska Academy at Gothenburg University, Gothenburg, Sweden; <sup>e</sup>Department of Neurology, The Sahlgrenska University Hospital, Gothenburg, Sweden

### ABSTRACT

**Background:** Occupational engagement encompasses both objective and subjective aspects of occupation. Long-term follow-up studies indicate that stroke can have a negative impact on the ability to perform IADL. Less is known about the subjective experiences of occupational engagement and how engagement may evolve after stroke.

**Objective:** To explore stroke survivors' experiences of occupational engagement and how engagement changed over time and across contexts.

**Material and methods:** Repeat, semi-structured interviews 15–18 years post-stroke, analysed using thematic analysis. Eight out of nine participants were classified as having had a mild stroke at onset.

**Results:** The analysis resulted in five themes that together formed the main theme 'It takes time – integrating consequences of stroke into everyday life by engaging in occupation, using internal resources and adapting to context'. This illustrated how occupational outcome was the result of a continuous process in which occupational engagement was a way of gradually integrating consequences of stroke into everyday life.

**Conclusion and significance:** Occupational engagement plays an important part in the process of moving on with life and can serve as both goal and means of achieving desired outcomes after stroke. Interventions that focus on enabling opportunities for occupational engagement in valued occupations and support the use of abilities and internal resources can reduce the impact of stroke in everyday life.

### ARTICLE HISTORY

Received 19 May 2020

Revised 25 November 2020

Accepted 25 November 2020

### KEYWORDS

Occupational therapy; occupational engagement; activities of daily living; adaptation



## Introduction

The focus of occupational therapy is to help individuals achieve health, well-being, and participation in life through engagement in occupations. A significant health event, such as a stroke, can cause a sudden and significant change in occupational ability [1]. Thus, the event of having a stroke carries the potential risk of affecting the ability to engage in occupations.

Globally, and in Sweden, stroke remains one of the leading causes of disability in the adult population [2–4]. Stroke is a chronic disease where the societal costs and consequences for those affected extend well

beyond the acute phase [5,6]. Long-term needs of stroke survivors place ongoing demands on resources [7], and there is a need for effective treatment during the acute phase as well as during rehabilitation and long-term follow-up to reduce the burden of stroke [8]. The increasing incidence of stroke in the younger population [8–10] adds to the large number of survivors who will live many years with stroke-related disabilities that may affect everyday life occupations.

In occupational therapy, the term occupations refers to 'the everyday activities that people do as individuals, in families and with communities, to occupy time and bring meaning and purpose to life.

**CONTACT** Charlotte Wassenius  [charlotte.wassenius@gu.se](mailto:charlotte.wassenius@gu.se)  Institute of Neuroscience and Physiology/Occupational Therapy, University of Gothenburg, P. O. Box 455, Gothenburg, 405 30, SE, Sweden

© 2020 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

Occupations include things that people need to, want to and are expected to do' (WFOT 2010). In rehabilitation research, the term instrumental activities of daily living (IADL), including domestic, social and work-related activities [11], is often used interchangeably with occupation to refer to the more complex activities that constitute most of our everyday life. IADL is an area where the responsibilities and demands on younger stroke survivors differ from those of older stroke survivors [12–15]. Long-term follow-up studies have indicated that stroke can have a negative impact on the ability to perform IADL [16–18]. Long-term consequences include reduced performance of IADL [19,20], restricted participation and autonomy [21] and a greater number of occupational gaps compared to age-matched controls [22]. Most studies have used objective measures for exploring the association between IADL and stroke-related consequences. However, inability to resume previously performed activities is reported to be related not only to specific physical, cognitive or emotional impairments, but also to an ability to adapt [23].

Occupational adaptation is a construct used within occupational therapy to describe the process and/or outcome of the interaction between the person, occupation and environment in response to occupational challenge [24]. By performing daily activities, stroke survivors have been reported to gradually discover their strengths and weaknesses [25], which can lead to new priorities as well as negative feelings and the loss of occupations [1,26,27]. In a systematic review, Sarre et al. [28] found adjustment after stroke to be non-linear, marked by both setbacks and successes, and varying in relation to time and context. Occupation can provide the means of adaptation [29,30], and occupational engagement has in turn been linked to capacity to adapt after a stroke [28,31]. The same review by Sarre et al. [28] found that many studies reported engagement in meaningful activities as a key part of adjustment. The experience of meaning is subjective; therefore, there is a need to address personal experiences when exploring long-term outcome after stroke. The current study used the construct of occupational engagement to encompass both objective and subjective aspects of occupation, in similarity to definitions used in most previous studies [32]. Thus, incorporating both the performance or doing of an occupation and the subjective experience which may provide a greater understanding of the long-term consequences after stroke. The subjective experiences can yield important insights for designing interventions and long-term support for stroke survivors.

## Objective

An objective of this study was to explore stroke survivors' experiences of occupational engagement. Further, this study aimed to explore how engagement may have changed over time and across different contexts.

## Methods

This study used a qualitative design with individual interviews and inductive thematic analysis. We recognize that the individual experience of occupation is subjective and affected by contextual factors, but also that the researcher is a subjective part in interviews and analysis. Epistemologically this study most closely aligns with interpretivism and more specifically constructivism as it aims at understanding the experiences of participants by interpreting the personal experiences of occupation. Occupation is viewed as contextually bound. Interpretivism and constructivism embrace subjectivity and are context sensitive [33,34]. Thus, the interpretative approach aims at grasping the diversity of experiences [35].

## Participants

Participants were recruited from a subsample of the Sahlgrenska Academy Study on Ischaemic Stroke (SAHLSIS) at the University of Gothenburg. All interviews took place 15–18 years after index stroke. Inclusion criteria were: previously participating in SAHLSIS with data from baseline and 7-year follow-up, 18–60 years of age at time of index stroke, and verbal ability in Swedish. Persons with language or cognitive dysfunctions were excluded only if it affected their ability to understand oral and written information. Persons with a concurrent acute illness during the recruitment phase were discussed with a physician and excluded if this was considered to affect the interview topics. The number of eligible participants was 18. A purposive sampling was attempted, striving for variation with regard to demographics and vocational status. An invitation letter explaining the purpose of the study along with a contact form and prepaid return envelope was sent to 11 eligible participants. A follow-up phone call was made after two weeks to answer possible questions and, if verbal consent was given, to schedule a time and place for the interview. Of these 11 persons, 6 were able to take part in interviews and further sampling continued until attempts had been made to contact all 18 eligible participants, resulting in a total of 9 participants.

**Table 1.** Characteristics of participants,  $n = 9$ .

|  |                       |   |
|--|-----------------------|---|
| At time of index stroke                        |                       |   |
| Age  |                       |   |
| 45–50 years                                    |                       | 1 |
| 51–55 years                                    |                       | 4 |
| 56–60 years                                    |                       | 4 |
| Sex  |                       |   |
| Female   |                       | 5 |
| Male   |                       | 4 |
| Living situation                               |                       |   |
| Alone  |                       | 1 |
| Cohabiting with another adult                  |                       | 8 |
| Children                                       |                       |   |
| Yes  |                       | 9 |
| Education                                      |                       |   |
| ≤ 9 years                                      |                       | 4 |
| 10–12 years                                    |                       | 4 |
| > 12 years                                     |                       | 1 |
| Vocational status                              |                       |   |
| Full time                                      |                       | 6 |
| Part time                                      |                       | 2 |
| Not working                                    |                       | 1 |
| Previous stroke                                |                       |   |
| No   |                       | 9 |
| SSS <sup>a</sup> score acute phase             |                       |   |
| Median   | 56 (min/max 36/58)    |   |
| NIHSS acute phase <sup>b</sup>                 |                       |   |
| Very mild (0–2)                                |                       | 6 |
| Mild (3–4)                                     |                       | 2 |
| Moderate (5–15)                                |                       | 1 |
| Follow-up                                      |                       |   |
| Vocational status at follow-up (7 years)       |                       |   |
| Full time                                      |                       | 1 |
| Part time                                      |                       | 3 |
| Not working                                    |                       | 5 |
| At time of interview                           |                       |   |
| Age  |                       |   |
| Mean, SD (min-max)                             | 71 years, 4.5 (64-77) |   |
| Living situation                               |                       |   |
| Alone  |                       | 5 |
| Cohabiting with another adult                  |                       | 4 |
| Vocational status                              |                       |   |
| Paid employment                                |                       | 1 |
| No paid employment                             |                       | 8 |
| Receiving help in managing everyday activities |                       |   |
| No   |                       | 9 |
| Recurrent stroke since baseline                |                       |   |
| No   |                       | 9 |

<sup>a</sup>Scandinavian Stroke Scale.<sup>b</sup>National Institutes of Health Stroke Scale. Converted from SSS score.

Reasons for non-participation were as follows: ongoing illness (2), declined (3), not able to be reached (3) and unable to understand verbal information due to cognitive dysfunction (1). Characteristics of the participants are presented in Table 1.

### Data collection

Demographic data and information about stroke severity at onset were collected from the SAHLSIS database and by a brief questionnaire at the time of the interview. All interviews were individual and conducted face-to-face by the first author (CW). Given the long timeframe of the study and that participants were stroke survivors who might not be able to

participate in long interviews, a choice was made of interviewing each participant twice with a week in between. This was aimed to offer support in dealing with feelings brought to surface by the first interview, to provide participants time to reflect on the questions and to provide the interviewer time to prepare for the second interview. An interview guide was constructed to cover four main areas: Returning to everyday life after stroke, Occupational engagement over time, Occupational engagement within different contexts and development and application of strategies in everyday life. The questions were open-ended, and prompts and follow-up questions were used to encourage participants to elaborate further. The interviewer listened to the first interview and made notes before the second interview took place. The second interview began with the interviewer asking participants if they had any thoughts or questions that they wanted to start with. If not, a brief summary was made of the previous interview and the interviews were focussed on clarifying and elaborating what had been discussed in the previous interview. The first set of interviews was planned as a pilot to test both the interview guide and the strategy of interviewing each participant twice. The pilot was discussed between authors and as no changes were made to either the interview guide or the strategy, the pilot was included in the study.

Interviews were carried out between February and August 2019. The median total interview time for each participant was 106 min (min 38, max 133). The mean number of days between the first and second interview was seven days for all but one participant. For this participant, the time between interviews was 45 days due to difficulties in reaching the participant at agreed time. This delay was not related to a lack of interest in participating, whereby the interviews were included. Seven participants chose to be interviewed in their homes. One participant chose to be interviewed at a clinic and one in the home of a significant other. Two of the participants chose to have a significant other present during the interviews. For one, this was due to the responsibility for a significant other who was unwell. This person did not participate in the interview but was present in the room. For the other participant, this was due to communication difficulties caused by the stroke. The significant other did participate in the interview, but only when the person being interviewed asked for clarifications. All interviews were audiotaped and transcribed verbatim by the first author (CW).

## Analysis

Data were analysed using inductive thematic analysis following the six phases described by Braun and Clarke [36]. Two authors (CW and GC) were active in all phases. Further, two authors (CB and LC) read all transcripts, coding schemes and themes. Regular meetings were held to discuss the progression of the analysis. The first author (CW), conducting the interviews and responsible for the analysis has more than 10 years of clinical experience of working with stroke survivors and PhD- level training in qualitative methods. The last author (GC), active throughout all phases of the analysis has more than 25 years of experience of interviewing people with stroke and various qualitative methods. The analytic process continuously moved back and forth between themes, codes and data set, ensuring that codes and themes remained grounded in the data. The data program NVIVO 12 pro was used throughout the analysis, enabling authors to sort and move between different levels of data. Mind-maps were used to visualise potential themes and subthemes, serving as a method for merging themes. An example of the analytic process is illustrated in Table 2. A fifth co-author (KJ) was involved to provide input in finalising the themes. During the initial coding it became evident that work was a central occupation and a core aspect in the life of participants. Therefore, extracts addressing aspects of work were coded specifically. Due to the magnitude of these codes, they are addressed in a separate paper.

## Ethical considerations

The study was approved by the Regional Ethical Review Board in Gothenburg, Dnr: 1100-17 (interviews) and Dnr: 413-04 (data relevant to prior participation in SAHLSIS). All participants gave verbal and written informed consent prior to the interviews.

## Results

The analysis resulted in five themes that together form the main theme 'It takes time – integrating consequences of stroke into everyday life by engaging in occupation, using internal resources and adapting to context' (Table 3).

### An (un)controllable context

Living in a society means that occupational engagement occurs in and is impacted by social, cultural

and physical factors. Participants described how the impact of stroke on occupational engagement varied with contextual circumstances. In particular, participants gave examples of when the context became a barrier for occupational engagement, and this was often related to factors that were beyond their control, such as societal changes, pressure from others and significant life events.

When unable to control the context, participants had to choose between the consequences of engaging or withdrawing from the occupation. For many, this meant avoiding places or situations where they risked having to deal with the unforeseen, as this could increase the impact of stroke. Many preferred the familiarity and predictability of their own home environment. For some, the ability to engage in occupation was directly related to environmental factors such as sound and the presence of others. Being with, or in proximity of other people was described as increasing fatigue and affected the ability to concentrate. An occupation that could be performed with ease when they were alone could become difficult in the presence of others.

Since the onset of stroke, societal changes over time presented challenges as well as opportunities for occupational engagement. Many felt that societal development had become more rapid, referring to both the increasingly wound-up pace in society and the technological development. For some, this not only had a negative impact on their ability, but also on their motivation to engage, as they felt that society had become more ruthless and stressful. Some participants also acknowledged a discrepancy between their own reduced pace and the high pace in society.

Society has changed. And most of all humanity. My brother and I sometimes talk of that we can't stand modern man. It is often an agitated younger person, driving without signalling. And always rushing and being stressed. Whole of society has become wound up. But that may also be because I have become wound down.

One aspect of societal changes that many participants spoke of was the expectation concerning availability, which increased worry and stress. This meant that participants had to balance their own well-being with a willingness to help and not wanting to let others down. Some had attempted to control the feeling of being pressured by others by setting boundaries but had been met by negative reactions. Others spoke of the change in society but did not feel that it made an impact on their everyday life. Further, some felt

Table 2. Examples illustrating the analytic process.

| Extract   | Coding                                | Coding   | Subtheme   | Theme   | Main theme  |
|---|---------------------------------------|--|--|---|---|
| With regularity I can manage fatigue better. I don't want it to become too much ... unforeseen ... someone just shows up at my door. I don't like that. I prefer knowing what is going to happen. | Difficult to handle unforeseen events | Life in a context<br>Context as a prerequisite | An uncontrollable context                              | An (un)controllable context   | It takes time-integrating consequences of stroke into everyday life by engaging in occupation, using internal resources and adapting to context |
| If I have made a promise I don't want to disappoint. I want live up to that promise   | Living up to expectations             |  |  |   |   |
| Today it all goes so fast. And that will in many cases have consequences  | Societal changes                      |  |  |   |   |
| Not being able to read felt difficult at first. But then I had these books with larger text. And then I would gradually go back to normal text and now I read ordinary books.                     | Solutions to maintain interests       | Finding solutions                              | Understanding and adapting to changed abilities        | Getting to know abilities and finding solutions through occupational engagement |   |
| Then I go and lie down for about half an hour before I go back out and continue   | Resting                               | Strategies                                     |  |   |   |
| And they told me I might not be able to ride a bike. And when I got home I had to try. And yes, I could.  | Trying early on what she could do     | Getting to know abilities                      | Being allowed opportunities to discover a changed self |   |   |
| I became, the way I see it, a bit more grateful for life really. In a way, feel that you have been given a second chance  | Re-evaluating life after stroke       | Rethinking life                                | Re-evaluation and acceptance                           | Moving on with life   |   |
| One thing I gave up was the house. I could not change the house facade, paint ... so we sold the house and moved here   | Moving to more manageable housing     | Moving towards acceptance                      |  |   |   |
| You have kind of accepted all that. And you don't really feel bad about it either. Of course, some things are annoying but it doesn't change your life as such.                                   | Accepting the situation               |  |  |   |   |

**Table 3.** Overview of themes and subthemes.

It takes time – integrating consequences of stroke into everyday life by engaging in occupation, using internal resources and adapting to context

| An (un)controllable context | Relying on internal resources  | Getting to know abilities and finding solutions through occupational engagement                           | Occupational losses and new opportunities   | Moving on with life          |
|-----------------------------|--|---|---|------------------------------|
|                             | Believing in and mobilising own resources<br>Taking responsibility and valuing own efforts | Understanding and adapting to changed abilities<br>Being allowed opportunities to discover a changed self | Replacing occupations<br>Balancing value and consequence<br>Value as a prerequisite for continued engagement<br>Feeling like a changed person | Re-evaluation and acceptance |

that the development had made their life easier and that the technological development had made the impact of stroke less prominent.

Participants described how their life both before and after stroke had been affected not only by other illnesses of their own, such as diabetes or chronic obstructive pulmonary disease, but also by events and illnesses in the close family circle. Several of the participants had suffered the death and loss of children or a spouse, affecting how they viewed their own life and posing new challenges to be faced. Others were at the time of their stroke responsible for significant others, which meant having to give support rather than receiving support after stroke. Participants also described how positive experiences in their life before stroke helped them in accepting the present. Having had personal, social and financial resources to experience a good life before stroke led to a greater appreciation for life as it was after stroke.

### ***Relying on internal resources***

Most participants shared an internal drive forwards and a pragmatic approach to new challenges. Facing the consequences of stroke, participants described how they used and relied on internal resources, took on responsibility and valued their own effort.

### ***Believing in and mobilising own resources***

Participants ascribed their motivation and success in doing things not only to personality traits such as being stubborn and having an ‘everything is possible’ attitude towards life, but also to an ability to ask for and accept help from others when needed. They provided examples showing that they had always been prone to take on new challenges and viewed life after stroke as another challenge to be dealt with. However, not all personality traits were expressed in positive terms, and one participant spoke about how being an

all or nothing person could become a barrier. Always aiming to work hard and not being able to adapt to abilities meant that it was sometimes better to do nothing than too much.

Trusting their own ability to make the right decisions for themselves, participants described how they had become more accepting towards themselves and how they feel. Many had made new priorities and had become more selective in what they spent their time on. One aspect of this was ageing, which eased the way for making new priorities in life. For some who had had a stroke at younger age, demands such as work and family responsibilities were expressed as positive because they spurred on recovery. However, most participants also experienced ageing as positive, as it reduced expectations from both themselves and others and allowed them to be selective in choosing what they felt was important to do in their everyday lives.

Most of all I do the things I want to do, and I say no to things I don't want to do. That has become more... I just don't do that which is boring. And I think, when you are this old you shouldn't have to. Like, I used to do a lot of gardening before but that, I don't do that anymore. Flowers and such I take care of but not the heavy chores. So, I choose what I want to do more.

Allowing themselves to be selective not only meant choosing between occupations but also allowing themselves to be alone. Participants described not being able to value or enjoy social events and gatherings in the same way after their stroke, which led them to re-evaluate social participation and sometimes distance themselves from others.

- I avoid it. I think sometimes (somebody says) can't we go to a concert or something. I say, no you go. My reward is that I don't have to go

- And you are ok with that? Or do you sometimes feel that you would have liked to if the circumstances...

- No, that feels ok. I feel that the value of being able to make these decisions and ... doing so ... that, that is worth a lot

### ***Taking responsibility and valuing own efforts***

Providing examples of how hard they had worked, often over long periods of time, participants emphasised that their present situation was a result of investing both time and effort to move forward after their stroke. The examples reflected the ability of many participants to have faith in their own decisions, to value their own efforts and credit themselves when accomplishing something which they had strived for. In particular, participants valued taking their own responsibility for recovery and described how they initiated their own opportunities for practice and gradually improved by means of physical exercise and conscious use of everyday occupations.

Everything you do at home. And that's not saying a little. It's not. Making the bed was really difficult. To vacuum was practice. And sometimes I would sweep instead to practice the other arm. And then I had these rubber bands and. And I got to go to rehab as well. I would sleep at home and go there during the day, for exercise. Yes. So, it was practice the whole time.

They continued to do things that were difficult for the sake of improvement and for the positive feeling evoked by finally accomplishing something one has worked hard for.

### ***Getting to know abilities and finding solutions through occupational engagement***

Participants described how they came to understand and adapt to changed abilities after stroke and that this was dependent upon being allowed opportunities to engage in occupation.

### ***Understanding and adapting to changed abilities***

Through occupational engagement participants were able to discover not only what they could not do, but also what they could do. It was also the means through which participants found new solutions to remain active in valued occupations. By not allowing consequences of stroke to become a barrier that stopped them, they focussed on discovering ways to adapt through continued engagement. For some this was an ongoing process of trial and error over many years.

Then of course I did not have the strength. So, there were some screws that were more difficult to undo, but still you never gave up. You came up with your own solutions somehow. So, yes but, I just took longer then, to do some something.

One specific way of solving problems in occupational engagement was through the development and use of various strategies. Strategies were described as a way of dealing with stroke-related consequences such as language impairment, fatigue, sensitivity to stress or impaired memory. Although the need for and type of strategies varied among participants, many described how the use of different strategies enabled them to remain active and maintain valued occupations. Strategies led to feelings of being in control, helped reduce the impact of stroke-related consequences and contributed to an overall feeling of well-being.

### ***Being allowed opportunities to discover a changed self***

Although participants had a strong internal drive to try their abilities, the opportunities for engaging in occupation were also dependent on the support of others. Participants described how feeling entrusted encouraged them to try new things. Highlighting the importance of being allowed to discover abilities through their own doing, participants described how opportunities to try their abilities enabled them to discover what they could and could not do. Being allowed to perform in accordance with their abilities was important. Thus, participants stressed that it was not a matter of doing something in the right or wrong way, but of being allowed to find their own way of doing.

- Has it been important to do things, to try? Or has anybody been able to tell you that you can't and you've been ok. Or did you have to ...

- I have never let ... (people tell me)

- I have never (encouraging to continue)

- Laughter.

No

- Try first?

- Yes

//Participant with language impairment. Brackets used for what was implicitly understood in the situation of the interview



### **Occupational losses and new opportunities**

After stroke, participants experienced both personal and occupational changes. The new circumstances resulted in both occupational losses and new opportunities, and continued engagement was dependent on the experienced value of an occupation. With time, participants often learned to foresee and balance consequences with value.

### **Replacing occupations**

For some the onset of stroke affected the frequency of engaging in occupations. For others, it meant having to give up specific occupations, such as work, reading or playing musical instrument. While some were able to replace lost occupations with new, others experienced a gradual decrease. When they were no longer able to work or take part in previous interests, a need for finding new occupations to fill the day arose. For some, this initially meant spending time on rehabilitation and finding new ways of doing household occupations. However, for many, this was with time replaced by new interests. Participants give examples such as replacing physiotherapy with joining a boule club to maintain physical exercise and social belonging, or spending more time helping others.

Every week, I drive pensioners to town to do grocery shopping//...//That keeps me busy and it keeps them busy. So, I help them a bit.

Most spent less time working than before stroke. Having more time available to spend on other occupations provided an opportunity to make new priorities and participants described spending more time with family and friends and on personal interests. Appreciating the advantages of more time, participants also described feeling less pressured and being able to appreciate the small things in life and enjoy the present.

But you know, then I did not have as much time. So, I did not have quite the same life before (no) as I have after stroke. It is time that is much more now.

Participants who felt more affected by contextual factors and fatigue described leading a quieter life after stroke.

- I have more or less created my own quiet world. I have actually done that. I find that it is pretty good here. I am miles away from the city. It is quiet on that side. Over there is a very quiet family (point to surrounding houses) and down there are good people as well. As long as it stays that way it, it is well.

- So, you have preserved an existence that enables it (life) to function?

- Cemented boredom ... laughter

Creating a calm environment reduced the impact of stroke-related consequences and for some contributed to well-being. However, living a quiet life for some led to a feeling that something had been lost when life became more uneventful, and this contributed to a loss of interest and sense of lost meaning.

### **Balancing value and consequence**

Through occupational engagement participants discovered different consequences of stroke and how these came to affect their ability to engage in different occupations. However, there were also consequences of engaging as this could increase symptoms. Understanding these interactions, participants were able to foresee the consequences of engaging and could evaluate whether an occupation was worth doing or not.

While some consequences were related to specific occupations such as not being able to write, do one's hair or go to the cinema, participants also spoke of a more general impact on everyday life. Engaging in occupations described as more demanding, such as work or social occupations, participants discovered how the more they tried to do, the more difficult it became due to consequences such as fatigue and sensitivity to stress. For some the impact of consequences led them to avoid or let go of occupations to preserve their energy for more valued occupations. Others described choosing to engage in occupations, despite consequences, because the value of the occupation outweighed the consequences. Investing all energy into work, one participant described being able to perform at work but having to pay the price afterwards, as he lacked the will and energy to engage other occupations.

- You had to sharpen up. To the utmost.

- Did it work?

- Yes, I have to say that it did. But the whole time it came with a price.

- What price?

- The price of fatigue.

### **Value as a prerequisite for continued engagement**

Participants stressed the importance of being active and spoke of always wanting to keep busy, both before and after stroke. Being active was not necessarily connected to specific occupations, and value was

ascribed not to an occupation in itself but rather to having interests that enabled participants to experience happiness, that kept them busy and that served as a way to divert thoughts.

I have, sometimes perhaps too much to do. But at least I have something to keep me a bit busy. I think that's very healthy.

If an occupation was considered as valuable to oneself or others, it contributed to positive experiences and continued engagement. Maintaining previous interests such as cooking, gardening or house maintenance with concrete and visible results were common examples of valued occupations.

Not being able to resume previously valued occupations had an overall impact on how participants valued not only specific occupations, but also life in general. One participant described that life began to feel uneventful when she no longer had work to fill her days. Although she was able to perform other previously highly valued occupations, after stroke they no longer evoked the same experiences. When occupations no longer provided the same sense of meaning, this led her to gradually turn away from previous interests.

... I think it was a lot after this stroke. Not the event (stroke) as such, and just the therapy and all that and interest. I kind of just felt that it lacked meaning in a way. And that's where this gradual decrease began.

### **Feeling like a changed person**

Comparing life before and after stroke, participants described what they experienced as direct symptoms of stroke such as being more tired, more emotional or forgetful, and how these had an impact on the way they felt towards doing things. Some felt that the changes went beyond specific consequences and had a more overall impact on the way they viewed themselves. They felt that their personality had changed and that they had become someone who was more pessimistic and who no longer had the same ability to laugh and feel as before. Others experienced positive changes such as becoming mentally stronger, calmer and less inclined to anger.

### **Moving on with life**

The onset of stroke increased awareness of how frail life can be and contributed to participants reflecting upon and re-evaluating life. Feeling that the stroke could have had worse consequences combined with an appreciation for life here and now contributed to acceptance and leaving stroke behind them.

### **Re-evaluation and acceptance**

Participants spoke of feeling glad and fortunate in having had what they expressed as a mild stroke, often followed by expressions of how things could have been worse. Having previous experiences of others with worse consequences of stroke, they described initial fears of ending up in a wheelchair or in need of constant care. The feelings of doing well in comparison to how it could have been led participants to feel happy about where they were today. Reflecting upon their present situation, participants expressed the importance of enjoying life and described feeling pleased with how things have turned out. Many felt in control of their lives and were able to do all or most things that they wanted to.

No, I mainly think that it could have been much worse. That I had, I think I was lucky in this misfortune so to say. Because I can travel and I can do many of the things that I wanted to do. What we wanted to do then. I can still have that. Now at least. During the first time it did not go as well but now it works well.

For many participants, feelings of having been given a second chance in turn also resulted in positive lifestyle changes.

Also, I find that... that there are benefits of this because, firstly you see how fragile life is, secondly you realise the importance of you dealing with things that require dealing with. Both exercise and diet.

As 15–18 years had elapsed since their stroke, many felt that the stroke was now behind them and no longer occupied their mind in the same way. No longer experiencing any consequences of stroke made acceptance easier. However, even those who continued to live with the consequences of stroke described moving on with life. Some felt that acceptance was the only choice in order to move forward, and their ability to take in advice from others early on had made life easier. Others described an ongoing process of trial and error and stressed that accepting did not mean giving up. Participants still took on new challenges, but it had become easier to accept the things that did not work or to accept that they had to do things differently. The aspect of time contributed to acceptance, and participants described this as a gradual process where they had come to terms with the consequences of stroke and found ways to get on with life. This involved being aware of the fact that the consequences of stroke might not improve that much, but that accepting them could improve how they lived with the consequences.

- Do you feel that you have recovered from your stroke today?
- No. Yes, there is a little left. And it will always be left, a little. And the mental fatigue, it will always be there. So, you will never be recovered completely, but better.

## Discussion

This study explored the experiences of people who had lived 15–18 years with potential consequences of stroke to gain an understanding of how they experienced occupational engagement and how this changed over time and across contexts. The subjective experiences shared by participants highlight the complexity of understanding and evaluating long-term outcome. These experiences show that outcome at an individual level is not just a matter of increased or decreased performance, as an increased performance can be positive for some while having negative consequences for others. In this study, occupational outcome was the result of a continuous process in which occupational engagement was a way of gradually integrating consequences of stroke into everyday life and involved a continuous interaction with internal resources and contextual factors. In line with our findings, ongoing interaction between the stroke survivor and the physical and social environment during a process of re-engaging in valued activities after stroke has previously been reported in a number of studies [37]. We found that re-engaging in valued occupations was not only the goal but also the means of achieving desired outcomes. This highlights the importance of stroke survivors having the opportunity to engage in occupations.

Familiar environments where stroke survivors feel able and secure have previously been reported to enhance re-engagement and also serve as a way through which stroke survivors are confronted with and learn to adjust to limitations [37]. We found that occupational engagement was a way to discover and understand changed abilities after stroke. Thus, it was also an opportunity for participants to find ways of adjusting that suited not only their abilities but also their preferences and context. Our findings suggest that supporting stroke survivors to find their own way of dealing with occupational challenges can help the process of adaptation after stroke. This can be done by enabling opportunities for occupational engagement in valued occupations.

The ability and choice to engage in occupations were dependent on context as well as personal preferences. As most participants had mild stroke at onset,

with few or no physical impairments, contextual barriers in our study were mostly related to social and cultural contexts. In similarity to our findings, occupations are reported to occur more within the home environment [37], and a decline in social participation is common after stroke [19,38,39]. However, while Woodman et al. [39] found that studies report that participants can become socially isolated, spend many hours alone, housebound and excluded from social interactions, our study showed that a decline in social occupations was not necessarily always experienced as negative. Although this was the case for some, other participants in our study expressed that it was not a matter of feeling excluded or isolated but instead an active and valued choice. Re-evaluating occupations after stroke, they described how value can be derived from engaging in occupations but also from not having to.

We found that with time participants experienced both occupational losses and gains. What became clear throughout the interviews was how the experienced value of an occupation was central for engagement and how participants made priorities by balancing value against potentially negative consequences. The fact that experienced value will affect how an occupation is prioritised is likely the case for most people. However, after stroke, survivors describe that it is no longer just a matter of personal preferences, but also of constantly appraising value in relation to consequences [39,40]. If the consequences of an occupation are considered to be worse than the value, this can result in avoidance and loss of occupations [40]. Such examples of losses were also expressed by participants in our study. However, many described how they continued to engage in valued occupations, despite knowing the consequences, because they felt that the value of engaging was greater than the negative consequences.

We found that participants to a high degree relied on their own abilities and internal resources to engage in occupations and make priorities after stroke. This is in line with previous research showing that stroke survivors consider personal characteristics important for adjustment and moving forward after stroke [28,39,40]. Participants in our study placed great value on the time and effort spent on recovery and took on responsibility for their success. However, attributions to internal resources are mostly made in the light of positive outcomes. Although personal resources can be employed to gain motivation and positive outcome, not all personal characteristics will result in desired outcomes. In a review Sarre et al. [28] found

that uplifting characteristics are noted in a majority of studies, but that less is known about how a gloomy or depressive inclination can impact adjustment. In our study participants made improvement, thereby allowing for positive appreciation and motivation to keep engaging in various occupations.

Although time might lead to greater acceptance and integrating stroke into normal life [38,40], consequences can still move in and out of salience and require different adjustment over time and context [28]. Throughout the interviews, it was clear that time was an important factor for integrating stroke into everyday life. However, although time might reduce the impact of stroke, it is important to note that there is no specific timepoint at which stroke survivors can be claimed to have reached full integration. Rather, due to the ongoing interactions between personal factors and context, new occupational challenges as well as opportunities will arise with contextual and personal changes.

### **Methodological considerations**

Qualitative studies are valuable for exploring and gaining a greater depth of understanding regarding the experience of engaging in occupation following stroke [31]. The inductive approach used in this study with open-ended questions resulted in rich data, and thematic analysis provided a suitable method for analysing the content of large units of text.

Prior to inclusion we used a model presented by Malterud et al. [41] to guide sample size based on information power. With a broad aim, limited theoretical background and a cross-case analysis, we estimated a priori that 8–10 participants would be required to capture a variety of experiences, and we attempted to employ a strategic sampling to increase specificity. However, a strategic sampling proved difficult to achieve and the final sample was instead the result of convenience sampling where all available participants that agreed to take part in interviews were included. When all nine available participants had been interviewed the model by Malterud et al. for considering information power was reviewed again. The two dimensions affecting information power that we could not control for beforehand were specificity and dialogue. Despite the convenient sampling there was judged to be sufficient specificity within the sample and the dialogue was generally strong. Thus, the researchers together decided the information power was sufficient and that no further recruitment was necessary. The inclusion of people with communicative difficulties in interviews is considered a strength

as this is common in stroke survivors but still often an exclusion criteria. Participants with communicative difficulties, although not as articulate, were able to provide important insights. The interviewer had good background knowledge and experience of dialogue with stroke survivors that helped in enabling participants to elaborate on the research areas. Further, all participants were interviewed twice, which strengthened the dialogue by providing more time to build trust and understanding and by allowing for clarifications to be made. The first author has more than 10 years of experience working as an occupational therapist in the area of stroke rehabilitation, as well as PhD student research experience. The co-authors all have more than 20 years of research experience along with extensive clinical experience within various areas of stroke rehabilitation and medicine. Hence, all had a pre-understanding of the research area. Although this may have biased the findings to some extent, it was also considered a resource allowing for stronger dialogue during interviews and a greater understanding of nuances throughout the analysis. Reflexivity was enhanced through regular discussions within the research group, where the different backgrounds allowed for the pre-understanding of authors to be challenged.

Transferability of this study has limitations as the sample is selective and therefore may not be representative for other stroke populations. Results should therefore be interpreted in relation to demographic and contextual aspects and may not be transferable to stroke survivors of other ages, social situations and cultural backgrounds. Participants in our study ascribed value to own resources and efforts, whereby it is important to consider that these descriptions are made by people who consider themselves to have moved on, and represent a selective group of people that are able to, and willing to participate in studies long-term. Further, the interviews took place 15–18 years after stroke and the sample is skewed towards those with fewer neurological deficits. In our sample, six out of nine participants had suffered a very mild stroke based on the NIHSS scale at onset, and transferability to people with more severe stroke is therefore limited. Transferability is also affected by the time frame of the study as it is possible that having a stroke today can be experienced differently than 15–18 years ago.

### **Conclusion and implications**

The inductive approach of this study has provided rich descriptions of occupational engagement in the

lives of long-term stroke survivors. The subjective experiences gave a nuanced picture of outcome that focussed more on abilities and ways of moving on with life, thereby providing an important complement to quantitative studies that often focus on understanding disability.

This study explored the experiences of a group with predominantly mild stroke, a group that with new treatments and improvements in acute stroke care is likely to increase and a group that may require a different approach to rehabilitation. Our findings suggest that understanding and adapting to changed abilities takes time and requires opportunities for occupational engagement. The findings contribute to a growing number of studies that suggest a need for long-term rehabilitation and support to stroke survivors as they face new occupational challenges over time.

Findings of this study support a need for interventions that focus on enabling opportunities for occupational engagement in personally valued occupations. Interventions should support the use of abilities and internal resources to reduce the impact of stroke in everyday life. Such interventions require flexibility of the timeframe for interventions and need to be individualised, taking personal and contextual aspects into account.

## Acknowledgements

The authors express a warm thank you to the participants in this study for sharing your experiences.

## Disclosure statement

The authors report no conflict of interest.

## Funding

This work was supported by Alice Swenzons Stiftelse för Vetenskaplig Forskning; Norrbacka-Eugeniastiftelsen; Department of Research, Education and Innovation at Södra Älvsborg Hospital; the Research and Development Council of the County of Södra Älvsborg; Sparbanken Sjuhärads Foundation; Stiftelsen Handlanden Herman Svensson; STROKE-Riksförbundet; Stiftelsen Handlanden Hjalmar Svenssons.

## ORCID

Charlotte Wassenius  <http://orcid.org/0000-0002-2791-8407>

## References

- [1] Walder K, Molineux M. Occupational adaptation and identity reconstruction: a grounded theory synthesis of qualitative studies exploring adults' experiences of adjustment to chronic disease, major illness or injury. *J Occup Sci.* 2017;24:225–243.
- [2] Norrving B, Barrick J, Davalos A, et al. Action Plan for Stroke in Europe 2018-2030. *Eur Stroke J.* 2018; 3:309–336.
- [3] Feigin V, Krishnamurthi R, Parmar P, et al.; GBD 2013 Stroke Panel Experts Group. Update on the Global Burden of Ischemic and Hemorrhagic Stroke in 1990-2013: The GBD 2013 Study. *Neuroepidemiology.* 2015;45:161–176.
- [4] Socialstyrelsen. Nationella riktlinjer för vård vid stroke – Stöd för styrning och ledning. Stockholm (Sweden): Socialstyrelsen; 2020.
- [5] Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. *Lancet.* 2011;377:1693–1702.
- [6] Ghatnekar O, Persson U, Asplund K, et al. Costs for stroke in Sweden 2009 and developments since 1997. *Int J Technol Assess Health Care.* 2014;30: 203–209.
- [7] Saka Ö, McGuire A, Wolfe C. Cost of stroke in the United Kingdom. *Age Ageing.* 2009;38:27–32.
- [8] Feigin LV, Norrving AB, Mensah AG. Global burden of stroke. *Circ Res.* 2017;120:439–448.
- [9] Rosengren A, Giang KW, Lappas G, et al. Twenty-four-year trends in the incidence of ischemic stroke in Sweden from 1987 to 2010. *Stroke.* 2013;44: 2388–2393.
- [10] Krishnamurthi RV, Moran AE, Feigin VL, et al.; GBD 2013 Stroke Panel Experts Group. Stroke prevalence, mortality and disability-adjusted life years in adults aged 20-64 years in 1990-2013: Data from the Global Burden of Disease 2013 Study. *Neuroepidemiology.* 2015;45:190–202.
- [11] Christiansen CH, Townsend EA. Introduction to occupation. Upper Saddle River (NJ): Pearson Education; 2004.
- [12] Maaijwee NAMM, Rutten-Jacobs LCA, Schaapsmeeders P, et al. Ischaemic stroke in young adults: Risk factors and long-term consequences. *Nat Rev Neurol.* 2014;10:315–325.
- [13] De Groot MH, Phillips SJ, Eskes GA. Fatigue associated with stroke and other neurologic conditions: implications for stroke rehabilitation. *Arch Phys Med Rehabil.* 2003;84:1714–1720.
- [14] Synhaeve NE, Arntz RM, van Alebeek ME, et al. Women have a poorer very long-term functional outcome after stroke among adults aged 18–50 years: the FUTURE study. *J Neurol.* 2016;263:1099–1105.
- [15] Rutten-Jacobs LCA, Maaijwee NAM, Arntz RM, et al. Risk factors and prognosis of young stroke. The FUTURE study: a prospective cohort study. Study rationale and protocol. *BMC Neurol.* 2011;11: 109–109.
- [16] Walsh ME, Galvin R, Loughnane C, et al. Community re-integration and long-term need in the first five years after stroke: results from a national survey. *Disabil Rehabil.* 2015;37:1834–1838.

- [17] Wolfe CD, Crichton SL, Heuschmann PU, et al. Estimates of outcomes up to ten years after stroke: analysis from the prospective South London Stroke Register. *PLoS Med.* 2011;8:e1001033.
- [18] Feigin VL, Barker-Collo S, Parag V, For the ASTRO study group, et al. Auckland Stroke Outcomes Study: part 1: gender, stroke types, ethnicity, and functional outcomes 5 years poststroke. *Neurology.* 2010;75:1597–1607.
- [19] Blomgren C, Jood K, Jern C, et al. Long-term performance of instrumental activities of daily living (IADL) in young and middle-aged stroke survivors: results from SAHLSIS outcome. *Scand J Occup Ther.* 2018;25:119–126.
- [20] Singam A, Ytterberg C, Tham K, et al. Participation in complex and social everyday activities six years after stroke: predictors for return to pre-stroke level. *PLoS One.* 2015;10:e0144344.
- [21] Palstam A, Sjodin A, Sunnerhagen KS. Participation and autonomy five years after stroke: a longitudinal observational study. (Research Article) (Report). *PLoS One.* 2019;14:e0219513.
- [22] Svensson JS, Westerlind E, Persson HC, et al. Occupational gaps 5 years after stroke. *Brain Behav.* 2019;9:e01234.
- [23] Davis CG, Egan M, Dubouloz CJ, et al. Adaptation following stroke: a personal projects analysis. *Rehabil Psychol.* 2013;58:287–298.
- [24] Grajo L, Boisselle A. Occupational adaptation as a construct: a scoping review or literature (Report). *Open J Occup Ther.* 2018;6:2.
- [25] Erikson A, Karlsson G, Borell L, et al. The lived experience of memory impairment in daily occupation after acquired brain injury. *OTJR.* 2007;27:84–94.
- [26] Carlsson GE, Möller A, Blomstrand C. A qualitative study of the consequences of 'hidden dysfunctions' one year after a mild stroke in person <75 years. *Disabil Rehabil.* 2004;26:1373–1380.
- [27] Nayar S, Stanley M. Occupational adaptation as a social process in everyday life. *J Occup Sci.* 2015;22:26–38.
- [28] Sarre S, Redlich C, Tinker A, et al. A systematic review of qualitative studies on adjusting after stroke: lessons for the study of resilience. *Disabil Rehabil.* 2014;36:716–726.
- [29] Walder K, Molineux M, Bissett M, et al. Occupational adaptation - analyzing the maturity and understanding of the concept through concept analysis. *Scand J Occup Ther.* 2019.
- [30] Schkade J, Schultz S. Occupational adaptation: toward a holistic approach for contemporary practice, Part 1. *Am J Occup Ther.* 1992;46:829–837.
- [31] Williams S, Murray C. The experience of engaging in occupation following stroke: a qualitative meta-synthesis. *Br J Occup Ther.* 2013;76:370–378.
- [32] Black MH, Milbourn B, Desjardins K, et al. Understanding the meaning and use of occupational engagement: findings from a scoping review. *Br J Occup Ther.* 2019;82:272–287.
- [33] Patton MQ. Two decades of developments in qualitative inquiry: a personal, experiential perspective. *Qualitative Social Work.* 2002;1:261–283.
- [34] Carcary M. The research audit trial - enhancing trustworthiness in qualitative inquiry. *Electronic J Business Res Methods.* 2009;7:11–24.
- [35] Kvale S. Interviews: an introduction to qualitative research interviewing. Thousand Oaks (CA): Sage; 1996.
- [36] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3:77–101.
- [37] Jellema S, van Der Sande R, van Hees S, et al. Role of environmental factors on resuming valued activities poststroke: a systematic review of qualitative and quantitative findings. *Arch Phys Med Rehabil.* 2016;97:991–1002.e1.
- [38] Törnbohm K, Lundälv J, Sunnerhagen KS. Long-term participation 7-8 years after stroke: experiences of people in working-age. *PLoS One.* 2019;14:e0213447.
- [39] Woodman P, Riazi A, Pereira C, et al. Social participation post stroke: a meta-ethnographic review of the experiences and views of community-dwelling stroke survivors. *Disabil Rehabil.* 2014;36:2031–2043.
- [40] Norlander A, Iwarsson S, Jönsson A-C, et al. Living and ageing with stroke: an exploration of conditions influencing participation in social and leisure activities over 15 years. *Brain Inj.* 2018;32:858–866.
- [41] Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res.* 2016;26:1753–1760.