

# Lived experience of active and balanced everyday life among informal caregivers of persons with stroke

Mandana Fallahpour<sup>1</sup>, Susanne Guidetti<sup>1</sup>, Ann-Helen Patomella<sup>1</sup>, Mona Dür<sup>1,2</sup>

Karolinska Institutet, Department of Neurobiology, Care Sciences, & Society, Division of Occupational Therapy, Sweden

<sup>2</sup>Duervation GmbH, Austria

## Background

Stroke not only impacts the everyday life of the persons affected but also their significant others who are involved in providing care and support as informal caregivers. There is a knowledge gap regarding how the phenomenon of occupational balance characterizes itself among informal caregivers of persons with stroke.

This study is a substudy of *the BeWELL Active™ research project* focusing on occupational balance among persons with stroke and their significant others as informal caregivers.

## Aim

The study aimed to explore the lived experience of active and balanced everyday life among informal caregivers of persons with stroke.

## Findings

The analysis is still in progress. The demographic characteristics of the participants are described in Table.

## Methods

A purposive sample of 13 informal caregivers of persons with stroke who provided caregiving support for at least 3 months post-stroke, lived in Sweden, could communicate in Swedish, and were not financially compensated for their caregiving were recruited for the study. A qualitative design with individual in-depth interviews was conducted. The empirical phenomenological perspective (EPP) method was used to analyse the data. The data analysis is in progress.

### **The phenomenon of active and balanced everyday life as lived by informal caregivers:**

An **active and balanced everyday life** is experienced not as a stable state, but as a *fragile and constantly negotiated condition*, shaped by responsibility, moral obligation, and restricted freedom.

### Summary of participants characteristics (n = 13)

Characteristic	Description
Gender	9 women, 4 men
Age	Range: <b>38-82 years</b> (mean: <b>62 years</b> )
Relationship to person with stroke	Wives: <b>4</b> Husbands: <b>2</b> Partners: <b>3</b> Adult children: <b>2</b> (1 daughter, 1 son) Other: <b>2</b> (1 mother, 1 ex-wife)
Work status	Working: <b>6</b> Retired: <b>6</b> Studying: <b>1</b>

This study is a substudy of the BeWELL Active™ project financed by Funding for Research in Health Care Sciences (SFO-V), PI: Dr Mandana Fallahpour, Karolinska Institutet

### **Meaning structure of the phenomenon:**

For informal caregivers of persons with stroke, an **active and balanced everyday life** is constituted by the following interrelated characteristics:

#### **1) Access to discretionary time**

Active and balanced everyday life is experienced as having moments of time that are not fully governed by caregiving demands time, that can be used for rest, movement, or personally meaningful activities.

#### **2) Possibility for self-directed activity**

Active and balanced everyday life involves engaging in activities chosen for oneself, supporting identity, vitality, and continuity with life before caregiving, rather than activities defined solely by obligation.

#### **3) Experienced freedom within responsibility**

Active and balanced everyday life is lived as a fragile sense of freedom to move, leave the home, and act continuously negotiated in relation to moral responsibility for the partner and family.

#### **4) Relational and structural conditions enabling balance**

The experience of active and balanced everyday life depends on relational reciprocity and access to external support that temporarily relieves responsibility, making space for recovery and personal activity.

### **Essence**

*For informal caregivers of persons with stroke, an active and balanced everyday life is experienced as a fragile way of living in which time, activity, and freedom are continuously negotiated. It is lived through moments of having time of one's own and engaging in self-chosen activities, while simultaneously being constrained by responsibility for others and an ongoing moral tension. This everyday life unfolds within changed relationships marked by altered reciprocity and is dependent on accessible external support that temporarily relieves responsibility and creates space for balance.*

### **For further information, contact:**



**Mandana Fallahpour**, PI of the research project  
Associate Professor, Senior Lecturer  
Division of Occupational Therapy  
Karolinska Institutet  
[mandana.fallahpour@ki.se](mailto:mandana.fallahpour@ki.se)

### **Other research team members in the BeWELL Active™ project:**

Linda Timm  
Sandra Hakkarainen  
Elisabeth Rydwik  
Zarina Nahar Kabir