



Challenges and enablers for an active partnership in research between academic researchers and people with stroke



Malin Tistad, Fredrik Sandman, Mikael Åkerlund, Jeanette Nelson, Lena von Koch, Lill Hultman

Introduction

To incorporate experience-based knowledge of living with stroke throughout the research process, we formed a “co-research group” in the context of a larger research project at Karolinska Institutet,

- three co-researchers with stroke employed specifically for the study.
- two academic researchers

The group met mainly digitally, 1,5 hour/week.

Work tasks included:

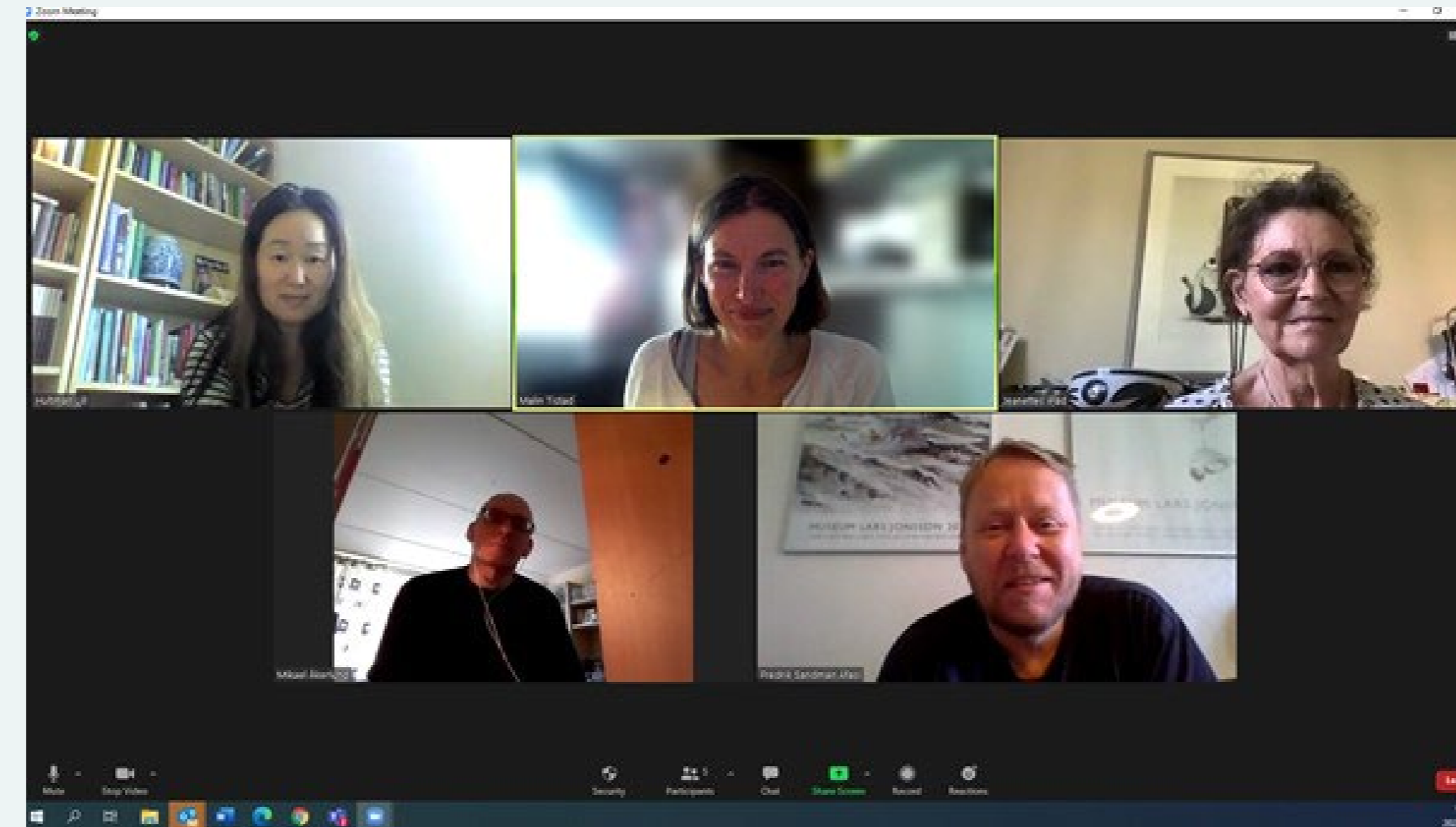
- deciding study contexts
- developing interview guides
- strategies for participant recruitment
- data collection and analysis
- dissemination activities

The **aim** of this study was to explore the work processes in the co-research group focusing on challenges and enablers for an active and creative partnership.

Conclusion

Time is a key factor in the creation of an active and creative partnership in research work processes.

- continuity to create engagement
- a “trial and error approach” in development of work methods



Work meeting with the co-research group

Methods

In this study, interviews with members of the co-research group and reflection notes was analysed in an autoethnography approach using thematic analysis.

Results

Enablers

- Digital meetings enabled weekly meetings
- Continuity in the work enabled creation of engagement and shared understanding



Challenges

- Balancing the co-researchers’ roles and time in the project between full participation in specific studies or consultants in the whole
- Unfamiliarity with reading academic texts and/or aphasia challenged involvement



In our ongoing study, we explore Facebook groups as contexts for sharing experience-based knowledge of living with stroke

