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## Enjoyable company in sharing stroke experiences; - lifestyle groups after stroke

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### ABSTRACT

**Background:** Even people with mild to moderate stroke will experience changes in their abilities to perform everyday occupations. Group interventions may be appropriate in late-stage rehabilitation. The aim of this study was to explore how the participants involved themselves in person-centered lifestyle groups after stroke in Norway.

**Method:** Semi-structured interviews were performed with six older adults with mild-to-moderate stroke who had participated in lifestyle groups over a period of nine months. The interviews were analyzed using qualitative content analysis.

**Results:** The participants involved themselves in the lifestyle groups in a variety of ways by creating enjoyable company in sharing stroke experiences, sharing knowledgeable interest, pushing and forcing each other forward and reflecting on self-worth. Through doing group activities together, they created various ways of being, belonging and becoming, addressing development of strategies for regaining self-belief and a sense of autonomy, and for adapting to everyday life post-stroke.

**Conclusion:** The participants were active contributors in the groups and pushed each other and themselves regarding involvement in meaningful occupations. This active participation seemed to bring the participants' resources into focus and contrasted with the frequent negative perceptions of people post-stroke as 'victims'.

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### Introduction

A stroke often happens without warning and may influence a person's everyday life. People with mild-to-moderate stroke may experience changes in their ability to engage in everyday occupations and participate in everyday life [1]. Even several years after a stroke, older stroke survivors often continue to report on anxiety, depression, social isolation and loss of abilities to participate in meaningful occupations [2,3]. Everyday life after a stroke is about a process of adaptation that takes time and may be seen as a 'life project': a project that encompasses the physical, social and emotional aspects of one's life and involves developing a new understanding of oneself [4].

Many interventions for stroke survivors are interdisciplinary in nature and involve a range of professionals, including doctors, nurses, occupational therapists, physiotherapists, social workers and speech therapists. A literature search identified 48 studies relating to occupational therapy interventions

following stroke [5]. The aims in these studies were categorized in line with the International Classification of Functioning Disability and Health (ICF) [6]. This categorization showed that most of the interventions aimed at improving activities related to self-care, dressing, and outdoor mobility and were delivered individually. There were few studies focusing on activities and participation addressing psychosocial group-interventions after stroke that could particularly be relevant for people with mild-to-moderate stroke [7]. Two systematic meta-analyses demonstrated that group interventions that included social activities and were aiming particular target groups, such as stroke survivors, might prevent depression and social isolation, and contribute to promoting physical and psychological well-being [8,9]. In addition, several studies supported that a need existed to investigate what types of group interventions had positive effects on health and well-being in late-stage rehabilitation following stroke [10–12]. Thus we developed, implemented and evaluated an intervention on person-centered lifestyle

groups after stroke in Norway [5], inspired by the Lifestyle Redesign® program which is developed in the US [13].

### **The person centered lifestyle groups**

The lifestyle group intervention was influenced by the original Lifestyle Redesign® intervention which is based on occupational science that emphasizes the connection between human occupation, well-being and health [14,15]. Occupational science is a theoretical perspective in the lifestyle groups addressing what we do, what we want to do, and which occupations are important for our everyday well-being. Wilcock and Hocking present key concepts for understanding the connection between meaningful occupation, health and well-being: *doing*, *being*, *belonging* and *becoming* [15]. The lifestyle groups may be seen to synthesize all four concepts, all of which are significant to stroke survivors, whose strokes may be seen as events that constitute a biographical disruption [16]. *Doing* is about possibilities for being active and investigating new occupations; clearly these possibilities may be threatened by a stroke. *Being* concerns taking time to reflect, mediate, be present in the moment, rediscover the self, and spend time with people of importance to one's life. *Belonging* is addressing the importance of social interaction, experiencing a sense of community and mutual support, feeling included and being able to interact socially in the pursuit of meaningful occupations. *Becoming* concerns thinking about the future in a way that is linked to personal wishes and choices of occupations, and a process of reorientation towards new possibilities and possible changes in the occupations one wishes to or is able to engage in [15,16].

The concept of lifestyle groups has also been developed by ideas about user orientation, and the importance of peer exchange and sharing of useful ideas and solutions [14,17]. Another important purpose of the groups was to foster participants' understanding of the potential of different occupations for helping them to re-orientate their everyday lives post-stroke [17]. The overall aim of the lifestyle groups was to promote well-being, occupations and social participation after stroke.

The Lifestyle Redesign® intervention has been shown, to have a positive impact on the health and contentment of older people living independently at home [18,19]. The program materials have been translated and adapted for use in the United Kingdom, Sweden, Denmark and Norway and reports that the intervention can be feasible, but further research is needed [20–24]. To the best of our knowledge, these

occupation based group interventions have not been delivered to older adults with stroke. Therefore, this lifestyle group intervention for older adults post stroke was delivered in Norway in two municipalities at a total of six senior welfare centers during 2007–2011 and evaluated in a randomized controlled trial (RCT) [5]. The group intervention showed no statistically significant effects on levels of well-being, activity or social participation in older adults with mild-to-moderate stroke [25]. However, all the participants in both the intervention and the control group showed improvements. Thus the findings from this study revealed challenges in connection with the evaluation of complex psychosocial interventions, since such evaluations depend on access to data that is difficult to capture using quantitative methods alone [26,27]. This finding contributed to the development of the present qualitative study, which was also inspired by one participant's comment that '*We must have an opportunity to explain what it is like to take part in these groups – not just to complete these questionnaires.*' Accordingly, we developed this present study aiming to explore the participants' involvement in the lifestyle groups. Regarding the process of analysis we started by using explorative approaches and through several analysis we ended up by using a conceptual framework related to occupational science addressing doing, being, belonging and becoming to investigate how the participants involved themselves in person-centered lifestyle groups after stroke in Norway.

## **Material and methods**

### **Implementation of the lifestyle groups**

Lifestyle group meetings led by an occupational therapist were offered at senior welfare centers once a week, over a nine-month period. Each group had from two to eight participants. Prior to the first group meeting individual semi structured interviews with the Canadian Occupational Performance Measure [28] were applied as the needs assessments of the participants that were further discussed in the groups [17]. The participants developed and decided on the content of the meetings. The topics discussed included strokes; stroke prevention; avoiding falls; communicating with the public sector; social networks; medication; diet and nutrition; and cognitive exercises. The methods applied were peer exchange; didactic presentations (teaching); self-reflection; and performing occupations. The group interventions centered on performing occupations together, while reflecting on the

significance of the occupations in the participants' own everyday lives. The process of developing, conducting and evaluating the lifestyle groups has been described in two published articles [17,25].

### Participants

The participants in the present study were chosen from a sample of participants [29] who took part in the larger study designed as a randomized controlled trial concerning the development, implementation and evaluation of lifestyle groups [5]. Guided by purposive sampling [30] the inclusion criteria were that the participants had started in the groups three months post stroke and completed the weekly nine-month group intervention and had sufficient verbal language to participate in an interview. To ensure that the sample was varied and broad, participants from three different contexts (senior welfare centers) for the group interventions were invited by telephone. Four men and two women agreed to be interviewed, and resulted in two participants from the three senior welfare centers. All had mild-to-moderate stroke and were living at home. The participants' Barthel ADL Index measures [31] showed that they were independent in everyday occupations such as hygiene, eating and mobility. The participants' Mini Mental State Examination scores [32], showed that the participants had good cognitive capacity in areas such as memory, orientation, language abilities, comprehension and visual construction. Please refer to Table 1 for more detailed information about the participants.

### Interviews

Semi-structured interviews [29] were conducted to explore the participants' experiences of participating in lifestyle groups. Individual interviews were chosen to try to grasp the individual participants' involvement in the group. They were invited to feel free to address what they found to be important. In a focus group, they might have been more influenced by the other participants' opinions. The interviews were conducted at the participants' home by an occupational

therapist experienced in stroke rehabilitation that had not been involved in the RCT. The interviews were performed between one month to eight months after the participants had finished the group participation. Each interview lasted for approximately one hour and was inspired by an interview guide with open questions such as; i) Please tell me about what it was like to participate in the group sessions, ii) What did you do in the groups? iii) How did you take part in the groups? iv) Anything you would like to mention about what was of importance for you? (e.g. topics, relations with other group participants etc.). These open questions were followed up with questions that were more detailed. The interviews had a flexible structure, allowing the interviewer and the participant to engage in dialog during the course of the interview. The interviewer encouraged the participants to describe their experiences from their own perspectives [29].

### Ethical considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics and was conducted in accordance with the Helsinki Declaration. Participation in the study was voluntary, and we ensured that all participants were aware that they could withdraw from the study without explanation at any time. Each participant received oral and written information about the study and signed a declaration of consent. Names and other identifying characteristics have been modified in order to preserve the participants' anonymity.

### Analysis

The interviews were tape-recorded and transcribed verbatim. Great care was taken to reproduce each participant's speech as accurately as possible. The transcriptions were analyzed using qualitative content analysis [29]. The interview text was sorted into content areas related to how and in which ways the participants involved themselves in the lifestyle-groups. The text was divided into meaning units that were

**Table 1.** Description of participants following completion of a nine-month group intervention.

	Age	Social situation	Living situation	Mini Mental Status (best score 30)	Barthel ADL index (best score 20)
Per	66	Widower	Apartment	29	20
Åse	69	Widow	Self-contained house	27	17
Hans	76	Married	Self-contained house	28	20
Kari	79	Single	Assisted living	29	20
Martin	80	Married	Apartment	28	20
Ole	78	Married	Self-contained house	28	20

condensed to; a social dimension related to meeting others with stroke and an individual dimension regarding how the participants developed new strategies, autonomy and self-esteem. The meaning units were abstracted and labeled with the following codes; being in an enjoyable setting, being similar and being different, knowledge, changes in performing activities and mutual relationships. The analyzes started with using an inductive explorative approach. However through this work themes emerged and we found it useful to further analyze the materiel in line with a deductive way of thinking by using a conceptual framework related to occupational science [15]. In line with Brinkman and Kvale this way of combining inductive and deductive approaches is named a dynamic abduction approach and is a form of reasoning used in situations of uncertainty and unpredictable conversational world of human beings [29]. Thus the codes were sorted into categories inspired by occupational science theories [15]. The initial codes were compared across the interviews by the first and the second author and further discussed with the third author. Thus, the text was analyzed in the categories; being, doing, belonging and becoming. Finally, all the authors discussed the entire analysis and came to a consensus on the following main themes; *enjoyable company in sharing stroke experiences; sharing knowledgeable interest; pushing and forcing each other forward; reflecting on self-worth*. All the authors also discussed and agreed on the excerpts that best illustrated the themes presented in the results.

## Results

The results illustrate that the participants contributed and involved themselves actively in the lifestyle groups by exchanging experiences and developing social relationships during the group meetings. In the following part, we present examples of how the participants involved themselves in the lifestyle groups.

### *Enjoyable company in sharing stroke experiences*

The groups were seen as positive arenas where an important feature was the opportunity to meet other stroke survivors. Martin explained:

So the actual get-togethers were a positive experience that all of us enjoyed. (...) So that alone of course was a constructive thing after having had a stroke. [A place] where you're able to talk about the things you have experienced in this context.

The participants described the meetings as sociable, while also saying that there was more to them than mere enjoyment. Hans said:

Although we had coffee and waffles ... it didn't turn into a tea-party.

The fact that 'everyone sat cozily around the table' helped to create a feeling of openness within the group, as Per described it. All the participants talked about the importance of sharing experiences with other people who had experienced a stroke. They emphasized that it was not easy to talk about 'the stroke' with other people, such as friends and family. Åse said:

Yes, there's that thing about being able to talk openly to people about how we are doing. It's not always that easy. And people can't always be bothered to listen, as you know. I do have some good female friends, but I can't sit and talk about this every time I get together with them. That wouldn't be alright.

The participants expressed a need to learn more about stroke both in general and more specifically in relation to their own situations. For many of them it was important to understand what had happened. Åse explained:

There's so much that we're curious about. Why are we like this, and why does all this strange stuff happen (...). None of us knows anything about this, you know. And being able to hear a bit about it, it means a lot.

Information about stroke was supplied through talks delivered by the participants themselves, professionals and the group leader.

### *Sharing knowledgeable interests*

The participants emphasized the importance of presenting and sharing topics that they were interested in and particularly knowledgeable about. Martin explained how the participants contributed actively to the choice of topics to be discussed.

When we chose a topic for the next meeting, then we would talk about that topic, and think thoroughly about it, and sometimes we would bring with us some related materials that we had read in a newspaper or somewhere similar. (...) So I think we contributed a good deal, not just the two people leading the discussion, and I think the group was constructive and positive also from our point of view, that we were also able to make some contributions.

Kari was interested in local history and was challenged by other group members to share her knowledge. She felt that she had succeeded in doing this activity, and the positive feedback she received motivated her to invite the group to visit her at home.

For Kari, the sense of being able to contribute was important, since she had been feeling as though she was no longer of any use of others.

And she (another group participant) had done some baking, and I had made coffee, and we sat around the table. It was enjoyable. It was fun. I believe the others thought so too. Everybody thought it was enjoyable to visit someone's home.

Kari was living alone and now she enjoyed sharing her own knowledge. She also experienced positive feedback and feeling herself to be useful to others when she invited other participants to her home.

In the group meetings, some participants shared experiences of doing occupations in new ways or learning new occupations. They described how their groups discussed topics linked to diet, nutrition, and various forms of physical activity, and how they were challenged to follow up these discussions in everyday life. Martin and Ole described topics that were relevant both to stroke and to the fact that they were older men. Ole said:

So all this about training, physical training, trying to get fitter, exercises to, as you might say, train up parts of the body that don't work as a result of the stroke. We did do some talking about that. And then we talked about food and nutrition, and what one should avoid eating, and what it might be a very good idea to eat. (...) That was really more age-related than to do with strokes. But a great deal of that stuff, I think, was highly relevant for someone who, in addition to being old, has also had a stroke. So it was useful. Very good.

Where participants thought that topics were useful, this made it more likely that they would follow up in everyday life what they had learned. Martin explained a change in his daily occupations:

Both in relation to bread and in relation to other types of everyday food, we actually try to stick to this now. So I make an effort to buy a type of bread that's different to what I would have bought before. And when it comes to supper and so on, we try to have a reasonably balanced diet. (...) So yes, it has clearly had a stimulating effect, in relation to making intelligent food choices.

A sense of belonging was also developed through the process of paying attention to, and valuing, each other's ideas. Per explained:

So other people's ideas are very important (...) They drive me forward. It's exactly what you need when you're being knocked backward. Because you don't think about every aspect of life, but then suddenly you discover completely different aspects that you didn't have any idea about at all. That is what teamwork is about.

### ***Pushing and forcing each other forward***

The participants told stories about how they were making and receiving support that stimulated them to become active and take responsibility both for the group and for their own lives. The support and pushing came from the group leader, from other participants, and from the participant him- or herself. Ole put it like this:

The fact that we were forced to read things, think about things, talk about things. That was a clear stimulant. It forced you to move forward. (...) And that came about through the topics that were addressed and the, shall we say, descriptions of situations that we discussed in relation to each other and in relation to reports and articles about stroke patients. And the fact that we had to discuss things, that we had to have opinions about things, that we had to get on with it, and participate.

Here Ole describes the importance of participating and being forced to read, and to think through his own situation. The fact that the involvement in the group created a feeling of being forced and pushed forward both by other participants and by themselves contributed to engagement in a process of reflection and to participate actively both in the group and in everyday life.

Other participants addressed being challenged and supporting each other to participating in occupations. One example of being challenged in doing activities this way, can be seen in the planning of a group excursion to a local fortress. Hans explained how he was challenged to tell the group about the history of the fortress and how this required him to prepare himself for the group meeting.

So when we were going to go on an excursion to the fortress, and we agreed on that trip exactly as had been planned, I was given the task of finding out a little about the history of the fortress from the 14th century up until the present day. Since it was a pretty long story (...) of course I had to cut it down a little to a just few paragraphs that I thought were reasonable to include.

Åse explained that she was not very good at taking part in conversation within the group. She also said, however, that it was positive that others in the group tried to motivate everyone to participate actively and 'to be put under pressure'.

### ***Reflecting on self-worth***

The group meetings focused on various ways of dealing with everyday life post-stroke. Follow-up by the group leader and encouragement to engage in

self-reflection helped the participants to become aware of how to take responsibility for, and control over, their everyday occupations. Ole explained how the participants were followed up regarding doing activities also between the group meetings that he perceived as a process of being aware of that you are a master of your own happiness. In this example, Ole was going to prepare and present an article for the group and said:

Yes, such that in the group this was followed up by means of questions, control questions. 'What do you think about that?' and 'How did that go?' and such like. And through first trying something out, then being asked a question and realising that, it, that didn't really go quite right. I could have done a bit better. In other words, that process of being made me aware that you are the master of your own happiness, even though you have had a stroke. You won't get any help other than what you give yourself.

Per described how things were up to him now, it was now that the work was starting, and that through taking part in the group he had received help to find his own self-worth.

... everything comes to an end, but having that help along the way is incredibly important until you manage to find your own self-worth and the strength to do the work.

Per was also concerned with regaining his own identity, 'to be myself', which meant challenging himself, while at the same time challenging others to take responsibility and participate in the group. Per challenged quiet members of the group to speak out:

... because they were quiet, more quiet to start with. They didn't want to expressthemselves ... enough. So I tried to stimulate them in cooperation with [the groupleader]. I understood it was important. (...) So we worked together on that, on openingupand being honest. It was a very important point, and then the group began to worktogether better and better.

The results suggest that the participants took part in the lifestyle groups in a variety of ways by creating enjoyable company, sharing stroke experiences, sharing knowledge, paying attention to and valuing the ideas of others, supporting, pushing and stimulating each other to do things and reflecting on self-worth.

## Discussion

The findings will be discussed in relation to the terminology in occupational science by addressing how the participants in a variety of ways created being, belonging and becoming through doing activities together during the nine-month program of weekly

meetings. The being aspects of *doing* activities became visible when the participants were taking part actively in group meetings, for example, while presenting topics that they were interested in and had prepared themselves to talk about. Other participants explored the significance of *being* through a process of self-reflection linked to everyday occupations and regaining the sense of 'being oneself'. These findings address that doing and being can be seen as a part of a continuum and includes the need for satisfaction, having choices, finding pleasure, challenge meaning, fulfillment, opportunity and purpose that are prerequisites for health [15].

Through active interaction the participants developed mutual social relationships and a sense of belonging within the groups. This created a context that allowed the participants to challenge and support each other in the process of adapting to life post-stroke. By engaging in occupations together, the participants generated a supportive and inclusive environment by accepting each other's similarities and differences. This process is linked to the concept of *belonging*, which encompasses the significance of social relationships, mutual support, friendship, the feeling of being included, and the idea that the individual's life has a value for both the participant and others [16]. Hammel highlights that *belonging* is of particular significance following the type of biographical disruption that a stroke may represent. In addition, the participants in our study showed that *belonging* may encompass the process of making support of oneself and each other. The pushing and supporting were made by the group leader, by other participants and by each participant of him- or herself. The participants talked about being 'forced', 'pushed' and 'pressured', all of which contributed to giving them an experience of mastering occupations and developing a sense of self-confidence. We have not seen these experiences described in other studies. The human need to belong is central to well-being because it is intertwined with identity and being and having a place in the social world [15].

In addition to *belonging*, our study shows that the participants were also engaged in *doing* (by performing occupations), and *becoming* (by adapting their everyday occupations). *Becoming* was about the need to adapt everyday occupations and everyday life post-stroke. The participants' involvement of the lifestyle groups showed that they engaged actively in different ways in finding new solutions and making changes to their everyday lives. This finding is supported by Pound et al. [33] and Lund et al. [34] and

demonstrates that stroke survivors possess important resources for their own processes of adaptation if they are able to learn from each other. Our results may suggest that the participants' active use of the group in the process of post-stroke adaptation contributed to the development of a sense of autonomy, responsibility and control over everyday life. This finding is also supported by other research [35,36]. The idea of creating positive becoming is central to an occupational perspective of health that includes the ideas of growing, personal development and self-esteem [15].

Sharing stroke experiences and exchanges of ideas and solutions, was an important feature of the groups. The participants found it difficult to talk to friends and family about the stroke and its aftermath. It was important for them to understand that they were not alone in struggling to adapt their everyday lives. The study by Reed et al. also emphasizes that a lack of understanding by friends and family is a central feature of stroke survivors' experiences [37].

Schouten, Murray and Boshoff (2011) illustrated important psychosocial benefits of group interventions after stroke which were beyond the expected aims of the program related to 'a place to go', diversity of the group', the art of group design', awareness of abilities through doing, it's about relationships' and 'over and above' [38]. What our study adds is how the participants in different ways were 'supporting' 'stimulating' 'forcing' and 'pushing' each other to be involved in the group.

Opportunities for the participants to engage in occupations together and contribute their own knowledge within the group could have positive 'ripple effects' on everyday life [14]. This demonstrates that occupations shape our everyday lives and create both a historic and cultural context for our existence relating to well-being [15]. Pound et al.[33] describe how particular occupations and cultural values are formative of identity. For Per, it was important to take on a leadership role and help others. For him this was a way of regaining the sense of who he had been before the stroke. Doing occupations together with other people in a supportive environment may contribute to improving quality of life, despite impaired health [39,40].

The study demonstrates that the participants with mild-to-moderate stroke can contribute actively to adapting to life post-stroke through *doing* meaningful occupations, *being* together, developing a sense of *belonging* together and making individual *adaptations* to their everyday lives. This result puts focus on stroke survivors' resources and contrasts with the

frequent perception of stroke survivors as 'victims' [1,33]. Participation in the lifestyle groups seemed to facilitate these stroke survivors to work actively with meaningful occupations to creating control, autonomy, social relationships, adaptations and changes in everyday occupations that are important in rehabilitation after a stroke [36]. These findings supplement findings from the randomized study in which no significant positive effect was seen following group intervention in relation to well-being, activity and participation [25]. This contrast highlights the importance of combining randomized controlled studies with qualitative methods when designing and evaluating complex psychosocial interventions [27].

The present study has some limitations as well as some strengths. The sample was not representative of stroke patients in general. The purpose of qualitative studies is not to generalize [29]. However, by understanding the participants' involvement in a group in an occupational perspective, this study can contribute to further discussions of how occupational therapists may be aware of how people with stroke might create meaning in everyday life by addressing the participants' resources in creating meaning through being, doing, belonging and becoming after stroke [15]. One strength of the study is that the interviews were conducted in the participants' homes and that the interviewer had not been involved in the group interventions. This may have allowed the participants to feel that they could talk more freely. Individual interviews were chosen to get deeper information from each participant. Because this is a study of group intervention we found it important to talk separately to each person participating in our study. A potential weakness in the study relates to the selection process not resulting in an equal number of male and female participants. The results might have been influenced by the fact that the interviews took place from one to eight months after the participants had finished the group participation. The researchers involved in the process of discussion and analysis had prior experience working with stroke survivors, which has contributed to the rigorous debates that has been a strength of this study.

## Conclusions

The study shows the different ways in which some people with mild to moderate stroke involved in the lifestyle groups. Sharing experiences of stroke and knowledge, developing a sense of belonging, reflecting and working with meaningful occupations seem to be important for regaining a sense of self-worth, and



taking responsibility for, and control over, one's own life. The participants were active contributors who supported and 'pushed each other forward' regarding involvement in meaningful occupations. This active participation seemed to bring the participants' resources into focus and contrasted with the frequent negative perceptions of people post-stroke as 'victims'. The study demonstrates that people with mild-to-moderate stroke may benefit from participation in a psychosocial group in late-stage rehabilitation. The investigation of participants' experiences of group interventions generated knowledge to complement the findings of a randomized controlled study that failed to show any statistically significant positive effects. There is a need for further research both in order to evaluate and to implement group interventions for stroke survivors in late-stage rehabilitation. There is also a need to combine different research methods when designing and evaluating complex psychosocial interventions.

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No potential conflict of interest was reported by the author(s).


### Research ethics

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