SRYAHWA PUBLICATIONS

Open Journal of Geriatrics
ISSN: 2639-359X | Volume 6, Issue 1, 2024
https://doi.org/10.22259/2639-359X.0601001

RESEARCH ARTICLE

Finding Back to Being Myself Again: Stroke Patients' Experiences of a Novel Self-Management Intervention during Transition from Hospital to Daily Living at Home

Gunhild Mo Hansen[1,2], Sedsel Kristine Stage Pedersen[2], Hanne Pallesen[2]

[1]*Department of Physiotherapy, University College Northern Denmark, Aalborg, Denmark.*
[2]*Senior Reseacher, Associated professor, Hammel Neurorehabilitation and Research Centre, University of Aarhus, Hammel, Denmark.*

Received: 29 November 2023 Accepted: 13 December 2023 Published: 11 January 2024

Corresponding Author: G. M. Hansen, Department of Physiotherapy, University College Northern Denmark, Aalborg, *Denmark.*

Abstract

Background: Stroke individuals over the age of 65 belong to an especially vulnerable group with social challenges after leaving the labour market. Change of self-management, especially concerning how to supportively enable stroke individuals' social re-integration and participation in daily living, lack evidence. This study evaluates the experiences of stroke individuals over 65 and their close relatives' experiences of receiving self-management support intended to increase self-efficacy during transition from hospital stay to daily living at home.

Methods: Seven interviews with stroke individuals over the age of 65 and close relatives were undertaken. A qualitative phenomenological approach was applied.

Results and Discussion: Four categories emerged from the data analyses: I) mentor supporting finding back to own role again, II) organization and practical issues, III) mentor as mediator and expert and IV) considerations and concerns in having a mentor. The new initiative of organized self-management support was perceived as an overall positive experience. A few concerns were expressed, hereunder finding the right match between mentor and stroke individual. It seems that the interplay between sharing knowledge and link it to action in real life played a big role for the patients.

Conclusion: Self-management support intended to increase self-efficacy during transition from hospital stay to home benefitted stroke individuals over the age of 65. Experience and specific knowledge in the field of neurorehabilitation is found to provide individualized complex support that accomplish the process and needs of each stroke individual and their close relatives while taking concerns to match challenges and personal preferences of the stroke individual and mentor.

Keywords: Stroke, Self-Management, Self-Efficacy, Social Re-Integration, Daily Living.

1. Introduction

Stroke is a common illness among elderly people and can lead to considerable and often lifelong physical, cognitive, emotional, social, and financial consequences for the affected individuals, their families and their daily living (1–3). The age which one can retire (65 years in Denmark), lifestyle changes and/or predisposed factors are leaving the elderly people with the greatest health problems, both socially and biologically. Furthermore, we also know that those who thrive best in the transition from working life to retirement, and as old age pensioners in general, are the ones who conduct active lifestyles (4). It is known that elderly stroke individuals belong to an especially vulnerable group with factors as loneliness, social isolation, and social challenges after leaving the labour market (5). Change of self-management within learning and adapting processes have been studied. However, less among elderly despite these important difficulties, especially concerning how they supportively enable stroke individuals' social re-integration and participation in daily living.

Citation: Gunhild Mo Hansen, Sedsel Kristine Stage Pedersen, Hanne Pallesen. Finding Back to Being Myself Again: Stroke Patients' Experiences of a Novel Self-Management Intervention during Transition from Hospital to Daily Living at Home. Open Journal of Geriatrics. 2024;6(1): 01-09

©The Author(s) 2024. This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Two systematic reviews investigated the effects of self-management interventions and found that such interventions may improve quality of life and hence self-efficacy post-stroke (6,7). These studies did not specify which core elements of self-management interventions that are effective for stroke individuals over the age of 65 years. Another systematic review found that self-management interventions for stroke individuals over the age of 65 years may be beneficial for self-management, self-efficacy, quality of life, activity of daily living and other psychosocial outcomes (5). However, self-management has become part of the stroke care pathway, since it could support individuals facing the long-term consequences of stroke (7), and thus it could facilitate interventions related to transitional care (8). There is no clear, universal definition of self-management. Thus, self-management is often defined as "Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition (9).A study exploring how people with stroke understand and practice self-management during the post-acute phase, the interviewed participants interpreted self-management as 'taking care of their business' and 'being independent". However, they encountered difficulties performing daily activities, for which they felt unprepared. The participants did not report receiving specific advice from healthcare professionals (10).

The present study is embedded in a novel self-management intervention named "Stroke - 65 plus Continued Active Life" which aims to support elder stroke individuals and their close relatives to maintain their former active lifestyle, or to create a new, meaningful life perspective (11). "Stroke - 65 plus Continued Active Life" included four major supportive add-ons to usual care: 1) self-management in daily life activities; 2) social network and interaction in different social contexts; 3) self-management in self-assessed action competence and quality of life and 4) supporting close relatives in managing an active life without strain (11). Two experienced mentors (a physiotherapist and an occupational therapist) conducted the intervention. During the usual municipal neurorehabilitation, the assigned mentor focused especially on mapping and activating the stroke individuals` social network The usual municipal neurorehabilitation was followed up by six to eight supportive sessions (meetings, visits or telephone calls) of 45-60 minutes duration with the mentor. The supportive meetings were to stop nine months after discharge from the neurorehabilitation hospital/centre. Recently, the effect of "Stroke - 65 plus Continued Active Life" was evaluated in a randomised trial (12). This current study is a supplement to the effect evaluation as the intervention in the present study is evaluated from the stroke individuals' and their close relatives' perspectives.

1.1 Objective

The objective of this study is to elucidate people with stroke and their close relatives' experiences of receiving self-management support to increase self-efficacy during transition from hospital stay to daily living in their own context approximately one year after stroke.

2. Material and Methods

2.1 Design

A qualitative phenomenological approach was chosen as the purpose of the present study is to make sense of the phenomenon of receiving a novel self-management intervention from the informants' perspectives. The research question and the theoretical framework call for a qualitative semi-structured interview study (13,14). This will enable phenomenological experiences of stroke individuals to come forward with reflections and insights concerning experiences of participating in a self-management intervention which is integrated into usual practice. The interview allows the stroke individuals to express with their own words the perception of their experiences (15).

2.2 Study Setting and Participants

The novel self-management intervention evaluated in the present study was conducted in the home of the person and differed to the usual practice in municipal neurorehabilitation by making contact to the person before leaving the hospital and keep contact up to nine months after discharge from hospital. The contact was individualized and consisted primarily of conversations that could support self-management, see Figure 1. Stroke individuals were recruited from four different wards at a specialized neurorehabilitation hospital and two different wards at an in-patient municipality care centre placed in Central Denmark Region with a population of 1.3 million. Participants were recruited based on the following inclusion criteria: (1) age $\geq$ 65; (2) diagnosed with stroke (brain

infarction or brain haemorrhage); (3) living in the municipality of Aarhus (approx. 340,000 inhabitants) (4) no severe cognitive impairment, defined as < 17 on the Montreal Cognitive Assessment (MoCA); (5) discharged to own home; (6) able to speak and understand Danish. The intervention was carried out by a specialized neurorehabilitation out-patient centre in the municipality of Aarhus.

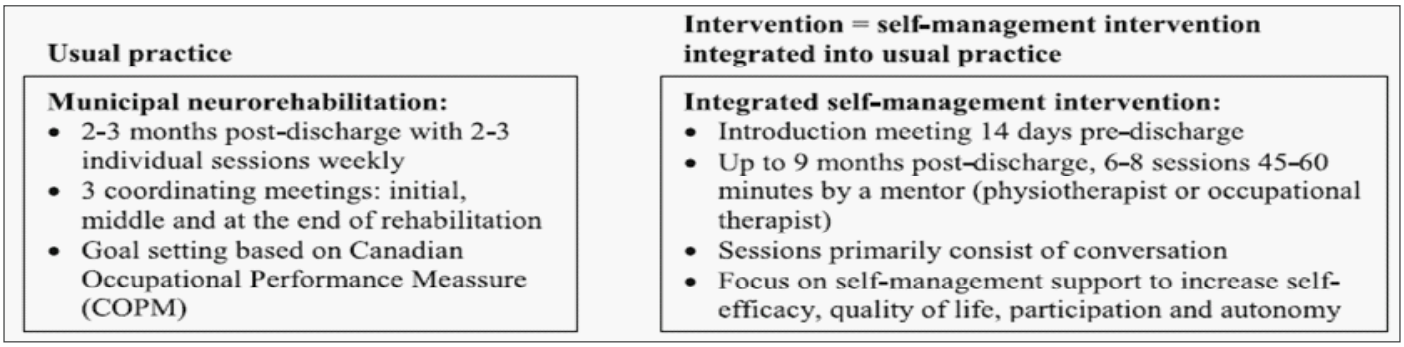

Figure 1. *Usual practice and the integrated self-management intervention by Sørensen et al (16).*

2.3 Selection of Participants

From March 2021 to November 2021 the last ten stroke individuals from the earlier mentioned RCT (12), were face to face or over the phone invited to participate in the present study. The number of participants were decided on in advance and the specific time interval was chosen due to practical reasons, i.e. to accomplish the interviews not too spread apart timewise. They all accepted the invitation. However, one person became seriously ill and died, one person was later excluded because of considerable different rehabilitation process due to Covid19 and one person was excluded due to severe Covid19 illness. This left seven stroke individuals for the present study. As the close relatives were encouraged to be involved in the integrated self-management intervention, they were also invited to participate in the interviews. Four close relatives participated. For an overview of the informants, see Table 1.

Table 1. *Characteristics of the informants*

Stroke Individuals (n=7)	
Sex, male/female	4/3
Age in years, mean (range)	74 (70-79)
Stroke duration in days, mean (range)	351 (311-397)
Stroke type, ischemic/haemorrhagic	6/1
Civil status, alone/with partner	3/4
Work status, employed/retired	0/7
FIM*, mean (range) - motor score - cognitive score	 68 (38-87) 26 (16-34)
Close relatives attending (n=4) Sex, male/female Age in years, mean (range)	 1/3 70 (69-71)
*FIM = Functional Independent Measure	

2.4 Interviews and the Interview Guide

Five interviews were conducted in the home of the stroke individuals and led by a moderator. Due to restrictions and special attention taken into consideration due to Covid19, two interviews were performed as telephone interviews with support person attending. In interviews three and six the first author (GH) was the moderator while the second author (SP) asked supplementary questions and in interviews one, two, four, five and seven SP was moderator and GH was asking supplementary questions. Both SP and GH were experienced in conducting interviews. Pilot testing was not performed. The interviewer introduced herself and described the purpose of the study to the participants. Questions and thoughts elucidated by the informants could be discussed and embellished during the interview session with the interviewees. The interview-guide was developed prior to the execution of the interviews with main topics to catch participants' reflections and performance: 1) self-efficacy at the present time, one year after stroke; 2) support in self-efficacy, support from the relatives; 3) relatives; 4) future, see Table 2. The moderator followed a standardized procedure of recording the data using audio recorder and immediately after finishing the interview transferring data to secured folder. Field notes were made during the interview. Each of the interviews lasted between 20 and 52 minutes.

Table 2. *Interview guide March 2021.*

Research	Interview Questions
Self-efficacy One year after stroke – of current interest	• Are you now equipped and ready to manage your everyday? • Shortcomings? What does it take? • Frustrations?
Support in self-efficacy Support for relatives and next of kin	• Have you profited from the support by the therapists/mentors in the Apo 65+? • If so, describe in which way: → Areas □ Is there something that can/should be improved? - Form? Dialog? □ Is there something that can/should be improved? - To what? □ How can/should the support be extended? - Do you feel as a relative that you have been reloaded by the support? • What is perceived as irrelevant/insignificant?
Future	• What will you do if there in the future will be difficulties/challenges? • What kind of wishes do you have for your future? • Will you recommend for other stroke survivors to say yes if they could have the chance to receive the same mentor support as you have? - Why/why not?

2.5 Transcription

After the interviews were conducted, all the data material from the interviews were transcribed verbatim by one person (GH) to secure nuances of the verbal language during the interview and secure a uniform method of transcription (13).

2.6 Data Analysis

Content analysis as described by Graneheim and Lundman was used to elucidate and interpret factors perceived as important to increase stroke individuals´ ability to maintain or increase self-management in their lives after experiencing stroke (17). To acquire a sense of the whole, the interviews were read through several times and data from each interview was analysed separately. According to content analysis methods, data was organized and condensated which involved shortening of material while still preserving the core meaning. GH and HP condensed the material while still preserving the core meaning and organized the material into meaningful units which were abstracted and coded considering the whole context. Further, the codes were firmly evaluated and classified in to four categories, see Table 3. In this process, author 1 (GH), author 2 (SP) and author 3 (HP) discussed potential categories.

Table 3. *Overview of categories*

Category	1. Mentor supporting finding back to being myself again
	2. Organization of practical issues
	3. Mentor as mediator and expert in the field of stroke
	4. Considerations and concerns in having a mentor

2.7 Ethical Considerations

The study is part of project "Stroke – 65 plus Continued Active Life" which is approved by the Danish Data Protection Agency (number: 1-16-02-66-17) and the Committee on Health Research Ethics of Central Denmark Region (number: 1-10-72-264-16). All participants gave written informed consent. The study follows the ethical principles of the Helsinki-declaration (18).

3. Results

A total of seven interviews were conducted in the period 1. March 2021 to 26. October 2021. There were altogether eleven participants in the study. Seven stroke individuals in the age-range of 70-79 were included. Three stroke individuals had their spouse participating by their side during the interview and one stroke individual had a good friend participating in the interview, see Table 4 for appellation of participants.

Table 4. *Presentation of the stroke individuals and relatives*

Participant	1	2	3	4	5	6	7
Relative	Relative 1	Relative 2	n/a	Friend 4	n/a	n/a	Relative 7

The materials led to following categories: category 1, "Mentor supporting finding back to own role again"; category 2, "Organization and practical issues"; category 3, "Mentor as mediator and expert", and category 4, "Considerations and concerns in having a mentor".

3.1 Mentor Supporting Finding Back to Being Myself

One focus expressed by all patients was the experience of mentor as a person with knowledge and understanding for the challenges that they underwent. They found the mentor as being a helpful person that knows what it is all about. Mentor support meant for some having a conversation partner they could talk to about everything, one that understood them and the situation they were in:

Participant 1: We had the security of the mentor being there and that has helped us getting started when we came home on our own. It has been super.

Participant 2: You also feel that there is someone that take a stand on some problems and your life and…. and sickness and what happened and so on. There is a caring angle on it.

Some expressed that they had changed after their stroke and appreciated the support the mentor gave to be able to behave or do things that they had done and been prior to stroke:

Participant 2: Mentor has given me support to give space for other people again.

Participant 3: Mentor said that I should kiss my husband on the chin – laughs – I am glad she did. I plan to do things at night, but when the day comes, it is difficult.

Also, the relatives elucidated on certain aspects that they found encouraging by having mentor support in the phase after the transition to home:

Relative 4: She looked up to mentor and could motivate her to do some things that she didn't do spontaneously.

Relative 2: He is often the one to reject…when something hurts (i.e. emotional painful) … and there, Mentor could be the one to keep on going so we both got the possibility to express ourselves. I think that was really good. Mentor asked some questions that we all three could talk about, and it´s like it helped me to tell him some things.

Participant 3: Sometimes when I am totally exhausted my husband says: don't you think we should talk to mentor? That is how we run it in our family. Mentor is just there.

Relative 1: Mentor could follow his humour and in such a good manner…well, support him. In that way she had a good influence on him.

For some of the participants, it meant that they could find their way back to fulfilling a role that had meaning for them and lead back to a way of living their life that resembles the way they lived prior to experiencing their stroke:

Participant 3: I have had help from the first meeting with Mentor. Today I don't think so much about the speech (problems), but instead of the tiredness…and to get back to being myself again. That is a big wish for me.

3.2 Organization and Practical Issues

The participants expressed that the mentors also covered an important role in considerations that were more organizational and relating to practical issues in the daily life at home. Factors that were mentioned by more participants were managing contact to other health personnel, for example psychologist and general practitioner. Further, support was given to organize about assistive devices, for example wheelchair, further physiotherapy treatment and transport related to training or other situations:

Participant 5: I really felt that she was interested in me…fantastic, I would never have gotten such a wheelchair if it wasn´t for Mentor. I would never have gotten to a dentist.

Relative 1: It was also a good help that they took care about him and listened to what he said, because he the whole way had pain in his arm...it was Mentor's earning that he was referred to scans and it was then found out that he had a frozen shoulder.

Mentor came along for the first meeting because she knew him and his pain limit…a huge help.

Participant 2: Mentor wrote a letter to my doctor that led to the general practitioner to turn around on his decision and write to me that he agreed on free of charge physiotherapy treatment.

The participants also expressed the importance of being able to do the things that had been essential for them prior to stroke, for example managing daily life activities in and around the house, working out in the fitness-centre or to walk in the forest again:

Participant 3: In the hospital they told me that I could get cleaning help. It took me eight months to say yes, and mentor supported me to say yes because it could give a possibility to have more strength during the day. I thought it was such a failure, but now the nicest person comes every second week and manage vacuuming and washing floors.

Relative 1: He used to work in a second-hand shop and after coming home he didn't really feel that he could fulfil that role. Mentor arranged with his boss and colleagues that he, together with mentor, could try it out.

There was also a focus towards managing daily life activities for some of the participants. This included other aspects of daily life, for example managing the excessive tiredness some persons can experience after brain injury and/or reduced motor function due to stroke.

Participant 4: ……you know, in addition to talking to Mentor about leg and arm and things like that you also can talk about many other things. It was Mentor that taught me to walk out to the mailbox and things like that.

3.3 Mentor as Mediator and Expert

One special focus was that the mentor not only played a part for the stroke individual, but also had a role in the life of the persons close to the stroke individuals by inspiring and guiding close family and friends:

Participant 3: The mentor also taught my family to say stop when I am pushing too hard. And they do. Then they say: what is it now that Mentor says? My husband and children have participated on many meetings with Mentor.

Participant 6: I have been able to tell my family about some of the things after conversations with Mentor – which has led to a bigger respect for me being tired and so they have taken more consideration.

Close relatives of the stroke individuals express that support from the mentor helped them after their close ones came home. They have had possibilities to ask questions that have been followed up with conversations with the stroke individual:

Relative 1: Mentor has cured him from answering dumb-smart when it´s getting hard. Also, Mentor has supported him by telling him that he has a tendency to dominate and talk a lot by giving him a talk about giving place to other people.

Relative 2: Mentor could soften up the conversation when he rejected because something was painful to talk about. Mentor also made him attentive of him pushing other people away, including the spouse.

Participant 3: It meant so much for the close relatives that had a very difficult time in the beginning. Mentor talked several times with spouse and close relatives. She explained much about how it is to experience a stroke and how it feels to be me.

3.4 Considerations and Concerns in Having a Mentor

The participants, both the stroke individuals and their close persons, agreed that they would not hesitate to recommend saying yes to a mentor if it was a possibility – both for the sake of the stroke individual, but also for the close relatives. They mentioned different reasons why they would recommend a mentor to other people in the same situation:

Relative 1: Accept because it is a good safety, that someone takes care of you, because it is a new situation you are in.

Patient 6: The mentor was a good support and understands you and the situation.

Two stroke individuals experienced just a few, or none, changes after the stroke and shed light on that some stroke individuals could be in the situation that they did not need support from a mentor when coming back to their daily life after experiencing a stroke:

Participant 7: It depends if you need it. I said yes to this project to help others. I could see that it was not so much help in it for me. But...that was lucky, wasn´t it.

Participant 2: I could see someone...that are affected seriously and that are older than us (i.e. participant 2 and relatives) and that have reduced functional level who could have a bigger need than us.

The stroke individuals and their close relatives also expressed some concerns, and even suggestions on how this support could be strengthened:

Participant 3: I can fear not having a contact to Mentor anymore because she has beaten the track and helped me very much.

Relative 1: It´s important with a good match (i.e. between stroke individual and mentor). If this should work in the future, I would recommend, that both parties meet and then you can sleep overnight and think about it, if that was someone that you could go together with or should you try someone else.

4. Discussion

Our objective was to evaluate stroke individuals' and their close relatives' experiences of receiving self-management support intended to assist the stroke individuals' ability to increase self-efficacy during transition from hospital to daily living in own home. Overall, all stroke individuals experienced support from mentor as being positive in their daily living and this was further supported by the close relatives. They perceived mentor as having expert knowledge. Stroke individuals expressed the support from mentor to find a way to live life again in more ways; mentally, physically, practical and by the support to close relatives. A couple of stroke individuals found that they could have done without the support from mentor and a concern was expressed about finding the right match between mentor and stroke individual.

More stroke individuals brought forward that they have found support in mentor who helped them to find a plan for going on with life. Stroke survivors work on finding their ways back to live their life again when coming home – meaning including different aspects of living. Coming home to everyday life means for stroke individuals to have time on their own to experience, explore and feel themselves again without being constantly monitored. This can support the persons in perceiving that they are the ones being the initiator of the action which can be enhanced by the support from the mentor. Enhancement of sense of agency is regarded to be important in relation to independence in daily living (19). The stroke individuals both expected and experienced the mentors as experts in the field. Mentors covered a huge area which included all aspects of living with aftermaths of stroke, e.g. cognitive, mood and physical issues. The mentors took action in more fields, also in the role as coordinator or mediator. This meant that they brought forward information where special steps had to be taken, for example write letters or making phone calls to general practitioner. It also meant that they played a huge part in some of the relatives' lives. The relatives expressed overall positive declaration about having a mentor attached during and after transition from hospital to home, although some of the relatives chose not to participate in this study. Distinct is the acknowledgement from the relatives expressing support from the mentor in daily situations where the stroke individuals had challenges in matching the social ground rules.

The mentors fulfilled a role of being a professional person with huge amount of experience within the field of stroke rehabilitation. In order to help some of the stroke individuals with some of the practical issues, there might have been an advantage to have extended knowledge of the municipality where the stroke individuals lived. This could mean that not everyone could have had the possibility to give support in such a targeted manner as mentors in this study had, and as such not all therapists within the field of neurorehabilitation would be able to solve the task of supporting the persons in all aspects of their life after stroke.

Although the mentors' tasks are individualized to the person (and relatives) in the present study, it is not clear what specific qualifications is demanded to provide and apply self-management intervention. Usual practice is often organized in such a manner that flexibility can be a concern. The mentors seemed to have flexibility in how and when the patients could contact them and about what tasks, challenges and difficulties they would work on in order to support the patients. This could represent a barrier for some therapists due to the certain amount of knowledge and capacity it seems to demand to fulfil the mentor function.

The mentors used a lot of their time to talk with the patients and the relatives. Also, the mentors participated in more practical activities and organizational tasks with contact to other health care professionals or colleagues. Conversation themes were individualized in one-to-one sessions depending on the need for the stroke individual, and eventual the need for the close relatives to be present. The interaction between the stroke individual and the close relative might be seen as a companionship where it is essential that the mentor in cooperation with the stroke individual and the close relative find what the focuses are that can motivate the rehabilitation process for the person. Goal setting has been acknowledged as an especially important process in administration of complex challenges within the field of neurorehabilitation (20–22). Added in this study are goals and interventions supporting the patient's autonomy, social participation, ordinary day life and leisure life in such a way that the close relatives are not burdened. It includes assessing the persons' capacity to active cooperation and also what goals to be worked with to support the persons' autonomy (23,24).

One important question to bring forward, is how the mentor function separates from usual practice after

stroke. This project shows that the support given by the mentors has a strength in its flexibility, both time used in the individual course and also type of tasks that is undertaken, ranging from visits in hospital, organising training at local health centre, contact to other relevant health professionals, supporting and providing knowledge to relatives and give feedback on concrete situations where cognitive deficits play a role for the situation between partners living in the same house. A consideration could be if other health care professionals could play the role of being mentor. It seems that the interplay between sharing knowledge and link it to action in real life (where real life is lived) has had a big impact for some of the patients. In the present study, a physiotherapist and an occupational therapist experienced in the field of stroke, have the knowledge to bring the coherence and match the requirement in the specific situation. Opposite to the effect evaluation of "Stroke - 65 plus Continued Active Life" (12), the present study highlights the stroke individuals and their close relatives' experiences, sensations and feelings of the integrated self-management intervention. The multispectral evaluation strategy made it possible to investigate not only the effectiveness of the intervention, but also the quality and relevance of the intervention. Despite no significant difference between the control and intervention group were found in the effect evaluation, the present study reveals interesting perspectives on how to improve stroke rehabilitation in the future.

4.1 Limitations of the Study

The present study is limited by having a small sample size. However, close relatives were invited to enrichen and provide more nuanced perspectives. The informants in the present study were a randomly selected group of stroke individuals randomized to the integrated self-management intervention in the last months of the project "Stroke - 65 plus Continued Active Life". There is no reason to believe that the informants in the present study differ from previous participants in "Stroke - 65 plus Continued Active Life" why the results are likely to be representative to all participants. Furthermore, the results may be transferable into other settings as the intervention was performed in a clinical context. The overall positive experience of receiving self-management support presented by the stroke individuals and their close relatives in this study also gives strength to the transferability.

5. Conclusion

Self-management support intended to increase self-efficacy during transition from hospital stay to daily living in own context was perceived as an overall positive support and experience by stroke individuals and their close relatives. This study provides profound understanding of how the self-management support requires experience and specific knowledge in the field of neurorehabilitation in effort to provide individualized complex support that accomplish the process and needs of each stroke individual and their close relatives. Additionally, it shows the wide range of tasks and situations the stroke individuals and their relatives found challenging and in need of support. Concerns were related to receiving mentor support that did not match the challenges and personal preferences of the stroke individual and the mentor.

Funding

The study is financial funded by the Velux Foundation. The Velux Foundation has no influence on the collection of data, analysis and presentation of results.

Declaration of Interest

The authors report no conflict of interest.

Funding Statement

Researchers wish to thank the Velux Foundation for funding the study.

Acknowledgements

This study is part of project ´Stroke 65 plus Continued Active Life`. We wish to thank the persons who attended, both stroke individuals and close relatives and support persons, for time and effort to cooperate in this study.

6. References

1. Haley WE, Roth DL, Hovater M, Clay OJ. Long-term impact of stroke on family caregiver well-being. Neurology. 2015 Mar 31;84(13):1323–9.
2. Barzel A, Ketels G, Tetzlaff B, Krüger H, Haevernick K, Daubmann A, et al. Enhancing activities of daily living of chronic stroke patients in primary health care by modified constraint-induced movement therapy (HOMECIMT): study protocol for a cluster randomized controlled trial. Trials. 2013 Jan;14:334.
3. De Wit L, Theuns P, Dejaeger E, Devos S, Gantenbein AR, Kerckhofs E, et al. Long-term impact of stroke on patients' health-related quality of life. Disabil Rehabil. 2017 Jul 3;39(14):1435–40.

4. Jonsson H, Borell L, Sadlo G, Head of Occupational Therapy I. Retirement: an occupational transition with consequences for temporality, balance and meaning of occupations. J Occup Sci. 2000;7(1):29–37.
5. Stage Pedersen SK, Lillelund Sørensen S, Holm Stabel H, Brunner I, Pallesen H. Effect of self-management support for elderly people post-stroke: a systematic review. Geriatrics. 2020;5(2)(38):21.
6. Wray F, Clarke D, Forster A. Post-stroke self-management interventions: a systematic review of effectiveness and investigation of the inclusion of stroke survivors with aphasia. Vol. 40, Disability and Rehabilitation. Taylor and Francis Ltd; 2018. p. 1237–51.
7. Fryer CE, Luker JA, Mcdonnell MN, Hillier SL. Self management programmes for quality of life in people with stroke. Vol. 2016, Cochrane Database of Systematic Reviews. John Wiley and Sons Ltd; 2016.
8. Eng JJ, Bird ML, Godecke E, Hoffmann TC, Laurin C, Olaoye OA, et al. Moving stroke rehabilitation research evidence into clinical practice: Consensus-based core recommendations from the Stroke Recovery and Rehabilitation Roundtable. International Journal of Stroke. 2019 Oct 1;14(8):766–73.
9. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Educ Couns. 2002 Oct 1;48(2):177–87.
10. Klockar E, Kylén M, Gustavsson C, Finch T, Jones F, Elf M. Self-management from the perspective of people with stroke - An interview study. Patient Educ Couns. 2023 Apr 5;1–6.
11. Pallesen H, Næss-Schmidt ET, Kjeldsen SS, Pedersen SKS, Sørensen SL, Brunner I, et al. "Stroke - 65 plus. Continued active life": a study protocol for a randomized controlled cross-sectoral trial of the effect of a novel self-management intervention to support elderly people after stroke. Trials. 2018 Nov 19;19(1).
12. Pallesen H, Petersen SKS, Sørensen SL, Næss-Schmidt ET, Brunner IC, Nielsen JF KSS. Note : This article will be published in a forthcoming issue of Stroke. "Stroke - 65 Plus. Continued Active Life". A randomized controlled trial of a self-management intervention for elderly people after stroke. Stroke.
13. Kvale S, Brinkmann S. Interview: det kvalitative forskningsinterview som håndværk. In: 3. udgave. Kbh.: Hans Reitzel; 2015.
14. Malterud K, Malterud K. Kvalitative forskningsmetoder for medisin og helsefag : en innføring. 4. utg. Oslo: Universitetsforlaget; 2017.
15. Kvale S, Brinkmann S. Learning the craft of qualitative research interviewing. Interviews: learning the craft of qualitative research interviewing. 2009.
16. Sørensen SL, Pedersen SKS, Pallesen H. Social psychological mechanisms and processes in a novel, health professional-led, self-management intervention for older stroke individuals: a synthesis and phenomenological study. BMC Health Serv Res. 2019;19(1):1–15.
17. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today. 2004;24:105–12.
18. World Medical Association. World Medical Association Declaration of Helsinki. Bulletin of the world health organization. 2013.
19. Oberg GK, Normann B, Gallagher S. Embodied-enactive clinical reasoning in physical therapy. Physiother Theory Pract. 2015;31(4):244–52.
20. Levack WMM, Weatherall M, Hay-Smith EJC, Dean SG, Mcpherson K, Siegert RJ. Goal setting and strategies to enhance goal pursuit for adults with acquired disability participating in rehabilitation. Cochrane Database of Systematic Reviews. 2015 Jul 20;2015(7).
21. Dekker J, De Groot V, Marie Ter Steeg A, Vloothuis J, Holla J, Collette E, et al. Setting meaningful goals in rehabilitation: rationale and practical tool. Clin Rehabil. 2020;34(1):3–12.
22. Rose A, Rosewilliam S, Soundy A. Shared decision making within goal setting in rehabilitation settings: a systematic review. 2017;100(1):65–75.
23. Brown M, Levack W, McPherson KM, Dean SG, Reed K, Weatherall M, et al. Survival, momentum, and things that make me "me": patients' perceptions of goal setting after stroke. Disabil Rehabil. 2014 Jan 1;36(12):1020–6.
24. Wade DT. What attributes should a specialist in rehabilitation have? Seven suggested specialist capabilities in practice. Clin Rehabil. 2020;34(8):995–1003.