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The role of the social network during inpatient rehabilitation: A qualitative study exploring the views of older stroke survivors and their informal caregivers

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ABSTRACT

Background: After discharge, stroke survivors and their informal caregivers need support from their social networks to resume their most valued activities. Rehabilitation professionals could help them establish a strong support system.

Objective: Explore how older stroke survivors and their primary informal caregivers expect to resume their valued activities after discharge, and discover their ideas about involving, informing and educating their family members, friends and important others during inpatient rehabilitation so that, once home, they will have adequate support.

Methods: We conducted semi-structured interviews with stroke survivors from three geriatric rehabilitation centres and their primary informal caregivers, used the pictures of daily activities to elicit their perspectives, and applied a descriptive and interpretive design to data analysis.

Results: Many participants had no concrete idea about how to resume their activities after discharge but nevertheless were optimistic they would. They expected help to be available and saw no need for professionals to involve their network during inpatient rehabilitation. However, once they had insight into the challenges to expect after discharge, they often appreciated the idea of professionals contacting their network. To better understand the challenges after discharge, it was helpful if professionals provided concrete, honest information about the stroke's consequences for daily life. Actually doing daily activities also helped gain better insights.

Conclusions: To enhance insight in the need of social support after discharge, we suggest that rehabilitation professionals are honest about what to expect and let stroke survivors explore their valued activities in a realistic context more often.

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Stroke; informal caregiving; valued activities; meaningful activities; social network; social support; rehabilitation

Introduction

Stroke is associated with serious perceptual, cognitive and motor impairments.^{1,2} As a consequence of these impairments, many stroke survivors have difficulty resuming previously valued activities, such as their social, family or leisure activities.^{2,3} For some, the struggle of renegotiating these activities persists for many years after the onset of stroke.^{3–7} However, the loss of activities not only applies to stroke survivors, but also to their primary informal caregivers.⁸ Because of their extensive caregiving task, these caregivers generally have no time and energy for their own activities, such as their social activities.^{8–11} In the long run, both stroke survivors and informal caregivers tend to become more homebound and have fewer social relationships,^{7,9,12–15} which easily results in social isolation.^{11,12,16,17} Research shows that loss of

valued activities and social isolation are related to depression and reduced wellbeing in both stroke survivors^{3,18,19} and informal caregivers.^{20–22}

Since engagement in valued activities and social relationships are predictors of better (mental) health and wellbeing,^{23–27} it seems important that rehabilitation professionals help stroke survivors and primary caregivers resume their valued activities and inform them about the importance of maintaining social relationships.^{8,28–30} Additionally, because an understanding and supportive social network is a prerequisite for activity resumption,^{8,10,28,29,31–34} several authors suggest that rehabilitation professionals should invite family members, friends and acquaintances to play an active role during inpatient rehabilitation.^{28,29,32,35–37} Professionals should inform and educate these social network members

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about how to support stroke survivors' and caregivers' activity resumption so that adequate support will be available once the stroke survivor returns home. Involving and educating social network members seems especially important in case of older stroke survivors because they generally suffer from more initial impairments and more severe strokes,^{38,39} resulting in a less favourable functional status and fewer possibilities to return to previously valued activities.^{3,40,41}

However, before developing ways to work with the broader network in inpatient settings, it is important to know whether older stroke survivors and their informal caregivers are open to the idea of involving their social networks during rehabilitation and, if so, what their preferences are. Therefore, this study aims to clarify the views of these stroke survivors and their primary caregivers with regard to: (a) their activity resumption after discharge, (b) the role their broader social networks could play in this respect, and (c) how their social networks could be involved during the institutional rehabilitation phase to equip them for the expected role.

Methods

To elicit the perspectives of these stroke survivors and their caregivers, we performed semi-structured interviews with them prior to the stroke survivor's discharge from a geriatric rehabilitation centre. To understand their ideas in depth, we applied a descriptive as well as an interpretive qualitative approach to our analysis. We used the Activity Card Sort,⁴² a validated photo series with pictures of activities, to support understanding of our interview questions. The study was approved by the local institutional ethics committee (HAN University of Applied Sciences Ethical Advisory Board, ACPO 38.06/16) and the rehabilitation centres where the study was conducted.

Participant recruitment

To obtain a diverse study population, we approached the rehabilitation teams from three geriatric rehabilitation centres. We informed them about the study's purpose and asked them to consider which stroke survivors and caregivers

would be willing to be interviewed for the study. Since we thought it would be easiest for stroke survivors and caregivers to discuss the roles they expected their social networks to play after discharge once discharge was imminent, the rehabilitation teams at the participating centres approached them about participation when the discharge date was scheduled. In order to be included in the study, stroke survivors had to be expected to be discharged home and have sufficient cognitive and communication skills to participate in the interviews. Exclusion criteria were severe visual or hearing impairments or severe aphasia, as they would hinder the stroke survivor's ability to recognise the photographs or understand the interview questions and answer them reliably. We asked each stroke survivor who was willing to participate to identify their primary informal caregiver, described as the person who would offer the most important support following discharge. If that person was available, we also invited them to participate in the study.

Prior to signing an informed consent, all participants were given information about the study, guaranteed anonymity and confidentiality regarding data management and publication, and informed of their right to withdraw at any time without explanation. Also, to ensure participants would feel free to share their opinions, they were informed that the researcher had no formal relationship with the rehabilitation centre and that the information they gave would not be shared with the team in a way that could be traced back to them.

Data collection

A researcher experienced in working with stroke survivors (SJ) conducted the interviews. She did so in accordance with the procedure and main topics described in an interview guide, which was developed during two research group consensus meetings and pilot tested before use through three interviews (two stroke survivors, one caregiver). The research group consisted of four experts from different allied health professions who were all trained both as clinicians and academics. These experts had extensive experience working with stroke survivors and their informal caregivers in a clinical setting.

The interviews took place in the stroke survivor's private room at the institution, one week to a few days before their discharge. Stroke survivors and caregivers were interviewed individually but within each other's presence, so they could complete each other's stories, if necessary. The stroke survivor was the first to be interviewed. Once they had provided all the information they wanted to share, the caregiver was asked whether they wanted to comment or add something. Then the caregiver was interviewed and the stroke survivor could add their comments afterwards.

During the interviews, which lasted 25 to 50 minutes, baseline demographic data were collected. Then the participants were asked about their most valued activities, their present activity experiences and expectations for the future, and the role they expected their social network to play in resuming or maintaining their valued activities. We also asked what, in their opinion, could be done to involve and inform their social network during institutional rehabilitation in order to equip them for the expected role. (see [table 1](#) for the interview guide).

To support understanding and enable the participants to systematically consider all kinds of activities and make a well-informed decision about which they valued most, we used the pictures

from the Activity Card Sort, Dutch version.⁴² The Activity Card Sort consists of a set of 79 photographs of elderly people doing all kinds of activities, such as shopping or reading to children. It was originally developed in North America and has been translated, adapted and validated in different countries, including in the Netherlands, and was found to hold good potential for assessing elderly people's activities.⁴² Unfortunately, a set of Activity Card Sort pictures validated for young Dutch adults does not yet exist. Therefore, if younger caregivers found that the photographs did not represent their situation, we asked them what activities they performed before the stroke, using a written list of the Activity Card Sort activities to help them consider a wide range of activities, before they decided which they valued most.

The interviews were audio recorded and transcribed verbatim. AtlasTi version 8 was used for data management and analysis. Confidentiality was assured by using pseudonyms to protect the participants' identities. Additionally, the anonymised research data were stored on a secured network drive at the research institute. The members of the research team were the only ones with access to the data.

Interviews were conducted until no new ideas about the involvement of social network members came up, which occurred after interviewing ten stroke survivors and eight caregivers. After interviewing an additional two stroke survivors and one caregiver, we decided that saturation had been reached.

Analysis

First, to give a comprehensive summary of the participants' ideas concerning activity resumption and social network involvement, we analysed the data using a descriptive approach. This kind of analysis is useful when straight descriptions of a phenomenon are required.⁴³ During this step, two researchers (KB and SJ) read through the transcript several times to get a sense of the text as a whole, and they individually extracted all text units that were somehow related to the study aims. These units were then coded to capture their central meaning. Subsequently, the codes that had a link with a specific study aim were related to each other following the constant comparison method⁴⁴ and then sorted into categories and themes. Next, to get a more in-depth understanding of the

Table 1. Interview guide.

1	What have been your activity experiences since <i>you/your loved one</i> ^a had a stroke? (What happened? How did the stroke affect your activities? Which activities have you performed or tried to perform so far? How did it go?).
2a	Can you please tell me about the activities you most value doing? (regardless of whether you have been able to do them after the stroke). Take a look at <i>this pile of pictures/this list</i> ^{a,1} and pick out the activities you value doing the most (e.g. because they are your favourite or doing them is just very important to you).
2b	Which of these activities would you most like to resume (or maintain) once <i>you/your loved one</i> ^a are/is home again?
3	What are your expectations about the resumption (or maintenance) of these activities after discharge?
4	What can the people important to you (e.g. your family members, friends or neighbours) do to help you resume (or maintain) these activities?
5	What, in your opinion, can be done during rehabilitation to make sure these people can help you resume (or maintain) these activities once <i>you/your loved one</i> ^a are/is home again? (What is the role you expect rehabilitation professionals to play with regard to these people? For example, what should professionals do, or what should they tell or show these people so they can help you resume (or maintain) these activities?)

^aquestions asked of the *stroke survivor/the primary caregiver*

¹The pictures and the list of activities of the Activity Card Sort (ACS), Dutch version,⁴² were used to support understanding and enable the participants to systematically consider all kinds of activities.

findings, the researchers took an interpretive approach to analysis: both considered all text units and codes again, searching for patterns that clarified the participants' perspectives in more depth.

During each step, 20 % of the data were analysed by both researchers individually, reaching consensus afterwards. The rest of the data were analysed by one researcher (KB) and checked by the other (SJ). The validity of the overall findings was verified by sending a summary to the participants and asking for their comments. All participants agreed with the findings and had no additional comments.

To enhance quality and transparency, the study was reported in conformance with the COREQ Guidelines.⁴⁵

Results

Twelve of the thirteen stroke survivors and nine of the eleven primary caregivers who were approached to participate in the study agreed to do so (one stroke survivor did not have an informal caregiver, two caregivers refused because they felt they were too busy). All participating stroke survivors and caregivers wanted to resume their most valued activities after discharge, such as long-distance walking or keeping birds (see table 2). The descriptive analysis of the transcripts resulted in three themes: 'sudden activity changes', 'an uncertain but hopeful future' and 'no need for the team to involve the network'. After applying interpretive data analysis, we added a fourth theme: 'improved insight and awareness through experience, knowledge and information' (table 3 shows the themes, categories and representative quotes).

Sudden activity changes

The stroke and subsequent hospitalisation had brought about abrupt activity changes for both stroke survivors and caregivers. The stroke survivors reported feeling physically limited. They tried to resume some basic activities, such as self-care, with varying degrees of success. Caregivers described being busy visiting the stroke survivor, taking over their former tasks and informing and consulting professionals. Additionally, they attended the stroke survivor's therapy, helped with exercises and arranged for them to return home safely. They also kept in touch with family members and friends, informing them about the recovery and scheduling their visits. As a consequence, many caregivers were so busy that they had little time and energy to enjoy their own activities.

An uncertain but hopeful future

When stroke survivors were asked if and how they thought they would resume their most valued activities after discharge, many reported that they had not devoted a great deal of thought to this. Their first priority was going home and, although some of them suffered from severe functional impairments, they expected to soon resume their activities there. Most stroke survivors were sure that all the arrangements they needed to return home safely would be made and considered help from people other than their primary caregiver unnecessary. However, they reported having friends and family members they could always ask for help, if necessary.

Table 2. Characteristics of the participating stroke survivors and primary informal caregivers (names are pseudonyms).

Name	Gender	Age	Stroke survivor			Primary informal caregiver	
			Weeks since stroke	Living with ...	Example of valued activity	Name and relationship to stroke survivor	Example of valued activity
Anna	f	79	7	spouse	household activities	André, son	work
Bep	f	76	8	spouse	embroidering	Ben, husband	keeping birds
Corry	f	85	7	-	watching TV	-	-
Dora	f	87	5	-	visiting family and neighbours	Danielle, daughter	family activities
Ed	m	78	12	spouse and son	traveling	-	-
Ferdy	m	88	15	spouse	driving	Fenna, daughter	raising a puppy
Geert	m	70	7	spouse	playing chess	Gerda, wife	sport activities
Hans	m	75	6	-	attending football matches	-	-
Jan	m	80	6	spouse	long-distance walking	Jolanda, daughter	writing
Kees	m	69	8	spouse	motorcycling	Kaatje, wife	playing tennis
Leo	m	71	8	spouse	bicycling	Lena, wife	going on outings
Mart	m	73	6	spouse	playing cards	Mara, wife	swimming

Table 3. Themes, categories and representative quotes (names are pseudonyms).

Sudden activity changes	<p><i>'My hand hasn't worked properly since I had this stroke, so fastening buttons and the like is difficult.'</i> (Kees, stroke survivor)</p> <p><i>'I used to go for long walks, but, for the time being, I won't be able to do so because of this wheelchair ...'</i> (Jan, stroke survivor)</p> <p><i>'Everything just stopped. I mean ... the everyday things you normally do, they just stop.'</i> (Gerda, Geert's wife)</p> <p><i>'I tried to take a tennis lesson, but I simply couldn't concentrate anymore.'</i> (Kaatje, Kees's wife)</p>
An uncertain but hopeful future	<p>Not having considered thoroughly/not knowing what activity limitations to expect after discharge:</p> <p><i>'Actually it hasn't crossed my mind ... Maybe I'll need some assistance [preparing a meal], but I'm not sure.'</i> (Hans, stroke survivor)</p> <p><i>'I'm not sure what activities will be difficult [after discharge] ... Just wait and see ...'</i> (Bep, stroke survivor)</p> <p><i>'It depends ... If I can leave my husband alone, I can do something of my own ...'</i> (Mara, Mart's wife)</p> <p><i>'We have to wait and see what she can do and what help she'll need from me. It is difficult to know in advance.'</i> (Danielle, Dora's daughter)</p> <p>(Yet) having a positive outlook:</p> <p><i>'I will be just fine, returning to my odd jobs around the house.'</i> (Kees, stroke survivor)</p> <p><i>'Recovery is just a matter of practice. You have to do your exercises.'</i> (Geert, stroke survivor)</p> <p><i>'Until now, everything has revolved around my husband's recovery. But once he's home, I am sure I can pick up my sports again.'</i> (Kaatje, Kees's wife)</p> <p><i>'I'm sure that once he's home I'll gradually be able to resume my work again ...'</i> (Jolanda, Jan's daughter)</p> <p>Help is not necessary (but will be available):</p> <p><i>'My wife and I will manage, we won't need any further help.'</i> (Mart, stroke survivor)</p> <p><i>'I guess I'll be all right ... And, if I need help, my godchild will help me out ... She is a nurse, you see.'</i> (Leo, stroke survivor)</p> <p><i>'[Once he is home], I won't be able to leave him alone too long yet. But I can always ask my friends to come over instead of going there.'</i> (Gerda, Geert's wife)</p> <p><i>'I will be fine ... If necessary, I can ask my father's friends to pay him a visit. So I will have some time to do something of my own.'</i> (Jolanda, Jan's daughter)</p>
No need for the team to involve the network	<p>No reason for (or: reasons against) network involvement:</p> <p><i>'The family is not their responsibility; therapy is there for the patient. It's us who have to do it, eh?'</i> (Anna, stroke survivor)</p> <p><i>'I only want my wife to be involved. I did not inform too many others that I am here; not everybody has to know. I just want some rest to try to accept that I'm here in the first place.'</i> (Mart, stroke survivor)</p> <p><i>'For us, there is no need to involve the wider network. We pass on the information ourselves.'</i> (Jolanda, Jan's daughter)</p> <p><i>'Maybe for other people who have a small network ... But not for us.'</i> (Kaatje, Kees's wife)</p> <p>Professionals already do enough:</p> <p><i>'They said to my wife, "You can always join the therapy if you want to" and then they explained what they did [so they already do enough].'</i> (Mart, stroke survivor)</p> <p><i>'Visiting hours are from ten to ten and everyone is welcome at any time. So that's great enough.'</i> (Jolanda, Jan's daughter)</p>
Improved insight and awareness through experience, knowledge and information	<p>(Previous) experience enhances insight and awareness:</p> <p><i>'The occupational therapist let me prepare a meal. At first, I thought I couldn't. But once I did, I thought: "Oh, that!" and she said I did well. So I assume the rest will come to me in time too.'</i> (Dora, stroke survivor)</p> <p><i>'Doing the groceries was a problem before, so it won't be any easier now that I use this walker.'</i> (Anna, stroke survivor)</p> <p><i>'My husband was home for the weekend. The therapist came by and we found that my husband could climb the stairs without help. It all went fine.'</i> (Gerda, Geert's wife)</p> <p><i>'My husband's family is very close. They are all eager to know how he is doing, and I have to inform them all ... It would have been helpful if someone [from the team] had invited them to come to the centre's family meetings ... Because together you know more.'</i> (Lena, Leo's wife)</p> <p>Knowledge and information enhance insight and awareness:</p> <p><i>'They say I won't be able to climb the stairs, so I'll have to apply for a stair lift.'</i> (Anna, stroke survivor)</p> <p><i>'The physical therapist told me that fatigue is very common in this case. So I guess I have to accept it for now.'</i> (Geert, stroke survivor)</p> <p><i>'The information meeting at the rehabilitation centre was helpful. Although the part about personality changes was quite hard to hear, it helped us to better understand what happened and what to expect.'</i> (Jolanda, Jan's daughter)</p> <p><i>'Our family practised walking the stairs, using the exercise bike and walking outside with him because [as a health care worker] I know that half an hour of therapy won't do the job. But that wasn't because the team asked our family to do it. Which actually is a pity because, just after a stroke, it is important that you have enough practice ...'</i> (Fenna, Ferdy's daughter)</p>

Although many informal caregivers acknowledged that some bridges had to be crossed before life would be as before, few had thoroughly considered the challenges to be faced after discharge. They had high hopes for the stroke survivor's recovery and their own subsequent abilities to resume their own activities once the stroke survivor would be home again. They found it hard to know whether they might need help after discharge and, if so, what support they might need. Most of them expected to manage without any help at all. However, similar to the stroke survivors, they were sure help would be available to them if they needed it.

No need for the team to involve the network

When stroke survivors were asked if they wanted professionals to actively invite and inform members of their social network during inpatient rehabilitation, many found it unnecessary. Some even strongly rejected this idea because they wanted to come to terms with their new situation first. Others thought professionals had already done enough; they were just happy that their family, friends and acquaintances were welcome to visit them in the centre if they wished to and did not expect professionals to play an active role with regard to their social network. In

their opinion, the professionals' main role was to provide physical care and exercises.

Although most caregivers understood that life after discharge might bring some challenges, many saw no need for professionals to involve or inform their network either. They stayed in touch with the stroke survivor's and their own family and friends themselves and thought it would be complicated for professionals to communicate with more than one person.

Improved insight and awareness through experience, knowledge and information

Although most participants did not know exactly what to expect after discharge, some had a more concrete idea. This seemed to result from experiences gained while trying to resume some of their former activities. For example, if stroke survivors had the opportunity during rehabilitation to try to resume the activities they valued most, such as cooking or shopping with a friend, they better understood what to expect after discharge. Likewise, informal caregivers gained better insight into future opportunities and challenges if they visited the stroke survivor's therapy, were shown how to perform a mutual activity, or if the stroke survivor returned home for some days. Honest and concrete information about stroke and its practical consequences also helped stroke survivors and caregivers gain insight into the challenges they might encounter after discharge and the help they might need. Those who understood what to expect after discharge were also more open to the idea of involving network members, such as close family members and close friends, during inpatient rehabilitation. Some were even disappointed that professionals had not encouraged their network to play a more active role during rehabilitation. Others had activated family members or friends themselves.

Discussion

This study explored how institutionalised older stroke survivors and their informal caregivers expected to resume their valued activities after discharge and what ideas they had about social network involvement. In general, participants were optimistic about their opportunities to resume

their activities after discharge. Probably because they were focussed on the stroke survivor's recovery and thought that the core task of rehabilitation professionals should be to exercise with stroke survivors, most of them saw no need for professionals to inform or educate their family, friends or acquaintances about how to support their activities after discharge.

Other studies have also found stroke survivors and caregivers to aim at full recovery during inpatient rehabilitation and to feel confident about resuming their activities at home.^{46–48} However, studies that examined the actual experiences of stroke survivors and caregivers after discharge found that it is often difficult for them to resume their activities.^{41,49–51} Once home, stroke survivors are fully confronted with the consequences of their stroke.^{47,49} They experience unexpected activity limitations, which affects their self-confidence.^{52,53} As a result, they often reduce the activities they enjoyed prior to the stroke, hoping they will improve physically over time.⁵² Gradually, however, many come to realise that the stroke also affected them mentally.⁴⁷ They begin to understand that life may never be the same.^{47,49} Informal caregivers often worry about leaving the stroke survivor and need someone to stay with them so they can enjoy some activities of their own.^{8,46,54} However, especially in the long run, there is often less assistance available to them than they expected.^{30,55}

In retrospect, many stroke survivors and caregivers feel ill-prepared^{48,49,56} and find that the information and training they received during rehabilitation does not translate well to home.^{49,56} In this respect, the predominantly biomedical model that underlies rehabilitation may be inadequate to address the problems stroke survivors and caregivers encounter after discharge. Because this model's main focus is on recovery from impairments instead of on valued activities in a real-life context,^{36,49,57,58} stroke survivors, caregivers and rehabilitation professionals may have insufficient insight into the daily problems that have to be dealt with after discharge.^{47,56}

This study showed that knowledge and real-life experiences can help stroke survivors and informal caregivers (and, most likely, rehabilitation professionals) better understand what to expect after discharge and become aware of the help that is needed.

Therefore, to facilitate the transition home, we suggest that, during institutional rehabilitation, professionals explore with stroke survivors and primary caregivers their most valued activities in a realistic context as much as possible. If stroke survivors and caregivers agree, professionals could also work there with their family members, friends and acquaintances, educate them about the stroke's consequences and show them how to support activity resumption. In this respect, previous research has shown that engagement in realistic life situations helps stroke survivors set relevant goals, become more motivated for rehabilitation and successfully adapt to their new circumstances.^{59–61} Additionally, it helps others better understand the stroke survivor's abilities and limitations.^{59,60} If stroke survivors or informal caregivers have no one that is able to provide support, professionals could encourage them to revitalise former social relationships,^{62,63} or recommend that they seek peer support.^{62,64}

Study strength and limitations

To our knowledge, this is the first study to address stroke survivors' and informal caregivers' ideas about involving their broader social networks during rehabilitation. The sample was diverse and saturation was reached, so we expect the findings to be transferable to comparable geriatric rehabilitation settings.

A strength was that we interviewed stroke survivors and caregivers in each other's presence, so they could complete each other's stories. This is especially useful when interviewing recent stroke survivors because they often find it difficult to remember everything or they feel insecure about expressing themselves. However, interviewing the participants together could also be considered a weakness because they may have influenced each other's opinions. Nevertheless, by interviewing them one by one, we believe they both had the opportunity to provide the information they wanted to share, without being interrupted or being influenced too much.

Stroke survivors with severe communication problems were excluded, which can be considered a weakness of this study. However, stroke survivors with mild communication problems could still take part in the interviews because the researcher had

experience working with stroke survivors (such as those suffering from aphasia) and understanding was supported by the pictures of the Activity Card Sort.

Future research should assess how older stroke survivors and their caregivers feel about network involvement once they have had time to experience what it is like to live with the consequences of the stroke. Those who strongly reject the idea of network involvement during institutionalisation may later become more open to the idea and their network can probably still be activated then. Also, researchers should explore effective ways for rehabilitation professionals to work with the social network so it is workable for them and meets the needs and preferences of the stroke survivors and their caregivers. In addition, they should investigate how family members, friends and others feel about taking a more active role during rehabilitation. Finally, researchers should examine whether working with the network does indeed result in higher levels of long-term activity engagement and improved quality of life.

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