



Activity resumption after acquired brain injury: the influence of the social network as described by social workers

Sandra Jellema, Sabine van Erp, Maria W. G. Nijhuis-van der Sanden, Rob van der Sande & Esther M. J. Steultjens

To cite this article: Sandra Jellema, Sabine van Erp, Maria W. G. Nijhuis-van der Sanden, Rob van der Sande & Esther M. J. Steultjens (2019): Activity resumption after acquired brain injury: the influence of the social network as described by social workers, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2019.1652855](https://doi.org/10.1080/09638288.2019.1652855)

To link to this article: <https://doi.org/10.1080/09638288.2019.1652855>



© 2019 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 20 Aug 2019.



Submit your article to this journal [↗](#)



Article views: 540







View related articles [↗](#)



View Crossmark data [↗](#)

Activity resumption after acquired brain injury: the influence of the social network as described by social workers

Sandra Jellema^{a,b} , Sabine van Erp^b, Maria W. G. Nijhuis-van der Sanden^{a,b} , Rob van der Sande^c  and Esther M. J. Steultjens^b 

^aRadboud Institute for Health Sciences, Scientific Institute for Quality of Healthcare, Radboud university medical center, Nijmegen, The Netherlands; ^bInstitute of Health Studies, HAN University of Applied Sciences, Nijmegen, The Netherlands; ^cFaculty of Health and Social Studies, HAN University of Applied Sciences, Nijmegen, The Netherlands

ABSTRACT

Purpose: To understand how the social network of patients with acquired brain injury facilitates or hinders resumption of their activities, such as social and leisure activities, and how this affects patients' well-being and quality of life.

Methods: Thematic analysis was applied to 70 narratives about family members, friends, neighbors and colleagues helping or hindering patients in resuming their activities. The narratives were derived from social workers with extensive experience with brain-injured patients and their social networks.

Results: The narratives show that an available, understanding and well-informed network enhances activity resumption by being inclusive and encouraging patients to develop their skills. This is in line with earlier studies based on patients' experiences. Whereas the patient-based studies emphasize that being unsupportive or overprotective hinders patients from resuming their activities, this study also shows that preventing patients from meeting others or placing too-high demands results in activity loss, social isolation and reduced well-being and quality of life.

Conclusions: Several social network factors play a role in activity resumption, well-being, and quality of life of after brain injury. Early after the brain injury, rehabilitation professionals should work with patients' family members, friends, and others and educate them about how to provide adequate support.

ARTICLE HISTORY

Received 18 October 2018

Revised 12 July 2019

Accepted 3 August 2019

KEYWORDS

Brain injury; social work; rehabilitation; valued activities; social network; well-being; social isolation

► IMPLICATIONS FOR REHABILITATION



- Since the patient's social network is an important determinant of activity resumption, rehabilitation professionals should analyze its features soon after brain injury, such as whether patients have an understanding network that encourages them and includes them in their activities.
- Since especially close network members tend to be protective of or place high demands on the patient, rehabilitation professionals should explain to them the importance of activity resumption for the patient's well-being and the adverse effects of being overprotective or over-demanding.
- Rehabilitation professionals should include other network members, such as friends or colleagues, in the rehabilitation process and educate them about how to support patients in resuming their activities.

Introduction

Acquired brain injury is associated with serious physical and cognitive impairments which can result in long-lasting problems such as an inability to walk, handle objects, or process information [1–3]. As a result, patients often lose the ability to partake in the activities they value most, such as in their work, family, or leisure activities [3–6]. Additionally, they often suffer from lack of self-confidence, making them hesitant to undertake activities that might end in failure [7–9]. As a consequence, they often come to live inactive, more homebound lives with fewer social relationships, which easily results in social isolation [10,11]. Because, in the long run, the loss of social and other valued activities is related to a decline in well-being and quality of life [12,13],

resumption of the patient's favorite activities is a major goal of rehabilitation after brain injury. To enable activity resumption, rehabilitation usually focuses on improving physical and cognitive functions and skills [14]. However, whether patients eventually manage to resume their valued activities not only depends on the nature and severity of their physical or cognitive impairments, but also on the features of their social environment [15–18].

Since knowledge about the social determinants of activity resumption is scarce and fragmented [15,19], we previously conducted two literature reviews [20,21] to bring together the available evidence. We included studies on stroke and found the evidence to mainly consist of qualitative studies based on patients' experiences. They showed that the availability,

CONTACT Sandra Jellema  sandra.jellema@han.nl  Institute of Health Studies, HAN University of Applied Sciences, Kapittelweg 33, 6525 EN Nijmegen, The Netherlands.

© 2019 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

understanding, brain-injury-related knowledge and encouragement of familiar others, such as family members and friends, were important facilitators, while others' lack of support and overprotection hindered patients from resuming their valued activities, which is in line with findings about traumatic brain injury [22,23]. Yet, these patient reports may have been biased, for example because patients overrate the influence others have because of their gratitude towards them or the fact that they feel dependent on them. Moreover, the scarce quantitative studies that have examined the effect of social determinants do not in all cases support the finding that social network members influence activity resumption [24–27].

To more thoroughly explore the influence of the patient's social network, we looked for another perspective to examine this topic; we used the experiences of social workers with specific expertise in brain injury, trained to at least a Bachelor's level in Social Work or a related scientific field. In the Netherlands, social workers generally are employed (and paid) by a healthcare or welfare organization that receives funding from the government. Although the experiences of these social workers are not often subject to study, we consider their perspectives to be highly valuable because, in contrast to many other rehabilitation professionals who work with brain-injured patients in clinical settings for a brief period of time, most social workers actually participate in the daily lives of these patients for a longer period, enabling them to observe these patients extensively within their own everyday physical and social contexts. Such "participant observation" can present a complementary perspective, reveal certain patterns, and provide valuable context and insights that might not otherwise be captured [28,29]. The perspectives of these social workers can help us better understand the features and behaviors of the social network and its short-term and long-term consequences for the patient's activity resumption and well-being. Study findings can inform other rehabilitation professionals, such as rehabilitation nurses or therapists, about how to work with patients' social networks in the early phase after brain injury to enhance ultimate rehabilitation outcomes.

The specific study aim was to understand how, according to these social workers, patients' social networks influence resumption of valued activities and, subsequently, well-being and quality of life after brain injury.

Methods

In this qualitative study, we used written narratives of social workers who work with adult brain-injured patients in the chronic phase of their disease. To capture a rich overview of social network factors that influence activity resumption, we invited each social worker to write down in detail two cases: one in which a patient was facilitated by his or her social network to resume a certain activity, and one in which a patient was hindered from doing so. Although face-to-face interviews would have allowed us to explore these social workers' experiences more in depth, we argued that writing down their narratives would encourage them to thoroughly think about and describe the essence of a situation as they saw it, providing us with rich information about a large number of patients and their social network members in a relatively short period of time. In this respect, a study comparing oral and written narratives [30] found that, although the content of the narratives was uniform across both modalities, in the written narratives, clauses and sentences were more compact and were less redundant. Using written narratives, we expected to collect

many, diverse, concise and relevant data, leading to data saturation.

Because we thought it was crucial that the social workers felt free to share sensitive information with us regarding the behavior of their patients and the social network members, we did not ask them to provide personal information along with their narratives but only kept a general attendance list. Based on this list, we were able to provide banded information about the group of participating social workers as a whole. By doing so, we believe we were able to guarantee maximum safety and anonymity so we could collect information that was as honest and detailed as possible.

Participants

Potential participants were recruited from a group of social workers employed at a regional (mental) healthcare organization that provides treatment and support to brain-injured patients living in the south-eastern part of the Netherlands. The organization was formed by a merger of smaller organizations and works with patients with complex needs, such as brain-injured patients who have physical as well as cognitive problems. The daily task of the recruited social workers was to assist these patients to reintegrate into their families, jobs and community. Prior to a planned in-house training session for social workers who work with adult brain-injured patients, we informed them about the study purpose. Subsequently, they were approached for participation. To obtain the narratives, we held a writing session with them, which, for efficiency reasons, took place at the beginning of the in-house training session. It was held in one of the organizations' conference rooms, hosted by one researcher (SJ) and assisted by the psychologists (JW and MP) who organized the training session.

To ensure that all the participating social workers had a similar understanding of the concepts of "resumption of valued activities" and "social network," the definitions used in the study were presented prior to the writing session. Resumption of valued activities was defined as "taking part in or performing again activities that were chosen voluntarily and of specific value to the patient." The social network encompassed all family members, friends, acquaintances, colleagues, and neighbors who play or played a role in the patient's daily life.

Data collection

During the writing session, we invited the social workers to try to recall one situation in which a patient who wanted to resume a valued activity was facilitated and one in which a patient was hindered by his or her social network and, subsequently, write down these situations in detail. Next, they were asked to write down what the social network members precisely did in the situations that influenced the patient's activity resumption, exactly why this helped or hindered the patient, and what was the result of this action for the patient and his/her situation.

Data analysis

We used conventional content analysis to define a final set of social network factors important to activity resumption, as well as to understand the influence of the social network more in depth. This type of analysis gains direct information from study participants without imposing preconceived categories or theoretical perspectives. It supports a study design that aims to describe a

particular phenomenon, and is appropriate when existing theory or research literature is limited or incomplete [31].

First, to ensure the quality of the data, the researchers (SE and SJ) excluded those narratives that did not contain information about what social network members precisely did in the described situation or what the concrete effect of this action was on the patient's activities and well-being. Next, to become familiar with the content as a whole, they thoroughly read through all the included narratives. Then, they independently extracted text passages that described a particular feature of the social network that influenced the patient's activity resumption (such as the network's size). They also extracted text passages describing what social network members actually did in a certain situation, how this affected the patients' activities, and what were the consequences of activity facilitation or hindrance for the well-being and quality of life of the patients. Any differences of opinion about which text passages needed to be extracted were resolved by discussion.

Subsequently, the researchers independently coded the text passages, using open coding. After ten narratives, the researchers decided on preliminary codes. They then independently coded the remaining narratives and recoded the original ones. They added new codes when encountering data that did not fit into an existing code, reaching consensus about the codes after every 20 narratives. Additionally, they grouped together similar kinds of codes related to social network factors and their consequences, after which categories and themes emerged describing the main social network factors, their influence on patients' activity resumption, and their influence on patients' well-being and quality of life.

For member checking, the researchers invited a subset of ten social workers with extensive experience with brain-injured patients to discuss the findings. They checked the findings for accuracy and added additional comments.

Results

Fifty-five social workers were approached to participate in the study, of which 41 (aged 22–64 years; 9 male) agreed. All were educated to a Bachelor's (40) or Master's level (1) in Social Work or Applied Psychology/Behavioral Sciences. Their experience in working with brain-injured patients ranged from three months to 20 years, with the majority (76%) having more than 5 years' experience. They worked with patients in their homes (17), workplaces (3), daytime activity centers (13), or residential care facilities (8). They all agreed that the social network is an important determinant of activity resumption after brain injury. Together, they described a total of 78 cases in which a patient was facilitated (41) or hindered (37) to resume a certain activity. Of all written narratives, 8 (6 facilitating, 2 hindering) were excluded because they were incomplete. The remaining narratives described how others helped or hindered a total of 70 patients (26 male, 24 female, 20 gender not specified) to resume their valued activities, such as walking/cycling/sports (8); self-care (2); household/finances (5); communication (2); work/volunteering (9); hobby/leisure (16); family/social activities (12); cultural activities and community outings (12), or "living independently" (4). Of the described patients, 61 lived at home, 9 lived in a residential care facility. The social network members mentioned in the included narratives were: spouses/partners (in 8 cases they facilitated activities/in 16 they hindered them), parents (1/8), sons/daughters (5/1), brothers/sisters (3/1), other family members (4/1), friends (3/1), colleagues/employers (3/1), neighbors (4/2), and acquaintances (2/1). In five cases, "the social network member" was not further specified (2/3).

Findings on the features and behaviors of the social network

With respect to the characteristics of the network, thematic analysis revealed the following themes (work setting of each social worker providing a quote is displayed between brackets).

Availability

For patients to resume their activities, it was important that social network members were available, both physically and emotionally.

His family drove him to the day activity center twice a week. There they kept in touch with the professionals so that they had a good understanding of what was going on in the patient's life. (social worker at a daytime activity center)

However, in some cases, patients had no vital social network, or their family or friends had (or took) little time to support them, or even retreated from the situation.

His parents couldn't handle the situation and gradually disappeared from his life. As a result, he was left to manage on his own. (residential care facility)

Acknowledgement

It was crucial that others were aware of the disabilities that resulted from the brain injury yet acknowledged the patient's remaining possibilities and skills.

His wife tried to find out what his abilities to communicate were. She arranged a communication device which enabled him to express himself in spite of his aphasia. (patient's home)

Her sister reminded her of her talents and helped her use her skills so that, in the end, she was able to live independently. (daytime activity center)

However, when network members underestimated or overestimated the patient's abilities, valued activities could not be resumed or were abandoned after a while.

He made plans for his future but was discouraged by his father who told him he could not accomplish them anyway. (patient's home)

He liked to work at a pub. However, as no one there took account of his disabilities and work demands were high, he finally had to quit the job. (vocational training facility)

In some cases, the patient was persuaded to join a certain activity or meet with people but could not cope with the complexity of the situation.

His friends convinced him to come and join them as he had done before, but he no longer could. Soon, he had to give up, which ultimately made him lose his friends. (patient's home)

His family persuaded him to go to the activity center, but soon he withdrew because he felt overwhelmed by all the stimuli. (daytime activity center)

Respect

For patients to resume their activities, it was necessary that others respected their wishes, concerns, and desires. Of help was if others took the time to listen and find out what was in the best interests of the patient.

She was unable to return to her former home, but by exactly determining her mothers' preferences and needs, her daughter finally succeeded in finding her a new, suitable place to live. (residential care facility)

On the other hand, others sometimes had to set boundaries so that patients did not violate their own interests.

The restaurant owner saw to it that the patient, who was a frequent visitor, always sat at his favourite table. However, [because the patient had trouble with appropriate social behaviour as a result of the brain injury] he also checked if the patient was decently dressed and didn't annoy the other guests. (patient's home)

However, if others did not listen at all, or took all the decisions for the patient, activities were often abandoned.

Her friend took her to flower arranging classes which, at first, was something she liked. However, her friend left her no space to make her own decisions, which made her quit after a while. (patient's home)

Inclusion

It was helpful if others invited the patient to take part in activities they did themselves.

A woman living nearby took her to the market, and they both enjoyed each other's company. (patient's home)

The neighbours invited her to join the neighbourhood gardening project and she accepted. (daytime activity center)

However, if there were no invitations, the patient was often left inactive and socially isolated.

She was homebound for many years because there was no one to stimulate her to leave her home and attend activities. (patient's home)

His social network never asked him to join them on an outing, so most of the time he was left on his own. (patient's home)

Activity enablement

It was beneficial if others helped patients to find creative solutions to compensate for their impairments and find "doable" activities. Also, providing practical assistance if necessary and persuading others to include patients in their activities, was helpful.

A young, sporty patient loved to be outside. His social network helped him find an activity he could do in spite of his brain injury. Finally, hand-biking perfectly suited his wish to go outside and be active. (patient's home)

The employer searched for tasks that the patient was able to do in spite of his disabilities. He also contacted other employers to search for doable work. As a result, the patient could continue working for a number of hours a week. (patient's home)

He was able to go to the concert with his friends, because they drove him there. (residential care facility)

However, if there was no one to help find doable activities or provide assistance, patients often became physically and socially inactive.

His friends wanted him to join their parties, but he couldn't handle it anymore. As his friends weren't able to find a more suitable way of socialising with him, he finally [quit going to their parties and] had to give up their friendship. (patient's home)

At first, her friend had assisted her with household chores. However, their friendship ended as result of a financial disagreement. Since no one else attended to her needs, she was left without help. (patient's home)

Encouragement

Sometimes patients were hesitant to start new undertakings. Then others' encouragement was helpful.

His wife encouraged him to come with her to the hobby club as she knew he would finally enjoy it, which he actually did. (patient's home)

However, if there was lack of encouragement, activities were often abandoned.

Her husband insisted on taking care of her, discouraged her from doing anything herself, and rejected professional help because of 'all of the fuss'. This resulted in her becoming inactive and socially isolated. (daytime activity center)

Skill development

It was beneficial if others helped patients explore their capacities and develop their skills.

His father practised cycling with him so that he could eventually pick up the kids from school himself. (patient's home)

After his stroke, he started painting as a hobby. His wife supported him by buying paint supplies and looking for examples of things he could paint. (daytime activity center)

On the other hand, if patients were not given room to explore, were overprotected and not assisted in developing their skills, this resulted in loss of activities and social life.

She was of foreign descent and was looked after by her foreign 'friends'. They took advantage of her and did not allow any professionals to interfere [to help her become more independent]. In the end she became socially isolated and bankrupt, and her children were placed in a foster home. (residential care facility)

Within their narratives, many social workers commented on 'a process' that had to take place after the patient acquired a brain injury. They gave several examples of situations in which the patient was able to go through a process of trial and error, mourning and, subsequently, acceptance and development, which finally resulted in a more satisfactory life and good relationships, in spite of sustained disability. However, they also described situations in which there was no possibility for this process to start because of others not giving the patient the space to experience their new reality, come to terms with it, adapt to it, and practice their skills. This resulted in stagnation and the patient not being able to develop a new "identity," built a new satisfactory life or maintain his or her social contacts. In this respect, one social worker commented on the fact that after brain injury, a patient's confidence tends to be gone, and that it has to gradually grow again.

Findings on well-being and quality of life

Apart from resumption or abandonment of activities, a diversity of other consequences of social network features and behaviors were mentioned in the narratives. The social workers described how an available network, acknowledgement, respect, inclusion, encouragement, activity enablement and help with skill development, made patients feel more peaceful; balanced; secure; supported; needed; appreciated; heard and seen. It resulted in growth of their self-esteem, enthusiasm to undertake (even more) activities, a broader social network, and more satisfying relationships.

His (disabled) friend supported him in going to the theatre. Together they managed without help from others, which made them feel confident to plan even more outings. (residential care facility)

Being invited by her neighbours, the patient joined the gardening project. As time went by, she became more and more enthusiastic and found pleasure in participating in the project. (daytime activity center)

A young patient was invited by his brother and friends to participate in their outings. This made him feel 'one of the guys' and it enhanced his

self-esteem. It broadened his social network and stimulated him to make plans for his future. (patient's home)

He felt happy and supported because his wife had helped him to find a doable hobby, which also worked out positively for their relationship. (daytime activity center)

However, if others were not available, underestimated or overestimated the patients' skills, did not understand them or take them seriously, or did not help or encourage them, the patients felt insecure; unheard; sad and lonely. Often in these cases, patients let others decide for them and quit the activities they had once valued. They withdrew from social interactions or gradually lost their social contacts. Intimate relationships seemed to worsen, and disputes were common.

Her husband did not understand why she was no longer able to do the home administration. His reactions towards her were rather insensitive, which made her feel even more insecure. (patient's home)

His sister gave him no opportunity to decide for himself and even spoke for him. He fell silent and let her make all the decisions. (daytime activity center)

They all wanted to interfere with her life, but she couldn't handle it. So she told them not to come anymore (patient's home)

His children didn't understand his behaviour. They withdrew and finally broke with him. (patient's home)

In several cases, the situation deteriorated with time and the patient's condition worsened.

His family kept him housebound for years. He did not get the chance to develop his skills, be part of the community or live independently. Over time, his condition worsened [and he became more and more dependent on his family]. (patient's home)

Her husband took care of everything so that, one year after her brain injury, her condition had worsened. She had gained weight and, although during rehabilitation she had been able to walk, she could do this no longer. (daytime activity center)

Member check

Eight of the ten social workers invited to participate in the member check, ultimately agreed. They confirmed our study findings and emphasized how important it is for patients to resume those activities that make them feel a valued member of their family and society again, such as their work. They also highlighted the importance of a social network that understands how brain injury affects the patient's functioning and behavior, acknowledges the patient's feelings of loss and grief and that is also able to support the patient in developing new skills. They even stated that, in some cases, it is better to first address the network before working with the patient, because a well-informed, understanding and supportive network is a prerequisite for the patient to achieve successes and grow in self-esteem. However, in their experiences, in about 70% of the patients they work with, the social network somehow prevents patients from resuming their activities rather than being supportive and facilitating. Moreover, even in the case of a supportive network, success is not guaranteed. For example, if patients suffer from severe fatigue or show no initiative at all, even an ideal network cannot prevent patients from becoming inactive. Additionally, if patients are unaware of their deficits, facilitating activities without defining clear borders is contra-productive, as is taking over everything due to fear for the patient's safety. The social workers of the member check therefore

emphasized how important it is that, in case of activity loss, brain injury experts work with the patient and the network to explain the impact of the brain injury and show them how to undertake doable and safe activities. They also emphasized how important it is that the patient's close loved ones take care of their own needs as well.

Discussion

Our study shows that, from the perspectives of social workers, the patient's family members, friends, colleagues, neighbors, and acquaintances play an important role in activity resumption (or abandonment) after brain injury. This supports findings from our two earlier literature reviews [20,21] that mainly included patient-based studies. However, whereas these patient-based studies emphasized that others can hinder activities by being unsupportive or overprotective, the present study also found examples of social network members being over-demanding or having too-high expectations, finally leading to activity abandonment. In addition, the present study shows that patients were sometimes withheld from meeting other people or attending professional help which resulted in lack of development, social isolation, an overall deterioration of the patient's condition, and sometimes even in (financial) abuse.

Together, findings from this and earlier studies suggest that it is crucial for social network members to find an adequate balance between, on the one hand, providing assistance without taking over and, on the other, encouraging the patient to explore (safe) activities and meet other people without being too demanding. As shown in the narratives, such a balanced approach seems not only to enable activity resumption, but can also initiate a process of achievement, pleasure and increased self-esteem, finally leading to even more activity, a broader social circle, more satisfying relationships, a new sense of identity and better well-being.

Other studies have also shown activity resumption to be a gradual process that can be initiated and enhanced by the social network [8,32]. Kubina et al. [32], for example, showed how social connection and being in charge allowed stroke survivors to take risks and test their abilities, which, in case of success, increased their hope of recovery and led to an (adapted) resumption of activities. Therefore, although others sometimes restrict patients' activities, they should realize that recovery, achievement and adjustment is best reached through learning by doing. In this respect, Satink et al. [18,33] found that actually doing activities increased patients' and others' insights in the patient's capacities. It also helped patients develop compensating strategies for their limitations and experience a sense of being in charge of daily life, which ultimately helped them to develop their confidence to undertake other engaging activities.

A remarkable finding from our study was that, of all the social network members described in the narratives, spouses and parents were relatively often mentioned in relation to hindering patients' activities. In this respect, other studies have reported that negotiations about activity resumption are more pervasive in case of intimate social relationships [34,35]. Brain injury often results in a loss of mutual activities and connectivity, and in changes in expectations, roles and responsibilities between partners [36–38], which can lead to high levels of stress [39–41]. Also, parents with a son or daughter with brain injury often experience high levels of stress and burden [42]. Roscigno and Swanson [43] found that these parents fulfill many roles, such as caregiver and medical decision maker. They report that many parents do not accept early negative constructions of their child's injury severity,

and that these parents feel alone in their quest to help maximize their son's or daughter's capacity. Parents may often have high expectations, which sometimes results in too-high demands, negative reactions to their son's or daughter's efforts, or even to their emotional withdrawal. Or, as one of the participating social workers mentioned, both patients and their close loved ones seem to go through a process of mourning and acceptance, but these processes rarely run in parallel. So possibly, because close social network members are often busy dealing with their own "issues," or have trouble accepting that life will never be the same, asking them to assist the patient with activity resumption is simply too much to be asked. Therefore, help from other social network members such as friends or neighbors, whose lives have changed less radically as a result of the patient's brain injury, may be helpful.

Practical implications

The social network seems to be an important determinant of eventual activity resumption after brain injury, so rehabilitation trajectories should not only focus on the improvement of brain-injured patients' functions and skills, but should also address the patients' social context, as was also suggested by other authors [44,45]. During early rehabilitation, it seems important that rehabilitation professionals explore the characteristics of each patient's network, such as whether others are available to the patient, understand the consequences of the brain injury and acknowledge the skills the patient has left. During clinical rehabilitation, they can start informing family members, friends and others on how to best support the patient, for example by showing them how to include the patient in their activities and how to encourage patients to develop new skills. In this respect, Elloker and Rhoda (2018) suggest that rehabilitation interventions should include group sessions with family members and others, where the focus should be on patients gaining independence [44].

In the long run, professionals should be aware of eventual activity withdrawal, social isolation, lack of support, and possible problematic or abusive relationships. Especially in the case of close relatives like spouses or parents, it appears crucial that rehabilitation professionals explain the importance of activity resumption and the adverse effects of being overprotective or over-demanding. In case of cognitive problems such as awareness deficits, they could help patients and others to negotiate activity preferences, find suitable and safe activities, and develop simple cues to alert them to the occurrence of problematic situations so that the patients' most valued activities can be resumed and well-being can be enhanced [46,47].

Study strength and limitations

The strength of this study is that we were able to collect rich data from a large group of experts who have extensive and unique experience working with patients with brain injury yet are underrepresented in research. This provided us with additional insights into the influence of social network factors on brain-injured patients' activity resumption. In their narratives, the participating social workers described many different examples of daily situations that endorsed the validity of the themes found. In addition, they worked in a variety of settings spread over a large region, were involved in different kinds of patient activities and worked with different members of the social network (e.g. family members in a home setting and colleagues in a vocational setting). It can therefore be assumed that their knowledge and

experience is so diverse, we can expect the results to be complete and transferable to similar care settings. However, because these social workers mainly work with rather severely affected patients, our findings might not be entirely transferable to patients that are more mildly affected and their social networks.

By using the procedure of written cases, we were unable to ask individual social workers to clarify interesting or incomplete aspects of their narratives. Therefore, although we obtained data from a large number of cases and checked the overall results through member checking, there is a possibility we missed information that would have emerged had we done individual face-to-face interviews. Additionally, since we only collected banded information about the participating social workers, our method of data collection did not allow us to make a distinction between the narratives of different subgroups of social workers, such as one based on years of experience. The quality or content of the narratives of the less experienced social workers may for example be different from those of their more experienced colleagues because they have had fewer opportunities to learn about the long-term impact of the social networks on patients' activities and well-being. However, by excluding low-quality narratives and including a large group of experienced social workers in our sample, we believe we were able to collect high-quality narratives that describe the short-term as well as the long-term consequences for patients.

Our study only represents one piece of the puzzle; in reality the social influence on resumption of activities is not a one-way street, but it has both the social network and the patient as actors. For example, if patients show no initiative, others will easily take the decisions for them. However, if patients are proactive and determined, they will decide themselves, in spite of others trying to prevent them from doing so. In future, to gain an even better understanding of the process of activity resumption, research should clarify the interplay that takes place between patients and their social network over the course of time, finally resulting in activity resumption (or abandonment). Additionally, research should find effective ways in which rehabilitation professionals can support patients and their network during this process. Our findings serve as a starting point, as we provide important insights in the elements of adequate and inadequate social network support.

Acknowledgements

We thank José van der Weide, Martijn Peeters, Petra de Boer, and all other employees of Pluryn who participated in the study for sharing their expertise with us.

Disclosure statement


The authors report no conflict of interest.

Funding

This work was funded by a HAN University of Applied Sciences PhD scholarship.

ORCID

Sandra Jellema  <http://orcid.org/0000-0003-4179-6845>

Maria W. G. Nijhuis-van der Sanden  <http://orcid.org/0000-0003-2637-6877>

Rob van der Sande  <http://orcid.org/0000-0003-1410-900X>

Esther M. J. Steultjens  <http://orcid.org/0000-0002-4638-4375>

References

- [1] Walsh ME, Galvin R, Loughnane C, et al. Community re-integration and long-term need in the first five years after stroke: results from a national survey. *Disabil Rehabil.* 2015; 37:1834–1838.
- [2] McInnes K, Friesen CL, MacKenzie DE, et al. Mild traumatic brain injury (mtbi) and chronic cognitive impairment: a scoping review. *PLoS One.* 2017;12:e0174847.
- [3] Cawood J, Visagie S, Mji G. Impact of post-stroke impairments on activities and participation as experienced by stroke survivors in a Western Cape setting. *S Afr J Occup Ther.* 2016;46:10–15.
- [4] Lefebvre H, Cloutier G, Josee Levert M. Perspectives of survivors of traumatic brain injury and their caregivers on long-term social integration. *Brain Inj.* 2008;22:535–543.
- [5] Finch E, French A, Ou RJ, et al. Participation in communication activities following traumatic brain injury: a time use diary study. *Brain Inj.* 2016;30:883–890.
- [6] Lexell EM, Alkhed AK, Olsson K. The group rehabilitation helped me adjust to a new life: experiences shared by persons with an acquired brain injury. *Brain Inj.* 2013;27: 529–537.
- [7] Riley GA, Brennan AJ, Powell T. Threat appraisal and avoidance after traumatic brain injury: why and how often are activities avoided? *Brain Inj.* 2004;18:871–888.
- [8] Anderson S, Whitfield K. Social identity and stroke: ‘they don’t make me feel like, there’s something wrong with me’. *Scand J Caring Sci.* 2013;27:820–830.
- [9] Klinke ME, Hafsteinsdottir TB, Thorsteinsson B, et al. Living at home with eating difficulties following stroke: a phenomenological study of younger people’s experiences. *J Clin Nurs.* 2014;23:250–260.
- [10] Pallesen H. Body, coping and self-identity. A qualitative 5-year follow-up study of stroke. *Disabil Rehabil.* 2014;36: 232–241.
- [11] Haun J, Rittman M, Sberna M. The continuum of connectedness and social isolation during post stroke recovery. *J Aging Stud.* 2008;22:54–64.
- [12] Egan M, Davis CG, Dubouloz CJ, et al. Participation and well-being poststroke: evidence of reciprocal effects. *Arch Phys Med Rehabil.* 2014;95:262–268.
- [13] Moeller D, Carpenter C. Factors affecting quality of life for people who have experienced a stroke. *Int J Ther Rehabil.* 2013;20:207–216.
- [14] Cott CA, Wiles R, Devitt R. Continuity, transition and participation: preparing clients for life in the community post-stroke. *Disabil Rehabil.* 2007;29:1566–1574.
- [15] Whiteneck G, Dijkers MP. Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. *Arch Phys Med Rehabil.* 2009;90:22–35.
- [16] Hoyle M, Gustafsson L, Meredith P, et al. Participation after stroke: do we understand all the components and relationships as categorised in the ICF? *Brain Impair.* 2012;13:4–15.
- [17] Hammel J, Magasi S, Heinemann A, et al. Environmental barriers and supports to everyday participation: a qualitative insider perspective from people with disabilities. *Arch Phys Med Rehabil.* 2015;96:578–588.
- [18] Satink T, Josephsson S, Zajec J, et al. Negotiating role management through everyday activities: narratives in action of two stroke survivors and their spouses. *Disabil Rehabil.* 2016;8:1–11.
- [19] Wang PP, Badley EM, Gignac M. Exploring the role of contextual factors in disability models. *Disabil Rehabil.* 2006;28: 135–140.
- [20] Jellema S, van Hees S, Zajec J, et al. What environmental factors influence resumption of valued activities post stroke: a systematic review of qualitative and quantitative findings. *Clin Rehabil.* 2017;31:936–947.
- [21] Jellema S, van der Sande R, van Hees S, et al. Role of environmental factors on resuming valued activities poststroke: a systematic review of qualitative and quantitative findings. *Arch Phys Med Rehabil.* 2016;97:991–1002.
- [22] Heinemann AW, Magasi S, Hammel J, et al. Environmental factors item development for persons with stroke, traumatic brain injury, and spinal cord injury. *Arch Phys Med Rehabil.* 2015;96:589–595.
- [23] Takada K, Sashika H, Wakabayashi H, et al. Social participation and quality-of-life of patients with traumatic brain injury living in the community: a mixed methods study. *Brain Inj.* 2016;30:1590–1598.
- [24] Noreau L, Boschen K. Intersection of participation and environmental factors: a complex interactive process. *Arch Phys Med Rehabil.* 2010;91:44–53.
- [25] Beckley MN. Community participation following cerebrovascular accident: impact of the buffering model of social support. *Am J Occup Ther.* 2006;60:129–135.
- [26] Gottlieb A, Golander H, Bar-Tal Y, et al. The influence of social support and perceived control on handicap and quality of life after stroke. *Aging Clin Exp Res.* 2001;13: 11–15.
- [27] Dalemans RJ, De Witte LP, Beurskens AJ, et al. An investigation into the social participation of stroke survivors with aphasia. *Disabil Rehabil.* 2010;32:1678–1685.
- [28] Jorgensen DL. *Applied social research methods: participant observation.* Thousand Oaks (CA): SAGE Publications; 1989.
- [29] Hammer B, Fletcher F, Hibbert A. Participant observation: enhancing the impact measurement in community based participatory research. *Qual Rep.* 2017;22:439–455.
- [30] Pu M-M. Spoken and written narratives: a comparative study. *J Chin Lang Comp.* 2006;16:37–61.
- [31] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005;15:1277–1288.
- [32] Kubina L-A, Dubouloz C-J, Davis CG, et al. The process of re-engagement in personally valued activities during the two years following stroke. *Disabil Rehabil.* 2013;35: 236–243.
- [33] Satink T, Josephsson S, Zajec J, et al. Self-management develops through doing of everyday activities: a longitudinal qualitative study of stroke survivors during two years post-stroke. *BMC Neurol.* 2016;16:221–234.
- [34] Arntzen C, Hamran T. Stroke survivors’ and relatives’ negotiation of relational and activity changes: a qualitative study. *Scand J Occup Ther.* 2016;23:39–49.
- [35] Grigorovich A, Forde S, Levinson D, et al. Restricted participation in stroke caregivers: who is at risk? *Arch Phys Med Rehabil.* 2015;96:1284–1290.
- [36] Godwin E, Chappell B, Kreutzer J. Relationships after TBI: a grounded research study. *Brain Inj.* 2014;28:398–413.
- [37] Rudman DL, Hebert D, Reid D. Living in a restricted occupational world: the occupational experiences of stroke survivors who are wheelchair users and their caregivers. *Can J Occup Ther.* 2006;73:141–152.

- [38] Jellema S, Wijnen MA, Steultjens EM, et al. Valued activities and informal caregiving in stroke: a scoping review. *Disabil Rehabil.* 2018;17:1–12.
- [39] McPherson CJ, Wilson KG, Chyurlia L, et al. The balance of give and take in caregiver-partner relationships: an examination of self-perceived burden, relationship equity, and quality of life from the perspective of care recipients following stroke. *Rehabil Psychol.* 2010;55:194–203.
- [40] Savundranayagam MY, Montgomery RJ. Impact of role discrepancies on caregiver burden among spouses. *Res Aging* 2010;32:175–199.
- [41] Pierce LL, Thompson TL, Govoni AL, et al. Caregivers' incongruence: emotional strain in caring for persons with stroke. *Rehabil Nurs.* 2012;37:258–266.
- [42] Hawley CA, Ward AB, Magnay AR, et al. Parental stress and burden following traumatic brain injury amongst children and adolescents. *Brain Inj.* 2003;17:1–23.
- [43] Roscigno CI, Swanson KM. Parents' experiences following children's moderate to severe traumatic brain injury: a clash of cultures. *Qual Health Res.* 2011;21:1413–1426.
- [44] Elloker T, Rhoda AJ. The relationship between social support and participation in stroke: a systematic review. *Afr J Disabil.* 2018;7:357–366.
- [45] Dhand A, Luke DA, Lang CE, et al. Social networks and neurological illness. *Nat Rev Neurol.* 2016;12:605–612.
- [46] Flashman LA, McAllister TW. Lack of awareness and its impact in traumatic brain injury. *NeuroRehabilitation* 2002; 17:285–296.
- [47] Van Heugten CM, Bertens D, Spikman J. Richtlijn neuropsychologische revalidatie [Guideline on neuropsychological rehabilitation]. Utrecht (The Netherlands): Nederlands Instituut Van Psychologen [the Dutch Association of Psychologists]; 2017.