

research article

'Living the life of the other': carers' perspectives on changes in carer strain during the rehabilitation trajectory

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The needs of carers are still poorly understood in medical rehabilitation research. This article explores the lived experience of carers and the adverse effects of caring throughout the different phases of the rehabilitation care trajectory in the Netherlands, based on in-depth interviews with couples where one partner has acquired brain injury or spinal cord injury. The findings reveal that carers' needs vary during the rehabilitation trajectory, particularly because of varying availability or lack of 'personal time' and 'personal space'. Acknowledging this may improve the assistance of carers, attuned to their evolving needs, and thereby contribute to improved future rehabilitation treatment.

Key words carers • rehabilitation • persons with a disability • care trajectory

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Introduction

There is an increasing awareness of the importance of carers giving support to their family members with chronic health problems and disabilities (Keating et al, 2019). This includes carers in the rehabilitation setting, who play an essential role in supporting their loved ones when they go through a rehabilitation trajectory. Caring for another person requires attentiveness, feelings of responsibility, emotional attachment and practical competence (Tronto, 1993; Rand, 2020). However, when carers cannot meet these standards, they may struggle with their caring role, which can lead to feelings of strain and guilt.

There are many support programmes and interventions for carers in rehabilitation, focusing on (psycho-)education, counselling or social support by peers (Visser-Meily et al, 2005a; Brereton et al, 2007; Baker et al, 2017), but their success is limited (Brereton et al, 2007; Baker et al, 2017; Shepherd-Banigan et al, 2018). One reason is that the needs of carers throughout the different phases of the rehabilitation care trajectory

remain poorly understood (Scholte Op Reimer et al, 1998; McCullagh et al, 2005). This is the focus of this article.

Caring in the rehabilitation care trajectory

Persons with a disability (PWDs) who receive rehabilitation treatment after acquired brain injury (ABI), spinal cord injury (SCI) or other diagnoses with long-term impact go through different phases of recovery. The rehabilitation care trajectory consists of: (1) the acute phase of being admitted to the hospital; (2) the subacute phase of treatment at a rehabilitation clinic; (3) the transition from the clinic to home; and (4) reintegration into the community (Kirkevold, 2002; Rotondi et al, 2007; Stiekema et al, 2020). The transitional phase is characterised by the shift of environment from the clinical rehabilitation centre to home and the mostly practical adjustments this entails. The reintegration phase is characterised by efforts to find a new balance between limitations and abilities, also with regard to society outside the house. Although these phases vary in duration and can be partly overlapping, they represent distinct states that PWDs and their carers move through (Kirkevold, 2002).

The third phase has been pointed out as pivotal in the recovery trajectory (Cott et al, 2007; Rittman et al, 2007; Turner et al, 2007; 2008; 2011; Ellis-Hill et al, 2009; Van De Velde et al, 2010; Gustafsson and Bootle, 2013; Piccenna et al, 2016; Abrahamson et al, 2017). Carers and PWDs experience a gap between the protected environment during inpatient rehabilitation and life in the community (McKevitt et al, 2004; Visser-Meily et al, 2005b). Many PWDs and carers feel insufficiently prepared to cope with the disability in daily life (Salter et al, 2008). They have to find new routines in daily life activities (Piccenna et al, 2016; Abrahamson et al, 2017; Lynch and Cahalan, 2017; Greenwood et al, 2009a) and learn to cope with PWDs' altered abilities and changing life roles within the context of their home and family (Rittman et al, 2007).

Rehabilitation research on carers

Rehabilitation research has gained increasing knowledge about determinants affecting carers' well-being. Caring can enhance carers' satisfaction and self-esteem (MacKenzie and Greenwood, 2012; Kruithof et al, 2015; Scholten et al, 2019), but carers may also experience adverse effects on their emotional, social, financial, physical or spiritual functioning (Zarit et al, 1986; Rigby et al, 2009; Kruithof et al, 2016; Baker et al, 2017; Scholten et al, 2019). They may experience feelings of loss, impaired quality of life (Teasell et al, 2003; Post et al, 2005; Visser-Meily et al, 2006; Rigby et al, 2009), difficulties in caring (Schulz and Beach, 1999; Sales, 2003) and impoverished social relationships (Keating and Eales, 2017). We will refer to these negative aspects of caring as 'strain' or 'carer pressure'.

In previous research, carer pressure is mostly measured as effects on carers' health or psychological distress (Lyons et al, 2002; Rand, 2020). While this is very relevant, we need additional information to understand PWDs' and carers' everyday challenges and problems (Teasell, 2012; Walker et al, 2013; McPherson et al, 2015). Some studies do take this perspective (Cameron and Gignac, 2008; Greenwood et al, 2009a), but additional insight is needed, especially with regard to the way carers' needs evolve during the rehabilitation trajectory (Cameron and Gignac, 2008). There is one study

on stroke survivors' varying needs in the acute, rehabilitation and chronic phases by [Nanninga et al \(2015\)](#), but they did not address the carers' perspective. In this article, therefore, we want to understand the experienced strain and the changing needs of carers during the different transitions in the rehabilitation care trajectory. This knowledge can be used to adjust support ([Cameron and Gignac, 2008](#); [Greenwood et al, 2009b](#)). In the setting of rehabilitation in the Netherlands, we performed a qualitative study on the experiences of PWDs and their carers during the transition from clinic to home.

Method

Participants

This qualitative study is part of a multi-centre-controlled trial conducted in 2015 in 12 rehabilitation centres in the Netherlands among 328 clinically admitted patients with a diagnosis of acquired brain injury (ABI), spinal cord injury (SCI) or leg amputation and their carers ([Hillebrecht et al, 2018](#)). The aim was to improve self-efficacy and participation in daily living activities by offering the couples family-centred rehabilitation treatment by way of a family group conference (FGC) intervention while monitoring them through questionnaires. For a detailed overview of the study, we refer the reader to the study protocol ([Hillebrecht et al, 2018](#)).

For the qualitative part of the FGC study, we selected 55 PWDs and their carers from the 328 in the larger project. These 55 came from four rehabilitation centres. They were asked to agree to be interviewed with their carer. All patient-carer couples, most living in the same household, were approached by phone and asked to participate in the interviews as a couple. All PWDs and carers gave their written consent to participate in the FGC study and verbal consent for the interviews, and were guaranteed anonymity.

In addition to the diagnoses mentioned earlier (ABI, SCI and leg amputation), inclusion criteria were that patients should be ≥ 18 years and the patient, their carer or both should have a relatively low level of self-efficacy at the onset of clinical treatment, as measured with the self-efficacy scale questionnaire ([Bosscher et al, 1997](#); [Bosscher and Smit, 1998](#)); these PWDs and partners would supposedly benefit most from the FGC intervention. Research shows that higher self-efficacy is related to reduced feelings of strain in carers ([van den Heuvel et al, 2001](#); [Kruithof et al, 2016](#)). For this article, this entails that interviewed carers may have experienced more strain than carers with a higher self-efficacy score, a limitation we will address in our closing section. Couples were interviewed three months or more after discharge, so they had already had some time to adapt to the new situation of everyday coping with the disabilities and impairments.

We assumed that PWDs' and carers' needs and strain could best be perceived and discussed as interrelated. Although there are also disadvantages of interviewing couples together, which we describe in the limitations section, this did justice to the fact that caring is an inherently two-sided process, in which the needs of the PWD and the carer are intertwined. Moreover, it enabled us to see the interaction between them, for instance, carers reassuring or comforting the PWD, PWDs assuring their partner that they can manage alone at home without their partner's assistance, or couples discussing their relationship and explaining their ways of coping.

Ethical approval was given by the Medical Ethics Committee of the University Medical Center Utrecht (number 15617/C). The protocol for this study was filed in the Dutch trial register (NTR5742).

Data collection

Baseline demographic data were collected from patients and from carers. A topic list was used, based on the principles of [Kvale \(1996\)](#). Interviews took place face to face during the spring of 2018 and were carried out by the first author and four social work students, who participated in this study as part of their undergraduate research. Interviews lasted 60 minutes on average and were conducted at a location of each couple's choice, in most cases, the couple's home. Social work students received training, and 'try-out' interviews were conducted to fine-tune the questions in the topic list. The students worked in pairs, with one lead interviewer and a second interviewer who checked if all topics were answered and asked further in-depth questions. Interviews were recorded on a digital voice recorder and transcribed verbatim.

Data analysis

A thematic analysis was performed to identify themes and patterns ([Braun and Clarke, 2006](#)). For this article, we analysed all questions about the transition from clinic to home, changes in participation level and the felt strain of the carer. We used a three-stage process of open, axial and selective coding ([Corbin and Strauss, 1998](#)). Both participants were treated alike during the interview and data analysis. For example, when one interviewee shared their experiences, we also asked the other person's opinion about it. We coded in such a way that we could distinguish between what was said by the PWD and what was said by the carer.

Three interviews of couples were coded by all researchers and four research assistants, using the initial coding approach (open coding). Second, codes were grouped (axial coding), and after each interview, the (sub-)codings were compared. Subsequently a coding scheme was developed with increased overall agreement between all researchers. The code list was further enhanced into overarching themes and patterns after each interview (selective coding) throughout the in-depth analyses process. To ensure the rigour of the findings, a subset of the transcripts was dual-coded. Further discussion on (not) overlapping (sub-)codes took place between the researchers, until agreement was reached. Saturation was found when no new sub-codes emerged from the in-depth analyses. The qualitative data-analysis software MaxQDA was used for the analysis.

Results

A total of 55 patients and their carers from four rehabilitation centres were approached to participate in the qualitative interview study (see [Table 1](#)). Some 20 couples from two rehabilitation centres consented, for a total response rate of 36.4 per cent.

Of the 20 interviewed couples, 18 consisted of patients with their spouse as a carer and two were patients with their children as carers. In this article, we focus on spousal couples. Their characteristics are summarised in [Table 2](#).

Table 1: Participating couples

Rehabilitation clinics	Approached couples	Positive for interview
Centre 1	44	18
Centre 2	8	2
Centre 3	2	0
Centre 4	1	0
Total	55	20

Findings

Four phases of the rehabilitation trajectory were identified in our interviews, and we used these as a framework to report the results, except for the acute phase of hospitalisation, since in this phase, both patient and spouse tended to be in a ‘survival’ mode, where the carer can only provide emotional support. Our main finding is that carer strain varied throughout the later phases in terms of the availability or lack of ‘personal time’ for social activities, relaxing or work, and ‘personal space’ to retreat to. [Table 3](#) provides an overview of carers’ perspectives during the different recovery phases and the experienced carer strain in each of the phases.

Clinical inpatient treatment phase

All respondents received inpatient clinical rehabilitation treatment, ranging from a few weeks to months, depending on the severity of the diagnosis, recovery improvement or home situation. During this phase, the main focus was on achieving goals in the recovery of PWDs’ functions and daily activities, but the clinical rehabilitation phase had a huge impact on the carers’ life too. This impact mainly had to do with varying degrees of personal time and space, as we will explore in the following.

Little personal time and space

Ten carers reported visiting the clinic on a more or less daily basis. Seven also had to run a household with children. Attention and energy must be shared, which could be difficult, as the following quote of a carer reporting on her child’s perspective illustrates: “Dad is not here and you are away a lot at the rehabilitation centre, so I am alone a lot too” (Couple 3). In addition to daily visits to the clinic, healthcare professionals encouraged carers to be actively involved in the treatment, particularly when the clinical rehabilitation period was drawing to a close. Carers visited their partners’ therapies to be educated on how to give support in daily activities, attended consultations with social workers and/or psychologists, and received home visits by occupational therapists. They also attended family meetings for partners or children on the impact of the diagnoses affecting them as a couple or family.

Seven carers experienced these activities and meetings as positive, but they also reported a strain on their already-lowering energy levels. In this phase, they had very little time for themselves. However, they still had some personal space apart from their partner, since carer and partner did not live together during this phase. Home was an important place to regain strength and energy:

Table 2: Demographic characteristics of spousal couples

	PWD age group	M/F	Diagnosis	Traumatic cause	Clinical rehab (weeks)	Weeks since clinic discharge	Children living at home	Education- al level	Carer age group	M/F	Education- al level	Paid job
1	64-9	M	SCI	Yes	4	70	No	Low	64-9	F	High	No
2	64-9	M	SCI	No	12	51	No	Medium	64-9	F	Low	No
3	46-51	M	SCI	No	5	23	Yes	High	46-51	F	High	Yes
4	64-9	M	SCI	No	13	17	No info	No info	64-9	F	High	No
5	46-51	F	SCI	No	7	38	Yes	Medium	52-7	M	Low	No
6	52-7	F	SCI	Yes	13	28	Yes	Low	52-7	M	Medium	Yes
7	64-9	M	ABI	No	8	84	No	Low	64-9	F	Low	No
8	52-7	M	ABI	No	3	75	Yes	High	52-7	F	Low	Yes
9	52-7	M	ABI	Yes	7	57	Yes	High	46-51	F	Medium	Yes
10	58-63	F	ABI	Yes	12	54	No	Low	64-9	M	High	Yes
11	64-9	M	ABI	No	10	42	No	High	64-9	F	High	Yes
12	46-51	F	ABI	No	9	42	Yes	Low	46-51	M	Medium	Yes
13	46-51	M	ABI	Yes	6	44	Yes	Low	46-51	F	Medium	Yes
14	64-9	M	ABI	No	9	41	No	High	58-63	F	High	No
15	58-62	F	ABI	No	6	41	No	Low	64-9	M	Low	No
16	64-9	M	ABI	No	17	20	No	High	64-9	F	High	No
17	64-9	M	ABI	No	6	23	No	High	58-63	F	High	Yes
18	64-9	M	ABI	No	13	15	No	Medium	58-63	F	Low	No

Notes: N = 18. Age group: age at which PWD admitted to clinical rehabilitation centre. Educational level: low = primary and secondary education; medium = vocational education and training; high = higher education. Diagnose: SCI= Spinal Cord Injury, ABI= Acquired Brain Injury.

Table 3: Carers' perspectives per recovery phase

	Clinical rehabilitation	Transition from clinic to home	Community integration
Personal time	Little personal time Visiting clinic daily. Hardly time for oneself	No personal time Full hands-on support helping partner	Regaining personal time Slowly picking up activities aligned to the degree of support the partner needs
Personal space	Some personal space Evenings home alone	No personal space Little private space to retreat to	Regaining personal space Slowly returning personal space to retreat to in a compromise with the partner

'But at a certain point, you notice that your own home environment is ... the few hours you sleep in your own surroundings ... you really need that rest.... I didn't return home before half-past eight in the evening.... I did that every day for three months, continuously.' (Carer, Couple 4)

Some carers had a paid job. For some, work provided a bit of personal space and time. For others, work was an extra strain on top of the heavy care duties:

'The last few months when she was ... in the rehabilitation centre, I slowly started working again for a few days and tried to get some structure in my day.... Well, that worked out well and I was also lucky with my boss who let me work as much as I could.' (Couple 6)

'I even had to catch up on missed hours when I was in the intensive care with him.... It was not a nice working relationship actually.... And then I just kept going. And now I'm paying the price, and so is my employer, because I've been on sick leave since November.' (Couple 8)

Transition from clinic to home

During this third phase, most couples (15) struggled with the contrast between the clinic and the home environment. In the clinic, everything had been organised for them, which saved energy:

'In the beginning, it is quite discouraging.... At the centre, there is an adapted environment, which is stimuli-free. And at noon, you wheel into the restaurant with your plate ready with a glass of water put in front of you; you just have to shuffle it into your mouth.... [At home,] you have to do your shopping again, you have to cook food again, you have to do the laundry ... that's quite a lot.' (PWD, Couple 17)

Although the treatment sessions focused on optimising PWDs' independence in daily activities, such as cooking dinner or making the bed, the clinical environment offered few chances to put these skills into practice. This made the transition to the home environment challenging, as PWDs now had to practise daily activities by themselves.

No personal time and space

Seven carers had to perform all household chores in addition to supporting the rehabilitation of their partner. Most carers (16) reported that they now also had to provide full hands-on physical support for activities like dressing, preparing lunch or breakfast, or going to the toilet. They had no time left for themselves, which caused serious carer strain:

'But I really had to come back into my daily routines again.... It's all about the caring part first; I come second. And then I am thinking: "I mustn't push it now to do more and more' otherwise, I will become burned out.'" (Couple 18)

When partners needed a lot of support, some carers took time off from work for weeks. Some of them reported no longer feeling like a spouse. A carer responded:

'I had mixed feelings. I liked it, yes, but I found it very intense. I was 100 per cent caretaker. He could do so little. So, in reality, you have to do it all.... Sometimes, I felt more like his nurse than his wife.' (Couple 1)

Although carers explained that they do it all out of love, they underlined that it was very hard work that put enormous pressure on them and forced them to (temporarily) put their own lives on hold:

'All day long, there are things to organise, to support or to bring something to him.... We're both living the life of my husband.... My day is entirely committed to what my husband needs, and not just what he needs, but even how his life looks like.' (Carer, Couple 4)

The often-reduced energy level of their partner had a direct impact on the carers' social lives, as indicated in the following quote:

'What I find difficult is ... sometimes, when he's too tired ... you really can do much less together than before.... That's annoying when you, for instance, want to go to a party together, when he ... suddenly can't do it.' (Couple 14)

Most couples (15) reported feelings of fatigue. Basic morning activities, such as washing and dressing, already take up a lot of energy and time for PWDs. This low energy level of the partner also affected the carer: "This is your problem, but also my problem now" (Couple 14).

Couples had to think their activities through, plan in advance and create enough moments of rest. Even when the PWD was doing some activities separately, carers could not relax, as they were anxious that something might happen to their partner. As a carer described:

'You are more worried, yes. When I am watching television in the evening and she takes a shower, I keep an eye on the time. "That takes too long", and then I walk by three times to make sure she's alright.' (Couple 5)

Hence, carers do not easily leave their partner alone at home and remain homebound too. A carer described her feelings and concerns when she went off for the evening:

‘And then he had to stay home alone. At first, I found that very scary and was wondering if all went well. He might take a fall, you never know, it’s possible, right? But I did it anyway, and afterward, I went straight home.’
(Couple 7)

With the PWDs always at home and carers hesitating to leave them alone, carers also lacked personal space during this phase. However, some carers did manage to create personal time and space. A carer explained how she rewarded herself: “So, now I’ve earned it! And then I went somewhere to have a cup of tea. You must create a place for yourself to withdraw” (Couple 17). Carers try to slowly focus more on their own daily pursuits, while continuously taking into consideration what that means for their partner at home:

‘I am someone who loves to be around people and is always busy. I shouldn’t have to stay at home all the time because I still have my own life!... And he has to understand that. But that does not mean you always like it when I’m away.’ (Couple 7)

‘I also have my own activities and my groups of friends.... I have picked that up again.... A day at a museum with a couple of friends.... And then I will leave him in peace; I am not worried about that.’ (Couple 1)

Community integration phase

All interviewed PWDs (18) experienced a decline in their activity and participation level, and described a significantly changed life and altered expectations of their future. Many couples (12) reported grief and feelings of loss: “Yes, it’s a real process of grieving. At first, your brain sort of switches off, like: ‘I have to do other things; first, pick up the rest of my life again’” (PWD, Couple 6). They also felt anger, and between them, there could be irritation. For example, when one of the partners was pessimistic about the future, the other got angry for not keeping their spirits up:

PWD: ‘It’s an unexpected disappointment. You think you will grow old peacefully. I always looked at my parents, who have grown old healthy, 81 years old ... and I don’t think I’ll make it.’

Carer: ‘You don’t know that at all.’

PWD: ‘Not healthy anyway.’ (Couple 16)

Sometimes, there was competition about whose life had become more difficult and who would therefore be entitled to more understanding:

PWD: ‘I am often told to be glad to be still alive ... but I don’t know if I’m happy about that at all.... I won’t be the same again. I know that, and I have to accept that, which is very difficult.... But you have very little patience with me.’

Carer: 'Sometimes, I am just completely exhausted ... surely you understand that?'

PWD: 'Well, yes, but I can't deal with that too.' (Couple 15)

Other couples managed to adapt and remain positive together:

PWD: 'You know ... coming to a place of acceptance can't be pinpointed to one moment. It's like a sliding scale. And, well, at a certain point, it is what it is and you have to accept that.'

Carer: 'If necessary, we start from scratch again. But we will continue and don't give up, no matter what!' (Couple 4)

Changed tasks, activities and roles

As time went by, the majority of couples (16) slowly settled down. Although carers could increasingly pick up activities outdoors and regain some personal time, they still had more tasks to perform at home than before. The division of roles between the couples was also changing due to the PWDs' disabilities, as well as such issues as low energy or lacking initiative that some experienced. Activities that the PWD performed before were taken over by the carer, which could frustrate both of them:

Carer: 'But then again, you can't do the hard work you've always done. He did, yes, he always did everything in the house.'

PWD: 'Yes, I find that annoying too. Very annoying.'

Carer: 'A while ago, our daughter said: "Well, Mom, you're the man in the house now!"' (Couple 1)

For carers, this could lead to additional strain:

Interviewer: 'What kind of role do you have now?'

Carer: 'Organiser, at this moment. And that's a strange double role next to being a grandmother and mother. In my opinion, there are sometimes too many roles to fulfil... I've got mixed feelings about this: which one do I let go, then?' (Couple 11)

Many carers (16) tried to protect and control their partner's energy levels. A carer explained how he saved his wife from energy-draining visits:

'There are people who don't understand her and who start talking about all sorts of other people and then she disengages. Her mother even; I had to slow her down because she kept talking about the past... Within half an hour, [my wife] was overtired. I told [her mother] that she shouldn't do that anymore or she should leave. Sometimes, I have to be strict.' (Couple 12)

These new roles in addition to the carer role were to the detriment of carers' personal activities:

'I used to be quite busy with pole vault in the summer, and during winters, I worked in the biscuit factory to pass the time. But I don't do that anymore. And I sometimes think about picking up things again, but as soon as he has one of his off days, I'm glad that I'm home.' (Carer, Couple 9)

Regaining some personal time and space

After a while, some carers (9) regained some personal time. This depended on their partner's level of independence. As a carer explained:

'The more he can pick up his own activities, the more space I get, more time in which he is in no way dependent on me. And that is actually very pleasant.... Yes, and that's a very natural process.' (Couple 17)

Support from their partner was an important factor for regaining their own activities:

Carer: 'I said right away: "The activities I did, I will continue to do."... I play sports a lot and I am a lunch supervisor at school.... There's my reading club.... No, that didn't change. Well, it did when he first came home.... Then, I just stayed home for six weeks or so.'

PWD: 'But other than that, yes, you just continued doing your hobbies and activities.' (Couple 2)

Carer: 'I'm kind of recalibrating my activities: what else do I want to do?... Because I also do volunteer work.... Well, then I think: "Can I allow myself to do that and how will that be for you?" I think that's going to be quite a challenge to work that out.'

PWD: 'I always say, "Just do it because I'll be fine", and that's the truth.' (Couple 11)

When a PWD can regain activities, this can also support carers' activities. A carer complimented her partner for this during the interview:

'You started cooking again at home, regularly. Not always, but there was a period when I did everything in the house.... And now, sometimes, you do the ironing.... We can have visitors for dinner again and then you cook rather extensively.' (Couple 14)

Regaining previous activities is a difficult process of give and take between the PWD and carer. It demands a lot of flexibility. Sometimes, roles must be reversed again because some activities that the carer had taken over temporarily can be executed again by the PWD after a while:

'When he wasn't there, I did [the bookkeeping] all by myself, and now I have to sort of let it go again. And although I think he doesn't carry it out to my satisfaction, it doesn't really bother me.' (carer, Couple 9)

Scaling back the carer role demands adjustments too. As one carer replied:

'But in the back of my mind, I still want things to be prepared for him, but that is actually not necessary anymore. He can do that himself. So, I have to force myself not to do that.' (Couple 1)

Although personal *time* and activities gradually returned, regaining personal *space* remained difficult. As long as the PWD is more or less homebound, the carer still has reduced home-alone time.

Discussion and conclusion

To understand caregiver strain and needs throughout the different rehabilitation phases, we explored the perspectives and interactions of carers and their partners with ABI or SCI. We found that the strain and needs of carers in different phases could be interpreted in terms of personal space and personal time. The explicitly spatial dimensions of caring relationships are vastly under-researched (Milligan, 2003). Using socio-spatial dimensions, such as (lack of) time and space (McKie et al, 2002; Milligan, 2003; Tronto, 2003; Milligan and Wiles, 2010), proved a useful means of conceptualising the experienced strain of caring (Milligan, 2003). What distinguishes our study is that we identified this lack of time and space *per phase*, transitioning through the rehabilitation trajectory. Intervention research has not focused that much on changes in carer well-being (Cameron and Gignac, 2008). Our study adds more knowledge of carers' needs so that they can receive help that fits their situation.

Our results show that during the clinical rehabilitation phase, carers have little personal time but do have some personal space. During the transitional phase of going from the clinic to home, carers have neither personal time nor space. During the community integration phase, most of them regain some personal time and space, particularly when their partners actively support this.

Milligan (2005; 2012) and Milligan and Wiles (2010) speak of carers having to renegotiate their caring identities with every switch of the care location. We found that this also holds for time. Prior research in the ABI field found that carers feel a great need to spend time on their own, performing activities outside their house (Sinnakaruppan and Williams, 2001; Chan, 2007; Smeets et al, 2012). The importance of moments away from the caring tasks, and the need for time to retreat, also featured in 11 of the 12 included studies in a qualitative meta-analysis of post-stroke spousal experiences (Quinn et al, 2014). To offer carers appropriate support, assistance must be attuned to the various rehabilitation phases (Cameron and Gignac, 2008; Stiekema et al, 2020). The following recommendations per phase might be helpful for professionals providing rehabilitation care and for the policy of rehabilitation clinics.

In general, in the clinical rehabilitation phase, carers' evenings are used for retreat and for regaining energy to visit the partner the next day. Rehabilitation professionals should try to not only involve the carer in the rehabilitation process, but also support carers to find time and space to recuperate. This entails being attentive to carers' needs when scheduling meetings, both in terms of frequency and timing. Also, more treatment during the clinical phase might be provided in couples' home environments to practise skills that could benefit the transition from clinic to home.

Furthermore, a better supervision of couples' transition home after discharge is recommended. For instance, a first step could be increasing the frequency of outpatients' treatment sessions for social work counselling or other relevant disciplines, rather than decreasing it (which is now the case). Moreover, a better continuity of care is needed. Both patients and carers would benefit from improved integrated collaboration between the rehabilitation centre and community health services.

Rehabilitation professionals should prepare carers for the transitional phase with little to no personal space and time. Recruiting social support from family and friends might be a solution (Visser-Meily et al, 2006), but previous research suggests that this road is fraught with difficulties (Bredewold et al, 2016; 2020). Couples felt reluctant to reach out to friends because they might never be able to reciprocate the help. Still, for some couples, finding additional help from their social network might offer relief (Suh et al, 2005; Rodakowski et al, 2012). Another option for rehabilitation professionals is to offer respite care. Although carers can have qualms about using respite care (Smeets et al, 2012) because they feel obliged to care for their partner themselves, it can be a (temporary) solution to prolonged informal care.

During the community integration phase, we would recommend that rehabilitation clinics organise a 'balance check-up' to probe for issues that PWDs and carers might face when reintegrating into the community. Rehabilitation care should concentrate on helping PWDs and their partners regain their social routines, activities and relationships, reposition their identity (Meijering et al, 2016), and adapt to the changed dynamic of their spousal relationship. As we have seen, there may be many reasons why carers cannot regain personal time and space. Further research will be needed to assess carers' perspectives on, and their preferences for, types of support in the different phases.

Limitations

This study draws on a rather low response rate of 36.4 per cent, as 20 out of 55 PWDs and their carers agreed to be interviewed. One explanation could be that all approached couples were still in the demanding recovery phase of adapting to the disability in their home environment. Given those circumstances, we were still relatively satisfied with the response rate.

Second, the 55 potential respondents were purposively selected, based on predetermined criteria. Although the non-response group (35) matched the response group (20) in terms of demographic data, the 55 originally invited to participate do not adequately reflect the whole population in rehabilitation care. This is especially relevant with regard to the self-efficacy of PWDs and carers. The larger project that this study is part of targeted PWDs and carers with low self-efficacy. Previous research suggests that people with high self-efficacy experience less carer strain (van den Heuvel et al, 2001; Kruithof et al, 2016), so our account of carer strain might be bleaker than would be the case in a response group with high self-efficacy. It might be worthwhile to compare both groups in future research to see whether carers with high self-efficacy manage to find more personal time and space during the rehabilitation trajectory, and how they do that.

Third, we interviewed the PWD–carer couples together. Although this was a deliberate choice, as it gave us insight into the interaction and dynamics between the PWD and carer, it may have restricted their chances to speak freely. Fourth, couples may have had difficulty recalling some of their memories of previous phases once they moved on to later ones. Although this is always a risk when interviewing people about past experiences, our respondents had very vivid memories of everything that had befallen them since the injury or accident; these are life events that stick in one's memory.

Fifth, within the study, we did not differentiate between the couples' perspectives by diagnosis of ABI and SCI. Overall, we saw that their perspectives were widely shared and not necessarily differentiated by diagnosis, possibly because differences within the group of ABI patients and that of SCI patients can be just as big as differences between both groups. Further studies should address differences per diagnosis to see whether our findings in this respect are robust.

Finally, the research took place within the context of the rehabilitation treatment setting in the Netherlands; translating our findings to a different setting in other countries warrants caution. Further research is needed to establish whether our findings are also applicable outside the Netherlands.

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Conflict of interest

The authors declare that there is no conflict of interest.

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