

'Let us be'. Social support needs of people with acquired long-term disabilities and their caregivers in rehabilitation practice in the Netherlands

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Abstract

In many European countries, including the Netherlands, current care policies encourage 'active citizens' to support each other rather than having individuals rely on paid professional help. Rehabilitation centres also put greater emphasis on social networks assisting adults with acquired long-term disabilities and their caregivers. Often these adults and their caregivers feel insufficiently prepared to cope with the disability in daily life and struggle with community integration. However, little is known about the factors that make vulnerable people accept or decline support from their social networks. We researched the social support needs of persons with acquired disabilities and their caregivers eligible for a family group conference intervention by conducting 19 semi-structured interviews in rehabilitation centres in the Netherlands. A thematic analysis revealed that most couples (15) were reluctant to request (more) support from their social network, even though many of them had a good network to rely on. We identified five reasons for this reluctance: (1) not accustomed asking support, (2) not wanting to be a (bigger) burden, (3) fear of intrusion into one's privacy and independence, (4) fear or problematic motivations such as curiosity or pity and (5) lack of reliability, competence, or comprehension. The main factor seemed to be the lack of reciprocity: couples do not see sufficient options to reciprocate the necessary support. Therefore, before instigating social support-centred interventions such as family group conferences, social care and other health professionals should be aware of any factors causing a sense of reluctance and explore the experiences of an imbalance in reciprocity.

KEYWORDS

caregiving, carers' needs, disabled people, rehabilitation, social support

1 | BACKGROUND

The transition from clinical rehabilitation admittance to reintegration into the community is a challenging phase. Adults with long-term disabilities such as acquired brain injury (ABI) or spinal cord injury (SCI) often feel insufficiently prepared to cope with their disability in daily life (Salter et al., 2008) and experience a significant, sometimes overwhelming difference between the

protected clinical environment and life in the community (McKevitt et al., 2004; Visser-Meily et al., 2005). This also has a major impact on their caregivers' lives. Caregivers are prone to feel burdened and experience increased feelings of responsibility and anxiety, which often results in a decrease in their participation in activities (Kerr & Smith, 2001; Rigby et al., 2009). Both patients and caregivers must learn to cope with the patient's altered abilities and find new

routines (Abrahamson et al., 2017; Greenwood et al., 2009; Lynch & Cahalan, 2017; Piccenna et al., 2016) and new social roles in their homes and families (Rittman et al., 2007).

In the Netherlands, as in many other European countries, significant reforms in long-term care policies (Pavolini & Ranci, 2008) have led to an emphasis on support from the 'social network': family, neighbours and friends (Dijkstra et al., 2016; Faulkner & Davies, 2005; Wissel et al., 2013). Under the concept of 'active citizens', more responsibility is assigned to members of the community under the expectation that they will provide mutual support (Tonkens, 2012). To support this shift, many new family-centred interventions are being introduced (Deek et al., 2016; Park et al., 2018) in various settings such as geriatric medicine, rehabilitative medicine, palliative care and psychiatry (Fronek, 2005; Hudson et al., 2009; Loupis & Faux, 2013; Wisby et al., 1996). One such intervention has spread across various welfare and care settings: the family group conference (FGC), consisting of meetings in which people in need and members of their social network develop a plan for collaborative support.

FGCs were first legislated in 1989 in New Zealand as a decision-making tool in cases of child neglect, abuse, or youth offence (Cunning & Bartlett, 2006; Merkel-Holguin, 2005). Although there is little evidence supporting the effectiveness of the FGC approach in adult care (Hillebregt et al., 2019), FGC is gaining prominence in various fields, including public mental healthcare (de Jong et al., 2016; de Jong, Schout, & Abma, 2015; de Jong, Schout, Pennell, et al., 2015; de Jong & Schout, 2013a; Wright, 2008), general social welfare (Johansen, 2014; Malmberg-Heimonen, 2011; Malmberg-Heimonen & Johansen, 2014) and social welfare for elderly clients (Metze et al., 2015a, 2015b).

In current rehabilitation practice in the Netherlands, FGCs have been initiated for adults with acquired disabilities and their caregivers (Hillebregt et al., 2018). FGCs are based on the presumption that receiving social support from family members and friends facilitates coping with a disability and helps patients going through the rehabilitation care trajectory during (1) the acute phase of being admitted to the hospital, (2) the subacute phase of treatment at an inpatient rehabilitation care facility, (3) the transition from the rehabilitation care facility to home and finally (4) reintegration into the community (Kirkevold, 2002; Rotondi et al., 2007; Stiekema et al., 2020).

However, thus far, couples in rehabilitation practice have shown little interest in FGC interventions (Post et al., to be submitted). Although social support can be beneficial in times of trouble (Kruithof et al., 2015; Post et al., 2005; Scholten et al., 2018), people can be reluctant to receive help. Implicit social codes and norms underlie social relations (Bredewold et al., 2020) that highly influence one's decision to accept or refuse informal care. Considerations of solidarity, social exchange and reciprocity influence motivations for both accepting help and for being helpful (Cropanzano & Mitchell, 2005; Trappenburg, 2015). Research shows that many people value achieving the right balance between giving and receiving. The weaker the emotional bond, the more important the balance (Maus, 2002).

What is known about the topic

- Adults receiving inpatient rehabilitation treatment and their caregivers can experience difficulty transitioning from the rehabilitation facility to live in the community.
- Caregivers can feel highly burdened and often decrease their own social activities.
- Many people with intellectual or psychiatric disabilities do not want to involve their available social network for fear of a lack of reciprocity in the relationship.

What this paper adds

- Concern over a lack of reciprocity in the relationship was revealed as a major factor for not asking for and accepting help in rehabilitation care.
- Other reasons were fear of questionable motives for offering help, such as curiosity or pity.
- People prefer to involve their social network on their own accord.

Among neighbours, for example, this balance is considered particularly important (Bredewold et al., 2020; Komter, 2003; Oorschot van & Komter, 1998). In addition, a recent study on people with intellectual or psychiatric disabilities showed that they were reluctant to ask for help from their social network for fear of not being able to reciprocate in kind (Bredewold et al., 2016, 2020). These considerations might also play a role in the rehabilitation setting.

This paper aims to explore the perspectives of patients and their caregivers who reintegrate into the community from a clinical rehabilitation setting to gain a better understanding of their support needs and preferences for how and when (not) to engage their social network. For this purpose, we analysed the social support needs and social networks of couples eligible for an FGC intervention and their reasons for declining.

2 | METHOD

This qualitative study is part of a multi-centre controlled trial performed in 2015 in 12 rehabilitation centres in the Netherlands with 328 clinically admitted patients with a diagnosis of ABI, SCI, or leg amputation and their significant others (Hillebregt et al., 2018). The aim was to improve self-efficacy and participation in daily living activities by offering the couples the FGC intervention whilst monitoring their progress with questionnaires.

For the qualitative part of the FGC study (presented here), eligible couples for the FGC intervention from four participating rehabilitation centres were invited to participate in semi-structured interviews. Inclusion criteria for patients' participation were as follows: patients should be ≥ 18 years and have been diagnosed with ABI, SCI or leg amputation. In addition, the patient, their

caregiver or both should have a relatively low level of self-efficacy at the onset of clinical treatment, as measured by the self-efficacy scale questionnaire (Bosscher et al., 1997; Bosscher & Smit, 1998), given the assumption that these are the people with disabilities (PWDs) and their caregivers who can benefit most from the FGC intervention.

Couples were interviewed at least 3 months after discharge, so they had already had some time to adapt to the new situation of coping with the disability in their home environment on a daily basis.

All couples were first approached by phone. Respondents provided written consent to participate in the FGC study and verbal consent for the interviews and were guaranteed anonymity. Ethical approval was granted by the Medical Ethics Committee of University Medical Centre Utrecht.

Baseline demographic data were collected from both caregivers and patients. For the interviews, we used a topic list based on the principles of Kvale (1996). Interviews were conducted face to face during the spring of 2018 by the first author and four social work students who participated in this study as part of their undergraduate research. Interviews lasted approximately 60 min on average and were performed at a location based on the couples' preferences. The interviewers worked in pairs of two with one lead interviewer and a second interviewer who checked if all topics were answered and asked further in-depth follow-up questions as needed. Interviews were recorded and transcribed verbatim.

A thematic analysis (Braun & Clarke, 2006) was performed to identify themes and patterns in the data. We used a three-stage process of open, axial and selective coding (Corbin & Strauss, 1998). A final coding scheme was developed with the consensus of all researchers. Both latent codes (deriving the underlying meaning) and semantic codes (deriving the surface meaning) were used (Boyatzis, 1998). Extra subcodes were discussed with the lead researcher during meetings. The code list was further enhanced into overarching concepts after each interview through in-depth analysis before reaching the phase of discovering themes and patterns. MaxQDA software was used for the analysis.

2.1 | Characteristics of participating couples

A total of 55 patients and their caregivers from four rehabilitation centres were approached to participate in the qualitative interview study (see Table 1). Among these, 20 couples from two centres consented to participate, for a total response rate of 36.4%.

One couple accepted the FGC intervention, 10 couples did not consent to it and 9 couples reported external reasons the intervention had not taken place, such as quick dismissal, no outpatient treatment or the social worker being on leave. For the latter, the concept of FGC was explained during the interview. In this study, we focus on

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

the social support needs and networks of the 19 couples eligible for the FGC intervention who did not follow through. Their characteristics are summarised in Table 2.

3 | FINDINGS

3.1 | Couples' experiences

We found two groups: (1) couples who were not reluctant to ask for social support, had a good social network and did not need (more) help and (2) couples who were reluctant to ask for (more) support although the majority had a good social network to approach for support (see Table 3). In the following sections, we will elaborate on the response patterns of both groups.

3.2 | 'Not reluctant to ask for support'

Four couples replied that they did not need additional social support (couples 3, 6, 12 and 14). Three of these were couples with children still living at home, which may have contributed to both their willingness to ask for help and to their refusal of an FGC. On the one hand, older children or young adults may have been involved in the care process. On the other hand, children residing in the home may have pointed out to their parents that additional help was needed. For these four couples, an FGC was redundant. A woman with a complete traumatic SCI recounted:

You only need to send one text message, and they are there for you.... I have two adult daughters who want to help me as much as they can, also. It has never been an issue, really. (couple 6).

A caregiver responded in the same manner:

Yeah, well, we got a lot of attention from many people asking us how things are going, visiting him. His brothers and sisters had to make a visiting arrangement, ...because they are with seven of them at home. So yes, yes, ...that was all right! (couple 12).

TABLE 2 Demographic characteristics of patient and carer couples (N = 19)

Couple	Age group/patient	M/F	Diagnose	Traumatic Cause	Clinical rehab. (wks)	Weeks being discharged clinic	Living situation/ Children living at home	Educational level	Age group carer	M/F	Relation with patient	Educational level	Paid job
1	64-69	M	SCI	Yes	4	70	Married, no children	Low	64-69	F	Partner	High	No
2	64-69	M	SCI	No	12	51	Married, no children	Medium	64-69	F	Partner	Low	No
3	46-51	M	SCI	No	5	23	Married, with children	High	46-51	F	Partner	High	Yes
4	64-69	M	SCI	No	13	17	No info	No info	64-69	F	Partner	High	No
5	46-51	F	SCI	No	7	38	Single, with children	Medium	52-57	M	Partner	Low	No
6	52-57	F	SCI	Yes	13	28	Married, with children	Low	52-57	M	Partner	Medium	Yes
7	52-57	M	ABI	No	3	75	Married, with children	High	52-57	F	Partner	Low	Yes
8	52-57	M	ABI	Yes	7	57	Married, with children	High	46-51	F	Partner	Medium	Yes
9	58-63	F	ABI	Yes	12	54	Married, no children	Low	64-69	M	Partner	High	Yes
10	64-69	M	ABI	No	10	42	Married, no children	High	64-69	F	Partner	High	Yes
11	46-51	F	ABI	No	9	42	Married, with children	Low	46-51	M	Partner	Medium	Yes
12	46-51	M	ABI	Yes	6	44	Married, with children	Low	46-51	F	Partner	Medium	Yes
13	64-69	M	ABI	No	9	41	Married, no children	High	58-63	F	Partner	High	No
14	58-62	F	ABI	No	6	41	Married, no children	Low	64-69	M	Partner	Low	No
15	64-69	M	ABI	No	17	20	Married, no children	High	64-69	F	Partner	High	No
16	58-63	F	ABI	No	5	25	Single, no children	Medium	28-33	F	Child	High	Yes
17	64-69	M	ABI	No	6	23	Married, no children	High	58-63	F	Partner	High	Yes
18	64-69	M	ABI	No	13	15	Married, no children	Medium	58-63	F	Partner	Low	No
19	64-69	F	ABI	No	6	15	Single, with children	High	28-33	M	Child	Low	Yes

Age: at onset of patient admitted in the clinical rehabilitation centre.

Diagnose: SCI = Spinal Cord Injury, ABI = Acquired Brain Injury.

Educational level: low = primary & secondary education, medium = vocational education and training, high = higher education.

TABLE 3 Response patterns of the couples (N = 19)

Response pattern	N	Explanation	Couple
Not reluctant to ask for support	4	We easily ask for (more) support; have a good social network and can manage on our own	3, 6, 12, 14
Reluctant to ask for (more) support	13	We do not want to ask (more) support although we have a good social network	1, 2, 4, 5, 7, 10, 11, 13, 15, 16, 17, 18, 19
	2	We do not want to ask (more) support, because we have a weak social network	8, 9

For this group, activating their social network with the help of the FGC intervention would have no added benefit. As this caregiver notes:

I cannot really get a clear picture of what those family group conferences would be like. We already do a lot ourselves and if we cannot manage I'll call the neighbours. (couple 14).

3.3 | 'Reluctant to ask for (more) social support'

Fifteen couples felt reluctant to ask and receive (more) social support from their social network. Two of these couples felt they did not have a reliable support system (couples 8 and 9).

The remaining 13 couples felt they had a good social network of friends and family but were reluctant to (further) involve them (couples 1, 2, 4, 5, 7, 10, 11, 13, 15, 16, 17, 18 and 19). Most caregivers in this group were female (10). Six of them did not have paid employment. Both gender expectations and the lack of competing obligations may have contributed to these couples' reluctance to further involve their social network. The reasons the 13 couples refrained from asking their social network for support can be clustered into five categories, which we discuss below (see Table 4). More than one reason could be given by a couple. There was no pattern in the responses related to the couples' background variables, but some reasons were mentioned more often than others. We first discuss the most frequently mentioned reasons and then proceed to those mentioned less often.

3.3.1 | Not wanting to be a burden to the support giver (and jeopardise their relationship)

Ten couples (1, 2, 5, 7, 10, 11, 13, 17, 18 and 19) described not wanting to be a burden on the people close to them. Among them were couples who felt they might turn to some family members such as brothers and sisters but not to their adult children, friends and more distant family. One couple explained:

I did not want to bother the children too much with that. The same with friends who always offered: 'if

you need help, give me a call'. But it's easier to ask your family. (couple 1)

A common reason for not wanting to trouble one's adult children was that they had busy jobs or families of their own. A man with a non-traumatic ischemic stroke replied, 'They have taxing jobs... you don't want to do that.' (couple 13).

Two other couples recounted

Our adult children do their best to help and support us, but they have their own family to take care of too... (couple 1).

As far as I am concerned: children must remain in their role as your children... I prefer the support of other adults... (couple 19).

The feeling of being a burden to others took on various forms, leading to many reasons and explanations for why it would be difficult to ask for and accept help. Couples felt hesitant to ask because some people lived too far away or help was needed so often that it would become uncomfortable to accept without feeling like they were burdening the helper. Sometimes members of the social network were deemed too old to ask for support. As this caregiver indicates: 'Our inner circle... They are almost all above 80 years!' (couple 18).

Another reason for not wanting to ask for more help was that couples were afraid doing so would jeopardise their relationships. One-sided dependency might alter a friendship into something altogether different. Occasional help may be integral to many relationships (especially if it can be provided on a give-and-take basis), but once help was needed more often, the fear of being a burden on others increased. For structural help, people preferred to approach paid household help or a professional organisation such as home care.

Caregiver: Suddenly, my neighbour was cleaning my windows because she saw I did not get to it... But there comes a time when you think 'People don't mind helping out for a short period but...'. So then I hired a housekeeper for three hours a week. (couple 17).

A woman (49) with an incomplete non-traumatic SCI explained she would rather keep some distance from family members:

TABLE 4 Reasons for not wanting (more) social support

Reluctant to ask for (more) support	
1	Not accustomed to ask for support
2	Not wanting to be a burden to the support giver (and jeopardise their relationship)
3	Not wanting intrusion of privacy and independence
4	Not wanting support out of pity or curiosity
5	Lack of reliability, competence or comprehension

It becomes very personal with family... well, I do not know... it might feel better if the person were an outsider... (couple 5).

Another disadvantage of involving the social network was that it was difficult to plan. When one couple was asked if they would ask their immediate family to help them on a structural basis, they answered:

Patient: *No, I would not ask my friend, my brother, not every week.*

Caregiver: While with home care, that is planned. Then you do not have to call for help anymore. They come every week, have a fixed schedule, with which you can be satisfied. (couple 5).

People also felt hesitant to express their wishes and preferences on how to receive support from their social network. They did not feel this hesitation towards a professional organisation because when help was paid for the care receiver could decide exactly what and how much help would be received. One caregiver explained: '...and now I have a cleaning lady. I pay her, which makes me also able to decide what I want' (couple 11).

3.3.2 | Not accustomed to asking for support

Seven couples (4, 5, 7, 11, 15, 18 and 19) indicated that they were not accustomed to asking for help, for instance, because they had never been in a vulnerable position before; in other words, they lived independently until the accident or injury took place. A caregiver of a partner with a brain injury, replied, 'We're gonna take care of it ourselves first!' (couple 11) Another couple found themselves capable enough and their reason for not requesting help was they had not done that for 60 years: 'We have always decided for ourselves' (couple 4). A respondent with a non-traumatic stroke explained that she always used to be the one whom everyone else could turn to but now it was the other way around. 'I really think that is terrible' (couple 19). Couples preferred to solve their problems on their own and were adverse to asking for outside support. When asked if they would turn to their family or friends for help, one couple answered:

Patient: *Oh, I do not do that so easily...*

Caregiver: Neither do I....

Patient: Only when it is absolutely necessary. If I really cannot do anything anymore, then I will ask someone to help me as my last resort. But as long as I can do it myself, I'll manage alone. (couple 7).

In response to the question of whether they had a support network they could rely on, another couple replied:

Caregiver: *We have our acquaintances and we will manage on our own just fine.*

Patient: We try to do as much as possible by ourselves. (couple 18).

Asking for support from their social network does not appear to fit their values and lifestyles, which are often based on independence and individuality. Most couples did not want to change this way of living.

3.3.3 | Lack of reliability, competence, or comprehension

Seven couples (2, 4, 5, 7, 10, 15 and 16) consider members of their social network to be unreliable, incompetent or incomprehensible; for example, when they offer help but fail to deliver and seem not to understand their situation. A caregiver of a male partner with a non-traumatic haemorrhagic stroke described how some people had let her down in the past when she was expecting support:

There is a group that does not really want to help. It's complicated. They say they will come by... but are still acting with their former attitude towards my husband... 'He was always so good in this'....'why is not he more active?'... 'doesn't he want to do it?' (couple 10).

Respondents recounted that some members of their social network seemed to presume that they still lived their lives the way they did before the injury. For example, due to an ABI, one man has cognitive and behavioural problems, but members of his social network had failed to grasp the impact of the ABI on his day-to-day life. His caregiver echoed this sentiment: 'The outside world remembers my husband's previous behaviour' (couple 10). Although couples understand this lack of adaptation to the new situation, this provides yet another reason to refrain from asking for support.

The last reason for not wanting to ask for support is assumed incompetence. Support tasks may not match with the support givers' competencies or may not be tenable due to their other obligations. A male respondent with an SCI observed:

One often does not have the skills or does not see what needs to be done... And yes, there are a lot of people who feel that they want to do something, but they actually cannot do it. And to be honest, it would not fit in their lives at all. (couple 4).

However, since recipients do not want to appear ungrateful, these feelings are rarely expressed. To avoid these situations in the future, receivers subsequently refrain from asking friends or acquaintances for assistance.

3.3.4 | Fear of intrusion into one's privacy and independence

Five couples (2, 5, 13, 15 and 19) feared receiving assistance would allow others to intrude on their privacy and independence. Whilst a large active social network can provide support, it can simultaneously be experienced as an invasion of privacy. As this caregiver describes:

A lot of people are coming over for dinner [to visit him]... But at a certain point, I said, 'I'm a bit done with that! I am always busy running to the shop, doing the extra cooking.' (couple 15).

One woman with a non-traumatic stroke reported feeling her sense of independence had been violated. She recounted how support from her children came with an unwanted sense of dependency:

And I'm also very dependent on my daughter and sons for what they have in store for me. Recently, my son took me to a swimming pool because his son had lessons there, you know. That sort of thing. I want to be able to drive my car myself as soon as possible. (couple 19).

As the following respondents explain whilst describing their fellow church members, well-meant support can become intrusive and invasive.

This... enormous enthusiastic church. So, those people also claim... they claim you, eh. In other words, when they come over, they really come over... Saying like, 'But I've cooked some extra, I'll bring some food tonight'. And I think: 'oops, I do not want that food at all'... But these are the things that you are being pushed into. (couple 2).

One couple reported experiencing an overload of support. For example, when they spent the weekend with friends for Christmas, a respondent with SCI recounts how she did not get an opportunity to do anything for others and instead was forced to remain passive:

... at one moment I thought I'd make some coffee... But I tell you, [my friend] was one step ahead of me every time. And in the end ... you get the feeling that you are useless, you know? You actually want to do something, but it's important I can do it my own way. And when we got home, I was stiff as a board. I just had had too little exercise. (couple 5).

3.3.5 | Not wanting support given out of pity or curiosity

Three couples (2, 11 and 18) felt that help was sometimes given for dubious reasons, such as curiosity or pity rather than genuine empathy. One caregiver explained:

Caregiver: Yes, and sometimes you say 'they are all curiosity seekers'.

Patient: Yes, curiosity seekers: 'Look at him being pathetic out there'. Well, that was... a disillusion. (couple 2).

Another couple told us about a very eager and curious neighbour. In the past, the patient could shut herself off from this neighbour, but now it cost her too much energy. As her caregiver explained:

There's this other neighbour you need to keep your distance from... She is pulling her strings. She does not do that on purpose, but it's just her character. Yes... and terribly nosy. She's a good woman really, but... (couple 11).

Occasional support givers can also react with too much empathy and show pity that is not appreciated:

Caregiver: There are a lot of people who come over saying: 'This is so sad'. To which I reply, 'It is not sad. He's still here...'

Patient: Yeah, I think the sad part is pathetic. That's so stupid. (couple 18).

4 | DISCUSSION

Our results show that the willingness of rehabilitation patients and their caregivers to receive social support from family members and friends is often limited, thus suggesting that social networks cannot provide an easy fix to facilitate the transition from the rehabilitation facility to home (Hillebregt et al., 2018) and reintegration into the community (Boschen et al., 2003). We found that most couples

had solid reasons for not wanting to invoke more support from their social network despite the presence of good connections. We identified five reasons for this reluctance: (1) not wanting to be a (bigger) burden, (2) not accustomed asking support, (3) a lack of reliability, competence or comprehension, (4) fear of intrusion into one's privacy and independence and (5) fear or problematic motivations such as curiosity or pity.

Some of these reasons resemble barriers found in previous studies in adult healthcare and welfare, such as the concern over being a burden (Metze et al., 2015b, 2019) and shame and fear of rejection (de Jong & Schout, 2013a, 2013b; de Jong, Schout, & Abma, 2015; de Jong, Schout, Pennell, et al., 2015; de Jong et al., 2018; Meijer et al., 2019; Metze et al., 2015a, 2015b; Schout et al., 2017; Schout & de Jong, 2017). The reluctance to ask for (more) support confirms prior research on the principle of reciprocity (Mauss, 2002) in public mental healthcare, general social welfare and elderly social welfare (Bredewold et al., 2016; de Jong, Schout, & Abma, 2015; de Jong, Schout, Pennell, et al., 2015; Malmberg-Heimonen & Johansen, 2014; Metze et al., 2015a, 2015b). As in other contexts, couples in rehabilitation care also consider reciprocity as the basis for interpersonal relationships and fear that asking more support would disturb the fragile balance of give and take in the relationships with the members of their social network. A lack of reciprocity is an oft-neglected reason for not wanting to ask for informal help and support (Bredewold et al., 2016, 2020).

The couples we interviewed were constantly striving for a balance between their needs and (potential) help offered by family, friends or neighbours. They were afraid to ask too much from others and lose their privacy and independence because of overbearing or sometimes even intrusive help. The 'burden of gratitude' (Galvin, 2004; Rummery & Fine, 2012) complicates this even more due to the implicit expectation that support from friends should be welcomed and gratefully appreciated. This makes it difficult to express feelings of tiredness or being overburdened by an overload of well-intended but sometimes also disempowering and dysfunctional support. Our study reveals that striking the right balance proved a daunting task for care receivers.

These findings on the reluctance to ask one's social network for care and support indicate that FGCs cannot be the quick fix for reintegration into the community that they are sometimes assumed to be. Patients and their caregivers can have solid reasons for not wanting to ask their social network to get involved or contribute more than they already do.

4.1 | Practical implications

As our results show, it is not self-evident that having a good social support system and being competent enough to ask for help will lead to the actual activation of the support network. The five identified reasons in our study to decline social support are implicitly present but often not explicitly talked about. The negative side of social

relations has been largely ignored and has received considerably less attention than the positive demonstrated health outcomes related to having a good social network. Accordingly, Lincoln (2000) calls for a dual nature of social support emphasising both positive and negative interactions (Lincoln, 2000). Translated into practice, this means that social care professionals in both clinical and community care have to assess and recognise the strength of an individual's social network on the one hand and detect the level of reluctance people feel towards asking for social support on the other.

Thus, besides estimating the capability, reliability and competence of the social support network, professionals must also discuss people's help-seeking behaviour. Are there feelings of being a burden present? Do patients and caregivers fear a loss of privacy or independence when seeking help from friends or family? Supporting people in overcoming feelings of shame can be helpful (Schout, 2020), but only after couples have indicated that they actually *want* to involve others but have never learned how to do that. If, by contrast, people indicate that they do *not* want to involve those in their social network, this should be respected.

It is clear by now that we can refute the assumption still prevalent in many Western welfare states that social support centred interventions such as FGC are beneficial for all. Instead, FGC should be offered as an optional alternative to formal, paid professional support.

4.2 | Conclusion

FGC is based on the presumption that people want to involve their social network and that their situation will improve if they do so; therefore, they need to be coached and coaxed into asking for support from their network. However, our study shows that this presupposition is not always founded. Several barriers can be experienced preventing patients and current caregivers from requesting assistance despite the presence of a strong social network. The fragile reciprocity balance between patient/caregiver and their network seems one major influencing factor in giving and receiving social support and community reintegration. These findings should lead to a tailor-made approach from healthcare professionals who need to be aware of both the positive and the negative aspects that come with receiving care.

4.3 | Limitations

This study draws on a rather low response rate of 36.4%, as only 20 out of 55 PWDs and their caregivers agreed to be interviewed. One explanation could be that all approached couples were still in the rather 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 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 sample size of 55 respondents is insufficient to adequately reflect the whole population. This is especially relevant with regard to the self-efficacy of PWDs and caregivers. The larger project that this study is part of was aimed at PWDs and caregivers with low self-efficacy. Previous research suggests that people with high self-efficacy experience less caregiver strain (Kruithof et al., 2016; Van den Heuvel et al., 2001) and therefore have little reason to request support from their network. Hence, people with high self-efficacy might be even less inclined to activate network support. It might be worthwhile to compare both low- and high-efficacy groups in future research to determine whether this expectation is well-founded.

Third, we interviewed the PWD/caregiver couples together. Although this was a deliberate choice as this provided us insights into the interactions and dynamics between PWDs and caregivers, it may have restricted some individuals from speaking freely.

Last, the research took place within the context of the rehabilitation treatment setting in the Netherlands. Thus, translating our findings to a different setting in other countries would require caution. However, we think that the content outlined in this study is not typical for just the Dutch population but may also apply in other Western countries as these have similar healthcare systems and a similar trend toward involving the social network. Further research would be needed to verify this supposition.

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CONFLICT OF INTEREST

The authors report no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author, [ET], upon reasonable request.

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REFERENCES

Abrahamson, V., Jensen, J., Springett, K., & Sakel, M. (2017). Experiences of patients with traumatic brain injury and their carers during

- transition from in-patient rehabilitation to the community: a qualitative study. *Disability and Rehabilitation*, 39(17), 1683–1694. <https://doi.org/10.1080/09638288.2016.1211755>
- Boschen, K. A., Tonack, M., & Gargaro, J. (2003). Long-term adjustment and community reintegration following spinal cord injury. *International Journal of Rehabilitation Research*, 26(3), 157–164. <https://doi.org/10.1097/00004356-200309000-00001>
- Bosscher, R. J., & Smit, J. H. (1998). Confirmatory factor analysis of the General Self-Efficacy Scale. *Behaviour Research and Therapy*, 36(3), 339–343. [https://doi.org/10.1016/S0005-7967\(98\)00025-4](https://doi.org/10.1016/S0005-7967(98)00025-4)
- Bosscher, R. J., Smit, J. H., & Kempen, G. I. J. M. (1997). Algemene competentieverwachtingen bij ouderen [General competence expectations in the elderly]. *Nederlands Tijdschrift Voor de Psychologie*, 52, 239–248.
- Boyatzis, R. (1998). *Thematic analysis and code development: Transforming qualitative information*. Sage Publications.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Bredewold, F., Tonkens, E., & Trappenburg, M. (2016). Solidarity and reciprocity between people with and without disabilities. *Journal of Community & Applied Social Psychology*, 26(6), 534–550. <https://doi.org/10.1002/casp.2279>
- Bredewold, F., Verplanke, L., Kampen, T., Tonkens, E., & Duyvendak, J. (2020). The care receivers perspective: How care-dependent people struggle with accepting help from family members, friends and neighbours. *Health and Social Care in the Community*, 28(3), 762–770. <https://doi.org/10.1111/hsc.12906>
- Corbin, J., & Strauss, A. (1998). Basics of qualitative research: Techniques and procedures. In *Basic qualitative research* (Vol. 36, Issue 3). Sage Publications.
- Cropanzano, R., & Mitchell, M. (2005). Social exchange theory: An interdisciplinary review article in *Journal of Management*. *Journals*. Sagepub.Com, 31(6), 874–900. <https://doi.org/10.1177/0149206305279602>
- Cunning, S., & Bartlett, D. (2006). *Family Group Conferencing: Assessing the long-term effectiveness of an alternative approach in child protection*. Centre of Excellence for Child Welfare.
- de Jong, G., & Schout, G. (2013a). Researching the applicability of family group conferencing in public mental health care. *British Journal of Social Work*, 43(4), 796–802. <https://doi.org/10.1093/bjsw/bcs006>
- de Jong, G., & Schout, G. (2013b). Breaking through marginalisation in public mental health care with Family Group Conferencing: Shame as risk and protective factor. *British Journal of Social Work*, 43(7), 1439–1454. <https://doi.org/10.1093/bjsw/bcs050>
- de Jong, G., Schout, G., & Abma, T. (2015). Examining the effects of family group conferencing with randomised controlled trials: The golden standard? *British Journal of Social Work*, 45(5), 1623–1629. <https://doi.org/10.1093/bjsw/bcv027>
- de Jong, G., Schout, G., & Abma, T. (2018). Understanding the process of family group conferencing in public mental health care: A multiple case study. *British Journal of Social Work*, 48(2), 353–370. <https://doi.org/10.1093/bjsw/bcx037>
- de Jong, G., Schout, G., Meijer, E., Mulder, C. L., & Abma, T. (2016). Versterken van eigen kracht en sociale steun: Opbrengsten van Eigen Kracht-conferenties in de openbare geestelijke gezondheidszorg [Enabling social support and resilience: outcomes of Family Group Conferencing in public mental health care]. *European Journal of Social Work*, 19(5), 731–748. <https://doi.org/10.1080/13691457.2015.1081585>
- de Jong, G., Schout, G., Pennell, J., & Abma, T. (2015). Family Group Conferencing in public mental health and social capital theory. *Journal of Social Work*, 15(3), 277–296. <https://doi.org/10.1177/1468017314547675>
- Deek, H., Hamilton, S., Brown, N., Inglis, S. C., Digiaco, M., Newton, P. J., Noureddine, S., Macdonald, P. S., & Davidson, P. M. (2016).

- Family-centred approaches to healthcare interventions in chronic diseases in adults: A quantitative systematic review. *Journal of Advanced Nursing*, 72(5), 968–979. <https://doi.org/10.1111/JAN.12885>
- Dijkstra, S., Creemers, H. E., Asscher, J. J., Deković, M., & Stams, G. J. M. (2016). The effectiveness of family group conferencing in youth care: A meta-analysis. *Child Abuse and Neglect*, 62, 100–110. <https://doi.org/10.1016/j.chiabu.2016.10.017>
- Faulkner, M., & Davies, S. (2005). Social support in the healthcare setting: the role of volunteers. *Health & Social Care in the Community*, 13(1), 38–45. <https://doi.org/10.1111/J.1365-2524.2005.00526.X>
- Fronek, P. (2005). *Insights from the family conference: Observations in rehabilitation*. Australian Social Work <http://onlinelibrary.wiley.com.proxy.library.uu.nl/doi/10.1111/j.1447-0748.2005.00235.x/full>
- Galvin, R. (2004). Challenging the need for gratitude: Comparisons between paid and unpaid care for disabled people. *Journal of Sociology*, 40(2), 137–155. <https://doi.org/10.1177/1440783304043453>
- Greenwood, N., Mackenzie, A., Wilson, N., & Cloud, G. (2009). Managing uncertainty in life after stroke: A qualitative study of the experiences of established and new informal carers in the first 3 months after discharge. *International Journal of Nursing Studies*, 46(8), 1122–1133. <https://doi.org/10.1016/j.ijnurstu.2009.02.011>
- Hillebregt, C. F., Scholten, E. W. M., Ketelaar, M., Post, M., & Visser-Meily, J. (2018). Effects of family group conferences among high-risk patients of chronic disability and their significant others: Study protocol for a multicentre controlled trial. *BMJ Open*, 8(3), e018883. <https://doi.org/10.1136/bmjopen-2017-018883>
- Hillebregt, C. F., Scholten, E. W. M., Post, M. W. M., Visser-Meily, J. M. A., & Ketelaar, M. (2019). Family group decision-making interventions in adult healthcare and welfare: A systematic literature review of its key elements and effectiveness. *BMJ Open*, 9(4), e026768. <https://doi.org/10.1136/bmjopen-2018-026768>
- Hudson, P., Thomas, T., Quinn, K., & Aranda, S. (2009). Family meetings in palliative care: Are they effective? *Palliative Medicine*, 23(2), 150–157. <https://doi.org/10.1177/0269216308099960>
- Johansen, S. (2014). Psycho-social processes and outcomes of family group conferences for long-term social assistance recipients. *British Journal of Social Work*, 44(1), 145–162. <https://doi.org/10.1093/bjsw/bcs100>
- Kerr, S. M., & Smith, L. N. (2001). Stroke: An exploration of the experience of informal caregiving. *Clinical Rehabilitation*, 15(4), 428–436. <https://doi.org/10.1191/026921501678310234>
- Kirkevold, M. (2002). The unfolding illness trajectory of stroke. *Disability and Rehabilitation*, 24(17), 887–898. <https://doi.org/10.1080/09638280210142239>
- Komter, A. (2003). *Solidariteit en de gift: Sociale banden en sociale uitsluiting [Solidarity and the gift: social ties and social exclusion]*. Amsterdam University Press.
- Kruithof, W. J., Post, M. W., Ma Visser-Meily, J., Center, B., & Magnus, R. (2015). Measuring negative and positive caregiving experiences: A psychometric analysis of the Caregiver Strain Index Expanded Article. *Clinical Rehabilitation*, 29(12), 1224–1233. <https://doi.org/10.1177/0269215515570378>
- Kruithof, W. J., Post, M. W. M., van Mierlo, M. L., van den Bos, G. A. M., de Man-van Ginkel, J. M., & Visser-Meily, J. M. A. (2016). Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: Determinants and prediction. *Patient Education and Counseling*, 99(10), 1632–1640. <https://doi.org/10.1016/j.pec.2016.04.007>
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Sage Publications Thousand Oaks.
- Lincoln, K. D. (2000). Social support, negative social interactions, and psychological well-being. *Social Service Review*, 74(2), 231–252. <https://doi.org/10.1086/514478>
- Loupis, Y. M., & Faux, S. G. (2013). Family conferences in stroke rehabilitation: A literature review. *Journal of Stroke and Cerebrovascular Diseases*, 22(6), 883–893. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2012.12.003>
- Lynch, J., & Cahalan, R. (2017). The impact of spinal cord injury on the quality of life of primary family caregivers: A literature review. *Spinal Cord*, 55(11), 964–978. <https://doi.org/10.1038/sc.2017.56>
- Malmberg-Heimonen, I. (2011). The effects of family group conferences on social support and mental health for longer-term social assistance recipients in Norway. *British Journal of Social Work*, 41(5), 949–967. <https://doi.org/10.1093/bjsw/bcr001>
- Malmberg-Heimonen, I., & Johansen, S. (2014). Understanding the longer-term effects of family group conferences. *European Journal of Social Work*, 17(4), 556–571. <https://doi.org/10.1080/13691457.2013.818528>
- Mauss, M. (2002). *The gift: The form and reason for exchange in archaic societies*. Routledge.
- McKevitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of stroke: A systematic review. *Stroke*, 35(6), 1499–1505. <https://doi.org/10.1161/01.STR.0000127532.64840.36>
- Meijer, E., Schout, G., & Abma, T. (2019). Family group conferencing in coercive psychiatry: On forming partnership between the client, social networks and professionals. *Issues in Mental Health Nursing*, 40(6), 459–465. <https://doi.org/10.1080/01612840.2018.1563254>
- Merkel-Holguin, L. (2005). The intersection between family group decision making and systems-of-care. *American Humane FGDM Issues in Brief*, 1–2.
- Metze, R. N., Abma, T. A., & Kwekkeboom, M. H. (2019). Family group conferencing for older adults: Social workers' views. *Journal of Social Work*, 19(3), 351–371. <https://doi.org/10.1177/1468017318761732>
- Metze, R. N., Kwekkeboom, R. H., & Abma, T. A. (2015a). The potential of Family Group Conferencing for the resilience and relational autonomy of older adults. *Journal of Aging Studies*, 34, 68–81. <https://doi.org/10.1016/j.jaging.2015.04.005>
- Metze, R. N., Kwekkeboom, R. H., & Abma, T. A. (2015b). "You don't show everyone your weakness": Older adults' views on using Family Group Conferencing to regain control and autonomy. *Journal of Aging Studies*, 34, 57–67. <https://doi.org/10.1016/j.jaging.2015.04.003>
- Oorschot van, W., & Komter, A. (1998). What is it that ties...? Theoretical perspectives on social bond. *Sociale Wetenschappen*, 41(3), 4–24.
- Park, M., Giap, T. T. T., Lee, M., Jeong, H., Jeong, M., & Go, Y. (2018). Patient- and family-centered care interventions for improving the quality of health care: A review of systematic reviews. *International Journal of Nursing Studies*, 87, 69–83. <https://doi.org/10.1016/j.ijnurstu.2018.07.006>
- Pavolini, E., & Ranci, C. (2008). Restructuring the welfare state: Reforms in long-term care in Western European countries. *Journal of European Social Policy*, 18(3), 246–259. <https://doi.org/10.1177/0958928708091058>
- Piccenna, L., Lannin, N. A., Gruen, R., Pattuwage, L., & Bragge, P. (2016). The experience of discharge for patients with an acquired brain injury from the inpatient to the community setting: A qualitative review. *Brain Injury*, 30(3), 241–251. <https://doi.org/10.3109/02699052.2015.1113569>
- Post, M., Bloemen, J., & de Witte, L. (2005). Burden of support for partners of persons with spinal cord injuries. *Spinal Cord*, 43(5), 311–319. <https://doi.org/10.1038/sj.sc.3101704>
- Rigby, H., Gubitz, G., & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke*, 4(4), 285–292. <https://doi.org/10.1111/j.1747-4949.2009.00289.x>
- Rittman, M., Boylstein, C., Hinojosa, R., Hinojosa, M. S., & Haun, J. (2007). Transition experiences of stroke survivors following discharge home. *Topics in Stroke Rehabilitation*, 14(2), 21–31. <https://doi.org/10.1310/tsr1402-21>

- Rotondi, A. J., Sinkule, J., Balzer, K., Harris, J., & Moldovan, R. (2007). A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *Journal of Head Trauma Rehabilitation*, 22(1), 14–25. <https://doi.org/10.1097/00001199-200701000-00002>
- Rummery, K., & Fine, M. (2012). Care: A critical review of theory, policy and practice. *Social Policy and Administration*, 46(3), 321–343. <https://doi.org/10.1111/j.1467-9515.2012.00845.x>
- Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: a qualitative meta-synthesis. *Journal of Rehabilitation Medicine*, 40, 595–602. <https://doi.org/10.2340/16501977-0238>
- Scholten, E., Kieftenbelt, A., Hillebregt, C., de Groot, S., Ketelaar, M., Visser-Meily, J., & Post, M. (2018). Provided support, caregiver burden and well-being in partners of persons with spinal cord injury 5 years after discharge from first inpatient rehabilitation. *Spinal Cord*, 56, 436–446. <https://doi.org/10.1038/s41393-017-0047-x>
- Schout, G. (2020). Into the swampy lowlands evaluating family group conferences. *European Journal of Social Work*, 25(1), 41–50. <https://doi.org/10.1080/13691457.2020.1760796>
- Schout, G., & de Jong, G. (2017). Collecting feedback as a tool to reduce care paralysis: Something for family group conferencing coordinators? *Child and Family Social Work*, 22(3), 1197–1206. <https://doi.org/10.1111/cfs.12336>
- Schout, G., van Dijk, M., Meijer, E., Landeweer, E., & de Jong, G. (2017). The use of family group conferences in mental health: Barriers for implementation. *Journal of Social Work*, 17(1), 52–70. <https://doi.org/10.1177/1468017316637227>
- Stiekema, A. P. M., Winkens, I., Ponds, R., de Vugt, M. E., & van Heugten, C. M. (2020). Finding a new balance in life: A qualitative study on perceived long-term needs of people with acquired brain injury and partners. *Brain Injury*, 34(3), 421–429. <https://doi.org/10.1080/02699052.2020.1725125>
- Tonkens, E. (2012). Working with Arlie Hochschild: Connecting feelings to social change. *Social Politics*, 19(2), 194–218. <https://doi.org/10.1093/sp/jxs003>
- Trappenburg, M. (2015). *Active Solidarity and Its Discontents* (23(3), pp. 207–220). Springer. <https://doi.org/10.1007/s10728-013-0260-5>
- Van den Heuvel, E. T., De Witte, L. P., Schure, L. M., Sanderman, R., & Meyboom-de Jong, B. (2001). Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention. *Clinical Rehabilitation*, 15(6), 669–677. <https://doi.org/10.1191/0269215501cr446oa>
- Visser-Meily, A., Post, M., Schepers, V., Ketelaar, M., van Heugten, C., & Lindeman, E. (2005). Spouses' satisfaction with caregiver support in stroke rehabilitation. *Scandinavian Journal of Caring Sciences*, 19, 310–316.
- Wisby, M., Rosendale, E., & Gorbien, M. J. (1996). The family meeting: A benchmark of high-quality geriatric care. *Continuum (Society for Social Work Administrators in Health Care)*, 16(5), 10–17.
- Wissel, J., Olver, J., & Sunnerhagen, K. S. (2013). Navigating the post-stroke continuum of care. *Journal of Stroke and Cerebrovascular Diseases*, 22(1), 1–8.
- Wright, T. (2008). Using family group conference in mental health. *Nursing Times*, 104(4), 34–35.

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