

# ‘Let us be’

Social support needs of people with  
acquired long-term disabilities and their caregivers  
in rehabilitation practice in the Netherlands



Chantal Hillebregt



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# **'Let us be'**

Social support needs of people with acquired long-term disabilities  
and their caregivers in rehabilitation practice in the Netherlands

# **'Laat ons'**

Sociale ondersteuningsbehoeften van mensen met langdurige  
beperkingen en hun naasten in de Nederlandse revalidatiezorg  
(met een samenvatting in het Nederlands)

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Prof. dr. L.H. Visser, Universiteit voor Humanistiek

**Navigate with your heart**

**The route is within you**

**Don't be afraid to fall**

**The bigger steps you will make**





# Contents

Chapter 1	Introduction	9
<b>Part I Evidence and POWER-study</b>		
Chapter 2	Effects of family group conferences among high-risk patients of chronic disability and their significant others: study protocol for a multicentre controlled trial	29
Chapter 3	Family group decision-making interventions in adult healthcare and welfare: a systematic literature review of its key elements and effectiveness	59
<b>Part II Social support and burden</b>		
Chapter 4	Barriers and facilitators of family group decision making in adult healthcare and welfare: a qualitative review	87
Chapter 5	'Let us be'. Social support needs of people with acquired long-term disabilities and their caregivers in rehabilitation practice in the Netherlands	111
Chapter 6	'Living the life of the other': carers' perspectives on changes in carer strain during the rehabilitation trajectory	135
Chapter 7	Conclusion	161
Appendices	Summary	183
	Samenvatting	191
	Dankwoord	199
	About the author	203



# CHAPTER 1

## INTRODUCTION



# Background

## Social context of caregiving in the Netherlands

More people are likely to develop chronic diseases in the future as the proportion of older people in the society increases. In 2015, there were 4,3 million people with (multiple) chronic diseases in the Netherlands. An increase of 28% is estimated in 2040, resulting in a total of 5,5 million people with chronic diseases (Hilderink & Verschuuren, 2018). Besides an aging population, also medical-technological progress is inducing healthcare expenditure (Chandra & Skinner, 2011; Liebenberg & Ungar, 2015; Newhouse, 1992; Newman & Tonkens, 2011; van Hees et al., 2020), which is expected to double by 2040 compared to 2015 (Hilderink & Verschuuren, 2018).

As in many other Western European countries, in the Netherlands this has led to significant reforms in long-term care policies (Pavolini & Ranci, 2008). Over the last few decades, the government has implemented major reforms to its caregiving regime (Newman & Tonkens, 2011). To reduce public expenditures for example, more responsibility is allocated to 'active citizens': citizens who aim to reduce their dependence on the welfare state (Newman & Tonkens, 2011) take responsibility for themselves and support each other (Tonkens, 2012). In line with this trend, citizens in the Netherlands have been encouraged to actively arrange care by themselves and are expected to rely more on the help of family and friends than on government support and professional expertise (Bredewold et al., 2020).

The idea is that the shift from formal to informal care can offset cuts in professional care. However, most people already provide care to their loved ones and do not need encouragement from the government or other formal agencies (Witteveen et al., 2021). In the Netherlands, almost 35% of people aged 16 years and older (almost 5 million people) provide informal care to family, friends, and others for an average of more than seven hours per week. Of these, 2 million combine the provision of informal care with paid work (de Boer et al., 2020; Kooiker et al., 2019; Witteveen et al., 2021). In this dissertation, we understand informal care as all unpaid care provided to dependent persons by a person with whom they

share a social relationship (Broese van Groenou & De Boer, 2016; de Boer et al., 2020).

In addition to economy-driven pressure, social network support can also be explained by the emancipatory movement that opposed the paternalism of professionals working in the welfare state at the time (Tonkens, 2004; Trappenburg, 2008). In the past decades, democratisation of healthcare and critiques of the power of professionals over clients have supported the idea that clients would be better off if professionals would step aside and delegate some of their power to clients and their networks (VWS, 2001). Informal care and support were supposed to be more accessible, personal and warm than the supposedly cold and paternalistic formal care (Mead & Bower, 2000).

At the same time, we observe several demographic and societal developments in contemporary Western society that have a negative impact on the quality and supply of informal care. For example, a high degree of individualisation, an aging population, and changing family structures are all factors that lead to poor social networks and weak family ties (Broese van Groenou & De Boer, 2016), which may influence the caregiving reform policy to channel citizens toward more informal care. Nevertheless, this shift from formal to informal care has led to many initiatives in different healthcare and welfare settings, with more emphasis on family involvement (Dijkstra et al., 2016; Wissel et al., 2013). This also has implications for the role of social professionals who are expected to assess clients' needs more and determine how their social network can support them (Newman & Tonkens, 2011).

### **Coping with disability: transition from inpatient care to home**

This trend to involve social networks also has an impact on current rehabilitation practices that provide care to people with disabilities (Visser-Meily et al., 2006). In the Netherlands, people are often admitted to rehabilitation centres when they have developed complex neurological disorders like acquired brain injury (ABI) or spinal cord injury (SCI). They receive inpatient care for weeks or months where multidisciplinary teams perform a comprehensive assessment and treatment of functioning (Bloemen-Vrencken et al., 2007).

## Chapter 1

The majority of these people return home after discharge. There has been increased awareness of the importance of the transitional phase from clinic to home in the recent years (Abrahamson et al., 2017; Cott et al., 2007; Ellis-Hill et al., 2009; Gustafsson & Bootle, 2013; Piccenna et al., 2016; Turner et al., 2007, 2008, 2011; van de Velde et al., 2010) and this has been recognised as the starting point of the community integration process (McCabe et al., 2007; Turner et al., 2007, 2011). However, many people with disabilities and their caregivers feel inadequately prepared to cope with disabilities in daily life and experience a significant gap between the protected clinical environment and life in the community (McKevitt et al., 2004; Visser-Meily et al., 2005). The transition from inpatient care to resuming life at home and reintegration into the community, can be quite challenging. Both the person with the disability and the caregiver must adapt to cope with the limitations in their own home environment while optimising their remaining abilities. They must devise new routines and re-familiarise themselves with activities of daily living (Greenwood et al., 2009).

In a split second the lives of Monique (66) and her recently retired husband Richard (67) abruptly turned into chaos. While visiting the library, Monique suddenly collapsed and suffered a stroke that paralysed her on the right side. After inpatient rehabilitation treatment, she was able to walk short distances again, but her arm and hand regained no function. The transition from the clinic to functioning home again was big. At home, Monique's energy level remained very low where it was necessary for her to rest after each activity. She still needed a lot of help to find her way at home in doing the daily chores. Richard tried to support her unconditionally, but experienced a lot of strain being her primary carer now. It was still too dangerous to leave Monique alone. Richard put his weekly volunteer work and other social activities on hold. They could never have imagined that they would have to spend their retirement like this and adjust to their new lives like this. Family and friends saw them struggling and did offer their help, but it was firmly rejected by Monique and Richard. It was just too hard to accept help when they were not able to reciprocate. They had never had to ask for help in their lives and preferred to take on the burden together as a couple.

*'All the people around me, have been working so hard to support me. But it is extremely difficult. I used to be always the one to whom everyone could turn to! Now, it's exactly the other way around. I can't do anything in return. I feel terrible!'*

In the vignette about Monique and Richard above, it is clear that Monique's disability has a huge impact on their daily lives. Serious chronic long-term illness leads to significant life disruption (Bury, 1991). There was a life before and after the injury. As we see in the case of this couple, it is not only the person with the disability who is struggling to cope. The people closest by struggle too. It is often the primary caregiver, in this case Richard, who is faced with challenges as all the care responsibilities fall on him. Caregivers of persons with chronic disabilities often encounter difficulties in their caregiving duties and face challenges in their responsibilities to meet the needs of the latter (Sales, 2003; Schulz & Beach, 1999). Consequently, they may experience constant anxiety, reduced social activities, and loneliness (Kerr & Smith, 2001; Rigby et al., 2009). Spousal caregivers provide most of the help compared to other family caregivers (de Boer et al., 2020; Kooiker et al., 2019; Witteveen et al., 2021).

### **Family involvement in social support**

In the last few decades, the emancipatory patient movement has altered the traditional professionally driven care ideology within rehabilitation too, wherein professionals used to have a monopoly on expertise. In current rehabilitation practice, patient-centred care is adopted as an approach in which patients are given increasing power and responsibility to make their own choices, participate in decision-making and exercise control over their own lives. Increasing emphasis is also placed on the social network to play a larger role in supporting the person with the disability and caregiver during treatment. This is consistent with the assumption that more family involvement can help with the transition from clinic to home, among other things. The social network is increasingly expected to act as an additional safety net and take on a more guiding and prominent role than before by taking over tasks from professionals (Bredewold et al., 2018), and reduce some of the burden of the caregiver by sharing tasks.

Family-centred care incorporates active involvement of the person with disability and their caregiver based on the following notions (Bamm & Rosenbaum, 2008; Kovacs et al., 2006; MacKean et al., 2005):

## Chapter 1

- The person with the disability and their families are the experts of their own needs;
- Partnership is fostered between the person with a disability, the family, and the professional;
- The person with disability and the family's role in decision making is supported.

The focus of family centred care interventions, including the potential to reduce the burden of the caregiver, among others, lies in engaging the broader social network of *the family* as part of the treatment. The term “family” in general, includes extended family members, friends, neighbours, and significant others (Sundell & Vinnerljung, 2004).

### **Family Group Decision Making**

An example of an intervention that incorporates these notions of family centred care is family group decision-making (FGDM). This intervention is characterised by invoking shared decision-making and active social support of family members. Patients, caregivers, and their social networks work closely together to create an action plan and reflect on their goals (Connolly, 1994; de Jong et al., 2015; Morris & Connolly, 2012; Shlonsky et al., 2009). FGDM consists of structured meetings wherein the balance of power is shifted from the professional to the person in need, the caregiver, and their social network (Lupton, 1998), with the aim of supporting them.

FGDM originated from the New Zealand Family Group Conferences (FGC) model first legislated in 1989 (Merkel-Holguin & Marcynyszyn, 2015; New Zealand Legislation, 1989) and has been implemented in for child care and welfare in more than 30 countries worldwide (Frost et al., 2014). In the Netherlands, the Dutch Foundation FGC initiated conferences called “Eigen Kracht conferenties” (Empowerment conferences) (*Eigen-Kracht.Nl*, n.d.). Although FGDM is relatively new among the adult population, studies have expanded to include public mental healthcare (de Jong et al., 2015, 2016; de Jong et al., 2015; de Jong & Schout, 2013; Wright, 2008), general social welfare (Johansen, 2014; Malmberg-Heimonen, 2011; Malmberg-Heimonen & Johansen, 2014) and elderly social welfare (Metze et al., 2015b, 2015a).



Interest in a family centred care approach is growing in the rehabilitation medicine setting too (Visser-Meily et al., 2006). In 2015, the implementation of FGDM in rehabilitation practice in the Netherlands was initiated. It was expected that through the support of family and friends, both the patient and caregiver would become more empowered after undergoing a sudden life event, such as acquiring a disability. Thus, the FGDM would accelerate participation and integration into the community. However, scientific research on FGDM in rehabilitation is still lacking. First, little is known about the feasibility and effectiveness of FGDM. Second, the perspectives of the persons in need and their caregivers, their needs for social support, and the perceived burden of caregivers are still unexplored. Both these factors are the focus of this study.

### **The POWER-study: evaluation and effectiveness**

This gap in the body of knowledge has led us to initiate a study to evaluate the feasibility of implementing FGDM in a rehabilitation medicine setting. The Center of Excellence for Rehabilitation Medicine Utrecht (UMC Utrecht Brain Center and De Hoogstraat Rehabilitation) initiated the POWER study (short for emPOWERment), a multicentre controlled trial conducted from 2015 to 2019 in 12 rehabilitation centres in the Netherlands. Rehabilitation centres are clinics where people with a disability receive inpatient treatment for a set period. The hypothesis was that FGDM could contribute to facilitating the transition from clinic to home by increasing patients' and caregivers' self-efficacy and participation levels through social support from family and friends.

The first part of this thesis begins by describing our initial intervention study with the following aims:

- *Evaluate the effectiveness and implementation of FGDM in rehabilitation practice*
- *Evaluate the effectiveness of FGDM interventions in other adult healthcare and welfare settings*

As part of the POWER-study, a study protocol was written and a systematic review was initiated as there is no research to date on the effectiveness of FGDM interventions in adult healthcare and welfare settings. Patients and caregivers were

## Chapter 1

included in the FGDM intervention based on their level of self-efficacy (Bosscher et al., 1997; Bosscher & Smit, 1998). The intervention consisted of three meetings. The first meeting was scheduled at clinical admission and supported both the patient and the social network during the discharge to home phase. The second and third meetings were continued at 1.5 and 3 months post discharge until the completion of the outpatient rehabilitation period.

A total of 329 dyads of clinically admitted patients and their significant others were included (Scholten, 2020). All patients studied were eligible for FGDM-intervention and clinically admitted to a rehabilitation centre, followed by a period of outpatient care after discharge to their own homes. Most patients suffered from acquired brain or spinal cord injuries. Although the desired sample size was 82 couples in the intervention group and 82 couples in the usual care group, only 4 couples accepted the intervention (Hillebregt et al., 2018). Therefore, the aim of the intervention study to evaluate the effectiveness could not be met.

Low participation rates are not uncommon, as is clear from other studies implementing FGDM in adult healthcare and welfare settings, for example in public mental health (de Jong et al., 2015), general social welfare (Malmberg-Heimonen & Johansen, 2014) or social services for the elderly (Metze et al., 2015b). The initial evaluation of the POWER study showed that in addition to barriers to the implementation of FGDMs in a medical rehabilitation setting, there were organizational reasons too for this failed intervention (no referral to the centres' outpatient rehabilitation program, time constraints, too short rehabilitation period).

However, the most striking and common barrier was the refusal of couples to participate. Most people proved to be very reluctant to ask their networks for support (Post et al. to be submitted). This was not anticipated. Particularly, since a thorough preliminary study was conducted wherein representatives of various patient associations had been interviewed about their need for social support and contributed to the design of this study. The exact reasons for this reluctance were unknown and thus had to be further explained. Consequently, this raised a series of new questions and took us back to the drawing board to design further in-depth research on this issue. The second part of this thesis is dedicated to finding answers to what caused the reluctance toward social support.

## **Reluctance to receive social support**

First, are there lessons to be learned from other settings in health and adult welfare regarding the implementation of FGDM and its barriers and facilitators? For example, do we see a general pattern of previous (un)successful implementation when reviewing the literature on FGDM in adult health and welfare settings? Alternatively, in the absence of a general pattern, are the barriers encountered typical of the rehabilitation setting? For example, there is a high dropout rate during the FGDM process and inadequate use of action plans (Dijkstra et al., 2019) in the field of FGDM implementation in child welfare. As there was no review of FGDM implementations in relation to barriers and facilitators in adult healthcare, this thesis has addressed this.

Second, it is pivotal to explore the participants' reasons for their reluctance to seek social support. Did they not need help and support or were they afraid to ask? Indeed, we know from the literature that there are several social codes and norms underlying social relationships (Bredewold et al., 2020) that greatly influence one's decision to accept or refuse informal care, such as considerations of solidarity, social exchange, and reciprocity (Cropanzano & Mitchell, 2005; Trappenburg, 2015). We examined the experiences of both individuals with disabilities and their family caregivers regarding their social support needs to learn more about participants' motives.

Finally, caregivers play an essential role in supporting their loved ones during rehabilitation treatment (Keating et al., 2019). Although caring for someone can be a source of fulfilment and meaning, caregivers do experience adverse effects too on their emotional, social, financial, physical, or spiritual functioning (Baker et al., 2017; Kruithof et al., 2016; Rigby et al., 2009; Scholten et al., 2019; Zarit et al., 1986). It is plausible that the needs change over time. For example, they may be different in the clinical phase than in the transition phase after discharge to home, or the community integration phase. Unfortunately, few studies have specifically focused on the lived transition experiences of people with disabilities and their caregivers (Turner et al., 2008). Additional insight is needed to properly tailor an intervention to the level of perceived burden, specifically regarding how needs evolve during the rehabilitation care trajectory (Cameron & Gignac, 2008). Through qualitative research we were able to gain valuable

## Chapter 1

knowledge about the perceived burden and changing needs of caregivers in the rehabilitation caregiving care trajectory.

### Study aim

In the second part of the study, we have evaluated the perspectives of 20 patient and caregiver couples eligible for FGDM-intervention regarding their social support needs and experienced burden throughout the rehabilitation trajectory.

Furthermore, we conducted a qualitative review on the barriers to and facilitators of FGDM implementation in adult healthcare.

The aim of this second part of the thesis, was as follows:

*Understanding the necessary conditions for FGDM implementation and its feasibility in rehabilitation practice by (1) gaining comprehension of the barriers and facilitators of FGDM implementation in the existing literature in other adult healthcare and welfare settings; (2) gaining a better understanding of the reluctance of persons with disabilities and caregivers regarding social support; and (3) gaining insight into the caregivers' perceived burden and needs during the rehabilitation care trajectory.*

#### **Sub questions are:**

- What are the barriers and facilitators of FGDM implementation within adult healthcare or welfare according to participants' perspectives on their experiences with FGDM?
- What are the reasons of reluctance of social support of couples eligible for the FGDM intervention in rehabilitation practice?
- What are the experienced burden and the changing needs of spousal patient-/carer couples during the different transitions in the rehabilitation care trajectory?

### Outline of this Thesis

In the first part of this thesis, we introduce an intervention study to evaluate the effectiveness of implementing FGDM in a rehabilitation medicine setting. **Chapter 2** includes the study design, rationale, content, and protocol of the POWER study. **Chapter 3** reports a systematic literature review of the effectiveness of FGDM in adult healthcare and welfare. The second part of the thesis shifts to a qualitative

## Introduction

approach with the aim of understanding the patient-/ and carers' reasons for reluctance on social support and by researching existing literature on the conditions of FGDM implementation in other settings.

First, **Chapter 4** reports a qualitative systematic literature review that provides a comprehensive overview of the conditions (barriers and facilitators) of FGDM in adult healthcare and welfare. Second, the content of **chapters 5 and 6** are related to understanding couples' reasons for reluctance to engage in social support from family and friends. **Chapter 5** explores the social support needs and social networks of couples eligible for the FGDM intervention. **Chapter 6** describes the experienced caregiver burden transitioning through the rehabilitation trajectory from the couples' perspectives. Finally, **chapter 7** summarises and discusses the main results of all studies presented in this thesis, along with implications for clinical practice, further research, and lessons learned.

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## Chapter 1

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# PART I

## EVIDENCE AND POWER-STUDY







A vertical silhouette of a person standing on a ledge or railing, positioned on the left side of the page. The person is facing right, with their hand on their hip. The background is a light, textured grey.

# CHAPTER 2

## EFFECTS OF FAMILY GROUP CONFERENCES AMONG HIGH-RISK PATIENTS OF CHRONIC DISABILITY AND THEIR SIGNIFICANT OTHERS: STUDY PROTOCOL FOR A MULTICENTRE CONTROLLED TRIAL

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### Abstract

**Introduction** Many patients and family members experience a large gap between the protected environment during inpatient medical rehabilitation and life in the community after discharge. They feel insufficiently prepared to cope with the consequences of their disability in daily life. This study protocol describes the design measuring the effectiveness and implementation of family group conferences on the empowerment of patients with a high risk of chronic disability and their significant others.

**Methods and analysis** A multicentre controlled trial will be carried out in 12 rehabilitation centres in the Netherlands. A total of 328 clinically admitted patients will participate ( $\geq 18$  years, diagnosed with acquired brain injury, spinal cord injury or leg amputation), and their significant others will be included. During three family group conferences, supported by the social worker, the patient, significant other and their social network will be stimulated in collaboration, to set up participation goals, determine the needed help and make a concrete action plan. Self-reported questionnaires will be collected at baseline, clinical discharge, and 3 months and 6 months following clinical discharge. Empowerment as the primary outcome is operationalised as self-efficacy and participation. Secondary outcome measures are psychological (eg, coping, neuroticism) and environmental (eg, family functioning, social support) factors. This is the first controlled trial evaluating the effectiveness of family group conferences in rehabilitation medicine among adult patients and their significant others, providing us with knowledge in improving rehabilitation care.

**Ethics and dissemination** This study has been approved by the Medical Ethics Committee of the University Medical Center Utrecht (number 15-617/C). The results will be published in peer-reviewed journals and presented in local, national and international conferences.

**Trial registration number** NTR5742; Pre-results.

#### Strengths and limitations

- This study is the first multicentre controlled trial evaluating the effectiveness and the implementation of 'Family Group Conferences' in rehabilitation medicine, with the potential to improve future treatment
- Rehabilitation treatment focussing on both patient, significant other and social network simultaneously is relatively new and expected to be more effective than focusing solely on the patient.
- Study limitations come with pragmatic reasons that prevent random treatment assignment



## Background

The majority of patients admitted to inpatient rehabilitation after onset of a serious physical condition return to their homes after discharge. There they are faced with a new reality of coping with chronic physical and/or cognitive disabilities and possible dependence on others. Many patients feel restricted in their social participation<sup>1,2</sup> and experience adverse psychological outcomes (eg, depression, anxiety, feelings of helplessness and poor quality of life)<sup>3,4</sup>. Their family members may also experience difficulties in aspects of caring<sup>5,6</sup>, high levels of burden and impaired quality of life<sup>7-10</sup>. A large gap is experienced by many patients and their relatives between the protected environment during inpatient rehabilitation and life in the community, feeling insufficiently prepared to cope with the disability in daily life<sup>11,12</sup>. Existing interventions focus primarily on the needs of patients, not on the needs of the significant others<sup>13</sup> (usually the partner, but can be everyone who is important in one's wellbeing). Empowering both patients and significant others as part of rehabilitation treatment may help to reduce this gap, reduce distress and enhance participation in daily activities.

## Family-centred rehabilitation

Medical rehabilitation in the Netherlands often exists as a period of clinical admittance followed by a period of outpatient care after discharge. A comprehensive assessment and treatment of functioning is performed by multidisciplinary teams (ie, physical, psychological, social and communicative functioning, and functioning regarding activities of daily living)<sup>14</sup>.

The awareness of the important role of the family during rehabilitation treatment is growing<sup>13,15</sup>, and although family meetings are regularly conducted in a number of inpatient settings<sup>16</sup> there is limited empirical research in this area<sup>17,18</sup>. Furthermore, these family meetings are usually professional-driven, not family-driven, and consequently power disparities between patient, family and professional are still present, restricting full participation of both the patient and the family in the rehabilitation<sup>16,19,20</sup>. A method focusing on empowerment and active involvement of patients and significant others is family-centred care, which has the following key values<sup>15,21,22</sup>:

## Chapter 2

1. recognising patients and their families as the experts of their own needs
2. promoting partnership between patients, family and health professionals
3. supporting the patients and the family's role in decision making.

Whereas these family-centred values are widely implemented in youth healthcare, this proved more difficult in the healthcare for adult patients in general<sup>15,23</sup>, although there are some examples of family meetings in dementia care with a more family-centred approach<sup>24,25</sup>. In rehabilitation care though, these examples are sparse<sup>26–28</sup>.

### Family group conference

One approach incorporating these family-centred values is the 'Family Group Conference' (FGC) model. FGC originates in New Zealand, where FGC was legislated in 1989 as the decision-making process to be used in cases of child abuse, neglect and youth offending<sup>29,30</sup>. FGC offered a new perspective that challenges paternalistic practices, in which instead of professionals assessing problems, the family and the person in need have the main voice in what concerns them<sup>31</sup>. An FGC is a structured meeting in which the person in need and members of their social network reflect on goals with respect to participation in daily activities. During FGCs the participants share ideas on possible solutions to achieve these goals and decide on a concrete plan to support the person in need in the way they want. Drawing up an action plan with involvement of a wider network is one of the three important philosophical pillars of the original FGC model in child care. Second is using an independent coordinator who prepares the FGC with collaborating family members, and the third is using private time for the family group to develop a plan<sup>31–33</sup>. The FGC approach is 'family driven', meaning that the approach is not *aimed* at the family, but achieves results through the *contributions* of the family<sup>31</sup>.

A major difference with current family meetings is that the person in need together with their social network sets the agenda and develops the plan, not the professional. The traditional method where professionals are in control is abandoned<sup>34</sup>, making the FGC rather proactive than reactive, and more responsive to the family's needs<sup>13</sup>. As the FGC stimulates the decision-making process, a rearrangement of tasks and responsibilities takes place, enlarging the

empowerment of the person in need <sup>35</sup> by shifting the balance of power towards the family within the decision-making process <sup>34</sup>.

The major advantages are that FGC uses resources already existing within society, namely the family and others <sup>36</sup>, who are often better able to find workable solutions <sup>34</sup> consistent with their own culture, lifestyle and history than professionals <sup>37</sup>.

Research examining the impact of FGC is mainly based on qualitative evaluation research <sup>38</sup>. Evidence supporting the effectiveness of the FGC approach is still sparse <sup>38-40</sup> due to study designs lacking a control group <sup>38,41</sup>, although positive results were seen in studies with people with intellectual disabilities <sup>42</sup> and in child welfare <sup>43</sup>. So far, there has been no research conducted evaluating the effectiveness of FGC among the adult population and their social network in the field of rehabilitation medicine. In response to this lack of knowledge, an FGC model is developed and implemented, adapted to the medical rehabilitation setting, evaluating the effectiveness in a multicentre controlled trial embedded in a larger prospective cohort study. A conceptual empowerment framework of the study is introduced, outlining the positioning of FGC in rehabilitation medicine.

### **Study aims**

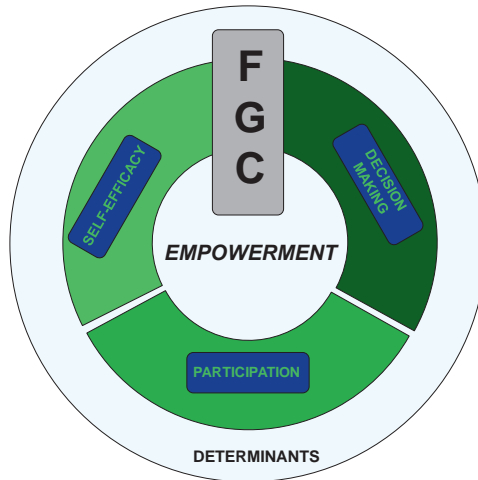
The following are the specific aims of the study:

- examine the hypothesis if optimising the decision-making process during FGCs gives an increase of empowerment in both the patient and the significant other
- examine the effectiveness of FGC compared with regular rehabilitation care to increase empowerment of patients and families
- identify predictors at admission to inpatient rehabilitation of long-term empowerment in patients with physical disabilities and their significant others
- clarify causal mechanisms and identify contextual factors associated with variation in outcomes to optimise the design of future interventions by conducting a process evaluation assessing fidelity and quality of implementation.

## Conceptual framework

The study is conceptualised using the framework outlined in figure 1.

**Figure 1** Family group conference (FGC) empowerment model (edited by Hillebregt & Scholten 2017) Reproduced with permission from Zimmerman MA <sup>44</sup>.



## Empowerment

The concept of empowerment is operationalised in diverging ways <sup>35,45,46</sup>. The WHO <sup>47</sup> has adopted the definition of Rappaport <sup>48</sup>: 'empowerment is a process by which people, organizations and communities gain mastery over their affairs' (p122). In the last decade many publications have been written discussing empowerment in the context of rehabilitation, but relatively little attention has been paid to exploring the relationships between the various empowerment variables and rehabilitation outcomes <sup>45,49</sup>.

The intrapersonal, interactional and behavioural framework of psychological empowerment is used to identify the outcome of FGC <sup>49</sup>. The intrapersonal component Refers to how people think about themselves, the interactional component refers to how they also relate to their social environment, and the behavioural component refers to the specific actions the individual takes to participate in the community <sup>49</sup>. An increasing number of scientists stress the

importance of a fourth component: social and interpersonal relations, also called relational empowerment<sup>50–54</sup>. In the context of FGC it explains the importance of the support from members in the social network and the necessity of having meaningful relationships<sup>55</sup>.

Overall, on the level of the individual, empowerment in FGC in medical rehabilitation can be understood as the process to enhance control over life situations, participation and social relations<sup>47,56</sup> through influencing and increasing the decision-making process in families, with self-efficacy and participation as important outcomes<sup>47,57</sup>.

### **Self-efficacy and participation**

The hypothesis is that due to optimising the decision-making process during FGCs by including the family, self-efficacy and participation of both the patient and the significant other increase.

Self-efficacy is a core concept of the social cognitive theory and refers to perceptions about one's ability to achieve desired outcomes<sup>58–60</sup>. Self-efficacy can, therefore, be seen as the psychological component of empowerment. Participation is a core concept of the International Classification of Functioning, Disability and Health and refers to the involvement in a life situation and thereby as the behavioural component of empowerment<sup>61</sup>. Self-efficacy and participation are closely interrelated. Research shows that patients with higher self-efficacy are able to function better, show increased participation and satisfaction with their participation, and experience higher quality of life than patients with lower self-efficacy<sup>62–64</sup>. In

informal caregivers, higher self-efficacy is related to less feelings of burden and distress<sup>65,66</sup>.

### **Decision making**

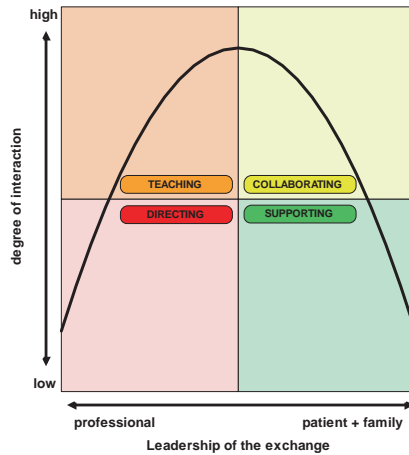
The adaptive practice model of Feldman et al<sup>67</sup> is used to discuss and clarify a decision-making interaction approach during the FGCs, where the goals are to have (1) productive decision making, (2) family group inclusion and (3) professional supportiveness<sup>68</sup>. The aim of the interaction between patient/significant other, the

## Chapter 2

family and the professional is to optimise the family decision making, being a process of alternate phases of sharing knowledge and skills, coaching, shared decision making, and eventually fully empowered participation.

In the adaptive practice model, different interaction styles optimising family decision making are described (directing, teaching, collaborating and supporting interaction) (see figure 2) <sup>67</sup>.

**Figure 2** Decision-making model. Reprinted with permission from Feldman et al. <sup>67</sup>.



### Determinants

Various psychological (eg, neuroticism, depression and purpose in life) <sup>1,62,64,69</sup> and environmental (eg, family relationships and functioning, social support, emotional and practical support) <sup>10,70,71</sup> variables have been identified as determinants of self-efficacy and participation. However, it is not clear if these variables measured during early inpatient rehabilitation may predict long-term empowerment outcomes.

### Methods and analysis

#### Study design and setting

A multicentre prospective cohort study will be conducted among patients with leg amputation, acquired brain injury or spinal cord injury who have been admitted as

inpatients at a rehabilitation centre and their significant others. The study will be conducted in 12 out of a total of 22 rehabilitation centres in the Netherlands, subdivided into intervention centres where FGC will be implemented and control centres with regular care (see table 1).

**Table 1** Participating centres

<b>Intervention centres</b>	<b>Control centres</b>
Hoogstraat Rehabilitation (Utrecht)	Adelante Rehabilitation (Hoensbroek)
Revant Rehabilitation Center (Breda)	Heliomare (Wijk aan Zee)
University Medical Center Groningen	Rehabilitation Center Merem/De
Beatrixoord (Haren)	Trappenberg (Huizen)
Roessingh Rehabilitation (Enschede)	St. Maartenskliniek (Nijmegen)
	Rijndam Rehabilitation (Rotterdam)
	Reade Rehabilitation (Amsterdam)
	Rehabilitation Friesland (Beetsterzwaag)
	Vogellanden Center for Rehabilitation (Zwolle)

Patients decide who will be allocated as their significant other ( $\geq 18$  years with a close relationship to the patient), and according to their goals and action plan they decide together which individuals of their social network they want to invite. Eligibility of the participants is screened with the inclusion and exclusion criteria (see box 1). A process evaluation will be conducted to monitor the fidelity of the implementation of the FGC and possible influencing factors affecting the outcomes.

**Box 1** Inclusion and exclusion criteria for the cohort study

**Inclusion criteria**

1. Recent onset of leg amputation, acquired brain injury or spinal cord injury (patient)
2. Expected stay in the rehabilitation centre: at least 4 weeks (patient)
3. At least 18 years old (patient and significant other)

**Exclusion criteria based on clinical judgement**

1. Full recovery or nearly full recovery of the patient is expected (patient)
2. Discharge home: not expected (patient)
3. Limited life expectancy (patient)
4. High degree of cognitive or intellectual problems (unreliable measurements) (patient)
5. Patient has no significant other (patient)
6. No informed consent (patient and significant other)

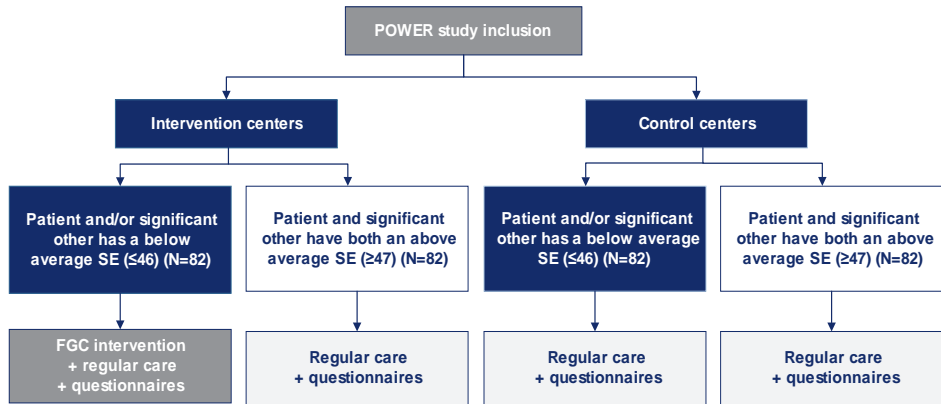
### **Study procedure**

The study is divided into two parts, which will be introduced separately to patient–significant other couples: the cohort study and the FGC intervention. In the first week after admittance, inclusion and exclusion criteria are checked, and information letters about the cohort study and informed consent forms are handed out to patients and significant others by the physiatrist. All included patients and significant others will complete the questionnaires four times: shortly after admission to the clinic (T0), shortly before clinical discharge (T1), and 3 months (T2) and 6 months (T3) after clinical discharge. In the intervention centres, participants will be included in the FGC intervention, based on their level of self-efficacy measured with the Self-Efficacy Scale <sup>72,73</sup> (see figure 3). It is expected that the FGC intervention will be less effective in individuals who already possess an above-average self-efficacy at admission. Couples in which both the patient and significant other score above average ( $\geq 47$ ) on the Self-Efficacy Scale <sup>72,73</sup> and all couples in the control centres will participate only in the cohort study and will receive regular rehabilitation care from multidisciplinary professionals (see figure 3). This also includes conventional psychosocial support from the social worker (giving diagnosis-specific information and consequences in daily living, involvement in goal setting, support caregivers, community services advice and so on).

Couples in which the patient and/or significant other score below average ( $\leq 46$ ) will be invited by the social worker for a FGC. Within this cohort, a controlled trial is executed to evaluate the effects of the FGC in addition to regular social work support. A second informed consent for admittance to the FGC will be obtained.



**Figure 3** Allocation of participants



FGC, family group conferences; SE, self-efficacy.

## Intervention

### ***FGC intervention***

The FGC intervention is an approach starting at clinical admittance, supporting both patient and social network through the phase of being discharged to home, and continues to following up until the outpatient rehabilitation period is finalised. In this time span there are three fixed meetings (at clinical discharge, and 1.5 and 3 months after discharge) and in between social work contacts with different accents (see table 2). The first meeting is a preparatory meeting, explaining the concept of FGC to the patient, significant other and family. The second meeting is the actual FGC in which the patient, significant other and their social network reflect on their goals when being at home, and the support needed to make these goals achievable. They discuss and compose a concrete plan to participate in daily activities that correspond to their aims. The last meeting is to evaluate the achievements of the goals and plans made. All FGC meetings are part of the rehabilitation existing budgets concerning social care, which in case of success make the implementation more straightforward. Some adaptations have been made to translate the original FGC model originated in child care to an adult population in the medical rehabilitation setting. The most important key elements will be adopted, such as the family-driven approach, focus on decision making, the

## Chapter 2

involvement of a wider network and drawing up an action plan. Other key elements as 'independent coordinator' and 'private time' required adaptations more suitable and appropriate for the adult population.

Instead of having an independent coordinator setting up the FGC, more responsibility is given to the adult participants themselves, where a representative of the family (family coordinator) is appointed to take account of the FGC coordination activating family members, fixing time and place, and so on, all in close collaboration with the social worker. This dyadic relationship between the family member and the professional is based on equality and has the potential to increase ownership of the FGC.

The opportunity of private family time without professionals being present (one of the core principles of FGC) is introduced and often already part of the normal interaction and collaboration between family members (sometimes in self-organised family meetings, WhatsApp groups, online applications used to set up an action plan and so on).

### **Workshop and coaching**

All social workers in the intervention rehabilitation centres will be trained once in a 1-day workshop to introduce the FGC manual with the decision-making tools and the theory behind the decision-making process. From each intervention centre, a social worker representative is appointed, who will be in close contact with the researchers concerning the implementation of FGC in their centre and among their colleague-social workers. Return meetings will be organised to refresh the learnt skills and to allow exchange of experiences. All social workers will receive coaching by an independent coach experienced in family-centred rehabilitation as well as coaching groups by giving advice regarding the decision-making interaction with the patient and their family. For this purpose, meetings will be videotaped and observed after given informed consent.

**Table 2** Decision-making tools

WHAT + WHEN	ACTION	TOOL
Social work contact with couple (0-2 wks. after clinical admittance till end clinical admittance)	Inform patient/significant other about allocation family group conference in multidisciplinary rehabilitation care Inventory Caregiver Strain Index significant other Inventory of Social support network Inventory of attendees present at family group conference Nominating 'family coordinator' by social network Assess level of empowerment of couple	Overview disciplines/programs  Caregiver Strain Index <sup>78</sup> Social Network Analyses <sup>79</sup>  Empowerment-tool (self-composed)
Preparatory meeting Meeting 1 with family, couple + social worker (at clinical discharge)	Insight in goal attainment participation daily activities  Discuss level of social network support Activation of social network Introducing action plan Inform 'family coordinator'  Assess level of empowerment of couple	Goal attainment scale 'the entire live' <sup>80</sup> Questionnaire participation (USER) <sup>81</sup> Social Network Analyses <sup>79</sup>  Apps, phone, other Action plan <sup>82</sup> Manual 'family coordinator' Empowerment-tool (self-composed)
Social work contact with couple + family coordinator (end clinical admittance till 1,5 mth. after clinical discharge)	Preparing 'family coordinator' Evaluating deployed actions Assess level of empowerment of couple	Manual 'family coordinator' Empowerment-tool (self-composed)
Family Group Conference Meeting 2 with family, couple + social worker (1,5 mth. after clinical discharge)	Setting up action plan  Assess level of empowerment of couple	Action plan <sup>82</sup>  Empowerment-tool (self-composed)
Social work contact with couple + family coordinator (1,5 -3 mth. after clinical discharge)	Evaluation deployed actions 'family coordinator' Evaluation of execution of action plan Assess level of empowerment of couple	Manual 'family coordinator' Action plan <sup>82</sup>  Empowerment-tool (self-composed)
Evaluation meeting Meeting 3 with family, couple + social worker (3 mth. after clinical discharge)	Insight in goal attainment participation daily activities  Assess level of empowerment of couple	Goal attainment scale 'the entire live' <sup>80</sup> Questionnaire participation (USER) <sup>81</sup> Empowerment-tool (self-composed)

### **FGC manual**

The social worker systematically uses and introduces several tools using a detailed manual and protocol for each FGC meeting and in between meeting describing the decision-making tools in detail, such as (1) a social network analysis: gaining insight of the support system and encouraging participation of both the patient and the significant other; (2) an action plan: setting up goals concerning daily activities and the help needed to attain them; and (3) a Caregiver Strain Index: making an inventory of burden experienced by the significant other (see table 2). The tools are designed to increase motivation and equal partnership, and promote participation and self-efficacy <sup>74</sup>.

### **Sample size**

Sample size is calculated based on analysis of covariance in a parallel group design <sup>75</sup>. Due to the absence of a formal quantitative evaluation of the FGC to date, results from a systematic review of the effectiveness of behaviour change techniques in order to increase self-efficacy <sup>76</sup> are used to estimate the effect size <sup>77</sup>. A moderate effect size of 0.5 is expected. With this expected effect size, a pretest and a post-test 3 months postintervention, correction for dependency in the clusters (n=38 social workers), an intraclass correlation of 0.05, a two-sided alpha value of 0.05 and a power of 80%, the required total sample size is n=150. The total sample size will be 164 when taking into account a 10% dropout of participant couples during the study. Therefore 82 couples with a below-average self-efficacy will receive FGCs in the intervention group and 82 couples with a below-average self-efficacy will receive regular care in the control group.

For the identification of predictors of self-efficacy and participation, we additionally include participant couples in the intervention and control centres with above-average self-efficacy scores. An equal number of participant couples will be recruited in these groups as in the two mentioned groups (82 each). Therefore, the total sample size will be n=328, which is estimated to be achievable based on known patient flows, recruitment rates and study retention rates.

## Study outcome measures

An overview of all instruments that are used at different time points in the study is shown in table 3. The majority of the instruments have validated scales. Self-efficacy <sup>72,73,83</sup> and participation <sup>81,84–87</sup> are the primary outcomes. The secondary outcomes are distress, <sup>88–91</sup> life satisfaction <sup>92–95</sup>, experienced continuity of care <sup>96,97</sup>, care empowerment <sup>98,99</sup>, assistance from the social network (patient only) <sup>8</sup>, provided assistance (significant other only) <sup>8</sup>, burden of care (significant other only) <sup>78,100–103</sup> and caregiver mastery (significant other only) <sup>104,105</sup>.

Additional determinants will be measured: demographic factors, functional status factors (independence in self-care and mobility, patient only), cognition impairment (acquired brain injury, patient only) and injury-specific information (patient only). Finally, an assessment battery of concepts which are identified as predictive for long-term adjustment problems will be used in order to identify predictors of long-term (up to 6 months) self-efficacy and participation <sup>1,10,62–64,71,106,107</sup>

**Table 3** Measurements for patients and significant other

Outcome measures	Instruments	T0	T1	T2	T3
<b>Primary outcome measures</b>					
Self-efficacy	University of Washington Self-Efficacy Scale short form <sup>83</sup>	X	X	X	X
Participation (pre-injury)	Utrecht Scale for Evaluation of Rehabilitation-Participation <sup>81</sup>	X	X <sup>C</sup>	X	X
<b>Secondary outcome measures</b>					
Distress	Hospital Anxiety and Depression Scale <sup>88,89</sup>	X	X	X	X
Life satisfaction	LS2 <sup>92,95</sup>	X	X	X	X
Experienced continuity of care	Consumer Quality index Brain Injury (collaboration subscale) <sup>96,97</sup>				X
Care empowerment	Patient Assessment of Chronic Illness Care (selection) <sup>98,99</sup>				X
Assistance from social network	<i>Adapted version of existing list of activities</i> <sup>8</sup>				X <sup>P</sup>
Provided assistance	<i>Adapted version of existing list of activities</i> <sup>8</sup>				X <sup>C</sup>
Burden of care	Caregiver Strain Index <sup>78</sup>			X <sup>C</sup>	X <sup>C</sup>
Burden of care	Self-Rated Burden scale <sup>103</sup>	X <sup>C</sup>	X <sup>C</sup>	X <sup>C</sup>	X <sup>C</sup>
Caregiver mastery	Caregiver mastery scale <sup>104</sup>				X <sup>C</sup>

## Chapter 2

**Table 3** continued

<b>Determinants</b>					
Demographic factors	Age, gender, ethnicity, family income, level of education <sup>108</sup> , marital status, family composition	X			X(2)
Functional status	Utrecht Scale for Evaluation of Rehabilitation (Self Care and Mobility subscales) <sup>109</sup>	X <sup>P</sup>	X <sup>P</sup>		
Cognition impairment	Montreal Cognitive Assessment <sup>110</sup> (ABI)	X <sup>P</sup>			
Injury specific information	Cause of injury; comorbidity; American Spinal Injury Association Impairment Scale (SCI) <sup>111</sup> ; Special Interest Group on Amputation Medicine (SIGAM) - Working group Amputation and Prosthetics (WAP) score <sup>112,113</sup> (Amputation); Bamford/Oxford classification <sup>114</sup> , Stichting Afasie Nederland schaal (Dutch Aphasia Foundation scale, SAN) <sup>115</sup> , National Institutes of Health Stroke Scale (NIHSS) <sup>116</sup> (ABI)	X <sup>P</sup>			
Self-efficacy	Self-Efficacy Scale (ALCOS-12) <sup>72,73</sup>	X			
Personality characteristic neuroticism	Eysenck Personality Questionnaire Revised Short Scale (Neuroticism subscale) <sup>117,118</sup>	X			
Proactive coping	Utrecht Proactive Coping Competence Scale (short version) <sup>119</sup>	X			
Passive coping	Utrecht Coping List (passive coping subscale) <sup>120,121</sup>	X			
Appraisal	Appraisal of Life Events (treat and loss subscales) <sup>122</sup>	X			
Resilience	Connor-Davidson Resilience Scale <sup>123</sup>	X			
Purpose in life	Purpose in Life Short Form <sup>124,125</sup>	X			
Family functioning	Family Assessment Device (subscales general functioning) <sup>126</sup>	X	X	X	X
Fatigue, general health, mood	Numeric Rating Scale	X	X	X	X
Existing social network	<i>Self-composed</i>	X			
Perceived social support (pre-injury)	Social Support List 12 (interactions subscale) <sup>127,128</sup>	X			

T0: shortly after admission of the patient in the rehabilitation center; T1: shortly before clinical discharge of the patient from the rehabilitation center; T2: 3 months after discharge; T3: 6 months after discharge. X: patient and informal caregiver, X<sup>P</sup>: only patient, X<sup>C</sup>: only informal caregiver.

ABI, Acquired brain injury; ALCOS-12= Algemene Competentieschaal 12 (General Competence Scale 12 questions); LS2, Life Satisfaction (2 questions)

## Process evaluation

A process evaluation is an integral part of the study and will be conducted in each of the participating rehabilitation centres according to the Medical Research Council framework <sup>129</sup>. This framework assesses fidelity and quality of implementation, clarifies causal mechanisms and identifies contextual factors associated with variation in outcomes <sup>130</sup>. This indepth information regarding the fidelity and feasibility of the implementation of FGCs can be used to optimise the design of future interventions and possible nationwide implementation if effectivity is determined.

In order to conduct this trial in a uniform way, compliance will be assessed in the intervention centres, evaluating which components of the FGCs are implemented and delivered. A detailed manual and protocol for each FGC have been written describing the decision-making tools. Social workers will administer all used decision-making tools with a self-reported checklist right after each meeting (see table 2). Further compliance will be assessed monthly by administering the delivered and attended FGCs. Researchers will monitor the study, monthly evaluating the checklists, visiting the social workers and research assistants, and attending sessions of the FGCs at all participating centres.

Semistructured interviews will be held with social workers (n=15) concerning the barriers and the facilitators implementing FGCs. Case studies (n=8 unique patient cases) will take place gathering information on both patients, significant others, members of social network and professionals regarding their satisfaction with the FGC, the decision-making process, and made and achieved action plans and goals.

Qualitative data will be written as verbatim, coded and analysed using content analyses <sup>131</sup> using the qualitative analysis software MAXQDA <sup>132</sup>.

## Statistical methods and data management

First, multivariate regression analysis will identify predictors of long-term self-efficacy and participation. Nesting of the data and participation in the intervention will be accounted for. Multilevel random coefficient analysis of covariance comparing preintervention and postintervention scores on the primary outcomes

## Chapter 2

will be used to analyse the effectiveness of the FGCs. Multilevel analysis allows for correction due to nested data and to inclusion of persons with partly missing data in the analyses. Data will be analysed according to the intention-to-treat principle. Per-protocol analyses will be performed in order to explore which elements of the FGC can be considered effective and for whom. SPSS statistical program for Windows will be used, and effects with a P value below 0.05 (two-tailed) will be regarded as significant.

Data will be gathered by two researchers (CFH, EWMS) supervised by the research team closely collaborating. Data and backup information will be stored on a secured computer file.

### **Ethics and dissemination**

All participating rehabilitation centres have approved the study protocol. The results will be published in peer-reviewed journals and presented in local, national and international conferences. The protocol for the multicentre controlled trial was entered in the Dutch trial register (NTR5742).

### **Discussion**

This study will be the first multicentre controlled trial evaluating the effectiveness and the implementation of FGCs among the adult population and their significant others in the field of rehabilitation medicine. With this study we expect to gain knowledge on the effectiveness of implementing FGCs in rehabilitation care. We can identify predictors of self-efficacy and participation up to 6 months after clinical discharge. This enables development of a screening on risk factors in an early stage of rehabilitation treatment. Also, a structured and theoretically based FGC will be developed, tested and evaluated in different Dutch rehabilitation centres. Several aspects of the study will contribute to its strength:

- Focusing on the patient and significant other simultaneously is relatively new and, based on former research <sup>133</sup>, expected to be more effective than focusing solely on the patient.
- The social network of the patient and the significant other will become more closely involved in the rehabilitation process in an early stage of rehabilitation.



This new aspect of rehabilitation care seems promising in the recovery and adaptation process of the patient<sup>71</sup> and in moderating caregiver distress<sup>134</sup>.

- Conducting FGCs requires a paradigm shift of patient/significant other but also the social workers, especially on the domain of decision making. Social workers who are often proactive in their counselling must now withhold themselves more in order to enlarge the empowerment of the patient, significant other and their network. Implementation of the FGCs will gather insight into these decision-making processes and possible barriers and facilitators acquiring this paradigm shift.
- The results of the study will be representative of a broad range of rehabilitation patients in three diagnostic groups (acquired brain injury, spinal cord injury and leg amputation).
- With the identification of predictors of self-efficacy and participation, a more scientifically based selection tool can be developed that may help in deciding to deploy FGCs in the future. Furthermore, in the intervention group, subgroups may be distinguished based on the effectiveness of the FGC.
- Implementing and evaluating the FGC in a structured and theoretically grounded way is intended to enlarge the evidence in social work in medical rehabilitation care
- The implementation, monitored by a process evaluation, will clarify causal mechanisms and gain knowledge about possible influencing barriers and facilitators, making it possible to optimise the design of future interventions.
- The longitudinal design of the study offers the possibility to explore the effectiveness of the FGC after a follow-up period of 6 months.

The following are some limitations of this study:

- Due to the subjective nature of most variables, self-administered questionnaires will be used. Results can be biased due to socially desirable answering; however, the instructions clearly note that there are no right or wrong answers and that participants should complete the questionnaire independently. A research assistant will provide assistance when needed.

## Chapter 2

- Aiming to develop a feasible intervention, the FGC was designed keeping in mind that it should fit in the current organisation and financing of rehabilitation care. Variables to be considered were the type of population (adults), duration of clinical admittance and outpatient rehabilitation, time until FGC referral and time needed for family to set up a plan and so on. In some respect, this limits the possibilities and probably the effectiveness of the FGCs; for example, the timing of the meetings is fixed due to financial restrictions, and there will not be an independent coordinator (a family coordinator instead) who will support the participating family, which is part of the original FGC model in child care<sup>31–33</sup>. However, it is evident that the design has to be adapted to the adult population and be time and cost-effective in order to have any prospects for future implementation in routine care.
- The study is not a randomised controlled trial, which is the preferred study design to examine intervention effects. In a situation of random allocation of FGCs within social work teams, it cannot be ruled out that the social workers also implement (aspects of) the FGCs in patients excluded from the intervention. Therefore, admittance in either a control or intervention centre, instead of random allocation, determines if the patients will receive the FGC. Patients and caregivers who do not participate in the FGC will receive 'regular care', which may vary between rehabilitation centres. Differences will be monitored.
- Although it is expected that the intervention could be beneficial for all patients and their social network, in this study we decided to focus on the group that we expect (based on previous findings) has the most potential to benefit from it. In former research, a relationship between self-efficacy and participation was found<sup>64,63</sup>. Based on these findings it is assumed that the intervention (which is aimed to improve self-efficacy and participation) will be less effective for couples with a relatively existing high level of self-efficacy at onset. Accordingly, only couples with a relatively low level of self-efficacy at onset will follow the intervention.

In summary, we have described a study evaluating a novel FGC intervention for rehabilitation patients and their significant others that is aimed to enlarge their self-

efficacy, participation and decision making. It has the potential to detect efficacy and explain the influencing determinants to improve future rehabilitation care.

### **Contributors**

CFH and EWMS developed the first version of the manuscript, in collaboration with JMAV-M, MWMP and MK. JMAV-M, MWMP and MK supervised the writing process and gave critical comments on several drafts of the manuscript. JMAV-M, MWMP and MK provided statistical and methodological advice. CFH and EWMS wrote the final version of the manuscript.

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## Chapter 2

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# CHAPTER 3

## FAMILY GROUP DECISION-MAKING INTERVENTIONS IN ADULT HEALTHCARE AND WELFARE: A SYSTEMATIC LITERATURE REVIEW OF ITS KEY ELEMENTS AND EFFECTIVENESS

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## Abstract

**Background** Family group decision making (FGDM) is a structured decision-making process, with the aim of shifting the balance of power from the professional towards the person in need and their family. It differentiates from other family-centred meetings by the presence of three key-elements: 1) plan with actions/goals, 2) family-driven, 3) three phases of meetings gradually increasing empowerment. FGDM studies are increasing in different settings in adult healthcare/welfare, although effectiveness is unknown at this date.

**Objectives** (1) to systematically review the presence of the three key elements in family-centred interventions in adult care and welfare, (2) to evaluate the effectiveness of FGDM interventions

**Design** Systematic Review

**Data Sources and eligibility criteria** A total of 14 relevant electronic databases and 1 academic search machine were searched until February 2018. First, family-centred studies were selected with controlled trial designs in adult healthcare/welfare. Second, interventions categorised as FGDM if all three key elements were present.

**Data extraction and synthesis** Studies were examined concerning their (1) characteristics (2) quality/level of evidence (3) presence of FGDM key elements and (4) results.

**Results and conclusion** Six articles from three studies on family-centred interventions were selected from a total of 1680 articles. All were of low quality. One study (two articles) met all criteria for an FGDM intervention, describing the efficacy of family group conferences among social welfare recipients on mental health outcomes. Although the intervention group showed significantly better outcomes after 16–23 weeks; no differences were seen at the 1-year follow-up. Controlled studies of both family-centred interventions and FGDM are still low in quantity and quality. No conclusions on FGDM effectiveness can be drawn. Further high-quality intervention studies are required to evaluate the impact of FGDM on adults in need, including their families; as well as evaluation research detecting possible barriers and facilitators influencing FGDM implementation.

**PROSPERO registration number** CRD42017077585

### Strengths and limitations of this study

- This is the first review of the effectiveness of family group decision-making (FGDM) intervention studies in adult healthcare and welfare to date.
- A search of 14 relevant electronic bibliographic databases was conducted which gives this review breadth and comprehensiveness.
- Studies were only assessed when written in the English language.
- Identification of FGDM studies only when all three FGDM key elements were present.
- Narrative analyses because of heterogeneous studies and few high-quality studies

## Background

### Family Group Decision Making

The family group decision-making (FGDM) model is implemented in child care and welfare in more than 30 countries worldwide <sup>1</sup>. The roots of FGDM originate from the family group conference (FGC) model in New Zealand <sup>1</sup> where it was legislated as the decision-making process to be used in cases of child abuse, neglect and youth offending in 1989 <sup>2,3</sup>. Since then, the model is subject to change resulting in many variants with a range of models <sup>4</sup>, which all can be referred to under the umbrella of the broader term FGDM <sup>5</sup>. While outside the USA, meetings are referred to as FGCs, within the USA, different variants are named such as: family unity meeting, team decision-making meeting, family decision meeting, family team conferences and family team meeting <sup>4,6-12</sup>.

In FGDM the person in need and members of their family reflect on goals with respect to participation in daily activities through structured meetings. The term 'family' is widely interpreted with the inclusion of extended family members, friends, neighbours, and significant others <sup>13</sup>. During FGDM, the participants share ideas on possible solutions to achieve goals and decide on a concrete plan to support the person in need in the way he or she wants. The ownership of this plan remains with the family; they are responsible for contributing, controlling and executing the actions/goals of the plan including inviting people they want to the conference, with little contribution from professionals. In this way, FGDM aims to stimulate the decision-making process, with a rearrangement of tasks and responsibilities to shift the balance of power from the professional towards the person in need and the family within this decision-making process <sup>14</sup>. FGDM is expected to facilitate the assessment of problems into a new perspective where the family and the person in need have the main voice in matters that concern them <sup>15</sup>, enlarging their empowerment <sup>16</sup>. Major advantages are that FGDM uses resources already existing within society namely the family and others <sup>17</sup>, who are often better able to find workable solutions <sup>14</sup> consistent with their own culture, lifestyle, and history than professionals <sup>18</sup>.

## Chapter 3

Families often experience the FGCs as very positive and helpful <sup>19,20</sup>. Various process evaluations in child care for instance, show that participants feel listened to <sup>1</sup> and are satisfied <sup>21</sup>, even though a recent meta-analysis of FGC (one of the variants of FGDM) involving fourteen controlled studies, showed no effectiveness in child related outcomes <sup>7</sup>.

### **Key-elements of FGDM**

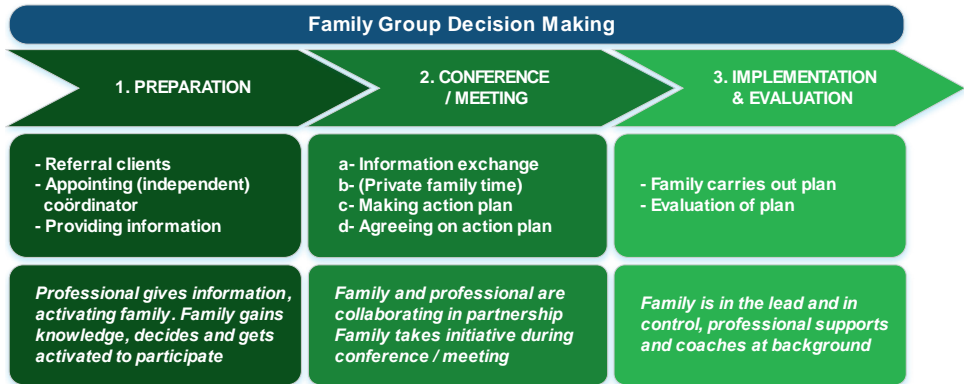
All variants under the umbrella of FGDM, have a common philosophy <sup>5</sup> of engaging the family with a central role in the decision-making process <sup>8,22-24</sup>, characterised by three key elements. These key elements are important because they indicate the difference between FGDM and more general family-centred meeting interventions. The first key element is the importance of drawing up an action plan serving as a basis for the action-oriented perspective and to clarify, monitor and achieve goals. Second, the understanding that FGDM decision models are 'family driven', meaning that the approach is not aimed at the family, but achieves results through the contributions of the family. The person in need together with the family set the agenda, develop and implement the plan. They possess the executive role rather than the professional. Here, FGDM distinguishes itself from 'traditional' approaches of family meetings that are often 'family centred' <sup>15</sup> where the professional remains in their executive role.

The third important key-element is the three phases characterising the FGDM process <sup>8,25,26</sup>; the preparation phase, the conference phase and the evaluation phase (see figure 1). Through these meetings, a gradual shift takes place in the balance of power from professional towards increased empowerment of the person in need and their family. In the preparation phase, the referral commences and the concept of FGDM is explained to the person in need and their family and a conference coordinator is appointed. In the original FGC model dating from the 1980s, the key values of having an independent coordinator and private family time <sup>1</sup> are quite fixed. However, these can vary between the different FGDM types <sup>4,9</sup>. Depending on the type of FGDM, this coordinator can be a member of an independent agency or the family may decide, based on their preference for example to a member of the professional team <sup>21,27</sup>. In the conference phase, the actual FGDM takes place in which the person in need and the family members



reflect on their goals and the support needed to make these goals achievable. Depending on the FGDM type, the family can choose if they want to schedule private family time, without professionals being present, to develop a concrete action plan<sup>21,27</sup>. In the evaluation phase, the achievements resulting from the goals and action plan are evaluated.

**Figure 1: Key elements of family group decision-making**<sup>26</sup>



### FGDM in the adult healthcare/welfare

Involving the family in adult healthcare and welfare is not new and is implemented in a number of settings. Predischarge and follow-up family meetings, are conducted in geriatric medicine, rehabilitative medicine, palliative care, and psychiatry<sup>28-32</sup>, for instance. These meetings are often held to improve communication between the multidisciplinary team and family members discussing patient's health condition and progress<sup>33</sup>. In some healthcare settings like rehabilitation medicine, a goal-directed programme, using an action plan and a predetermined set of preparation and evaluation meetings, is already part of the regular rehabilitation programme. Although two out of three key elements characterising the FGDM process<sup>8,25,26</sup> (action plan and the meeting set-up in three phases) are present, these meetings do not qualify as FGDM. One of the important differences with FGDM is that these family meetings lack the family-driven key element. Despite the fact that the family is often engaged in the decision-making process setting up a plan; the coordination of tasks and the ownership of the plan remains with the professionals<sup>29,34,35</sup>. First, more awareness

## Chapter 3

is needed to understand the importance of distinguishing the more commonly implemented family-centred meetings and FGDM by its key elements. Second, with FGDM studies slowly increasing within different settings among adults in public mental healthcare<sup>8,36–39</sup>, rehabilitation medicine<sup>40</sup>, general social welfare<sup>41–43</sup> and social welfare for elderly<sup>44,45</sup>; it is important to systematically examine the effectiveness of FGDM. To our knowledge, such a review has not been published in adult healthcare and welfare to date.

### **Objectives**

The objectives of the present study are: (1) to systematically review the presence of the three key elements of FGDM in family-centred interventions in adult care and welfare, and (2) to evaluate the effectiveness of the FGDM interventions.

### **Methods**

#### **Research design and methodology**

We followed the systematic review methodology using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement<sup>46</sup> and the Cochrane Handbook for Systematic Reviews for Interventions<sup>47</sup> which specify different phases concerning the search strategy and screening (preparation phase, title-/abstract screening, full-text screening and extraction)<sup>47</sup>.

#### **Patient involvement**

As this is a review screening literature, no patients/clients are involved.

#### **Data sources and search strategy**

A comprehensive search of 14 relevant electronic bibliographic databases and 1 academic search engine (Google Scholar), was conducted (Pubmed/Medline, CINAHL, PsycINFO, Cochrane Library, International Bibliography of the Social Sciences, Campbell library, Social Science Research Network, ASSIA Applied Social Sciences Index and Abstracts, Social Care Online, sociological abstracts /

social services abstracts, Web of Science, Scopus, SocINDEX, ERIC). It was a deliberate choice to only include the intervention eligible criteria into the search strategy, including most common variants of the intervention FGDM (see online supplementary appendix 1, example full electronic search strategy). Articles not eligible to the other criteria were screened out within the title abstract phase. This resulted in a broad screening process aiming to be as thorough and accurate as possible. The search string was adapted for use with different bibliographic databases. All articles were searched until 21 February 2018, with no further predetermined date limitation. Only studies in the English language were included.

### Eligibility criteria

The PICOCs process framework<sup>48</sup> was used to formulate the eligibility criteria according to the concepts: Population, Interventions, Comparators, Outcomes, Context and Study design. Studies were included if they met the following eligibility criteria:

- Types of population (P): The target population of the study is aged eighteen or older.
- Types of interventions (I): We use a two-step selection approach. Aim 1: family-centred interventions including FGDM. Aim 2: only FGDM interventions. For the first aim, we selected all family-centred studies, defined as studies of interventions to engage family/friends in the decision-making process. Furthermore, we screened these family-centred studies for the presence of the three FGDM key elements (1) plan with goals/actions, (2) family-driven, (3) three phases). For the second aim, we included only interventions qualified as FGDM with all three key elements present.
- Comparators (C): Treatment as usual or no treatment was identified as comparator.
- Types of outcomes (O): All outcomes were included. Studies must have included at least one quantifiable outcome measure
- Context (C): Any setting that serves for adult healthcare or welfare
- Types of study design (S): Studies using controlled trial designs (randomised and non-randomised) with a comparison group

### Screening

#### *Preparation phase*

The citation management software programme Mendeley was used to import studies from the 14 electronic bibliographic databases. One masterfile was created merging the studies of the 14 databases after removing all duplications. All articles were uploaded to the systematic literature review software Rayyan <sup>49</sup> where studies were categorised and labelled according a predetermined coding scheme.

#### *Title abstract and full-text screening*

All articles were first selected in which some kind of engagement of family/friends in the decision-making process was described. We have named these 'family-centred studies'. All family-centred studies were further screened for eligibility according to the other eligibility criteria (eg. population, study design, etc). When a decision could not be made based on title and abstract, the full paper was obtained for detailed assessment. One researcher performed the title abstract screening (CFH) with 10% double-screening (EWMS). Inconsistencies were discussed with a third researcher (MK) until consensus was reached. The full-text screening was conducted by two researchers (CFH 100%; EWMS and MK 50% each). Inconsistencies were discussed until consensus was reached.

### **Data extraction, methodological quality and level of evidence**

The remaining studies were extracted and 100% double assessed (CFH/EWMS) concerning their (1) characteristics, (2) quality/level of evidence and (3) presence of the key elements of FGDM: (1) plan, (2) family driven, (3) three phases. The identification of the FGDM key elements was deliberately postponed to the data extraction phase instead of the full-text screening phase. Consequently, an overview of family-centred outcome studies versus FGDM intervention studies can be presented as support for our first research aim.

A standardised data extraction form from the Cochrane Collaboration <sup>47</sup> was used to extract the following data from the eligible studies: author, year, country, design, sample cohort, intervention, measures, main findings, limitations.

The quality of the studies was determined using the Quality Assessment Tool for Quantitative Studies <sup>50</sup> judged to be suitable in systematic reviews of effectiveness <sup>47,50</sup>. The tool assesses six domains: (1) selection bias, (2) study design, (3) confounders, (4) blinding, (5) reliability and validity of data collection method; and (6) withdrawals/ dropouts. With use of the tools guideline <sup>51</sup>, a global quality score can be calculated ranging from 1 to 3, with 1 being the best score reflecting no 'weak' domain rating; 2 reflecting one 'weak' rating and 3 reflecting two or more 'weak' ratings <sup>50</sup> (see table 1).

**Table 1: Quality Assessment Tool for Quantitative Studies <sup>50</sup>**

COMPONENTS	STRONG	MODERATE	WEAK
<b>Selection bias</b>	Very likely to be representative of the target population and ≥80% participation rate	Somewhat likely to be representative of the target population and 60-79% participation rate	All other responses or not stated
<b>Design</b>	RCT and CCT	Cohort analytic, case-control, cohort, or an interrupted time series	All other designs or design not stated
<b>Confounders</b>	Controlled for at least 80% of confounders	Controlled for 60-79% of confounders	Confounders not controlled for, or not stated
<b>Blinding</b>	Blinding of outcome assessor and study participants to intervention status and/or research question	Blinding of either outcome assessor or study participants	Outcome assessor and study participants are aware of intervention status and/or research question
<b>Data collection methods</b>	Tools are valid and reliable	Tools are valid but reliability not described	No evidence of validity or reliability
<b>Withdrawals and dropouts</b>	Follow-up rate of ≥80% of participants	Follow-up rate of 60-79% of participants	Follow-up rate of <60% of participants or withdrawals and dropouts not described

The level of evidence was checked using the classification developed by the Oxford Centre for Evidence-Based Medicine <sup>52,53</sup> ranking the studies conform their probability of bias <sup>54</sup> (conform the study design criteria, only level 1 and 2 studies are included) (see table 2).

**Table 2: Level of evidence** <sup>54</sup>

Level	Type of evidence
1A	Systematic review (with homogeneity) of RCT's
1B	Individual RCT (with narrow confidence intervals)
1C	All or none study
2A	Systematic review (with homogeneity) of cohort studies
2B	Individual cohort study (including low quality RCT e.g. <80% follow up
2C	"Outcomes" research. Ecological studies
3A	Systematic review (with homogeneity) of case-control studies
3B	Individual case-control study
4	Case series (and poor quality cohort and case-control study)
5	Expert opinion without explicit critical appraisal or based on physiology bench research or "first principles

## Results

### Screening

#### *Preparation / Identification*

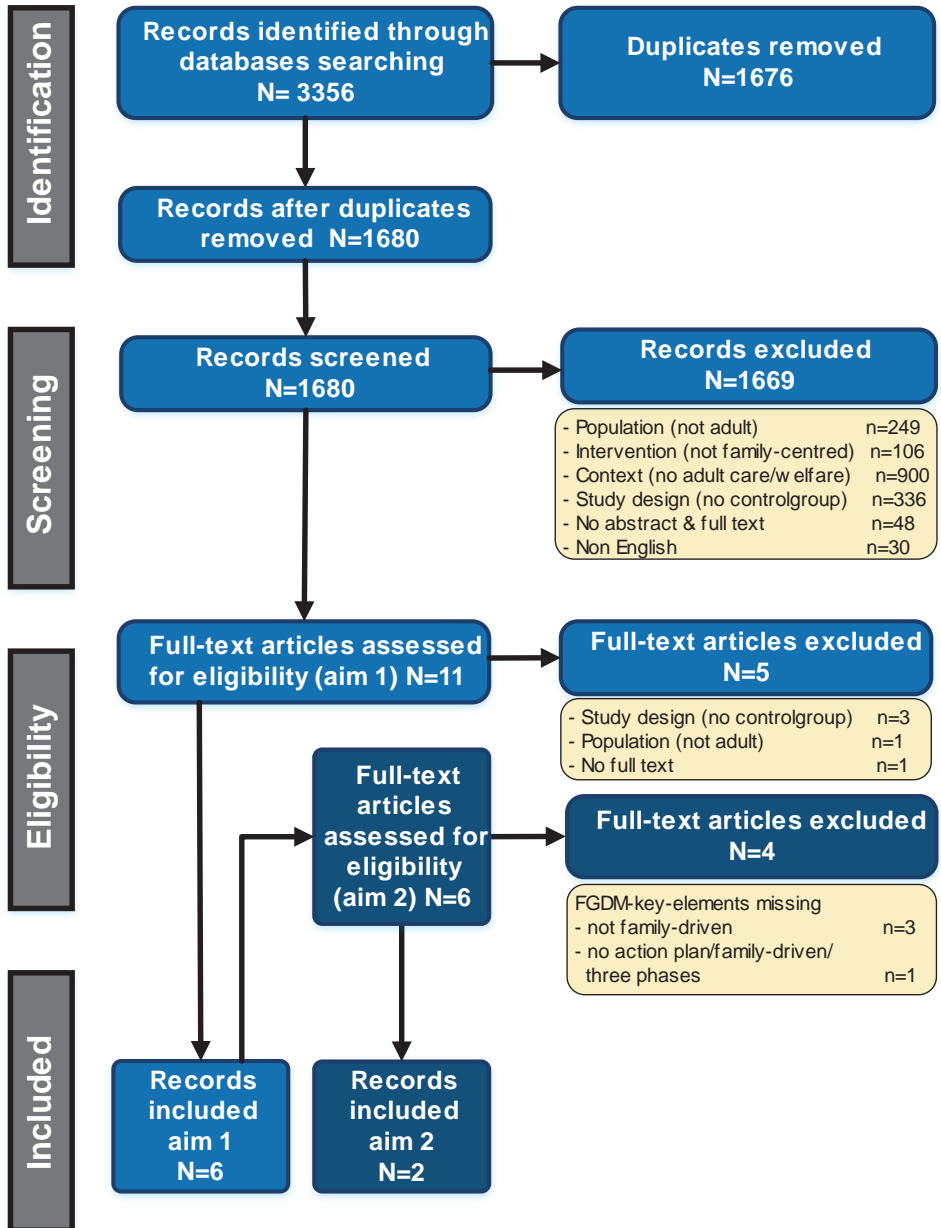
The search yielded a total of 3356 hits retrieved from the database searches. After removing duplicate citations (n=1676), a total of 1680 unique records were left. The articles were published in the time period ranging from 1948 till 2018 (see figure 2).

#### *Title abstract and full-text screening*

A total of 1680 articles were screened in the title-/abstract search conform all eligible criteria, including the first step of the intervention eligible criteria ( family-centred studies). In total 1669 articles were excluded on studies in another context (consumer purchase decision- making, marital decision making, etc) that did not meet the study design criteria of pertaining a controlled trial, did not meet the population criteria of the participant being adult, were not family centred, had no abstract and full text (inaccessible information of meetings, conferences, etc) and were non-English. The 10% double screening (CFH/EWMS) showed good inter-rater agreement (85% consensus; kappa = 0.61) <sup>55</sup>.

A total of 11 articles were double checked on the eligibility criteria (CFH/EWMS/MK). Non-consensus articles were discussed until consensus was reached. In total, five studies did not meet the following eligibility criteria: study design (n=3) <sup>31,56,57</sup>, population (n=1) <sup>58</sup> and no full text (n=1) <sup>59</sup>.

Figure 2 : Prisma flowchart of search and selection process <sup>46</sup>



### **Data extraction and quality assessment**

Of the remaining six family-centred articles <sup>41,42,60–63</sup> data were extracted and summarised concerning their (1) characteristics, (2) quality/level of evidence and (3) presence of the key elements of FGDM (see table 3).

#### *Characteristics of extracted family-centred studies*

All six articles reported information conform the PICOCS process frame work <sup>48</sup> eligibility criteria. However, the heterogeneity in outcome, context, intervention and participants was high and the results varied greatly. Therefore, it was not possible to analyse the articles quantitatively. Instead, the data extraction tool <sup>47</sup> formed the basis of a narrative synthesis.

The articles were published between 2011 and 2017. The six articles originated in total from three studies, emanated in Norway from Malmberg-Heimonen and Johansen <sup>41,42</sup>, the Netherlands from Joling *et al* <sup>60–62</sup> and the USA from de Havenon *et al* <sup>63</sup>. Two studies had a randomised controlled trial (RCT) design, one study was a pilot controlled trial. Different context fields were described: mental health, dementia care and intensive care unit.

There was a widespread of sample sizes: ranging between 22 and 192 participants. There were three groups of study participants who were questioned on different outcome variables: social welfare recipients, caregivers and patients dyads and family members. The comparison condition for the studies was either treatment as usual or no treatment. The outcome measures for the Malmberg-Heimonen and Johansen study <sup>41,42</sup> were prominently self-reported questionnaires measuring social support, life satisfaction and mental health of social recipients. The study conducted by Joling *et al* <sup>60–62</sup> reported nursing home placements, depression, anxiety and cost-effectiveness. The study by de Havenon *et al* <sup>63</sup> described a family meeting survey reporting the satisfaction with audio-visual family meetings.

#### *Quality/level of evidence of the extracted family-centred outcome studies*

With use of the Quality Assessment tool for quantitative studies <sup>50</sup>, six domains were assessed from the three studies: (1) selection bias, (2) study design, (3) confounders, (4) blinding, (5) reliability and validity of data collection method and



(6) withdrawals / drop-outs (see online supplementary appendix 2 for detailed information). The 100% double screening (CFH/EWMS) resulted in 88% consensus with a very good inter-rater agreement of 0.81 (kappa score)<sup>55</sup>. Although two of the three eligible studies had a strong study design (RCT), the overall quality of the three studies was low. All studies reported challenges with a low participation rate (<60%) of the initial eligible group participants or presented no documentation of the participation rate. The low participation rate also affected the level of evidence<sup>52,53</sup>, resulting in level 2B studies (n=2) and level 2C (n=1) (see table 3).

Furthermore, blinding of participants was in all studies not possible due to the nature of the intervention. To conclude, limited information was available on the reliability and validity of used data collection methods.

#### *Presence of FGDM key elements in family-centred interventions*

To examine the presence of the three key elements of FGDM in family-centred interventions in adult care and welfare (see table 4); all six articles of the three studies were 100% double screened (CFH/EWMS) and resulted in a good inter-rater agreement (83% consensus with kappa of 0.67)<sup>55,64,65</sup>. Some differences in agreement were found in labelling the key elements of the Joling *et al* study<sup>60-62</sup>. It was not instantly clear if the study was family driven and had a set-up of a plan with actions/goals.

The family meetings intervention consisted of two individual sessions with the primary caregiver and four family counselling sessions including family members and friends<sup>60-62</sup>. Aims were to improve emotional and instrumental support given to the patient by relieving the burden of caregiving through mobilising the existing family networks of the patient and primary caregiver; teach problem-solving techniques as well as offer psycho-education to the primary caregiver. The counsellor (professional) led the family meetings in a directing role. Consequently, we cannot speak of a family-driven approach. Although the extended family is mobilised, increasing tasks, commitment and family support, it was not clarified what exactly the support consisted of. Therefore, we examined additional information in a manual written for family meetings counsellors<sup>66</sup>. In the manual, a plan was mentioned but the ownership of the plan remained with the professionals.

Table 3: Summary of included studies, quality assessment, level of evidence

Study	Goal	N total intervention/control	Year	Population	Intervention comparison	Eligible to aim	Family group decision-making intervention	Context	Outcome variables	Design	Quality	Level of evidence	Results
<b>Malmberg-Johansen et al.<sup>41,42</sup> (Norway)</b>	Evaluation of the effects of FGC's on social support and mental health on persons receiving long-term social assistance. <sup>42</sup> Evaluation of the longer-term effects of FGC's on social support and mental health of 149 social recipients. <sup>41</sup>	149 96/53	2011 <sup>42</sup> 2014 <sup>41</sup>	Social recipients	FGC + usual social services versus usual social services	1+2	Yes	Mental health	social support life satisfaction mental health	RCT	3	2B	Significant increases of the intervention group were demonstrated (follow-up of 16-23 weeks) in life satisfaction and decreases in mental distress and anxiety and depression; with no significant changes in the control group. <sup>42</sup> The one-year follow-up identified neutral effects of the intervention compared with the control group regarding the outcomes life satisfaction, social support, mental distress, anxiety and depression and employment. <sup>41</sup>
<b>Joling et al.<sup>60-62</sup> (Netherlands)</b>	Evaluation of the effectiveness of family meetings in intervention with - postponing nursing home placements of dementia patients <sup>60</sup> - preventive effects on mental health of primary caregivers <sup>61</sup> of dementia patients <sup>61</sup> - cost- effectiveness in comparison with usual care over a period of 12 months <sup>62</sup>	192 96/96	2012 <sup>60</sup> 2012 <sup>61</sup> 2013 <sup>62</sup>	Dyads of dementia patients living at home + primary caregiver	Family meetings versus usual care	1	No	Dementia care	- Nursing home placements <sup>60</sup> /anxiety <sup>61</sup> - Quality: quality of life, costs, depression /anxiety <sup>62</sup>	RCT	3	2B	No significant results were identified (12-18 months follow-up) of family meetings postpone patient institutionalization more than usual <sup>60</sup> , have preventive effects on the mental health of family caregivers <sup>61</sup> and no significant differences in costs and effects between the intervention and usual care groups were found <sup>62</sup> .
<b>De Havenon et al.<sup>63</sup> (USA)</b>	Evaluation of the effects of audio-visual family meetings in the intensive care unit (ICU)	22 6/16	2015	Family members	Audio-visual family meetings versus regular family meetings	1	No	ICU	Family meeting survey	Pilot study CT	3	2C	No significant group differences between the treatment and comparison conditions were found regarding the outcomes withdrawal of care or overall hospital length of stay.

They set the agenda, leading the meeting. In summary, although the set-up of an action plan and three phases of the meetings could be identified (preparatory meetings with the caregiver, family meetings with family and friends and an evaluation meeting), the study did not meet with the FGDM key element of a family-driven approach.

de Havenon *et al*<sup>63</sup> compared audio-visual family meetings versus in-person family meetings with both a set-up initiated by professionals to enhance discourse and decision-making with the patients family members to facilitate medical decisions. Consequently, we cannot speak of a family-driven approach. The other FGDM key elements (action plan, three phases) were also not present.

The Malmberg-Heimonen and Johansen study<sup>41,42</sup> implemented a FGC model with the following characteristics: (1) it is the participant's meeting, he/she is in charge and decides who is invited; (2) the participant gets assistance from an independent FGC facilitator (not employed by the same organisation); (3) the extended network of the participant is invited; (4) private time: extended network discusses alone in the second part of the meeting without members of public organisations; (5) the FGC process results in an action plan.

One meeting is divided into three parts: (1) information part; (2) the meeting between the participant and his or her private network; (3) the concluding part. In summary: we can speak of a family-driven intervention where all FGDM key elements are met.

**Table 4 Overview of eligible studies to the FGDM key elements**

	Title/abstract phase	Extraction phase		
		FGDM key elements		
	Family-centred studies	Plan	Family driven	Three phases
Malmberg-Heimonen and Johansen <sup>41,42</sup>	X	X	X	X
Joling <i>et al</i> <sup>60-62</sup>	X	X *	- *	X
De Havenon <i>et al</i> <sup>63</sup>	X	-	-	-

\* = information found in additional family meetings manual<sup>66</sup>  
 FGDM, family group decision-making.

### **Evaluation of the effectiveness of FGDM interventions**

For the purpose of evaluating the effectiveness of FGDM interventions, only two papers of the Malmberg-Heimonen and Johansen study were included<sup>41,42</sup>, since the Joling *et al* and de Havenon *et al* studies were excluded for having not all<sup>60-62</sup> or none<sup>63</sup> of the FGDM key elements present. The study described the effectiveness of FGC among social welfare recipients regarding the outcomes life satisfaction, social support, mental distress, anxiety and depression and employment<sup>41,42</sup>. Although there were significant increases regarding the outcome measures of the intervention group after a follow-up period of 16-23 weeks; the 1-year follow-up identified neutral effects of the intervention compared with the control group. It can be concluded that the positive effect faded away with time<sup>41</sup>.

### **Discussion and implications for future research**

The first aim of this review was to systematically review the presence of the three key elements of FGDM<sup>26</sup> (plan with actions/goals, family-driven, three phases of meetings) in family-centred interventions in adult care and welfare. An extensive search of 1680 articles from 14 databases resulted in six articles on three studies of family-centred interventions. One study<sup>41,42</sup> possessed all the key elements required to qualify as FGDM. Of the two other family-centred interventions<sup>60-63</sup>, key elements of FGDM (in particular the family-driven element) were missing. This might be exemplary for family meetings in adult healthcare/welfare. Although the patient and family may be engaged in the decision-making process, the way these meetings are organised fails to really put the patient and family in the driver's seat. Often there are also multifactorial reasons related to decision-making processes such as personal factors as well as, clinician/professional and organisational factors<sup>67</sup>. More research is needed in the requirements and the desire to 'upgrade' these meetings to a next level from a collaborative to a family-driven model where the professional remains low profile and supports the family in order for them to take over the executive role.

The second aim was to evaluate the effectiveness of FGDM interventions in adult healthcare/welfare. While the one intervention study<sup>41,42</sup> described short-term

effectiveness of FGDM among social welfare recipients, this effect was neutralised after the 1-year follow-up<sup>41,42</sup>. Reciprocal interaction seemed difficult to maintain over time, indicating the importance of offering follow-up meetings shortly after the first FGC, sharing responsibility and accountability to fulfil the action plan<sup>38,41</sup>. The lack of rigorous studies of effectiveness of FGDM in adult healthcare/welfare limited answering the second aim. Regardless, this evaluation still adds to our body of knowledge of FGDM in adult healthcare and welfare. Primarily, it highlights the need for high-quality controlled trials. To gain further understanding in the reasoning behind the lack of outcome research, it might be wise to look at the development of FGDM outcome research conducted in child healthcare, which has overcome its own share of obstacles. First, we need to recognise that outcome research of FGDM interventions only started off in the last decennia. It was not until the year 2000 when one of the first controlled studies<sup>68</sup> was published internationally, comparing FGC intervention versus regular treatment<sup>21</sup>. Second, multiple studies reported challenges detecting the efficacy of FGDM through time<sup>69</sup>. Researchers faced difficulties including enough family group conferencing cases to evaluate, resulting in a small sample size<sup>21</sup>. Furthermore, there was a lack of ability to follow people and their outcomes over a long period of time, this made them unable to measure the long-term effect<sup>69</sup>. Third, researchers faced challenges conducting high-quality controlled trials using scientific research methods in a socially complex environment with many unpredictable influencing factors as is often the case in a clinical practice setting<sup>69,70</sup>. Lastly, the only conducted meta-analysis of FGDM in child care included 14 controlled trials from 2000 to 2016, overall showing no overall effectiveness in child-related outcomes<sup>7</sup>. The majority of the included articles were low in quality and were limited in information on programme fidelity. The authors stressed the importance of gathering information on programme fidelity making it able to understand a lack of effect due to possible poor implementation<sup>7</sup>. Indeed, this review also both reveals the urgency of high-quality controlled trials but simultaneously highlights the need to evaluate their implementation to gain more understanding of influencing factors such as possible barriers and facilitators. Exploring experiences and opinions of both patients, family and professionals who are already participating in the FGDM-meetings is essential and highly needed. The fact is that despite the low quantity

## Chapter 3

and evidence of FGDM outcome research, there is a widespread use and enthusiasm for the implementation of FGDM worldwide in more than thirty countries to date <sup>1</sup>. These future directions in research can accelerate new comprehension and acknowledgement that shifting the balance of power from professional towards the person in need and their family is most essential in democratising healthcare and welfare.

### **Limitations**

Several limitations to this systematic review need to be acknowledged. First is the inability to assess studies written in languages other than English, leading to possible selection bias. Nevertheless, we think that the majority of the studies could be assessed, only a small amount of studies were written in a language different than English.

The second limitation concerns the operationalisation used to identify the FGDM meetings. We only identified FGDM studies when demonstrating meetings involving extended family in the decision making process with the three key elements of FGDM present ((1) plan, (2) family-driven, (3) three phases). We have made the decision to integrate the most described key elements with general consensus found in literature, which can frame the outcome of the review. Third, all extracted studies scored low on their quality assessment score and the heterogeneity was high in both types of population, intervention, context and outcomes. This made mutual comparison of the studies difficult.

Last, it was quite a challenge to identify the intervention eligibility criteria of the articles. The majority of the articles provided limited information about the actual intervention; there was often a lack of detail reporting specific characteristics and content of the intervention. For example, no articles were found to have implemented the Template for Intervention Description and Replication (TIDieR) guidelines <sup>71</sup>, a 12-item template to explain and elaborate on the intervention improving quality.

## Conclusion

This is the first review to systematically differentiate FGDM interventions from other family-centred interventions and evaluate its effectiveness within the adult population. Although the studies are still low in both quantity and quality, we have gained an understanding of the differences of FGDM and family-centred intervention studies by means of the identification of the FGDM key elements. The majority of the extracted studies (2/3) are still using the collaborative model of engaging patients and family in the decision-making process instead of the family-driven perspective whereby the professional remains low profile and supports the family in order for them to take over the executive role. These results might be exemplary for a lot of family meetings in the adult healthcare/welfare.

We could not sufficiently answer our second aim regarding the effectiveness of FGDM among adults due to the lack of outcome studies in the adult healthcare/welfare. Further high-quality intervention studies are required to evaluate the impact of FGDM on adults in need, including their families. Moreover, insight into barriers and facilitators influencing FGDM will support our understanding how to empower persons in need, further democratising healthcare and welfare.

### Author contributions

CFH developed the first version of the manuscript, in collaboration with EWMS, JMAV-M, MWMP and MK. JMAV-M, MWMP and MK supervised the writing process and provided feedback on several drafts of the manuscript. EWMS and MK executed the double screening. JMAV-M, MWMP and MK provided methodological advice. CFH wrote the final version of the manuscript.

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The authors declare that they have no competing interests.

### Data sharing

The data that support the findings of this study are available from the corresponding author, (MK), upon reasonable request.

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## Chapter 3

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Appendix: Scores of the Quality Assessment tool <sup>50</sup>

Studies	Selection Bias	Study Design	Confounders	Blinding	Data Collection	Withdrawals Dropouts	Intervention Integrity	Quality score*
Malmberg-Heimonen et al (2011) <sup>42</sup>	<b>Weak</b> Randomisation 96/53 Less than 60% agreed to participate. Participation: 38% (149/395)	<b>Strong</b> RCT	<b>Strong</b> No differences between groups prior to intervention	<b>Weak</b> Non blinded	<b>Moderate</b> Reliability described for all measurements, validity not for all	<b>Moderate</b> 60-79% completed the study Intervention group 63.5% (61/96) Control group 79.2% (42/53)	43% (41/96) completed the FGC intervention process 24% (23/96) participated in major parts of the FGC process 33% (32/96) failed to participate in the intervention	<b>3</b>
Malmberg-Heimonen et al (2014) <sup>41</sup>	<b>Weak</b> Randomisation 96/53 Less than 60% agreed to participate. Participation: 38% (149/395)	<b>Strong</b> RCT	<b>Strong</b> No differences between groups prior to intervention	<b>Weak</b> Non blinded	<b>Moderate</b> Reliability described for all measurements, validity not for all	<b>Moderate</b> 60-79% completed the study Intervention group 63.5% (61/96) Control group 79.2% (42/53)	43% (41/96) completed the FGC intervention process 24% (23/96) participated in major parts of the FGC process 33% (32/96) failed to participate in the intervention	<b>3</b>
Joling et al (2012) <sup>50</sup>	<b>Weak</b> Equal randomisation 96/96, Less than 60% agreed to participate. Participation: 32% (192/602)	<b>Strong</b> RCT	<b>Strong</b> 80-100% of confounders is controlled for. Imbalances found between intervention and usual care group on three of the baseline variables. One is related to outcome and controlled for	<b>Moderate</b> Researcher was blinded to randomisation status, participants were aware of the intervention	<b>Weak</b> Primary outcome=nursing home placements	<b>Moderate</b> 60-79% completed the study Intervention group 76.0% (73/96) Control group 81.3% (78/96)	The majority of the intervention program (i.e. preparation session plus at least 3 family meetings) was completed by 55% (53/96) of the caregivers	<b>3</b>
Joling et al (2012) <sup>51</sup>	<b>Weak</b> Equal randomisation 96/96, Less than 60% agreed to participate. Participation: 32% (192/602)	<b>Strong</b> RCT	<b>Strong</b> 80-100% of confounders is controlled for. Imbalances found between intervention and usual care group on three of the baseline variables. One is related to outcome and controlled for which is related to the	<b>Moderate</b> Researcher was blinded to randomisation status, participants were aware of the intervention	<b>Weak</b> Reliability and validity not described for measurements	<b>Strong</b> 80-100% completed the study Intervention group 84.4% (81/96) Control group: 89.6% (86/96)	91/96 participated in the preparation session, 73/96 attended 1 or 2 family meetings and 44/96 (45.8%) adhered (i.e. completed the preparation session plus 3 or 4 family meetings within 12 months)	<b>3</b>
Joling et al (2013) <sup>82</sup>	<b>Weak</b> Equal randomisation 96/96, Less than 60% agreed to participate. Participation: 32% (192/602)	<b>Strong</b> RCT	<b>Strong</b> 80-100% of confounders is controlled for. Imbalances found between intervention and usual care group on three of the baseline variables. Controlled for 3/3 (100%)	<b>Moderate</b> Researcher was blinded to randomisation status, participants were aware of the intervention	<b>Weak</b> Reliability and validity not described for measurements	<b>Weak</b> < 60% completed the study Careers: Intervention group: 46% (44/96). Control group: 59% (57/96). Intervention group patients: 50% (48/96). Control group: 56% (54/96)	Caregivers completed intervention = 45.8% (44/96)	<b>3</b>
De Havenon et al (2015) <sup>63</sup>	<b>Weak</b> The percentage of selected individuals agreed to participate is not mentioned	<b>Weak</b> non-randomised prospective pilot-study	<b>Weak</b> Not mentioned	<b>Weak</b> Non blinded	<b>Weak</b> self-administered survey	<b>Weak</b> not mentioned	Not mentioned	<b>3</b>

\* Notes: Quality score 1 to 3, with 1 being the best score reflecting no "weak" domain rating; 2 reflecting one "weak" rating, and 3 reflecting two or more "weak" rating.



# PART II

## SOCIAL SUPPORT NEEDS AND BURDEN












# CHAPTER 4

## BARRIERS AND FACILITATORS OF FAMILY GROUP DECISION MAKING IN ADULT HEALTHCARE AND WELFARE: A QUALITATIVE REVIEW

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*Revision*

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### Abstract

Interest in family group decision making (FGDM) meetings among the adult population has increased over the past decade. Although it is surrounded by high expectations, little is known about the barriers and facilitators to success. This qualitative review assessed the following: (1) the total number of referrals to FGDM, meetings held and failed, and (2) the participants' perspectives, based on a selection of seventeen articles from public mental health, dementia care, general social service, and social service for the elderly. A total of 185 referrals could be identified, of which 82 failed (44.4%). After an in-depth analysis, the barriers could be clustered into two categories of (1) "unable to participate" due to causes beyond the control of participants (organisational aspects, professionals' attitude towards FGDM, difficulties of coordinators in facilitating the meeting, and the inability of clients' social support system to participate in the FGDM); and (2) "reluctant to participate" due to participants' own intrinsic motivation (fear of losing control, burdening their social network, lack of reciprocity, shame, and fear of rejection). The first type of barriers may be remedied, but the unwillingness of potential clients and members of their social network to participate is more fundamental and should be respected.

**Keywords:** Family interventions, Social networks, Social Support, Family Group Conferences, Adult healthcare and welfare

### Samenvatting

De belangstelling voor 'family group decision making' (FGDM) bijeenkomsten voor volwassenen, is de afgelopen tien jaar toegenomen. Ondanks de hoog gespannen verwachtingen, is er nog weinig bekend over de barrières en faciliterende factoren voor succes. Dit kwalitatieve review beoordeelde het volgende: (1) het totaal aantal doorverwijzingen voor FGDM, gehouden en mislukte bijeenkomsten, en (2) de perspectieven van de deelnemers op basis van een selectie van zeventien artikelen uit de geestelijke gezondheidszorg, dementiezorg, algemene sociale zorg, en sociale zorg voor ouderen. In totaal konden 185 doorverwijzingen worden geïdentificeerd, waarvan er 82 mislukten (44,4%). Na een grondige analyse konden de belemmeringen worden geclusterd in twee categorieën: (1) "niet in staat om deel te nemen" vanwege oorzaken waarop de deelnemers geen invloed op hadden (organisatorische aspecten, houding van professionals ten opzichte van FGDM, moeilijkheden van coördinatoren bij het faciliteren van de bijeenkomst, en het onvermogen van het sociale netwerk van cliënten om deel te nemen aan de FGDM); en (2) "niet bereid om deel te nemen" vanwege de eigen intrinsieke motivatie van de deelnemers (angst om de controle te verliezen, angst om hun sociale netwerk te belasten, gebrek aan wederkerigheid, schaamte, en angst voor afwijzing). Terwijl het eerste type belemmeringen kan worden verholpen, lijkt de onwil van potentiële cliënten en leden van hun sociale netwerk om deel te nemen fundamenteel van aard en moet derhalve worden gerespecteerd.

### Trefwoorden

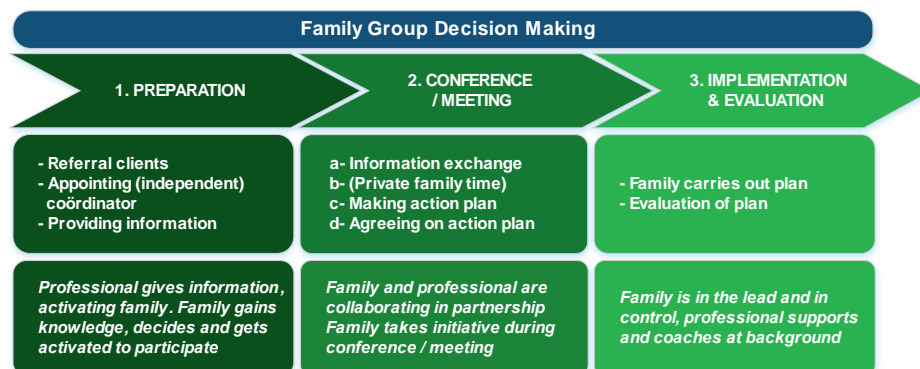
Gezinsinterventies, Sociale netwerken, Sociale steun, Family group conferences, Gezondheidszorg en welzijn voor volwassenen

## Introduction

The involvement of the family has gained importance in healthcare (Carman et al., 2013) and welfare settings (Dijkstra et al., 2016). It is expected to lead to improved quality, safety, and better experiences of care (Carman et al., 2013). An intervention that seriously engages the family (Connolly, 1994; de Jong, Schout, & Abma, 2015; Morris & Connolly, 2012; Shlonsky et al., 2017) is family group decision making (FGDM). It consists of meetings where the balance of power is shifted from the professional to the person in need and their family (Hillebregt et al., 2019; Lupton, 1998). With the help of a coordinator, family members set the agenda and develop and implement a plan (Merkel-Holguin, 2004). A wide interpretation of the term “family” is used for FGDM-participants including friends, extended family members, neighbours, and significant others (Sundell & Vinnerljung, 2004). Under the umbrella of FGDM (Sheets et al., 2009), many variants and local adaptations can be found (Havnen & Christiansen, 2014). FGDM originates from the New Zealand Family Group Conferences (FGC) model legislated in 1989, where it was used for decision-making processes in cases of child abuse, youth offending and neglect (Merkel-Holguin & Marcynyszyn, 2015; New Zealand Legislation, 1989).

FGDM is characterised by three key elements: (1) having a plan with actions and goals; (2) family-driven, meaning that the approach is not aimed at the family, but achieves results through their contributions (Merkel-Holguin, 2004); (3) after referral, the process consists of three phases (de Jong, Schout, & Abma, 2015; Meijer et al., 2017; Sundell et al., 2001): the preparation phase where the family is activated, the conference/meeting phase when the meeting takes place, and the implementation/evaluation phase where the plan is carried out and evaluated (see figure 1).

An underlying theory to explain how network interventions like FGDM function, is missing to this date (Metze, Abma, et al., 2015). Nevertheless, there is a common understanding that FGDM rests on theories of interpersonal psychosocial processes and mechanisms and psychological theories pointing to the importance of social support for individual well-being (Johansen, 2014).

**Figure 1: Phases of Family Group Decision Making**

There has been a rise in studies on FGDM in 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), rehabilitation medicine (Hillebregt et al., 2018), general social welfare (Johansen, 2014; Malmberg-Heimonen, 2011; Malmberg-Heimonen & Johansen, 2014) and social welfare for the elderly (Metze, Kwekkeboom, et al., 2015b, 2015a). However, only a few effectiveness studies with a controlled design have been published. In a recent systematic review focusing on the effectiveness of FGDM within the adult population, we have differentiated FGDM interventions from other family-centred interventions by identifying key elements (Hillebregt et al., 2019). Only one study, described in two papers, (Malmberg-Heimonen, 2011; Malmberg-Heimonen & Johansen, 2014) met the strict inclusion criteria for an FGDM-intervention in a controlled study design. In this study, the effectiveness of FGDM in social welfare recipients for mental health outcomes was evaluated. Besides the urgency of high-quality controlled trials to gain more understanding of the effectiveness of FGDM, there is also a need for a better comprehension its implementation (de Jong, Schout, & Abma, 2015; de Jong & Schout, 2018; Dijkstra et al., 2016; Hillebregt et al., 2019).

FGDM is relatively new within the adult population and although expectations are high (Metze, Kwekkeboom, et al., 2015b), there is little knowledge available on barriers and facilitators of FGDM. Additionally, it is unknown how many conferences have been held, and how many succeeded or failed among the adult population. This paper builds on the same databases and search strategy of

our previous review on the effectiveness of FGDM (Hillebregt et al., 2019). This qualitative review studies the experiences of all participants with FGDM, that is, the patient or client, their social network, the FGDM coordinator, and surrounding professionals. Identifying the experiences of all these parties will generate better insight into conditions that can contribute to successful FGDMs as well as factors that hamper successful implementation.

## Methods

We conducted a qualitative review based on a comprehensive systematic search of 14 relevant electronic bibliographic databases and 1 academic search engine. The search strategy included common variants of the intervention family group decision making (FGDM) that were published in English (for a detailed overview see Hillebregt et al. (2019). For this qualitative review, an update was performed from the search till 4 April 2022, with no further predetermined date limitation. Studies included were about FGDM in adult healthcare and welfare (aged 18+). All study designs were accepted. For each of the studies we analysed: *a) basic characteristics*, like author, year, country, design, intervention, setting, data collection, and main findings. *b) the total number of FGDM referrals*, followed by the number of FGDMs that took place as well as the number of referrals that did not result in an FGDM or where the conference failed to come up with a plan, and *c) participants' perspectives*: perspectives of clients, their social network, coordinators and professionals.

## Results

The previous search of 3356, along with the recent update of 759 articles yielded a total of 4115 hits retrieved from the database searches. After removing duplicate citations (n=2054), a total of 2061 unique records were left. See figure 2 for the flowchart of the search and selection process. The 2061 articles were screened according to the eligibility criteria based on their title and/or abstract. 2017 articles on studies in another context (consumer purchase decision making, marital decision making, etc), that did not involve adults, pertain to FGDM, report

## Chapter 4

outcomes, had no abstract and full text (inaccessible information of meetings, conferences, etc) or were not in English were excluded. A total of forty-four articles went through to the full-text phase and were double-checked on eligibility criteria. In total, twenty-seven studies did not meet the following eligibility criteria: adult population (n=10), FGDM (n=3), outcome (n=10), other factors (n=4), leaving seventeen articles included. Data was extracted from the remaining seventeen articles (Bredewold & Tonkens, 2021; de Jong et al., 2014; de Jong, Schout, Pennell, et al., 2015; de Jong & Schout, 2011; de Jong & Schout, 2013b; Górska et al., 2016; Johansen, 2014, 2020; Malmberg-Heimonen & Johansen, 2014; Meijer et al., 2017, 2019; Metze et al., 2019; Metze, Kwekkeboom, et al., 2015a, 2015b; Schout, Meijer, et al., 2017; Schout, van Dijk, et al., 2017; Schout & de Jong, 2017).

### **a) Basic characteristics and description of extracted studies (see table 1)**

The seventeen articles related to four different public healthcare and social welfare settings: mental healthcare (de Jong et al., 2014, 2018; de Jong, Schout, Pennell, et al., 2015; de Jong & Schout, 2011; de Jong & Schout, 2013b; Meijer et al., 2017, 2019; Schout, van Dijk, et al., 2017; Schout & de Jong, 2017), dementia care (Górska et al., 2016), social service for elderly (>60 yrs.) (Metze et al., 2019; Metze, Kwekkeboom, et al., 2015b, 2015a) and general social services for all age-groups (Bredewold & Tonkens, 2021; Johansen, 2014, 2020; Malmberg-Heimonen & Johansen, 2014). All articles applied to the most common variant of FGDM: family group conferences (FGC), using the same model as the one used in youth care (Merkel-Holguin & Marcynyszyn, 2015; New Zealand Legislation, 1989). To increase readability, we use the term FGDM in the result-section further-on. Participants interviewed can be divided into four groups: (1) clients/patients, (2) members from social network, (3) coordinators and (4) professionals. Five studies also interviewed non-participants, such as experts, managers, researchers, etc. (Bredewold & Tonkens, 2021; de Jong et al., 2014; de Jong & Schout, 2011; Metze et al., 2019; Schout, van Dijk, et al., 2017).

Figure 2: Flowchart of the search and selection process

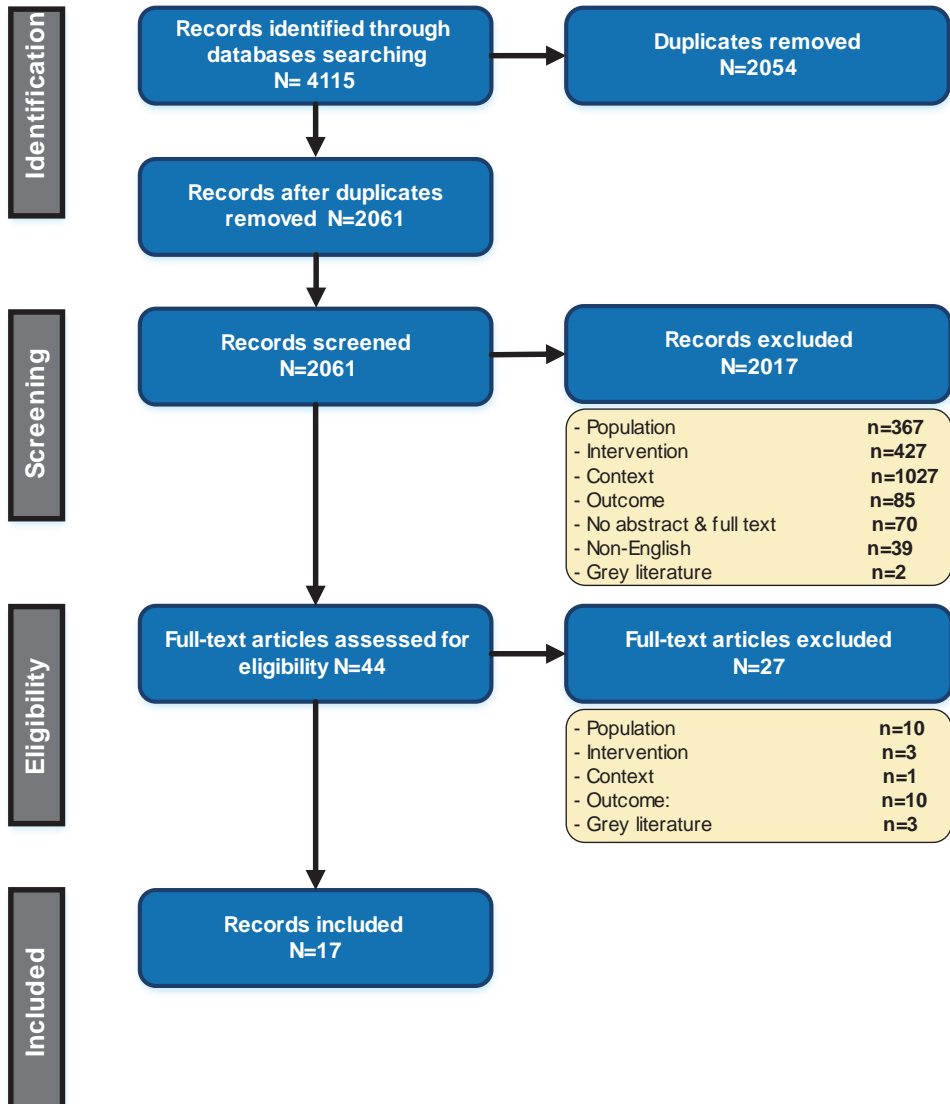


Table 1: Characteristics of extracted studies and study group

Study group: de Jong, Schout, et al. Setting: Primary mental health care, FGDM type: FGC, The Netherlands. Dataset: 41 FGC									
Article	Aim	Method, Study design	Data Collection	Participants	Coordinator	Professional	Patient/Client	Social Network	*Other
(de Jong & Schout, 2011)	To review the applicability of FGC in public mental health care	Qualitative, Descriptive exploratory study	Interviews	Experts including coordinators (n=10) with a background in public mental health care with experience in FGC	X	—	—	—	X
(de Jong & Schout, 2013)	To answer whether FGCs are valuable for clients in public mental health care as a means to generate social support, prevent coercion, and elevate the work of professionals.	Qualitative, Case study design	Interviews	Participants (n=13) from 2 FGC	X	X	X	X	—
(de Jong et al., 2014)	To understand the process of a FGC organized to ensure the social embedding of a man diagnosed with schizophrenia	Qualitative, Case study design	Interviews	Participants (n=11) from 1 FGC and non-participants (n=5)	X	X	—	X	X
(de Jong et al., 2015)	To reflect on the process and impact of 18 failed conferences	Qualitative, Case study design	Interviews	Participants (n=118) from 18 FGC	X	X	X	X	—
(Schout & de Jong, 2017)	To answer the question of whether breaking through a lack of initiative is a task of FGC coordinators, and if so, how do they fulfil this task?	Qualitative, Case study design	Interviews	Participants (n=18) from 3 FGC	X	X	X	X	—
(Schout et al., 2017)	To answer the question in what circumstances FGC cannot be deployed	Qualitative, Case study design	Interviews, Focus group	Interviewees: professionals (n=6) Focus group members: client (n=1), members of social network (n=1), professional (n=2), coordinator (n=1), other (n=4)	X	X	X	X	X
(de Jong et al., 2018)	To gain understanding from the perspectives of insiders on how FGC proceeds in public mental health care	Qualitative, Case study design	Interviews	Participants (n=312) from 41 FGC	X	X	X	X	—
(Meijer et al., 2017)	To study the process leading up to an FGC, the proceedings, and the impact of the conference	Qualitative/quantitative, responsive evaluation	Interviews with scaled answers	Participants (n=260) from 41 FGC	X	X	X	X	—
(Meijer et al., 2019)	To understand the process of FGC in the context of coercive psychiatry to assess its opportunities and limitations for forming a partnership between clients, their social networks, and mental health professionals.	Qualitative, Case study design	Interviews	Participants (n=289) from 41 FGC	X	X	X	X	—



Table 1 continue

Study group: Metzke, Kwekkeboom et al. Setting: Social service for elderly. FGDM type: FGC. The Netherlands. Dataset: 34 FGC's									
Article	Aim	Method, Study design	Data Collection	Participants	Coordinator	Professional	Patien/ Client	Social Network	*Other
(Metzke et al., 2015a)	To understand the FGC process with older adults by exploring the appropriateness of the concepts' resilience and relational autonomy, underlying FGC	Qualitative, Case-study design	Interviews	Participants (n=10) from FGC (n=2)	—	X	X	X	—
(Metzke et al., 2015b)	To examine the existing views and (resisting) attitudes of older adults concerning FGC	Qualitative, Responsive evaluation	Interviews (indiv + Focus group)	Older adults (n=74)	—	—	X	—	—
(Metzke et al., 2019)	To discover reasons for social workers' reluctance to refer clients to FGC	Qualitative, exploratory study	Interviews and Focusgroup \$	Interviewees: Social workers (n=4) and FGC regional manager (n=1) Social workers (n=12) from 3 focus groups	—	X	—	—	X
Study group: Malmberg-Heimonen & Johansen. Setting: General social service, all ages. FGDM type: FGC, Norway. Dataset: 96 FGC's									
Article	Aim	Method, Study design	Data Collection	Participants	Coordinator	Professional	Patien/ Client	Social Network	*Other
(Malmberg-Heimonen & Johansen, 2014)	To explore the participants' experiences with the FGC to explain the observed effects from the RCT	Qualitative/ Quantitative, Mixed methods design	Interviews	Social assistance recipients (n=15) participating from 15 FGC	—	—	X	—	—
(Johansen, 2014)	To explore which psycho-social processes and outcomes FGC generate for long-term social assistance recipients	Qualitative, Exploratory study	Interviews, FGC observation \$	Social assistance recipients (n=15) participating from 15 FGC	—	—	X	—	—
(Johansen, 2020)	To explore long-term social assistance recipients' experiences with FGC	Qualitative, Exploratory study	Interviews	Social assistance recipients (n=15)	—	—	X	—	—
Study group: Bredewold & Tonkens. Setting: Social welfare. FGDM type: FGC, Netherlands. Dataset: 4 FGC									
Article	Aim	Method, Study design	Data Collection	Participants	Coordinator	Professional	Patien/ Client	Social Network	*Other
(Bredewold & Tonkens, 2021)	To better understand under which conditions FGCs become (un)successful	Qualitative, Multiple exploratory case studies	FGC observation \$, interviews	Participants from 4 FGC Interviewees: clients (n=4), members of social network (n=7), coordinators (n=4), professionals (n=6) and manager (n=1)	X	X	X	X	X
Study group: Gorska, Forsyth et al. Setting: Dementia care. FGDM type: FGC, Scotland. Dataset: 10 FGC									
Article	Aim	Method, Study design	Data Collection	Participants	Coordinator	Professional	Patien/ Client	Social Network	*Other
(Gorska et al., 2016)	To evaluate the impact of the pilot FGC service, delivered to people with dementia and their families, in terms of the experience of care provided by families and care professionals involved in the project	Qualitative, Opinion Survey	Focus group interviews	Professionals (n=8) and members of social network (n=6)	—	X	—	X	—

\* Other: experts, lecturers, researchers, staff members, regional managers, etc.

### b) Total number of referrals, held and failed FGDM

A total of 185 FGDM referrals could be identified from the seventeen included articles, corresponding with five different research groups. Table 2 shows the total number of referrals, and held and failed FGDMs.

**Table 2: Total referral, held and failed FGDM's**

Setting	Study group	Referral (N)	Participated (N)	%	Failed to participate (N)	%
Public Mental Health Care	de Jong, Schout et al (de Jong et al., 2014, 2015, 2018; de Jong & Schout, 2011; de Jong & Schout, 2013; Meijer et al., 2017, 2019; Schout et al., 2017; Schout & de Jong, 2017)	41	23	56.1	18	43,9
General Social Welfare	Malmberg-Heimonen & Johansen (Johansen, 2014, 2020; Malmberg-Heimonen & Johansen, 2014)	96	64	66.7	32	33,3
	Bredewold & Tonkens (Bredewold & Tonkens, 2021)	4	2	50.0	2	50.0
Social Service for the elderly (>60 yrs.)	Metze, Kwekkeboom et al (Metze et al., 2015b, 2015a, 2019)	34	8	23.5	26	76.5
Dementia care	Gorska, Forsyth et al (Górska et al., 2016)	10	6	60	4	40
	<b>TOTAL</b>	<b>185</b>	<b>103</b>	<b>55.7</b>	<b>82</b>	<b>44.3</b>

In sum, slightly more than half of FGDM referrals (55.7%) led to a successful conference. Only the articles by research group de Jong et al. indicate in which phase discontinuation took place. Of the 18 failed conferences, 6 were in the preparation phase, 5 in the conference phase, and 7 in the implementation phase.

### c) Participants' perspectives

We conducted an in-depth analysis to better understand why the majority of meetings failed. All text segments of the seventeen extracted articles were 100% double coded by two researchers and reflected upon before they were clustered in two categories, with different underlying barriers for implementing FGDM. The first category, named "unable", pertained to reasons leading to different participants

being more or less “unable to participate” due to causes beyond their control. In the second category, reasons were clustered and named as “unwilling”, it consisted of participants being “reluctant to participate”. The studies by de Jong et al and Metzger et al., yielded the most codes due to the multiple articles included. In the following section, we will elaborate on these findings (see table 3).

#### *Unable to participate*

Organisational aspects, professionals' attitudes towards FGDM, and coordinators' having difficulties facilitating the meeting resulted in participants having difficulty or not being able to carry out FGDM meetings. First, a long preparation time between three weeks and three months is described in the mental healthcare setting, which negatively influences the progress of FGDM. Although the long preparation time ensures the FGDM is organised thoroughly and that the most suitable persons are invited, both clients and their social network may lose interest meanwhile (de Jong, Schout, Pennell, et al., 2015; Schout & de Jong, 2017).

Second, the failure of the social network to come up with a clear plan, for whatever reason, leads to clients losing interest (de Jong, Schout, Pennell, et al., 2015; Meijer et al., 2019). A clear set-up of a plan with transparent goals seems important for clients (de Jong, Schout, Pennell, et al., 2015; Górska et al., 2016; Malmberg-Heimonen & Johansen, 2014), as well as professionals, to increase their engagement in family-orientated practice (Górska et al., 2016). However, a clear plan is no guarantee of success, as an FGDM in general social welfare has shown. Here, family members overpowered the meeting with their negative personal behaviour, something coordinators should be aware of (Bredewold & Tonkens, 2021).

Third, a lack of follow-up was a central issue explaining the stagnation in the initially positive FGDM processes in the social welfare setting. A client described that the process of making desired changes started well after the FGDM, but that the support from his network declined after a while (Malmberg-Heimonen & Johansen, 2014). Without (enough) follow-up meetings, plans tend to dwindle (de Jong, Schout, Pennell, et al., 2015; Malmberg-Heimonen & Johansen, 2014). Furthermore, the timing of the follow-up meetings was important, and they should be organised relatively soon, to maintain participants' commitment (Johansen,

## Chapter 4

**Table 3: Barriers of FGDM participation**

	Barriers	Articles	Setting	
<b>Unable</b> <i>'Not able /difficult to participate'</i>	Time pressure and long preparation time	(de Jong et al., 2015; Schout et al., 2017; Schout & de Jong, 2017)	Public Mental Health	
	<b>Organisational factors</b>	Difficult to set up a plan	(Bredewold & Tonkens, 2021; de Jong et al., 2015; Górska et al., 2016; Malmberg-Heimonen & Johansen, 2014; Meijer et al., 2019)	Public Mental Health Dementia care General social service
		Late follow-up meetings	(de Jong et al., 2015; Johansen, 2020; Malmberg-Heimonen & Johansen, 2014)	Public Mental Health General social service
	<b>Professional</b>	Not accustomed (yet) to family-driven role	(Bredewold & Tonkens, 2021; Górska et al., 2016; Meijer et al., 2017a, 2019; Metze et al., 2019; Schout et al., 2017)	Public Mental Health Dementia care General social service Elderly social service
		Mistrust, reservations towards the coordinator	(de Jong et al., 2018; de Jong & Schout, 2011; Górska et al., 2016; Meijer et al., 2017b; Schout et al., 2017)	Public Mental Health Dementia care
	<b>Coordinator</b>	Unable to break through lack of initiative	(Bredewold & Tonkens, 2021; de Jong et al., 2015; Meijer et al., 2019; Schout & de Jong, 2017)	Public Mental Health General social welfare
	<b>Clients</b>	Limited or weak social network	(Bredewold & Tonkens, 2021; de Jong et al., 2015; Górska et al., 2016; Metze et al., 2015a)	Public Mental Health Elderly social service General social welfare Dementia care
	<b>Unwilling</b> <i>'Reluctance to participate'</i>	Fear of losing control	(Metze et al., 2015b, 2019)	Elderly social service
		Fear of feeling a burden	(Bredewold & Tonkens, 2021; Metze et al., 2015b, 2019)	Elderly social service General social welfare
<b>Clients</b>		Lack of reciprocity	(de Jong et al., 2015; Malmberg-Heimonen & Johansen, 2014; Metze et al., 2015a, 2015b)	Public Mental Health General social service Elderly social service
		Shame and fear of rejection	(Bredewold & Tonkens, 2021; de Jong et al., 2015, 2018; De Jong & Schout, 2013; Meijer et al., 2019; Metze et al., 2015a, 2015b; Schout et al., 2017; Schout & de Jong, 2017)	Public Mental Health Elderly social service General social welfare
<b>Social network</b>		Lack of initiative	(Bredewold & Tonkens, 2021; de Jong et al., 2015; Meijer et al., 2019; Schout et al., 2017)	Public Mental Health General social welfare

2020). One or two months after the first FGDM-meeting (Malmberg-Heimonen & Johansen, 2014) seemed a good directive.

Besides these organisational factors, some studies also blame professionals and coordinators for their inability to persuade and activate clients and their networks (de Jong, Schout, Pennell, et al., 2015; Schout & de Jong, 2017). Many examples of professionals' reluctance or hesitation toward family conferences are provided (de Jong et al., 2018; de Jong & Schout, 2011; Górska et al., 2016; Meijer et al., 2017; Schout, van Dijk, et al., 2017). Although professionals in the public mental healthcare setting had a positive attitude toward FGDM in general, they had difficulties implementing FGDM because it did not fit into their professional work routines (Meijer et al., 2019). It seemed challenging (de Jong et al., 2018) to actively commit to the FGDM approach (Meijer et al., 2017). "It is not in our system yet," as one respondent phrased it (Schout, van Dijk, et al., 2017). Some argued that they lacked the necessary skills while some professionals in public mental healthcare objected to the client and their network taking the lead (Schout, van Dijk, et al., 2017). Social workers in the Metze et al. study, (2019) were hesitant to refer their older clients because (1) they already worked with their clients' social network, (2) they were unsure how to best motivate their clients, or (3) they mistrusted the capacities of social networks (Metze et al., 2019). Although professionals involved in the dementia study (Górska et al., 2016), perceived FGDM as offering them the chance to develop more trusting and open relationships with families, they also struggled not to take over as professionals (Górska et al., 2016).

Furthermore, some coordinators struggled with their role to activate clients and their networks (Bredewold & Tonkens, 2021; Meijer et al., 2019), while this was found essential for the meeting to succeed (de Jong et al., 2018). Schout & de Jong, (2017) even questions whether breaking through of a state of care paralysis of the participants lacking initiative, is a task of the coordinator. The coordinators have multiple responsibilities, considering the long list of roles and competencies they should ideally possess. At the same time, high expectations are created for the coordinator to be skilled; they should ideally remain non-judgemental and neutral, manoeuvre between different interests of family members and clients, offer

## Chapter 4

help when necessary (de Jong et al., 2018; Górska et al., 2016), support and supervise (Johansen, 2020), facilitate the formation of a partnership (Meijer et al., 2019), create a mutual trust (de Jong et al., 2018; Meijer et al., 2019), establish a fruitful collaboration (de Jong et al., 2014), but at the same time remain a formal contact (Johansen, 2020) and exert social control (Johansen, 2014, 2020).

Therefore, when the coordinator is in a situation beyond their control wherein a social network cannot be activated, it is only conceivable to feel responsible and helpless (Bredewold & Tonkens, 2021). Some professionals in public mental health did indeed question the coordinator's ability to mobilise the network and deal with the often-difficult behaviour of the client, especially when the coordinator had no background as a care provider (de Jong & Schout, 2011).

Besides the organisational, professional, and coordinator factors which negatively influenced the clients' ability to carry out the FGDM meetings optimally, the inability of the clients' social support system to participate in the FGDM was an important factor too. Clients in the (elderly) social welfare setting indicated that their networks were often too small, vulnerable, or suffering from health conditions (Bredewold & Tonkens, 2021; Metze, Kwekkeboom, et al., 2015a), in addition to being old themselves. Clients with mental health conditions have often limited social capital and limited access to supportive external groups. Some clients had damaged contacts prior to the conference meeting, and as a result they can hardly rely on the capability of their contacts that are already often broken or faded after becoming disillusioned and worn down (de Jong, Schout, Pennell, et al., 2015). Family members sometimes avoid confrontation due to the experience of a lot of burden themselves, not knowing how to deal with the vulnerability of their relative (Meijer et al., 2019).

### *Unwilling: "reluctance to participate"*

Clients described several reasons for feeling reluctant to participate in an FGDM, all of which were related to their reluctance to invite members from their social network.

First, in the elderly social welfare setting, clients feared losing control over their situation by accepting help and support (Metze et al., 2019; Metze, Kwekkeboom,

et al., 2015b). They would rather not divulge their vulnerability and alarm their children (Metze et al., 2019), and preferred talking to a professional over family members (Metze et al., 2019).

Second, some older adults were afraid to burden their social network (Metze et al., 2019; Metze, Kwekkeboom, et al., 2015b). They declined an FGDM offer because they were reluctant to seek help from their friends and relatives who were old themselves and busy with their own lives (Metze, Kwekkeboom, et al., 2015b). Although they felt it would be okay to ask a neighbour to perform practical incidental tasks, more structural help would burden them beyond what was considered appropriate (Metze, Kwekkeboom, et al., 2015b).

A third reason for the reluctance to ask for social support was a (supposed) lack of reciprocity. Reciprocity (mutual dependence on “giving” and “receiving”) was considered crucial to receiving informal support and sustaining relationships in the public mental healthcare setting (de Jong, Schout, Pennell, et al., 2015).

Malmberg-Heimonen & Johansen, (2014), reported that a lack of reciprocity was one of the main reasons for the stagnation of an FGDM process in the general social welfare field. A lack of reciprocity in social relations could result in difficulties maintaining contact over time (Malmberg-Heimonen & Johansen, 2014). The balance between receiving support and giving something in return was also deemed important by elderly social welfare recipients (Metze, Kwekkeboom, et al., 2015a). Feelings of helplessness can be aroused when the ability to reciprocate decreases, and the older adult is only receiving support. It can even lead to the avoidance of the caregiver, negatively affecting their relationship (Metze, Kwekkeboom, et al., 2015b).

Fourth, shame and fear of rejection were important reasons for clients in public mental healthcare to not share their feelings with their immediate environment and ask for support (Meijer et al., 2019; Schout, van Dijk, et al., 2017; Schout & de Jong, 2017). Examples of clients deliberately excluding people from participating in the FGDM were given (de Jong et al., 2018). The fear of rejection was also a strong incentive for clients with mental health issues to avoid contact with their social network, resulting in withdrawal (de Jong & Schout, 2013b). In welfare care for the elderly, clients felt ashamed of their decreasing independence

## Chapter 4

and were unaccustomed to seeking help. As a result, often only adult children were invited to the FGDM (Metze, Kwekkeboom, et al., 2015a)

Besides the earlier described inability of a social network to give support, family and bystanders were sometimes also unwilling to participate in a meeting. In general welfare, asking others for help brought on feelings of guilt when the request was rejected by their friends: *“Then I felt guilty that I asked them”* (Bredewold & Tonkens, 2021). Several FGDMs in the public mental healthcare setting were not successful because of family and friends’ reluctance to participate. Subsequently, this lack of support nourished further tensions between clients and their networks (Schout, van Dijk, et al., 2017). In general social welfare, relatives participating in FGC even took the opportunity to blame the person who is asking for help (Bredewold & Tonkens, 2021). In dementia care, pre-existing family dynamics were an important determinant of the success or failure of the FGDM (Górska et al., 2016).

## Conclusion and discussion

This review aimed to gain a better understanding of the barriers and facilitators of FGDM implementation within adult healthcare or welfare by reviewing participants’ perspectives of FGDM conferences. An extensive systematic search resulted in the inclusion of seventeen articles focusing on different public healthcare and social welfare settings wherein only slightly more than half of FGDM conferences (55.7%) succeeded. As our findings indicate, a large number of barriers that could be clustered into two categories were identified: “unable to participate” and “unwilling to participate”.

Some of the factors that are clustered under “unable to participate” can be resolved. Our review indicated that if one wants to organise an FGDM, they first need to ensure sufficient access to training and education for professionals, coordinators, and network members. The coordinator must be allowed to gain enough skills, and have the right competencies to be a facilitator, stimulator and controller in identifying and solving problems in the dynamics between the FGDM participants. Professionals who are willing, but unable to participate in the FGDM because they cannot shift from the professional-driven to the family-driven attitude



might be able to acquire the necessary skills for instance through education. The social network might be screened for adequate capacities to give continuous support and aided in mastering new capacities. However, it is possible that they cannot easily acquire these capacities, due to factors like pre-existing family dynamics, or because of their own personal issues. In such cases, an FGDM should not be started. Additionally, our review also indicates that a number of essential organisational aspects, such as the importance to set-up a plan with goals and (multiple) follow-up meetings that are preferably scheduled shortly after the first conference meeting, need to be reconsidered.

It must be noted that the reasons clustered in “unwilling to participate”, are often glossed over. While a lot of attention in the FGDM discourse is focused on organisational improvement and the role of the professional or coordinator, this review shows that social network members as well as clients themselves have their own considerations to be reluctant to participate. Our review suggests that these considerations should be taken very seriously. First, before the start of the FGDM, it is important to know in advance professionals’ reluctance or hesitation towards family conferences for instance, by asking their opinion. They may have good reasons that should be seriously considered, and that may result in not starting an FGDM or referring clients to meetings.

Second, clients may feel ashamed to (re)connect with their social support system. This should be taken seriously too, as it can negatively influence the FGDM. But as opposed to the factors we reflect on below, the FGDM can also act as an engine to share these shameful feelings (de Jong et al., 2018; de Jong & Schout, 2013b) with members of their social network, experience forgiveness and thus reconnect to their social network.

Third, clients may also have good reasons to hold on to their autonomy and not accept help and support. Although FGDM ties in with Western European welfare policy which admonishes citizens to rely more on their strength and capacities to support each other (Metze, Abma, et al., 2015; Newman & Tonkens, 2011), people may have good reasons to reject this new paradigm (Clarke & Newman, 2007; Jager-Vreugdenhil, 2012; Tonkens, 2012) as empirical research also shows (Bredewold et al., 2020). Particularly, the elderly participants included

## Chapter 4

in the studies of this review cherished their autonomy and feared losing control by accepting support from an FGDM, despite the FGDM rhetoric about being in charge (Bredewold et al., 2020; Weele et al., 2018).

Fourth, our findings identified all sorts of clients' reluctance to ask for social support based on the lack of reciprocity. Clients may fear that they would be too much of a burden to others, as they cannot do much in return. The weaker the emotional bond, the more important is reciprocity (Bredewold et al., 2020). Again, clients may have good reasons to cherish reciprocity, understanding people's resistance and taking it seriously is of utmost importance.

Fifth, people may have good reasons to consider their social relations to be unstable, too complicated, or ridden with conflicts and unequal power relations (Tonkens, 2012). In youth care, families declined FGDM because they did not trust their family members and did not wish to share their problems with them (Barnsdale & Walker, 2007; Crampton, 2007). In short, to increase the implementation of FGDM in the adult healthcare and welfare settings, it is not enough to just perform FGDM properly as prescribed by the methodology. It should be acknowledged that participants: clients, coordinators, professionals, and social network members, may have legitimate reasons for reluctance or unwillingness to participate. Their willingness should be assessed and discussed before starting an FGDM. Otherwise, the chances for a successful FGDM are low. Moreover, an unsuccessful FGDM can also ruin already fragile social networks (Bredewold & Tonkens, 2021).

To conclude, high expectations of FGDM in adult healthcare and welfare are not matched by regular failures to implement FGDM. This review gained a better understanding of the barriers for FGDM implementation within adult healthcare or welfare and (legitimate) reasons for the unwillingness or inability to have FGDM. Additionally, it showed for whom this intervention might be beneficial. Information from this review can be very useful when considering FGDM in adult healthcare and welfare settings.

## Limitations

Several limitations to this review need to be acknowledged. First, its restriction to studies written in English leads to a potential selection bias. We think that the majority of the studies could be assessed; only a small number of studies were written in a language other than English. Second, we did not include grey literature to keep the studies as comparable as possible. Although this seems to be a valid argument, additional research focusing on grey literature might lead to more findings.

Last, we were unable to identify the causes for failure or success per distinct FGDM, as this info was absent in the majority of the articles included. Therefore, we relied on the perspectives of the total number of referrals, and held and failed FGDMs.

**Declaration of interest** The authors report no declaration of interest.

**Data sharing** The data that support the findings of this study are available from the corresponding author, upon reasonable request.

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## Chapter 4

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A vertical silhouette of a person standing on a ledge or railing, positioned on the left side of the page. The person is facing right, with their hand on their hip. The background is a light, textured grey.

# CHAPTER 5

## '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 network. 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

Social Support, Rehabilitation, Disabled people, Carers' Needs, Caregiving

### What is known about the topic

- Adults receiving inpatient rehabilitation treatment and their caregivers can experience difficulty transitioning from the rehabilitation facility to life 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 a fear of questionable motives for offering help, such as curiosity or pity.
- People prefer to involve their social network on their own accord.

## 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 offense (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 health care (de Jong et al., 2016; de Jong, Schout, &

## Chapter 5

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., 2021 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 a right balance between giving and receiving. The weaker the emotional bond, the more important the balance (Mauss, 2002). 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.

## 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 acquired brain injury (ABI), spinal cord injury (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 while 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  $\geq 18$  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 three 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. 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 minutes on average and were performed at a location based on the couples' preferences. The

## Chapter 5

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 sub codes 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.

### 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%.

**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
<b>TOTAL</b>	<b>55</b>	<b>20</b>

One couple accepted the FGC intervention, ten couples did not consent to it, and nine 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 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.

Table 2: Demographic characteristics of patient and caregiver couples (N=19)

Age group PWD	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 PWD admitted in 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

## Findings

### ***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.

**Table 3: Response patterns of the couples (N=19)**

Response pattern	N	Explanation	Couple
<b>Not reluctant to ask for support</b>	4	We easily ask for (more) support; have a good social network and we can manage on our own	3,6,12,14
<b>Reluctant to ask for (more) support</b>	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

### ***'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)*

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

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

### **'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.

**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

- ***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 didn't 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

## Social support needs of patients and their carers

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 didn't 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:

*It becomes very personal with family... well, I don't 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 wouldn't ask my friend, my brother, not every week.  
Caregiver: While with home care, that is planned. Then you don't 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

## Chapter 5

explained: *'...and now I have a cleaning lady. I pay her, which makes me also able to decide what I want' (couple 11).*

### - **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 don't do that so easily...*

*Caregiver: Neither do I...*

*Patient: Only when it is absolutely necessary. If I really can't 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 support from their social network does not appear to fit to their values and lifestyles, which are often based on independence and individuality. Most couples did not want to change this way of living.

- **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 incomprehensive; 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 doesn't 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 isn't 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 support.

A 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 doesn't have the skills or doesn't 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 can't do it. And to be honest, it wouldn't 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.

- **Fear of intrusion into one's privacy and independence**

Five couples (2, 5, 13, 15, and 19) feared receiving assistance would allow others

## Chapter 5

to intrude on their privacy and independence. While 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 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 while 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're 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)*

- **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 doesn't 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)*

## 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

## Chapter 5

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 health care and welfare, such as the concern over being a burden (Metze et al., 2015b, 2019) and shame and fear of rejection (de Jong et al., 2018; de Jong, Schout, Pennell, et al., 2015; de Jong & Schout, 2013b; 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 health care, general social welfare, and elderly social welfare (Bredewold et al., 2016; 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 in 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.



## 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 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 toward asking for social support on the other.

Thus, besides estimating the capability, reliability, and the competence of the social support network, professionals must also discuss peoples 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.

## 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

## Chapter 5

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.

### ***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 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 health care systems and a similar trend towards involving social network. Further research would be needed to verify this supposition.

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### **Declaration of interest**

The authors report no conflicts of interest.

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# CHAPTER 6

## 'LIVING THE LIFE OF THE OTHER': CARERS' PERSPECTIVES ON CHANGES IN CARER STRAIN DURING THE REHABILITATION TRAJECTORY

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### **Abstract**

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.

### **Keywords**

carers, rehabilitation, persons with a disability, care trajectory

### **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 (Rand, 2020; Tronto, 1993). 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 (Baker et al., 2017; Brereton et al., 2007; Visser-Meily, Van Heugten, et al., 2005), but their success is limited (Baker et al., 2017; Brereton et al., 2007; 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 (McCullagh et al., 2005; Scholte Op Reimer et al., 1998) 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 (Abrahamson et al., 2017; Cott et al., 2007; Ellis-Hill et al., 2009; Gustafsson & Bootle, 2013; Piccenna et al., 2016; Rittman et al., 2007; Turner et al., 2007, 2008, 2011; Van De Velde et al., 2010). Carers and PWDs experience a gap between the protected environment during inpatient rehabilitation and life in the community (McKevitt et al., 2004; Visser-Meily, Post, et al., 2005). 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 (Abrahamson et al., 2017; Greenwood, Mackenzie, Wilson, et al., 2009; Lynch & Cahalan, 2017; Piccenna et al., 2016) and learn to cope with the 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 (Kruithof et al., 2015; MacKenzie & Greenwood, 2012; Scholten et al., 2019), but carers may also experience adverse effects on their emotional, social, financial, physical, or spiritual functioning (Baker et al., 2017; Kruithof et al., 2016; Rigby et al., 2009; Scholten et al., 2019; Zarit et al., 1986). They may experience feelings of loss, impaired quality of life (Post et al., 2005; Rigby et al., 2009; Teasell et al., 2003; Visser-Meily et al., 2006), difficulties in caring (Sales, 2003; Schulz &

## Chapter 6

Beach, 1999), and impoverished social relationships (Keating & 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 (McPherson et al., 2015; Teasell, 2012; Walker et al., 2013). Some studies do take this perspective (Cameron & Gignac, 2008; Greenwood, Mackenzie, Wilson, et al., 2009), but additional insight is needed, especially with regard to the way carers' needs evolve during the rehabilitation trajectory (Cameron & 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 & Gignac, 2008; Greenwood, Mackenzie, Cloud, et al., 2009). 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 (Hillebregt 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 (Hillebregt 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, or leg amputation), inclusion criteria were that patients should be  $\geq 18$  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 & 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 (Kruithof et al., 2016; van den Heuvel et al., 2001). 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 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 can be best 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 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 University Medical Center Utrecht (number 15617/C). The protocol for this study was filed into the Dutch trial register (NTR5742).

### **Data collection**

Baseline demographic data were collected from both 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 couples' choice, in most cases, the couple's home. Social work students received training, and 'try-out' interviews were conducted to fine-tune the questions of 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 & 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 & 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 rigour of the findings, a subset of the transcripts were 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.

**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
<b>TOTAL</b>	<b>55</b>	<b>20</b>

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

Table 2. Demographic characteristics of spousal couples (N=18)

	Age group PWD	M/F	Diagnose	Traumatic cause	Clinical rehab. (wks)	Weeks being discharged clinic	Children living at home	Educational level	Age group carer	M/F	Educational level	Paid job
1	64-69	M	SCI	Yes	4	70	No	Low	64-69	F	High	No
2	64-69	M	SCI	No	12	51	No	Medium	64-69	F	Low	No
3	46-51	M	SCI	No	5	23	Yes	High	46-51	F	High	Yes
4	64-69	M	SCI	No	13	17	No info	No info	64-69	F	High	No
5	46-51	F	SCI	No	7	38	Yes	Medium	52-57	M	Low	No
6	52-57	F	SCI	Yes	13	28	Yes	Low	52-57	M	Medium	Yes
7	64-69	M	ABI	No	8	84	No	Low	64-69	F	Low	No
8	52-57	M	ABI	No	3	75	Yes	High	52-57	F	Low	Yes
9	52-57	M	ABI	Yes	7	57	Yes	High	46-51	F	Medium	Yes
10	58-63	F	ABI	Yes	12	54	No	Low	64-69	M	High	Yes
11	64-69	M	ABI	No	10	42	No	High	64-69	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	64-69	M	ABI	No	9	41	No	High	58-63	F	High	No
15	58-62	F	ABI	No	6	41	No	Low	64-69	M	Low	No
16	64-69	M	ABI	No	17	20	No	High	64-69	F	High	No
17	64-69	M	ABI	No	6	23	No	High	58-63	F	High	Yes
18	64-69	M	ABI	No	13	15	No	Medium	58-63	F	Low	No

Age: at onset of PWD admitted in 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



## 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.

**Table 3: Carers' perspectives per recovery phase**

	Clinical rehabilitation	Transition clinic to home	Community integration
<i>Personal time</i>	<b>Little personal time</b> Visiting clinic daily. Hardly time for oneself	<b>No personal time</b> Full hands-on support helping partner	<b>Regaining personal time</b> Slowly picking up activities aligned to the degree of support the partner needs
<i>Personal space</i>	<b>Some personal space</b> Evenings home alone	<b>No personal space</b> Little private place to retreat	<b>Regaining personal space</b> Slowly returning personal space to retreat to be compromised with partner

### 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

## Chapter 6

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:

*'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)

## Chapter 6

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 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*

## Carers' perspectives on carer strain

*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:

## Chapter 6

*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 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)*

## Carers' perspectives on carer strain

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 partners' 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"....'*

## Chapter 6

*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 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 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 the 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; Milligan & Wiles, 2010; Tronto, 2003), 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 & 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 & Wiles (2010) speak of carers having to renegotiate their caring identities with every switch of the care location (Milligan, 2005, 2012; Milligan & Wiles, 2010). 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 (Chan, 2007; Sinnakaruppan & Williams, 2001; Smeets et al., 2012). The importance of moments away from the caring tasks, and the need for a 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 & Gignac, 2008; Stiekema et

## Chapter 6

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 the couples' home environment to practice 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 counseling 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 (Rodakowski et al., 2012; Suh et al., 2005). 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 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 does not adequately reflect the whole population in rehabilitation care. This is especially relevant with regard to self-efficacy of PWDs and carers. The larger project that this study is part of was aimed at PWDs and carers with low self-efficacy. Previous research suggests that people with high self-efficacy experience less carer strain (Kruithof et al., 2016; van den Heuvel et al., 2001), so our account of carer strain might be bleaker than it would be with a response group with high self-efficacy. It might 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.

## Chapter 6

Fifth, within the study we did not differentiate between the couples' perspectives by diagnosis ABI and SCI. Overall, we saw that their perspectives were widely shared and not necessarily differentiated by diagnosis, possibly also 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 statement**

The Authors declare that there is no conflict of interest.

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# CHAPTER 7

## CONCLUSION



## Chapter 7

This concluding chapter will briefly summarize the main findings of our study and offer reflections on these findings. Furthermore, implications for practice and research, and the strengths and limitations of the study will be indicated. This chapter also describes our research journey. A journey wherein we explored varied directions with corresponding research methods to get to the heart of the matter. The findings of this thesis give us a better understanding of patient and caregivers' perspectives on social support needs and perceived burden during the rehabilitation trajectory of care. Additionally, our findings gave us further information about the necessary conditions for the implementation of a family-centred intervention like FGDM.

### Main findings

#### Part I: Evidence and POWER-study

In **chapter 3**, we performed a systematic review to describe how effective FGDM interventions were in adult healthcare and welfare. This revealed that controlled studies of family-centred interventions in general and FGDM in particular, are still low in quantity and quality in adult healthcare and welfare. Only one study (two articles) met all criteria for an FGDM intervention describing the efficacy of family group conferences among social welfare recipients on mental health outcomes. The intervention group showed significantly better outcomes after a follow-up period of 16-23 weeks, but no differences between the intervention group and control group were shown in the one-year follow-up. Although no conclusions on the effectiveness of FGDM can be drawn, this systematic review was the first one of its kind in adult healthcare and welfare setting. In addition to providing an overview of the different FGDM settings, we identified gaps in current research.

In **chapter 2**, we have introduced the "POWER-study" and the study protocol of this multicentre controlled trial, to be carried out in twelve rehabilitation centres in the Netherlands. The protocol described the design to measure the effectiveness and implementation of FGDM in patients with a high risk of chronic disability and their significant others. Because FGDM in the rehabilitation setting had not yet been performed in a research set-up and was not included in the

## Conclusion

systematic review, much had to be figured out from scratch. In designing the POWER-study, we first devoted considerable attention to adapting the FGC model (that originated in childcare) to rehabilitation practice. We made sure to adopt the important key elements of FGDM, such as the family-driven approach, the focus on decision-making, the involvement of a broader network, and the creation of an action plan.

Secondly, as part of the multicentre controlled trial and to outline the positioning of FGDM in rehabilitation medicine, we introduced a conceptual framework based on the outcome of empowerment, self-efficacy, and participation. Empowerment was understood as the process of enhancing control over life situations, participation, and social relations (Fisher & Howell, 2010; Wallerstein, 2006) operationalised by means of the measures of self-efficacy, decision making, and participation. A clear theoretical model of FGDM in the rehabilitation medicine setting has been lacking till date, in the Netherlands as well as internationally. It was hypothesized that by influencing and increasing the decision-making process in families, the level of participation and self-efficacy would also increase. Both outcome measures were therefore rated as very important.

However, we have not been able to test that. Despite the inclusion of 329 dyad couples in the POWER study, only four couples responded positively regarding the FGDM intervention. Therefore, it was not possible to answer our first research question regarding the effectiveness of implementing FGDM in patients with a high risk of chronic disability and their significant others in rehabilitation practice. However, we gained valuable results when we attempted to find further answers to participants' motives for asking or not asking for social support from their social network using qualitative research. We researched the perspectives of twenty patient-/carer couples eligible for the intervention.

### **Part II: Social support needs and burden**

In our qualitative review in **chapter 4**, we gained a better understanding of the barriers, facilitators, and the necessary conditions of FGDM implementation within adult healthcare or welfare which were derived from participants' perspectives about their experiences with FGDM. From the 17 articles that were included, 185

## Chapter 7

FGC referrals could be identified, out of which a substantial amount of 82 FGDMs failed (44.3%). Although all settings had their own struggles implementing FGDM, from the perspectives of the participants (clients, social networks, professionals, and coordinators), two main causes were identified for the failure of more than half of the planned FGDMs: the first factor that was described was, “*unable to participate*,” caused by reasons beyond the participants' control, such as organisational or contextual aspects (external factors). The second factor was “*not wanting to participate*,” caused by personal motivations such as shame or feelings of being a burden.

In **chapter 6**, eighteen patient-/spouse couples were interviewed to understand the experienced burden and changing needs during the different transitions in the rehabilitation trajectory. Qualitative analysis of their perspectives described changes in experienced burden per rehabilitation phase which could be identified through concepts of personal time and space. During the clinical rehabilitation phase, carers have little personal time, but do have some personal space; in the transitional phase between clinic and home, carers have neither time nor space; and during the community integration phase, most of them regain some personal time and space, particularly when their partners actively support this. Our study provided insight into the fact that caregiver burden changes during the rehabilitation trajectory. Acknowledging this paves the way for a more tailored support approach of assistance attuned to the carers varying needs.

In **chapter 5**, we interviewed nineteen patient-/carer couples who were all eligible for the FGC intervention, but did not follow through. They were asked about their needs for social support and willingness to ask their friends and family for help. The interview analyses revealed that although the majority of the couples felt they had a reliable network, they nevertheless experienced barriers and limitations to seek support from their network. We identified five reasons for this reluctance: (1) being unaccustomed to seeking support, (2) not wanting to be a (bigger) burden, (3) fear of intrusion of their privacy and independence, (4) fear of problematic motivations such as curiosity or pity, and (5) belief that people in their social network lacked reliability, competence or understanding. The main factor

seemed to be the lack of reciprocity where couples do not see sufficient options to reciprocate the necessary support.

### Reflections of the main findings

Large numbers of informal caregivers already provide care in the Netherlands (de Boer et al., 2020; Kooiker et al., 2019; Witteveen et al., 2021). Government policy in the Netherlands, on the other hand, still encourages citizens to actively arrange care by themselves more with help of friends and family, and cease being dependent on the welfare state (Bredewold et al., 2020). In this dissertation, we have critically examined the extra stimulation of people to seek help from their social network through family-oriented interventions like FGDM. In the previous chapters we discussed how this was accompanied by several challenges. In this section, we divided these into three main themes, namely “barriers of FGDM,” “reluctance to seek social support,” and “burden of the caregiver.”

### Barriers of FGDM

When we initiated the POWER study to evaluate the feasibility of implementing FGDM in a rehabilitation medicine setting, we were confronted with a low participation rate of patient-/carer couples who rejected the FGDM intervention. We were unaware of the exact reasons for this at that time. It seemed unlikely that the barriers encountered were typical of the rehabilitation setting. However, we could not be certain of this because research in the rehabilitation setting was lacking. We conducted a review of the barriers and the facilitators of FGDM in adult healthcare and welfare as one did not exist at the time.

When we examined the results of the review and understood that slightly less than half of the planned FGDMs failed of the included studies, we identified two main causes: participants were *unable* or *not wanting* to participate. The first cause of participants being unable to participate were often due to causes beyond their control. For example, professionals from different settings showed reluctance or hesitation towards family conferences (de Jong et al., 2018; de Jong & Schout, 2011; Górska et al., 2016; Meijer et al., 2017; Schout et al., 2017). Or it did not fit

## Chapter 7

into their work routines (Meijer et al., 2019). Barriers referred to organisational or contextual aspects may be remedied though.

However, the barriers of people who do not want to participate, seemed more fundamental because they are sprouting from their deepest emotions. First, we found that a lack of reciprocity was an important phenomenon for not wanting to participate in the intervention in multiple health and welfare settings for adults. This was true for public mental health, general social welfare, and elderly social welfare settings (de Jong et al., 2015; Malmberg-Heimonen & Johansen, 2014; Metze et al., 2015a, 2015b). The balance between receiving and giving social support was of specific importance. People like to reciprocate the help they receive. Other elderly people, however, liked to “give” social support, but not “receive” it, which complicated reciprocal relationships (Metze et al., 2015a). Second, people did not want to burden their social network. The study by Metze et al., (2015a) on older social welfare recipients for example, showed a high level of shame and fear of rejection.

Although the general opinion about FGDM in child healthcare and welfare seems to be positive (Asscher & Dijkstra, 2014; Havnen & Christiansen, 2014), our qualitative review identified two types of main causes (participants unable/unwilling) why FGDM may be failing in adult healthcare and welfare. Overly positive expectations should therefore be adjusted.

### **Reluctance to seek social support**

Our review showed that the most important reasons why people did not want to participate in FGDM are closely linked to the participants' own intrinsic motivation to decline social support from their network. We were very eager to find out if the social support needs of the patient-carer couples within the rehabilitation setting, matched the conclusions of our review. After we evaluated the perspectives of 20 couples of patients and carers who were eligible for an FGDM intervention, we found some interesting answers regarding their needs for social support and perceived burden during the rehabilitation trajectory. We explored several barriers that patients and current caregivers may experience that prevents them from seeking help. As in the review, our results from the interviews showed that a lack of



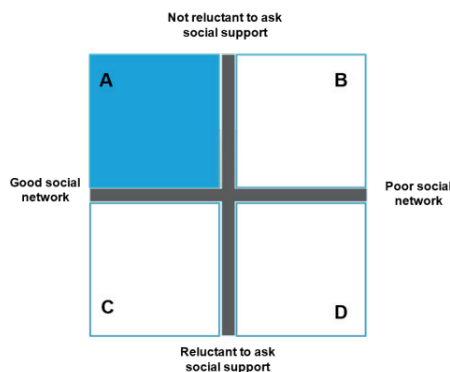
## Conclusion

reciprocity seemed to be a most important underlying factor: the interviewed couples constantly strived to balance their needs with the (potential) help offered by family, friends, or neighbours. Asking for support would disturb this balance.

We visualised the need for social support in relation to the quality of the social network in a cross-sectional diagram. Thus, we can theoretically distinguish different groups of patients and carers, that we will describe below. While we acknowledge the difficulty to capture individuals in groups due to their heterogeneity and considerable intersectionality (Larkin et al., 2019), this diagram does provide a much-needed lens to apprehend the social and emotional complexity of caring (Tonkens et al., 2009). Each quadrant represents a group of people for whom asking and accepting social support embodies a different meaning.

### *“Active citizens” (quadrant A)*

People belonging to group A would have a good social network that they actually consult when necessary. Therefore, current policy would qualify them as “active citizens” (Newman & Tonkens, 2011) who do what the government in the Netherlands expects from them: actively arrange care themselves with the help of friends and family (Bredewold et al., 2020). People in quadrant A experience little hesitation in asking for help. Because the informal safety net is active and present, the expectation is that little to no support will be needed from formal care such as social work to strengthen their network. However, our results show that there is a risk of getting stuck with well-intentioned help that may not match the couple's needs at all.

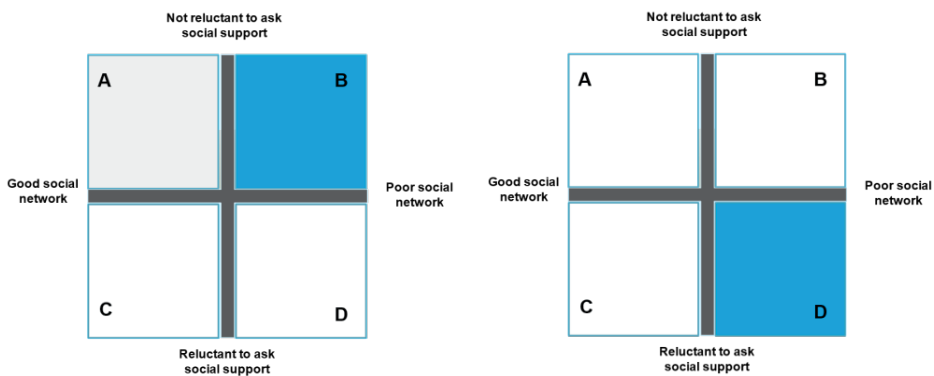


## Chapter 7

Many people though, cannot be classified as “active citizens” with good social networks, but have poor social networks and weak family ties instead (Broese van Groenou & De Boer, 2016). Reasons for this include having family members living far away or being busy with their own lives, having an illness or disability or being of age oneself with declining social networks due to the loss of friends; those people will fit in the categories B and D.

### *People with poor social network (quadrants B and D)*

Both quadrants B and D, represent people with poor social networks that differ in the extent to which they seek help. As we can see in the cross-diagram, people in quadrant D are more reluctant to seek social support than those in quadrant B.



Of all four quadrants, couples in quadrants B and D have traditionally received much attention from social professionals. Indeed, as part of the government's social policy, the social professional is also expected to promote the client's self-reliance and participation in society. People who do not have a good network are expected to take the initiative to strengthen their ties in their environment to seek more informal help; for instance, to ask a neighbour, family or friends. Rehabilitation social workers support them as they pay close attention to people with a vulnerable social network and try to help in strengthening their network, preventing isolation or involving volunteers.

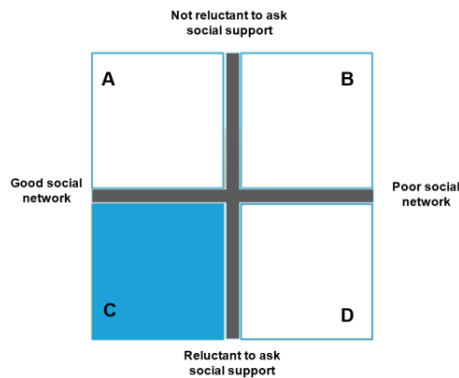
Social workers make an inventory of the social network (Beun et al., 2009; Kruijswijk et al., 2014) by looking at its size, composition, density, stability and

## Conclusion

accessibility (Kruijswijk et al., 2014; Witteveen et al., 2021). Questions social workers tend to ask include the extent to which the couple feels supported by their social network. And if the social network can act as a safety net or if support is lacking and action is needed to strengthen these ties. But when all these questions are answered satisfactorily, a very important question is easily overlooked: how willing are they to ask their family and friends for (more) support? What is often overestimated is the actual desire of people to involve their network.

### *“The neglected group” (quadrant C)*

Our research showed that, many of the interviewed couples did not belong to group B or D with a poor social network, or to group A of the “active citizens” contrary to our expectations. Our research confirmed that the majority of the interviewed patient-carer couples belong to group C instead. They do possess a good network, but preferred not to seek (more) help from their informal network.



At first glance, the people in quadrant C actually seemed to be managing just fine with enough social support available; but what sets them apart from the rest is their reluctance to ask (more) support from family and friends. An important factor for not asking for and accepting help within rehabilitation care was the concern about a lack of reciprocity in the relationship. We identified five reasons for this reluctance: (1) not accustomed to asking support, (2) not wanting to be a (bigger) burden, (3) fear of intrusion of their privacy and independence, (4) fear or

## Chapter 7

problematic motivations such as curiosity or pity, and (5) lack of reliability, competence, or comprehension of the network.

In general, one can say that the first reason stems from people “being unable” to ask for support, while the other reasons stems more from people “not wanting to”. We saw in our study in **chapter 5** that patient-/carer couples could give more than one reason for their reluctance. This reluctance may also have implications in the functioning of social professionals. When people are (willing but) not able to receive support, for example, because they are not accustomed to seek support, a logical response of the social professional is to support them to practice asking. However, when people do not want to ask for support from their network, social professionals have no reason to help them asking.

While government policy focuses on the active citizens of group A, professionals' centre of attention is groups B and D with poor social networks, the (possibly large) group C is neglected. People from group C are extra vulnerable because they often adopt the role of carer for their loved one alone, resulting in a high risk of burden.

### **Burden of the caregiver**

One in five informal carers in the Netherlands belongs to the so-called *alleenhelpers* [*solo helpers*]: informal carers of a partner (or child) who do not share the care with others (de Boer et al., 2019). Our results in **chapter 6** showed that the majority of the couples (mostly spouses) belonged to group C and can also be categorised as *solo helpers* [*alleenhelpers*] (de Boer et al., 2019). In our research, these solo helpers who are also called *pivotal caregivers* [*spilzorgers*] (Tonkens et al., 2009) provide care for their loved ones largely on their own and prefer no (more) interference from their family and friends. Because of the aforementioned reciprocal aspects, they don't ask others for (more) help; they desire to be independent of those around them, and don't wish to burden them with their problems (de Boer et al., 2019; Tonkens et al., 2009).

The couples we interviewed radiated a strong sense of a "two-unit bond" with a high degree of self-efficacy to face challenges together. In their scoping reviews on carer related research, (Henwood et al., 2017; Larkin et al., 2019) call

## Conclusion

for more recognition that caregiving is actually embedded within a relationship. Although this seems to be an obvious point, “the nature of the dyad” (i.e., whether spousal, friends, parent/child, or “other”) is still overlooked in carer literature. In addition to the methodological challenge of determining the impact of a treatment or intervention on a dyad as opposed to individuals, research is often focused on an individual rather than a pair, idem for interventions that are often only offered to either “carers” or “patients”, but not both (Larkin et al., 2019).

Sebern & Whitlatch, (2007) explain that the nature of the relationship, in our case, spousal couples, significantly influences the experience of being a carer (Larkin et al., 2019; Sebern & Whitlatch, 2007). Our research has focused on the patient-carer dyad and the results showed a strong connection between both persons where the majority of the interviewed caregivers put their lives “on hold” to accept the role as carer for their loved one unconditionally. This caring role tends to be viewed as a normative extension of their existing role of wife or husband (Larkin et al., 2019). Despite the fact that this seems to be a conscious choice, they are also nurtured in this by the prevailing norms and values in society that promote a high degree of autonomy and independence.

Paradoxically, this two-unit bond and the preference to be as independent as possible without the help of others meant greater interdependence with each other, in the majority of the cases the partner who now takes on most of the care. This is in line with research on spousal relationships that identified frequent and strong interdependence between two partners, with intertwined lives where one partner’s thoughts, emotions, and behaviours influence the other (Smith & Mackie, 2000). When one of the spouses acquires a disability, this interdependence will become even higher. Above all, this makes this group of caregivers susceptible to a high degree of burden. More recognition is needed for this “neglected group” of caregivers, for whom their reluctance to involve their social network also comes with a price.

Our results from the exploration of the perspectives and interactions of carers and their partners with ABI or SCI, showed that spousal couples have different needs in terms of space and time per rehabilitation phase, as visualised in Table 1. Our research contributed to a better recognition of the recovery phase a

## Chapter 7

carer is in, and to identification of the experienced burden that can affect the dynamics between the partners, so that a more timely and appropriate rehabilitation treatment can be offered. Our results are in line with existing research that assistance must be at least tailored to the different rehabilitation phases (Cameron & Gignac, 2008; Stiekema et al., 2020).

**Table 1: Carers personal time versus space during the rehabilitation phases**

	Inpatient treatment	Transition clinic to home	Community integration
Personal space	+	-	- / +-
Personal time	-	-	- / +-

Now that we have a better understanding of the different factors that influence people's reluctance to provide social support, gained insight into the caregivers' perceived burden and needs during the rehabilitation care trajectory, as well as the barriers and necessary conditions for the implementation of FGDM, how can we answer our main question about its feasibility in rehabilitation practice?

First, we can refute the assumption that still dominates the care policies in many Western welfare states namely that social support oriented interventions like FGC are beneficial for everyone and provide an easy solution to facilitate the transition from the rehabilitation facility to home (Hillebregt et al., 2018) and reintegration into the community (Boschen et al., 2003). Indeed, research on the reform of the decentralisation of long-term care in the Netherlands, which evaluated the government's policy decisions, indicated that overly positive assumptions were made about the self-reliance and empowerment of its citizens. It was assumed too positively that all people with needs have a social network to fall back on and, that they are capable to ask for them. Moreover, it was assumed that these social networks were willing and able to provide the necessary assistance (Bredewold & Tonkens, 2021; Bussemaker, 2021; Kromhout & Klerk, 2018).

Second, this thesis showed that having a good social support system and being competent enough to ask for help is not that self-evident and does not automatically lead to the actual activation of the support network. Promoting social support-oriented interventions such as FGC is only beneficial for those people who

## Conclusion

are also willing to involve their network. The emphasis should not be entirely on how strong and good your network is. Instead, the focus should first lie on scrutinizing the willingness to engage this network as there are potentially many people fitting in this neglected group.

Third, we can conclude from our study that network-centred care such as FGC is also not the answer to address the couples' perceived burden. The first point described is that network meetings and seeking social support from family and friends comes with possible "reciprocal reluctance" from the patient-/carer couples in rehabilitation care. A second point is that it does not specify the rehabilitation phase someone is in. Our results identified that increased perceived burden was particularly experienced in the transition phase from clinic to home, where the carer experienced a lack of time and space, was busy with supporting their partner in the daily activities. In the community integration phase, carers described that the amount of personal time slowly increased as the partner became more independent, although the amount of personal space remained scarce or varied. Consistent with this finding, more acknowledgement is needed that carers' needs vary during the rehabilitation trajectory, particularly with the varying availability or lack of "personal time" and "personal space".

A tailored treatment approach, needs to be further designed and developed to provide caregivers with more timely and appropriate rehabilitation treatment. It is important that the social professional, the client and their relatives, as well as the policy, are well aware of this aspect. We will discuss this in more detail in the implications.

## Methodological considerations

Besides the methodological limitations mentioned in the individual chapters, there are some general considerations about methodological issues.

Two study designs were used for this thesis: a multi-centre controlled trial, and when the participation rate was low, an explorative qualitative design to find some answers. Furthermore, two reviews were executed, a systematic literature review and a qualitative literature review. Our research journey has largely determined the order of the written articles and reviews. In hindsight, it would have been better to

## Chapter 7

conduct the qualitative review before the start of the multi-centre controlled trial. This review gave us a lot of valuable information about the barriers of FGDM. For instance, our understanding of the importance of reciprocity, that is, whether or not people accepted social support, could have been used to alter the design of the study.

The majority of the 20 patient and carer couples we interviewed were spousal couples. As we have seen in previous chapters, their relationship existed with a strong two-unit bond specific to spouses. Therefore, we cannot make statements about non-spousal patients/carers dyads like brothers and sisters or close friends.

In the original design of the POWER study, the inclusion of participants depended on the degree of self-efficacy of the patient and carer measured by a questionnaire. Reflecting on this, we should have given social workers a more important role in the FGC referral process. One possibility would be for them to first explore people's willingness to involve their social network before surveying their motivation for FGC.

### **Implications for rehabilitation care**

After a life-event such as acquiring illness or disability, people often hit rock bottom and find themselves in the most vulnerable phase of their lives. As we have seen, not all people are empowered enough to face these challenges, or can act as well-informed consumers of care (Leget & Smits, 2016). It is clear that the positive view of “active citizenship” as envisioned by the government is too narrow and does not do justice to the reality of living with an illness or disability, or being a primary carer of a loved one who is ill (Newman & Tonkens, 2011) .

Our research found not only that few citizens could be labelled as “active citizens,” but also that they differed in their ability to activate their network, the level of experienced burden, and the degree of reluctance to reach out to their social network.



### **(Attention for) Reluctance to ask for social support**

An important question that is missing in both policy and professional practice, is what people's real needs are to receive help from family and friends, and whether this should be reinforced or not. In this thesis, twenty couples have been able to share their opinions and experiences, and very valuable information has emerged from these interviews. What they said was clear: they don't really feel like asking their family and friends for help for multiple reasons. Our results also showed how difficult it was for people to make these desires and wishes to receive support explicit. Therefore, we propose to gain more awareness about the different types and needs of patients and carers, their support networks, and to take into account the social context and environments in peoples' lives and adjust the policy accordingly.

Moreover, to ensure that the care provided matches the needs of the carers as closely as possible, it is necessary for both the care recipient and the caregiver to be empowered enough to choose the type of care they like and to receive and control how the care is given Rummery & Fine, (2012).

The social worker can support people with this, for example in exploring what they really (not) want in terms of receiving help. Social professionals are highly skilled in unravelling the complexity and dynamics of the social network (Witteveen et al., 2021). However, their focus on optimising informal care can also be their pitfall. Our research findings showed that any reluctance to ask family and friends for social support can easily be overlooked. The second recommendation would therefore be that social professionals should not only unravel the strength, reliability, competence and power of a person's social network, but also carefully assess any reluctance to social support. It is essential that professionals are able to distinguish what kind of reciprocal relationship people have and which reciprocal aspects play a role in accepting or refusing social support. Furthermore, it is important that the social worker discusses both the positive and the negative aspects of social support (Lincoln, 2000). Social professionals' competence to explore this reciprocal reluctance can be further increased with the ability to distinguish the couples in one of the four groups in the quadrants as visualised

earlier in the cross diagrams. When there is more awareness and competence among social professionals, a tailored approach that allows the person in need and the carer to make an informed choice whether or not to seek help from family and friends can be offered .

### **Changing traditional rehabilitation treatment**

Our findings show the difficulties that patients and their caregivers experience in the transition from the rehabilitation clinic to home, and at the same time, we also see that the majority prefer not to burden their family and friends to ask for (more) help during this difficult period. Therefore, we have described three important factors for support that might better fit the patient and carers' needs.

The contrast between the rehabilitation centre and the home environment is currently too high. While the fully adapted environment of the rehabilitation centre is designed to enable people with disabilities to function better, the home environment can by contrast be experienced as a disabling environment. Participants described the lack of opportunities to practice skills in a real-life environments during inpatient care (**chapter 5**). (McPherson et al., 2015) explains that traditional rehabilitation programmes indeed focus on functional and functions retrieval to maximise functional independence. They pay little attention to coping with the chronic conditions in the context of the clients' and carers' own environment and life. As a result, rehabilitation treatment fails to prepare clients for the real world (McPherson et al., 2015). Therefore, treatment in the context of one's own home environment with a focus on how to return to a meaningful life, involvement in valued roles, or working on positive sense of self-worth is needed (Hammell, 2004; McPherson et al., 2015). When people are better prepared to function at home, the gap between the inpatient clinic and home will be smaller, with positive consequences for integration into the community. When the carer has to provide less support, this may even reduce the experienced burden.

Furthermore, we need to ensure that both patients and carers have sufficient one-to-one sessions with the social worker or other social professional to better support the transition from clinic to home. Paradoxically, when the most challenging phase arrives (the transition from clinic to home), the frequency of

## Conclusion

treatment is being reduced. Rather than focusing on increasing informal care with family-centred interventions as FGDM, our findings show that there is a greater need for formal care in this phase of the rehabilitation trajectory.

Both patients and carers would benefit from improved integrated collaboration between the rehabilitation centre and community health services. A report that sets out the policy in rehabilitation medicine till 2025 in the Netherlands sums up a number of important challenges for the upcoming years in terms of both logistics and content (NSRM, 2018). For example, it indicates that patients and carers would benefit from increased attention to prevention and aftercare, better information provision and an improved cooperation with other professional disciplines (NSRM, 2018). Currently, when people are discharged, care is often handed over to other organisations offering their services in regional areas. Although we have a well-developed network of primary care providers in the Netherlands, people with illnesses or disabilities often have to deal with various fragmented health care and welfare organisations. To improve integrated collaboration, professionals from the community health organisations need to be involved when people are still in the outpatient-treatment phase. Another way to ensure optimal collaboration between the different organisations and to prevent carers becoming overburdened, is to appoint a professional who closely supervises couples' transition from clinic to home.

When the cooperation between organisations is well coordinated (e.g., good communication and transfer of knowledge), this will reduce carers' stress and facilitate the transition from clinic to home.

## Suggestions for further research

### Preferred care per phase

Through our research, we have distinguished the degree of carers' burden and their needs in terms of space and time per rehabilitation phase, but we do not yet know the preferred care per phase that would suit these needs. Questions that need to be answered include: what interventions are needed in what phase of the rehabilitation trajectory? What are patient's and carers preferences regarding the

## Chapter 7

timing of these interventions? We have seen that the transition phase is the most critical phase for patient-/carer couples. Many people experience a gap between the clinic and home. We also know that good timing is essential but that it will vary from couple to couple. For example, when people in the clinical phase are still in recovery mode, striving to recover as much as possible and improve functionality, they are often not yet engaged in the "home phase" at all. On the other hand, for some couples to wait with the intervention until they go home may already be too late. The transition from clinic to home may then be experienced as too harshly, causing couples to immediately go into survival mode to get through the days. More research is needed to explore the perspectives of patients and their carers about their preferred care to expedite the transition from clinic to home where more attention should be paid to the needs of each individual couple.

### **Inclusive participatory research**

To understand caring and the burden of caregiving, we need to rely more on the experiences and expertise of those involved; in this case, people with disabilities and their carers. More recognition is needed for the complexity of care and the differences in support-seeking behaviour of people. The rehabilitation setting would benefit from executing more inclusive research which consists of intensive collaboration between professionals, researchers, and the patients and carers (Knevel et al., 2022). When patients and carers are actively involved, for instance, with action-research, more recognition of the patient's and carers' perspective is gained. As mentioned earlier, when we attempt to understand care as relational (Brannelly, 2016), inclusive research can unravel the carer's needs and burden which will not be evaluated from the carer's perspective only, but also from the perspective of the person caring for, and considering the interactions between them in the social context (Yeandle et al., 2017). Inclusive research, also known as participatory research, is therefore an appropriate method to gain a deeper understanding in the complexity of care and care practices in the rehabilitation setting. At the same time, it can complement mainstream research on caregiver burden which is predominantly understood in terms of its measurable effects on carers (e.g., psychological distress, health) (Lyons et al., 2002; Rand, 2020).

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# APPENDICES

SUMMARY



## Summary

More people are likely to develop chronic diseases as the proportion of older people in the society increases. Over the last decade, Dutch care policies have increasingly stressed the importance of more social support from the 'social network' of family, neighbors and friends. Various policies and methods have been implemented to promote this. One such method, called family group decision making (FGDM) involves the social network in making and implementing a support plan.

This PhD thesis begins with the introduction of an intervention study to evaluate the effectiveness of implementing FGDM in rehabilitation practice. As the participation rate among patients' and their caregivers' was low, a shift was made to a different research question as we wanted to understand their reasons for reluctance on social support. Furthermore, we researched the conditions of implementing FGDM in settings other than rehabilitation practice to existing literature.

Often people with serious chronic long-term illness as Acquired Brain Injury (ABI) or Spinal Cord Injury (SCI) receive inpatient care for weeks or months in rehabilitation centres. Unfortunately, people with disabilities and their carers experience a large gap between the protected clinical environment and life in the community again. They feel insufficiently prepared to cope with the disability in daily life.

The assumption was that implementation of FGDM would result in greater family involvement and contribute positively to the transition from clinic to home. In the first part of the thesis the 'POWER intervention study' is described with the aim to evaluate the effectiveness and implementation of FGDM in rehabilitation practice.

However, based on a field experiment, two literature reviews, and 20 in-depth interviews, it was found that people with disabilities and their caregivers are very reluctant to ask their social network for (more) support. In the second part of this thesis, we analysed the reasons for this reluctance and its implications for policy and practice. Through qualitative research, we gained valuable knowledge about the perceived burden and changing needs of caregivers in the rehabilitation trajectory of care.

**Chapter 1** provides an overview of the social context of caregiving and recent developments in family centred care, family group conferences, and its research. This chapter provides a framework for the research conducted.

### **Part I: Evidence and POWER-study**

**Chapter 3** presents a systematic review to describe the effectiveness of FGDM interventions in adult healthcare and welfare. This showed that there were very few controlled studies of family centred interventions in general and FGDM in particular. The studies that had been conducted generally did not meet the scientific quality criteria. Only one study (two articles) met all the criteria for an FGDM intervention describing the efficacy of family group conferences among social welfare recipients on mental health outcomes. The intervention group showed significantly better outcomes after a follow-up period of 16-23 weeks. However, no differences between the intervention and control groups were observed at the one-year follow-up. Although no conclusions on the effectiveness of FGDM can be drawn, this systematic review is the first of its kind in adult healthcare and welfare settings. In addition to providing an overview of different FGDM settings, we identified gaps in the current research.

**Chapter 2** describes the introduction of the 'POWER-study' and the study protocol of this multicentre controlled trial, to be conducted in 12 rehabilitation centres in the Netherlands. The protocol described a design to measure the effectiveness and implementation of FGDM in patients with a high risk of chronic disability and their significant others. As FGDM in the rehabilitation setting had not yet been performed in a research setup and was not included in the systematic review, much had to be determined from the beginning. In designing the POWER study, we first devoted considerable attention to adapt the model (which originated in youthcare) to rehabilitation practice. The most important key elements of FGDM were adopted, such as the family driven approach, focus on decision-making, involvement of a broader network, and creation of an action plan.

Second, as part of a multicentre controlled trial and to outline the positioning of FGDM in rehabilitation medicine, we introduced a conceptual framework based on the outcomes of empowerment, self-efficacy, and

## Summary

participation. A clear theoretical model of FGDM in the rehabilitation medicine setting has been lacking to date in the Netherlands, as well as internationally. It was hypothesised that, by influencing and increasing the decision-making process in families, the level of participation and self-efficacy would also increase. Therefore, both outcome measures were rated very important.

However, we were unable to test this. Despite the inclusion of 329 dyad couples in the POWER study, only four couples were interested in participating in the FGDM intervention. As a result, it was not possible to answer our first research question regarding the effectiveness of implementing FGDM in patients at high risk of chronic disability and their significant others in rehabilitation practice. However, we obtained valuable results when we attempted to find further answers to participants' motives for asking or not asking for social support from their social networks using qualitative research. We researched the perspectives of 20 patient/caregiver couples eligible for the intervention and described the results in Chapters 5 and 6.

## Part II: Social support needs and burden

In our qualitative review in **Chapter 4**, we gained a better understanding of the barriers, facilitators, and necessary conditions of FGDM implementation within adult healthcare or welfare which were derived from participants' perspectives (clients, social networks, professionals, and coordinators) about their experiences with FGDM. From the 17 articles that were included, 185 referrals to FGDM's could be identified, out of which 82 failed (44.3%), meaning that these did not lead to an actual meeting. Although all settings had their own struggles to implement FGDM, from the perspectives of the participants, two main causes were identified for the failure of just under half of the planned FGDMs: the first factor that was described was, '*unable to participate*', caused by reasons beyond the participants' control, such as organisational or contextual aspects (external factors). The second factor was '*not wanting to participate*', caused by personal motivations such as shame or feelings of being a burden.

In **Chapter 5**, we describe the interviews of 19 patient/caregiver couples who were all eligible for the FGDM intervention but did not follow through. They

## Summary

were asked about their need for social support and willingness to ask their friends and family for help. The interview analyses revealed that although the majority of the couples believed that they had a reliable network, they nevertheless experienced barriers and limitations in seeking support from their network. We identified five reasons for this reluctance: (1) being unaccustomed to seeking support; (2) not wanting to be a (greater) burden; (3) fear of intrusion of their privacy and independence; (4) fear of problematic motivations, such as curiosity or pity; and (5) belief that people in their social network lacked reliability, competence, or understanding. The main factor seemed to be the lack of reciprocity, where couples did not see sufficient options to reciprocate the necessary support and preferred to face challenges together without the support of their network. Consequently, the couple's interdependence increases causing a high risk of burden on the carer, which we discuss in more detail in Chapter 6.

In **Chapter 6**, we describe the interviews of 18 patient/spouse couples to understand the experienced burden and changing needs during the different transitions in the rehabilitation trajectory. Few studies have specifically focused on the lived transition experiences of people with disabilities and their caregivers. Additional insights are needed to properly tailor and understand the conditions necessary for FGDM implementation.

Qualitative analysis of couples' perspectives described changes in experienced burden per rehabilitation phase which could be identified through the concepts of personal time and space. Caregivers have little time for themselves during the inpatient rehabilitation phase, although do have some personal space, especially at home, to retreat.

In the transitional phase between clinic and home, they have neither time nor space, and during the community integration phase, most of them regain some personal time and space, particularly when their partners actively support this. Our study provides insights into the changes in caregiver burden during the rehabilitation trajectory. Acknowledging this paves the way for a more tailored support approach for professional and/or informal assistance attuned to the caregivers' varying needs.

## Summary

Finally, **Chapter 7** summarises and discusses the main results of all the studies presented in this thesis, along with implications for clinical practice, further research, and lessons learned. The findings of this thesis provide a better understanding of patients' and caregivers' perspectives on social support needs and perceived burden during the rehabilitation trajectory of care.

After a life event such as acquiring illness or disability, people often hit the rock bottom and find themselves in the most vulnerable phase of their lives. This thesis reveals that people with disabilities and their caregivers differ in their ability to activate their network, the level of experienced burden, and the degree of reluctance to approach their social networks.

Additionally, our findings provide further information about the necessary conditions for the implementation of family centred interventions, such as family group conferences. More awareness is needed regarding people's actual requirements to receive help from family and friends, and whether this should be reinforced.

Furthermore, there is a need to develop a tailor-made approach to match the perceived burden per rehabilitation phase of the person with the disability and the caregiver alongside the needs for involvement of the support network. For social professionals, it is not only important to unravel the strength, reliability, competence, and power of a person's social network but also to carefully assess any reluctance to social support.







# APPENDICES

SAMENVATTING



## Samenvatting

Naarmate het aantal ouderen in de samenleving toeneemt, zullen steeds meer mensen chronische ziekten gaan ontwikkelen. In het afgelopen decennium heeft het Nederlandse zorgbeleid zich in toenemende mate gericht op het belang van meer sociale steun aan kwetsbare mensen door het inzetten van het sociale netwerk van bijvoorbeeld familieleden, burens en vrienden. Er zijn verschillende beleidsmaatregelen en methoden ingevoerd om dit te bevorderen. Eén zo'n methode, genaamd 'family group decision making' (FGDM), betreft het sociale netwerk in samenspraak met de kwetsbare persoon in kwestie, bij het maken en uitvoeren van een ondersteuningsplan. Dit proefschrift begint met de introductie van een interventiestudie om de effectiviteit van de implementatie van FGDM in de revalidatiepraktijk te evalueren. Omdat de participatiegraad onder revalidanten en hun naasten laag was, is er besloten een nieuwe onderzoeksvraag te stellen om meer inzicht te krijgen in de redenen voor deze terughoudendheid om hulp te vragen aan hun netwerk. Daarnaast hebben we onderzocht wat de voorwaarden zijn van de implementatie van FGDM in andere settings dan de revalidatiepraktijk volgens de bestaande literatuur.

Vaak worden mensen met een ernstige chronische langdurige ziekte zoals niet-aangeboren hersenletsel (NAH) of een dwarslaesie, weken- of maandenlang opgenomen in revalidatiecentra. Bij ontslag naar huis ervaren mensen met een handicap of beperking en hun naasten helaas nog een grote kloof tussen de beschermde klinische omgeving en het weer thuis functioneren. Zij voelen zich onvoldoende voorbereid op het dagelijks leven en participatie in de samenleving.

De veronderstelling was dat implementatie van FGDM zou resulteren in een grotere betrokkenheid van de familie en een positieve bijdrage zou leveren aan de overgang van kliniek naar thuis. In het eerste deel van het proefschrift is de 'POWER-interventiestudie' beschreven met als doel de effectiviteit en implementatie van FGDM in de revalidatiepraktijk te evalueren.

Op basis van veldonderzoek, twee literatuurstudies en 20 diepte-interviews blijkt echter dat mensen met een handicap of beperking en hun naasten zeer terughoudendheid zijn in het vragen van (meer) ondersteuning aan hun sociale netwerk. In het tweede deel van dit proefschrift hebben we de redenen voor deze

terughoudendheid en de implicaties daarvan voor beleid en praktijk geanalyseerd. Door kwalitatief onderzoek, hebben we vervolgens waardevolle kennis opgedaan over de ervaren ziektelast, belasting en veranderende behoeften van naasten gedurende het revalidatietraject.

**Hoofdstuk 1** geeft een overzicht van de sociale context van mantelzorg en de recente ontwikkelingen in familiegerichte zorg, 'family group conferences' en onderzoek daarnaar. Dit hoofdstuk biedt een kader voor het uitgevoerde onderzoek.

### **Deel I: Effectiviteit en POWER-studie**

**Hoofdstuk 3** beschrijft een systematische literatuurreview naar de effectiviteit van FGDM-interventies gericht op volwassenen in de zorg en welzijnssector. Hieruit bleek dat er zeer weinig gecontroleerde studies naar gezinsgerichte interventies in het algemeen en FGDM in het bijzonder zijn gedaan. De studies die waren verricht voldeden doorgaans niet aan de wetenschappelijke kwaliteitscriteria. Slechts één studie (twee artikelen) voldeed aan alle criteria die gesteld waren voor een FGDM-interventie en beschreef de effectiviteit van 'family group conferences' aan de hand van psychische uitkomstmaten bij volwassenen in de zorg en welzijnssector. De interventiegroep vertoonde significant betere uitkomsten na een follow-up periode van 16-23 weken. Maar bij de follow-up na één jaar werden geen verschillen tussen de interventie- en controlegroep waargenomen. Hoewel er geen conclusies kunnen worden getrokken over de effectiviteit van FGDM, is deze systematische literatuurreview de eerste in zijn soort in de zorg- en welzijn sector voor volwassenen. Naast een overzicht van de verschillende zorg- en welzijnsinstellingen waar FGDM is uitgevoerd, hebben we daarnaast lacunes in het huidige onderzoek geïdentificeerd.

**Hoofdstuk 2** beschrijft de introductie van de 'POWER-studie' en het studieprotocol van dit multicenter gecontroleerd onderzoek, uit te voeren in 12 revalidatiecentra in Nederland. Het protocol beschrijft een opzet om de effectiviteit en implementatie van FGDM te meten bij revalidanten met een hoog risico op langdurige handicap of beperkingen en hun naasten. Omdat FGDM in de

## Samenvatting

revalidatiesetting nog niet was uitgevoerd in een onderzoeksopzet en niet was opgenomen in de systematische literatuurreview, moesten we bij het begin beginnen. Bij het opzetten van de POWER-studie hebben we allereerst veel aandacht besteed aan het aanpassen van het bestaande model (dat zijn oorsprong vindt in de jeugdzorg) aan de revalidatiepraktijk. De belangrijkste kernelementen van FGDM werden overgenomen, zoals de gezinsgerichte aanpak, de focus op gezamenlijke besluitvorming, het betrekken van een breder netwerk, en het opstellen van een actieplan.

Ten tweede, als onderdeel van het multicenter gecontroleerd onderzoek en om de positionering van FGDM in de revalidatiegeneeskunde te schetsen, hebben we een conceptueel kader geïntroduceerd dat gebaseerd was op de uitkomstmaten empowerment, self-efficacy en participatie. Een duidelijk theoretisch model van FGDM in de revalidatiegeneeskunde ontbrak tot op heden in Nederland en internationaal. De hypothese was dat door het beïnvloeden en vergroten van het besluitvormingsproces in families ook het niveau van participatie en self-efficacy zou toenemen. Daarom werden beide uitkomstmaten als zeer belangrijk beoordeeld.

Wij hebben dit echter niet kunnen testen. Ondanks de inclusie van 329 koppels in de POWER-studie waren slechts vier koppels geïnteresseerd in deelname aan de FGDM-interventie. Daardoor was het niet mogelijk om onze eerste onderzoeksvraag betreft de effectiviteit van de implementatie van FGDM bij revalidanten met een hoog risico op langdurige handicap of beperking en hun naasten in de revalidatiepraktijk, te beantwoorden. We verkregen echter waardevolle resultaten toen we met behulp van kwalitatief onderzoek probeerden verdere antwoorden te vinden op de motieven van deelnemers om al dan niet sociale steun te vragen aan hun sociale netwerken. We onderzochten de perspectieven van 20 revalidant/naaste koppels die in aanmerking kwamen voor de interventie en hebben de resultaten van dit onderzoek beschreven in **hoofdstuk 5 en 6**.

## Deel II: Behoeftte aan sociale steun, ervaren ziektelast

In onze kwalitatieve literatuurreview in **hoofdstuk 4** hebben we een beter inzicht in de barrières, faciliterende en noodzakelijke voorwaarden van FGDM-implementatie verkregen binnen de zorg- en welzijnssector voor volwassenen. Dit inzicht werd afgeleid van de perspectieven van deelnemers (cliënten, sociale netwerken, professionals en coördinatoren) over hun ervaringen met FGDM. Uit de 17 geïnccludeerde artikelen konden 185 doorverwijzingen naar FGDM's worden geïdentificeerd, waarvan 82 mislukten (44,3%), dat wil zeggen dat deze niet leidden tot een daadwerkelijke bijeenkomst. Hoewel alle instellingen hun eigen moeilijkheden hadden om FGDM te implementeren, werden vanuit het perspectief van de deelnemers twee hoofdoorzaken geïdentificeerd voor het mislukken van iets minder dan de helft van de geplande FGDM's: de eerste factor die werd beschreven was *'niet in staat om deel te nemen'*, veroorzaakt door redenen buiten de controle van de deelnemers, zoals organisatorische of contextuele aspecten (externe factoren). De tweede factor was *'niet willen deelnemen'*, veroorzaakt door persoonlijke motivaties zoals schaamte of het gevoel tot last te zijn.

In **hoofdstuk 5** beschrijven we de interviews van 19 revalidanten/naasten die allen in aanmerking kwamen voor de FGDM-interventie, maar deze niet hadden gevolgd. Hen werd gevraagd naar hun behoefte aan sociale steun en hun bereidheid om hun vrienden en familie om hulp te vragen. Uit de interviewanalyses bleek dat hoewel de meerderheid van de koppels meende over een betrouwbaar netwerk te beschikken, zij toch belemmeringen en beperkingen ondervonden bij het vragen van steun van hun netwerk. We identificeerden vijf redenen voor deze terughoudendheid: (1) onwennigheid om steun te vragen; (2) geen (grotere) last willen zijn; (3) angst voor inbreuk op hun privacy en onafhankelijkheid; (4) angst voor verkeerde motivaties, zoals hulp bieden uit nieuwsgierigheid of medelijden; en (5) overtuiging dat mensen in hun sociale netwerk verminderd betrouwbaar, bekwaam of begripvol waren. De belangrijkste factor leek het gebrek aan wederkerigheid te zijn. Revalidanten en hun naasten ervaarden onvoldoende mogelijkheden om iets terug te doen in ruil voor de ontvangen steun en gaven er vervolgens de voorkeur aan om als koppel (zonder netwerksteun) de uitdagingen aan te gaan. Als gevolg hiervan nam de onderlinge afhankelijkheid van de koppels

## Samenvatting

toe met een hoog risico op verhoogde ziektelast en belasting van de naaste, waarop wij in hoofdstuk 6 nader ingaan.

In **hoofdstuk 6** beschrijven we de interviews van 18 revalidant-/partner echtparen om inzicht te verkrijgen in de ervaren ziektelast en veranderende behoeften tijdens de verschillende fases en transities in het revalidatietraject. Weinig studies hebben zich specifiek gericht op de beleefde transitie-ervaringen van mensen met een handicap of beperking en hun naasten. Aanvullende inzichten zijn nodig om de voorwaarden die nodig zijn voor de implementatie van FGDM, goed af te stemmen en te begrijpen.

De kwalitatieve analyse naar de perspectieven van de echtparen beschreef veranderingen in ervaren belasting per revalidatiefase die geïdentificeerd konden worden aan de hand van de concepten persoonlijke tijd en ruimte. Naasten hebben weinig tijd voor zichzelf tijdens de klinische revalidatiefase, maar hebben vooral thuis wel enige persoonlijke ruimte om op adem te komen en zich terug te trekken. In de overgangsfase tussen kliniek en thuis hebben zij tijd noch ruimte, en tijdens de fase van integratie in de samenleving krijgen de meesten van hen weer enige persoonlijke tijd en ruimte, vooral wanneer hun partners dit actief ondersteunen. Onze studie biedt inzicht in de veranderingen in de ervaren ziektelast en belasting van naasten tijdens het revalidatietraject. Erkenning hiervan maakt de weg vrij voor een meer op maat gesneden ondersteuningsaanpak betreft professionele en/of informele hulp die is afgestemd op de uiteenlopende behoeften van de naasten.

Tot slot zijn in **hoofdstuk 7** de belangrijkste resultaten van de gepresenteerde studies in dit proefschrift samengevat en besproken, samen met mogelijke implicaties voor de klinische praktijk, verder onderzoek en geleerde lessen. De bevindingen van dit proefschrift geven een beter inzicht in de perspectieven van revalidanten en naasten naar de behoefte aan sociale steun en de ervaren ziektelast en belasting tijdens het revalidatietraject.

Na een ingrijpende gebeurtenis zoals het krijgen van een ziekte, beperking of handicap bereiken mensen vaak een dieptepunt en bevinden ze zich in de meest kwetsbare fase van hun leven. Uit dit proefschrift blijkt dat mensen met een handicap of beperking en hun naasten verschillen in hun vermogen om hun

## Samenvatting

netwerk te activeren, de mate van ervaren belasting en de mate van terughoudendheid en behoefte om hun sociale netwerken te benaderen.

Daarnaast geven onze bevindingen meer informatie over de noodzakelijke voorwaarden voor de implementatie van familiegerichte interventies, zoals 'family group conferences'. Er is meer inzicht nodig in de werkelijke behoeften van mensen om hulp te krijgen van familie en vrienden, en of dit al dan niet moet worden aangemoedigd.

Wenselijk is de ontwikkeling van een aanpak op maat om per revalidatiefase de ervaren belasting van de persoon met een handicap of beperking en de naaste, af te stemmen op de behoeften aan betrokkenheid van het sociaal netwerk. Voor sociale professionals is het niet alleen belangrijk om de kracht, betrouwbaarheid, competentie en reikwijdte van iemands sociale netwerk te ontrafelen, maar ook om eventuele terughoudendheid ten aanzien van sociale steun zorgvuldig te beoordelen.





# APPENDICES

DANKWOORD



## Dankwoord

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# APPENDICES

ABOUT THE AUTHOR



## Curriculum Vitae

Chantal Hillebregt was born on January 2<sup>nd</sup> 1977 in Winterswijk, the Netherlands. She grew up in Eibergen and completed her secondary education at the Almere College in Kampen (HAVO and VWO). In 2000, she obtained her Bachelor of Science degree in occupational therapy from the Amsterdam University of Applied Sciences. She worked for eight years as an occupational therapist at rehabilitation center 'de Trappenberg' (MEREM) Huizen, giving treatment to patients with acquired brain injury.

In 2002, she took a year off and went to Bangladesh and Nepal to volunteer as an occupational therapist in two rehabilitation centers. This was a life-changing experience on many fronts, and motivated her to study further to understand more about health and illness in different social and cultural contexts.

From 2004 to 2008, she combined her work as an OT with her studies in Medical Anthropology and Sociology (MAS) at the University of Amsterdam, where she obtained her Master of Science degree in 2008. During the same period all her children were born.

Her work as a health-researcher at the Jan van Es Institute, the Netherlands Expert Centre of Integrated Primary Care, planted the seed to pursue her career in research. In 2015, she started to work again in the field of rehabilitation practice, but now as a PhD-candidate.

During her PhD, she worked as a researcher at Windesheim University of Applied Sciences Almere (lectoraat klantenperspectief in ondersteuning en zorg), where she conducted several action-based research projects in the field of acquired brain injury and dementia. She has developed herself as a practice-orientated researcher where the perspective and needs of the individuals involved (e.g., patients, caregivers, professionals) are constantly at the center of her projects. She currently works as a senior-researcher at Vilans Utrecht, the National Centre of Expertise for Long-term Care.

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