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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 (≥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 of this study

- 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 focusing 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[1 2] and experience adverse psychological outcomes (eg, depression, anxiety, feelings of helplessness and poor quality of life).[3 4] Their family members may also experience difficulties in aspects of caring,[5 6] high levels of burden and impaired quality of life.[7–10] 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.[11 12] Existing interventions focus primarily on the needs of patients, not on the needs of the significant others[13] (usually the partner, but can be everyone who is important in one's well-being). 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).[14]

The awareness of the important role of the family during rehabilitation treatment is growing,[13 15] and although family meetings are regularly conducted in a number of inpatient settings[16] there is limited empirical research in this area.[17 18] 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.[16 19 20]

A method focusing on empowerment and active involvement of patients and significant others is family-centred care, which has the following key values[15 21 22]:

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,[15 23] although there are some examples of family meetings in dementia care with a more family-centred approach.[24 25] In rehabilitation care though, these examples are sparse.[26–28]

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.[29 30] 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.[31] A 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.[31–33] 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.[31]

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,[34] making the FGC rather proactive than reactive, and more responsive to the family's needs.[13] As the FGC stimulates the decision-making process, a rearrangement of tasks and responsibilities takes place, enlarging the empowerment of the person in need[35] by shifting the balance of power towards the family within the decision-making process.[34]

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

Research examining the impact of FGC is mainly based on qualitative evaluation research.[38] Evidence supporting the effectiveness of the FGC approach is still sparse[38–40] due to study designs lacking a control group,[38 41] although positive results were seen in studies with people with intellectual disabilities[42] and in child welfare.[43] 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.

Empowerment

The concept of empowerment is operationalised in diverging ways.[35 44 45] The WHO[46] has adopted the

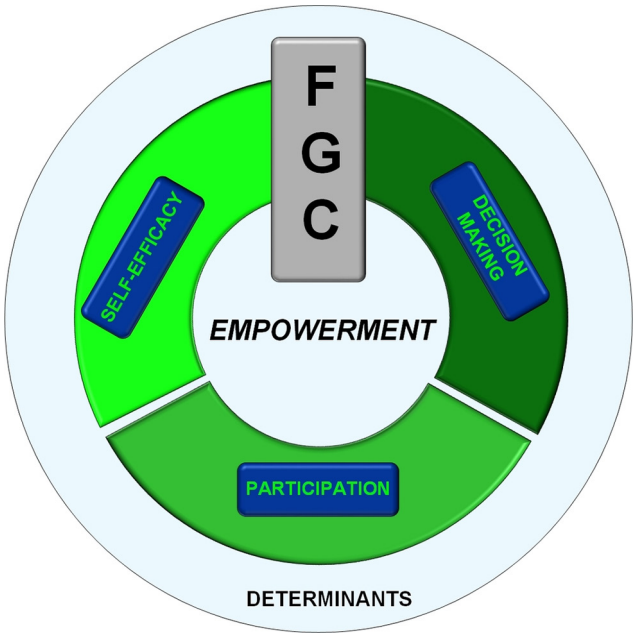

Figure 1 Family group conference (FGC) empowerment model (edited by Hillebregt & Scholten 2017) Reproduced with permission from Zimmerman MA.[109]

definition of Rappaport[47]: '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.[44 48]

The intrapersonal, interactional and behavioural framework of psychological empowerment is used to identify the outcome of FGC.[48] 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.[48] An increasing number of scientists stress the importance of a fourth component: social and interpersonal relations, also called relational empowerment.[49–53] 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.[54]

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[46 55] through influencing and increasing the decision-making process in families, with self-efficacy and participation as important outcomes.[46 56]

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.[57–59] 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.[60] 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.[61–63] In informal caregivers, higher self-efficacy is related to less feelings of burden and distress.[64 65]

Decision making

The adaptive practice model of Feldman *et al*[66] 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.[67] The aim of the interaction between patient/significant other, the 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).[66]

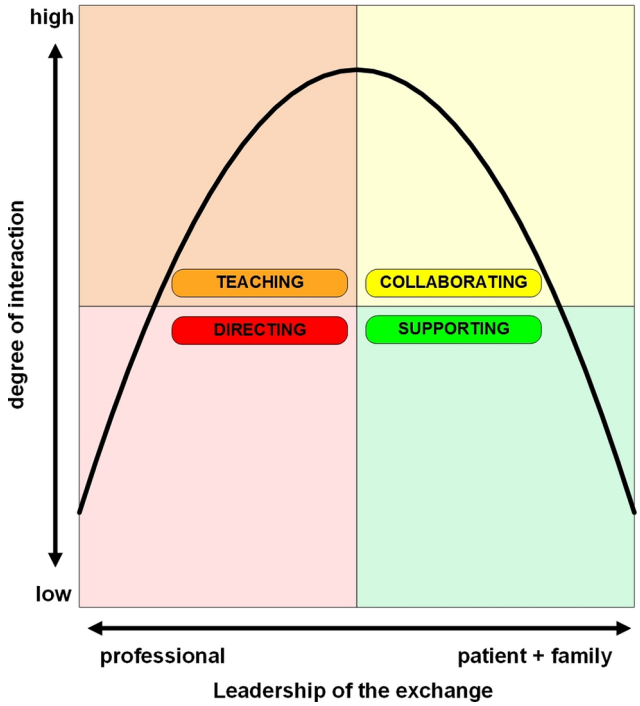

Figure 2 Decision-making model. Reprinted with permission from Feldman *et al*.[66]

Table 1 Participating centres

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

Determinants

Various psychological (eg, neuroticism, depression and purpose in life)[1 61 63 68] and environmental (eg, family relationships and functioning, social support, emotional and practical support)[8 69–71] 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). Patients decide who will be allocated as their significant other (≥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.

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[72 73] (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 (≥47) on the Self-Efficacy Scale[72 73] 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 (≤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.

Box 1 Inclusion and exclusion criteria for the cohort study

Inclusion criteria

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

Exclusion criteria based on clinical judgement

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

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

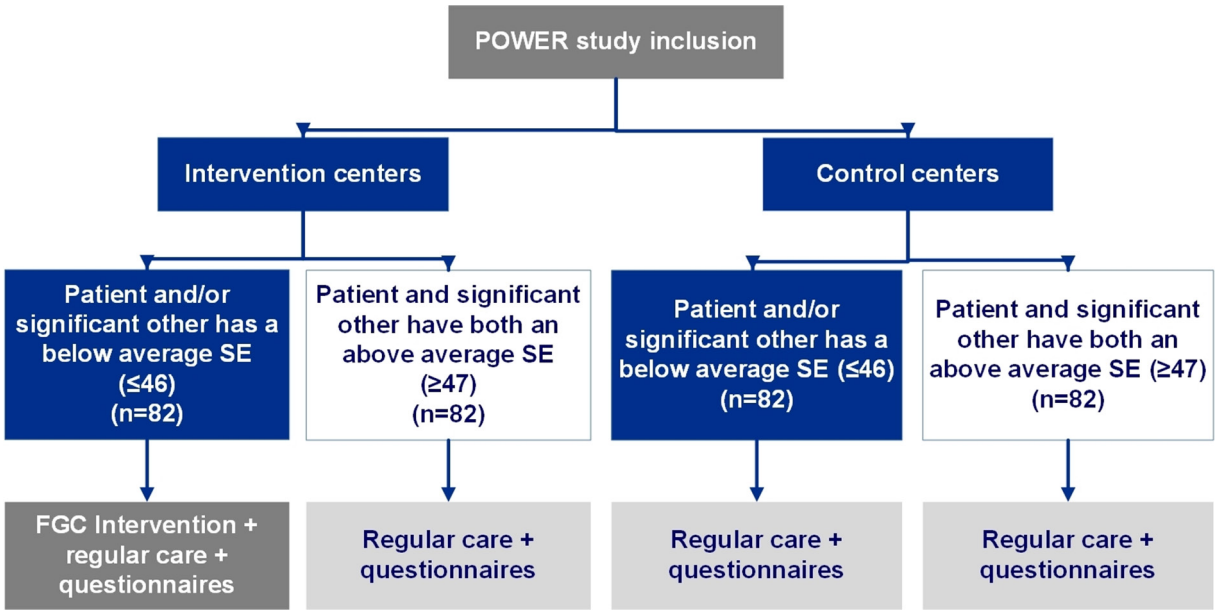

Figure 3 Allocation of participants. FGC, family group conference; SE, self-efficacy.

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 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.

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.[74]

Table 2 Decision-making tools

What+When	Action	Tool
Social work contact with couple (0–2 weeks after clinical admittance until end of clinical admittance)	Inform patient/significant other about allocation family group conference in multidisciplinary rehabilitation care	Overview disciplines/programmes
	Inventory Caregiver Strain Index, significant other	Caregiver Strain Index[96]
	Inventory of Social Support Network	Social network analyses[110]
	Inventory of attendees present at family group conference	
	Nominating 'family coordinator' by social network	
	Assess level of empowerment of couples	Empowerment tool (self-composed)
Preparatory meeting Meeting 1 with family, couple+social worker (at clinical discharge)	Insight in goal attainment, participation in daily activities	Goal attainment scale 'the entire live'[111] Utrecht Scale for Evaluation of Rehabilitation - Participation (USER-P)[79]
	Discuss level of social network support	Social network analyses[110]
	Activation of social network	Apps, phone, other
	Introducing action plan	Action plan[112]
	Inform 'family coordinator'	Manual 'family coordinator'
	Assess level of empowerment of couples	Empowerment tool (self-composed)
Social work contact with couple+family coordinator (end of clinical admittance until 1.5 months after clinical discharge)	Preparing 'family coordinator'	Manual 'family coordinator'
	Evaluating deployed actions	
	Assess level of empowerment of couples	Empowerment tool (self-composed)
Family group conference Meeting 2 with family, couple+social worker (1.5 months after clinical discharge)	Setting up action plan	Action plan[112]
	Assess level of empowerment of couples	Empowerment tool (self-composed)
Social work contact with couple+family coordinator (1.5–3 months after clinical discharge)	Evaluation of deployed actions, 'family coordinator'	Manual 'family coordinator'
	Evaluation of execution of action plan	Action plan[112]
	Assess level of empowerment of couples	Empowerment tool (self-composed)
Evaluation meeting Meeting 3 with family, couple+social worker (3 months after clinical discharge)	Insight in goal attainment, participation in daily activities	Goal attainment scale 'the entire live'[111] Utrecht Scale for Evaluation of Rehabilitation - Participation (USER-P)[79]
	Assess level of empowerment of couples	Empowerment tool (self-composed)

Sample size

Sample size is calculated based on analysis of covariance in a parallel group design.[75] 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[76] are used to estimate the effect size.[77] 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[72 73 78] and participation[79–83] are the primary outcomes. The secondary outcomes are distress,[84–87] life satisfaction,[88–91] experienced continuity of care,[92 93] care empowerment,[94 95] assistance from the social network (patient only),[9] provided assistance (significant other only),[9] burden of care (significant other only)[96–100] and caregiver mastery (significant other only).[101 102]

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.[1 8 61–63 68–70]

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.[103] This framework assesses fidelity and quality of implementation, clarifies causal mechanisms and identifies contextual factors associated with variation in outcomes.[104] 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[105] using the qualitative analysis software MAXQDA.[106]

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 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,[107] 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

Table 3 Measurements for patients and significant other

Outcome measures	Instruments	T0	T1	T2	T3
Primary outcome measures					
Self-efficacy	University of Washington Self-Efficacy Scale short form[78]	X	X	X	X
Participation (preinjury)	Utrecht Scale for Evaluation of Rehabilitation-Participation[79]	X	X^C	X	X
Secondary outcome measures					
Distress	Hospital Anxiety and Depression Scale[84 85]	X	X	X	X
Life satisfaction	Life Satisfaction (two questions)[88 89]	X	X	X	X
Experienced continuity of care	Consumer Quality index Brain Injury (collaboration subscale)[92 93]				X
Care empowerment	Patient Assessment of Chronic Illness Care (selection)[94 95]				X
Assistance from social network	*Adapted version of existing list of activities*[9]				X^P
Provided assistance	*Adapted version of existing list of activities*[9]				X^C
Burden of care	Caregiver Strain Index[96]			X^C	X^C
Burden of care	Self-Rated Burden Scale[97]	X^C	X^C	X^C	X^C
Caregiver mastery	Caregiver Mastery Scale[101]				X^C
Determinants					
Demographic factors	Age, gender, ethnicity, family income, level of education,[113] marital status, family composition	X			X^2
Functional status	Utrecht Scale for Evaluation of Rehabilitation (self-care and mobility subscales)[114]	X^P	X^P		
Cognition impairment	Montreal Cognitive Assessment[115] (ABI)	X^P			
Injury-specific information	Cause of injury; comorbidity; American Spinal Injury Association Impairment Scale[116]; Special Interest Group on Amputation Medicine-Working Group Amputation and Prosthetics score[117 118] (amputation); Bamford/Oxford Classification[119]; Stichting Afasie Nederland schaal (Dutch Aphasia Foundation Scale, SAN)[120]; National Institutes of Health Stroke Scale[121] (Acquired brain injury)	X^P			
Self-efficacy	Self-Efficacy Scale (General Competence Scale)[72 73]	X			
Personality characteristic, neuroticism	Eysenck Personality Questionnaire Revised Short Scale (neuroticism subscale)[122 123]	X			
Proactive coping	Utrecht Proactive Coping Competence Scale (short version)[124]	X			
Passive coping	Utrecht Coping List (passive coping subscale)[125 126]	X			
Appraisal	Appraisal of Life Events (treat and loss subscales)[127]	X			
Resilience	Connor-Davidson Resilience Scale[128]	X			
Purpose in life	Purpose in Life Short Form[129 130]	X			
Family functioning	Family Assessment Device (subscale general functioning)[131]	X	X	X	X
Fatigue, general health, mood	Numeric Rating Scale	X	X	X	X
Existing social network	*Self-composed*	X			
Perceived social support (preinjury)	Social Support List 12 (interactions subscale)[132 133]	X			

T0: shortly after admission of the patient in the rehabilitation centre; T1: shortly before clinical discharge of the patient from the rehabilitation centre; T2: 3 months after discharge; T3: 6 months after discharge.
X, patient and informal caregiver; X^P, only patient; X^C, only informal caregiver.
ABI, Acquired brain injury; ALCOS-12= Algemene Competentieschaal 12 (General Competence Scale 12 questions); LS2, Life Satisfaction (2 questions).

the recovery and adaptation process of the patient[70] and in moderating caregiver distress.[108]

- 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.
- 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.[31–33] 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.[63] 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.

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