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## Long-term outcomes of stroke rehabilitation

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**LONG-TERM OUTCOMES IN STROKE REHABILITATION:  
PATIENTS AND INFORMAL CAREGIVERS**

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PATIENTS AND INFORMAL CAREGIVERS**

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## **Authorship**

**Heike M Geschwindner** is responsible author for chapters 2, 7, 8, 9, 11.

**Horst Rettke** is responsible author for chapters 3, 4, 5, 6, 10, 12.

Shared authorship applies for Introduction and General Discussion.

## CHAPTER 1

# Introduction



## **Background**

For a person who has experienced an impairing condition, returning to normal life becomes a priority (Wood-Dauphinee, Opzoomer, Williams, Marchand, & Spitzer, 1988). It is the engagement of health care professionals in treatment, nursing and rehabilitation that makes such a return possible. Reintegration into normal living is a primary health outcome, not only for the individual, but also for society in general (Dijkers, 1998). The World Health Organization (WHO) has designated social participation as a major objective for individuals impacted by disease and impairment (Perenboom & Chorus, 2003).

However, reintegration into normal living and social participation remain difficult to realize, both on an individual and societal level. Incapacitating diseases such as stroke, chronic heart failure, dementia, COPD etc. can have a devastating effect on an individual's ability to function (Clarke, Black, Badley, Lawrence, & Williams, 1999; Haacke et al., 2006; Selman et al., 2007) as well as on his or her family and social context (Gautun, Werner, & Luras, 2011; Hynes, Stokes, & McCarron, 2012). While the degree to which the individual can regain normal life may be limited by impairments (Murtezani et al., 2009), environmental factors such as social support (Glass & Maddox, 1992; Glass, Matchar, Belyea, & Feussner, 1993; Knapp & Hewison, 1998) and physical barriers also play a role (Whiteneck et al., 2004). Nursing and rehabilitation aim to restore physical, psychological, and social functioning, and have the overarching goal of improving quality of life for patients as well as enabling persons with a disability to live their lives as normally as possible (Spichiger, Kesselring, & deGeest, 2006; Stucki, Cieza, & Melvin, 2007).

Living life as normally as possible has a different meaning for each person. For this reason it is important to formulate goals that correspond

to the individual's understanding of 'normal'. While taking the impairment into account, consideration must be given as to which goals are 'reachable' given the type of disease/impairment (Ertzgaard, Ward, Wissel, & Borg, 2011). Achieving the goal of living life as normally as possible involves not only the individual patient and health care professionals; it also involves persons close to the individual: spouse or partner, family, friends and neighbors (Glass & Maddox, 1992; Stalnacke, 2007). These persons close to the patient are usually called informal caregivers and play an important role supplemental to professional caregivers (Eldred & Sykes, 2008). Despite the popularity of this term, informal caregiver is not well defined. Definitions refer to the close relationship between caregiver and care recipient and the provision of any informal assistance and help to persons who are incapacitated and thus unable to provide daily care for themselves (Pearlin, Mullan, Semple, & Skaff, 1990; Ski & O'Connell, 2007).

This study is directed towards understanding the effects of rehabilitation interventions that focus on patient involvement and goal setting to achieve a state of living as normally as possible (often called 'independence'). Regardless of rehabilitation efforts, life experience and research indicate the importance of informal caregiving in reaching the 'independence', described above (Tooth, 2005). However, the informal caregiving process may also place a burden on the informal caregiver (Ski, 2007) and for this reason this study will also explore the role of informal caregiving after patients are rehabilitated.

For practical reasons, this study focuses on stroke patients and their informal caregivers. Much research has been conducted in this field. Most studies focus on the short-term effects, i.e. the first 6 to 12 months after stroke. We have chosen to focus mainly on long-term

effects, i.e. one to three years after discharge from an inpatient rehabilitation center.

### **Stroke: a major health care problem**

A marked decrease in stroke incidence has been observed over the past twenty years in Western European countries (Sarti, Rastenyte, Cepaitis, & Tuimilehto, 2000) and in the United States of America (Callow, 2006). In contrast, an increase has been reported in Eastern European countries (Sarti, et al., 2000), in Africa, Malaysia and the Middle East (Callow, 2006). Although overall figures for the Western World show a positive trend towards decrease in incidence, the fact remains that a considerable portion of stroke survivors need long-term assistance in activities of daily living due to incomplete recovery (Bonita, Solomon, & Broad, 1997). Furthermore the proportion of the population aged 65+ is rising in Western countries along with life expectancy (Truelsen et al., 2006). Given that age is an independent risk factor for stroke (Boysen et al., 1988) this may result in a future increase in stroke incidence. In Switzerland, the mortality rate of stroke has decreased considerably in women and men over the last 15 years (see table 1) Based on hospital statistics, overall stroke incidence is estimated to be 178.7 in men and 119.7 in women per 100'000 inhabitants (Meyer, Simmet, Arnold, Mattele, & Nedeltchev, 2009). When adjusted for age to the European standard population, the standardized incidence rates for first-ever ischemic stroke in Switzerland are lower in comparison with other developed countries (Gostynski et al., 2006). According to estimates of the World Health Organization (WHO), the incidence of stroke may stabilize worldwide by the year 2025. Nevertheless, stroke numbers will still see an increase due to population growth (Truelsen, et al., 2006).

**Table 1: Mortality for cerebrovascular disorders in Swiss population (per 100'000 inhabitants)**

| Year         | 1995 | 2000 | 2005 | 2009 | 2010 |
|--------------|------|------|------|------|------|
| <b>Women</b> | 41.0 | 34.3 | 27.7 | 24.5 | 22.4 |
| <b>Men</b>   | 53.6 | 41.5 | 34.3 | 27.9 | 28.3 |

The decrease in stroke mortality observed in Western countries (Sarti, et al., 2000) is attributed to the beneficial effects of stroke units (Stroke Unit Trialists' Collaboration, 2007) where evidence-based, multidisciplinary care is provided during the acute phase and/or during rehabilitation (European Stroke Initiative & European Stroke Initiative Executive Committee and the EUSI Writing Committee, 2003). Expertise, competence and effective coordination of services are at the core of stroke units (Alberts et al., 2000). Highly specialized stroke care requires highly specialized staff (Alberts, et al., 2000) particularly at stroke onset when, for afflicted patients, 'the whole world collapses' (Kirkevold, 1997). However, highly specialized staff is also necessary in the post-acute phase during rehabilitation. Rehabilitation is a continuum (Brandstater & Shutter, 2002), beginning as early as possible in the acute phase (Engelter, Lyrer, & Themengruppe "Stroke Unit", 2004) and extending into community reintegration (Teasell, Foley, Bhogal, & Speechley, 2003). As such, it is a cornerstone of stroke care (European Stroke Initiative & European Stroke Initiative Executive Committee and the EUSI Writing Committee, 2003; Langhorne, Bernhardt, & Kwakkel, 2011).

Many advances have been made in rehabilitation over the past decades, the most fundamental of which is a change from focusing solely on a medical approach to patients to including psychological and socio-cultural factors (Wade & de Jong, 2000). The emphasis in rehabilitation is no longer strictly limited to restoration of functioning but has shifted

to including quality of life and social participation, as described in the International Classification of Functioning, Disability, and Health (ICF) (Perenboom & Chorus, 2003; Stucki, et al., 2007). As a consequence, patients and their family members have become increasingly involved in their own health care processes (Haidet, Kroll, & Sharf, 2006). Goal setting in rehabilitation is an established procedure (Evans, 2012; Levack et al., 2006; Siegert & Taylor, 2004). The involvement of patients and their families in goal setting during the rehabilitation process is strongly advocated in the literature (Leach, Cornwell, Fleming, & Haines, 2010).

With treatment and rehabilitation having become more effective (Teasell et al., 2009) stroke patients live longer (Boysen, Marott, Gronbaek, Hassanpour, & Truelsen, 2009) and can more often be discharged home to live independently (Langhorne, et al., 2011). For this reason, the long-term effects of stroke are taking on more significance for society at large as well as for health care professionals.

## **Rehabilitation and caring for stroke patients**

### **Formal care**

Over the past decades stroke care has been increasingly organized along care pathways (Sulch, Evans, Melbourn, & Kalra, 2002). These encompass acute care, rehabilitation and prevention. Providing stroke care is synonymous with care provided by a multidisciplinary team (Strasser et al., 2005). The team approach has been shown to be especially effective in stroke rehabilitation (Prvu Bettger & Stineman, 2007; Yagura, Miyai, Suzuki, & Ynagihara, 2005). Team members may be medical specialists, nurses, physical, occupational and speech therapists or other professionals (Langhorne, et al., 2011), each providing distinct professional views, skills and approaches. While physicians manage medical conditions, physical therapists focus on the examination and treatment of

neuromuscular problems following stroke. Occupational therapists work with those skills that are necessary to independent living (Miller et al., 2010).

Nurses' contributions to stroke rehabilitation are described as manifold and include providing 24-hour rehabilitation nursing care (Burton, 2000) maintaining physical functioning and giving emotional support. To these should be added coordinating therapies and services (O'Connor, 1993). Nurses have the specific role of assisting patients to integrate all newly acquired skills learned in specialized training sessions into activities oriented towards achieving practical ends (e.g. getting out of bed, dressing, toileting) (Kirkevold, 2010).

In the provision of multidisciplinary team care, team conferences are essential in order to coordinate tasks and reach consensus on target outcomes concerning patient preferences (Jelles, van Bennekom, & Lankhorst, 1995; Wade, 2005) and reach consensus on target outcomes concerning patient preferences. Target outcomes are formulated by goal setting, a procedure considered to be 'best practice' in rehabilitation (Levack, et al., 2006; Siegert & Taylor, 2004). This does not mean that it is applied everywhere or even frequently nor does it mean that the effects are systematically evaluated (Lawson, 2005; Levack, et al., 2006). Indeed, there is a lack of research into the practice of goal setting (van de Weyer, Ballinger, & Playford, 2010). Patient participation in goal setting is strongly recommended in stroke guidelines (Laver, Halbert, Stewart, & Crotty, 2010; Turner-Stokes & Wade, 2004) including drawing on patients' preferences and needs during the goal-setting process (Rosewilliam, Roskell, & Pandyan, 2011).

Most patients want to be discharged home (Frank, Conzelmann, & Engelter, 2010) although, due to limiting effects of stroke, not all will

achieve this end (Massucci et al., 2006). It is the case that in Western countries a high proportion of stroke patients return home after staying in a hospital and/or rehabilitation facility with the proportion ranging between 62% and 87% (Frank, et al., 2010; Koyama, Sako, Konta, & Domen, 2011). Returning home after discharge creates challenges for patients (Pringle, Hendry, & McLafferty, 2008) (Wottrich, Aström, & Löfgren, 2012) and their families (Greenwood, Mackenzie, Wilson, & Cloud, 2009). To address this, appropriate interventions are needed in order for patients and their families to be best prepared for post-discharge living, whether back at home or in an institution. Lasting disabilities can have an impact on quality of life for stroke survivors and their family members even two years after the event (Baumann, Couffignal, Le Bihan, & Chau, 2012) or longer (van Mierlo et al., 2012).

### **Informal care**

More than 60% of stroke patients return home after inpatient rehabilitation (Frank, et al., 2010; Koyama, et al., 2011) regardless of the extent of remaining impairment (Nguyen, Page, Aggarwal, & Henke, 2007). This highlights the need for care after successful completion of acute medical treatment and the corresponding implications for society. Despite a range of professional healthcare arrangements in developed countries, informal caregiving is an important aspect of sustaining the provision of health care at home. It is also the means by which the appropriate continuum of care between formal and informal providers is ensured (Colombo, Llana-Nozal, Mercier, & Tjadens, 2011). The limited functionality that results from stroke creates a need for long-term care that assists the stroke survivor in terms of daily living and in social activities. These care demands may necessitate anything from a small amount of assistance provided at home to 24-hour care in a nursing home. Approximately 40% of overall stroke expenditures in Western

countries goes to care provided in nursing homes (Moon, Moise, Jacobzone, & the ARD-Stroke Experts Group, 2003). Informal care is usually unpaid, requiring less public expenditure, e.g. formal care services, and in this way has less fiscal impact (Vecchio, 2008). From a financial perspective institutional care is diametrically opposed to informal care (Colombo, et al., 2011). This makes informal caregiving all the more essential for cost containment in the realm of caring for persons suffering from chronic conditions (di Carlo, 2009; Low, Qureshi, & Low, 2010).

The economic burden of stroke is estimated as exceeding those of other diseases (Ski & O'Connell, 2007). In an investigation of the costs of brain disorders in European countries (all 25 EU countries plus Norway, Iceland, and Switzerland), Andlin-Sobocki et. al. (2005) stated that stroke was the second most costly neurological disease (€22 billion). But it is expected that this amount will prove to be an underestimation. The annual costs are distributed amongst various resources: direct health-care costs (hospital care, drugs) approx. 35%, direct non-medical costs (community care, transportation, adaptations and informal care) approx. 20%, and indirect costs of more than 40% due to lost workdays, i.e. sick leave and early retirement (Andlin-Sobocki, Jönsson, Wittchen, & Olesen, 2005). In the United States the average weekly caregiving hours range from 8.6 to 18.6 hours, resulting in an estimated average annual cost of \$3700 to \$7900 for informal caregiving (Hickenbottom et al., 2002).

At the same time, when facing disability or a need for care, most people prefer to live at home as independently and for as long as possible (Stoltz, Uden, & Willman, 2004). In many countries, informal care is seen as an important means of maintaining this independence. Receiving informal care means that a variety of needs are covered, ranging from the smallest to those taking all day. Informal care supports the



stroke patient in activities in daily living, in housekeeping, in psychosocial matters and when necessary, with social participation (van Eeden, Heugten, & van Evers, 2012). Informal caregiving can be ensured only when, and if, the caregivers in question are available and, to an even greater extent, are willing to overtake this task and responsibility. Usually informal caregiving is provided by close family members, friends, or both (McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Roche, 2009) because the preference is for caregiving to be based on social relationships (Gaugler, Zarit, & Pearlin, 2003). A widely reported phenomenon (not only in the context of stroke patients) is that a spouse or partner serves as primary informal caregiver, supported by children and other family members (Lyons & Zarit, 1999; Perrig-Chiello, Höpflinger, & Schnegg, 2010). More women than men perform the task of informal caregiving (King, Hartke, & Houle, 2010; Krevers & Öberg, 2011; McCullagh, et al., 2005). Regardless of who adopts the role, becoming a caregiver brings with it multiple changes in lifestyle, even for spouses. The sudden onset of stroke has a dual impact on the potential informal caregiver. The stroke patient is in a life-threatening condition that will most likely impart enduring physical, emotional and cognitive impairments which, in turn, trigger emotional and social reactions in the caregiver and his or her family. In addition, the overall uncertainty of how the situation will develop impacts the family system (Ski & O'Connell, 2007). The person who will serve as informal caregiver must cope with emotional and social reactions as well as dealing with a new role, new tasks and new responsibilities. The person taking on the caregiver role will also have to come to terms with as yet unknown problems that may become apparent in the long term with respect to the patient's course of disease (Elkwall, Sivber, & Hallberg, 2004; King, et al., 2010; Ski & O'Connell, 2007).

Depending on the patient's abilities and impairments the amount of care needed can vary considerably. In addition, care and assistance are

rarely restricted to a specific point in time and will sometimes have to be available throughout the day or may have to be adapted or directed to certain specific activities. In these circumstances informal care cannot be provided by one single person only. The involvement of additional persons may necessitate calling in professional home care services, thereby adding the roles of care manager and coordinator to the role and tasks of the primary informal caregiver (Perrig-Chiello, et al., 2010). If professional care is indispensable, most people prefer to receive such care, if at all possible, in combination with informal care at home. Admission to institutional care is seen as the last choice for both stroke survivor and informal caregiver (Stoltz, et al., 2004).

Whether providing informal care alone or in conjunction with other persons, research shows that informal care is not without consequence for the informal caregiver, i.e. burden, depression, health deterioration, changes in family and social context as well as an impact on quality of life (Adriaansen, van Leeuwen, Visser-Meily, van den Bos, & Post, 2011; Brodaty & Donkin, 2009; King, et al., 2010; van Durme, Macq, Jeanmart, & Geobert, 2012). Research reports predominantly on the negative impacts and consequences (van Durme, et al., 2012). These consequences apply not only in the case of stroke patients but also to other patient groups, who are (progressively) impaired by a chronic disease (Gaugler, et al., 2003; Kesselring et al., 2001; Rigby, Gubitz, & Phillips, 2009; Thommessen et al., 2002). It is therefore important to be aware of who is providing the care for these patients and how this type of caregiving affects the informal caregiver. Since, as stated, treatments are becoming more effective, it is important to study the long-term consequences of informal caregiving. In our study, the focus was on stroke patients and their informal caregivers after discharge from the rehabilitation facility. The effects on the caregiver could be seen as an indirect outcome of the stroke treatment and rehabilitation process.

## **The role of lay persons in the care process**

In past decades, far-reaching developments and changes have taken place in health care that go beyond the realm of medical treatments and health care services (e.g. success of treatment, new technologies, guidelines and protocols). These developments and changes have even influenced objectives of care and health care outcomes such as quality of care, social participation, or quality of life. As a consequence, the perception of the patient's role has changed substantially, i.e. a shift from a traditional, more paternalistic attitude toward an approach that values patients' autonomy and decision-making (Emanuel & Emanuel, 1992; Schrauth & Zipfel, 2005). This approach embodies a patient-centered care that respects the patient's perspective and takes individual patient preferences into account (N.N., 2012). In principle, the advantages and benefits of patient-centered care extend beyond a particular patient to society in general. Within patient-centered approaches, two concepts took on importance: patient empowerment and patient involvement.

Patient empowerment can be understood as a process by which patients are enabled to gain control and to take initiative and responsibility for themselves. For health professionals it includes aspects such as respecting patients' rights and enabling health literacy and (disease) self-management. Today those receiving health care have easy access to many sources of information, including the internet (Berland et al., 2001). This easy access to information has advantages and disadvantages due to the multitude and diversity of information available (McClung, Murray, & Heitlinger, 1998). The individual is confronted with the challenge of choosing the relevant information from amongst an overwhelming number of search results. The appropriate information helps an individual to formulate and state his or her priorities.

The patient empowerment approach calls for patient involvement and this has a dual significance. First, patient participation or involvement requires decision making, i.e. patients want (and are expected) to participate in defining the ultimate goal of the treatment process and to take responsibility for themselves as well as co-responsibility of what should be done over the treatment trajectory. This process pre-supposes the patient being involved and adequately informed of choices when asked for an opinion or for consent to further treatment (Beaver et al., 2007; Northen, Rust, & Nelson, 1995). Sharing the decisions between professionals and patients means also sharing the uncertainties about the future course of the disease (Beaver, et al., 2007). In the case of stroke, functional recovery is often set as the main objective (Kwakkel, Kollen, & Wagenaar, 1999). For patients, this presents the possibility of returning to living life the way they did before the stroke, i.e. to live independently and to participate in 'normal life'. However, stroke patients continue to age along with the rest of the population, which begs the question: "What consequences will the stroke have in the long term for patients and families?"

The second significance of patient participation is that research suggests that it has a beneficial effect on the cure and rehabilitation process. Patient participation enhances the individual's responsibility for his or her own health while increasing the patient's motivation, satisfaction and quality of life. Patients who are informed and aware of treatment consequences may have a better understanding and better control of their symptoms (Brownlea, 1987; Haidet, et al., 2006; Hämäläinen, Perälä, Poussa, & Pelkonen, 2003; Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007). Therefore, it would be interesting to analyze whether the goals set (and possibly reached) during rehabilitation are related to outcomes such as independent living or integration into normal life.

## **Objectives and research questions**

Based on the developments described in the previous paragraphs, there are several objectives to this study, but the focus is on two main themes: the evaluation of goal setting and evaluation of goal attainment as well as the role of informal care and its consequences for the informal caregiver.

- We intend to evaluate the influence of goals (set and attained during the rehabilitation process) on living arrangements immediately after discharge, the relationship between post-discharge goal attainment and living arrangements, as well as the integration into normal life of stroke patients at least one year following discharge from rehabilitation. Such goal attainment is affected by the recovery potential of the patient, which in turn depends upon the severity and the type of stroke. For this reason, functional impairments following stroke must be taken into account. Also, life events which occur after discharge from inpatient rehabilitation may have an intermediating effect on long-term outcomes such as living arrangements and reintegration into normal life.
- Goal setting presupposes patients' active participation in the rehabilitation process and we therefore intend to describe which validated instruments are available for assessing patient participation in rehabilitation activities.
- We will describe 'reintegration into normal living' in stroke patients at least one year after discharge from the rehabilitation clinic. Reintegration into normal living may be formulated as the ultimate goal after rehabilitation for (stroke) patients. This supposes a validated instrument to assess this reintegration.

- We will assess the psychometric qualities of an internationally recognized instrument 'Reintegration into Normal Living'.
- As stated, informal care is important to the way the stroke patient will live after rehabilitation. During the last decennium the stroke survival rate has increased, due to progress in medical care and advances in rehabilitation services. This leads to more stroke survivors living at home more or less independently which may in turn affect informal care giving. Therefore, we will review from the scientific literature what is known about long-term caregiver burden.
- We want to describe what care patterns stroke patients have after more than one year following discharge from the rehabilitation clinic.
- We will analyze the degree of subjective burden these informal caregivers experience more than one year after the stroke patient is discharged from the inpatient rehabilitation and which factors are related to this.
- To do so, we have to ensure the psychometric quality of the instrument to assess caregiver burden.

## Chapter 1

We have formulated the following research questions:

- 1 a. Which instruments are reported in the literature for assessing the extent of patient participation in physical rehabilitation activities?
  - b. What are the psychometric qualities of these instruments?
- 2 a. Which short-term goals are set regarding 'living arrangements' in stroke rehabilitation patients admitted from acute care hospitals?
  - b. To what degree are these goals achieved at discharge from inpatient rehabilitation?
  - c. Which patient-related factors are associated with the degree of short-term goal attainment?
- 3 a. To what extent do stroke patients achieve the long-term goal 'living arrangement' one to three years post-discharge from inpatient rehabilitation as compared to the goal set at discharge?
  - b. Which patient-related factors are associated with the degree of long-term goal attainment?
4. What empirical knowledge is available on long-term caregiver burden experienced by informal stroke or dementia caregivers providing care for patients for at least 18 months?
5. What are the patterns of informal caregiving for stroke survivors after at least one year following discharge from inpatient rehabilitation?
6. What are the psychometric qualities of two instruments used in scientific research and clinical practice in patients with long-term

disabilities, i.e. 'Reintegration in Normal Living' and 'Caregiver Burden Inventory', when applied to a patient population in German-speaking Switzerland?

7. What patient and caregiver characteristics determine the experience of 'Caregiver Burden' more than one year following the patients' discharge from inpatient rehabilitation?
8. Which factors are related to stroke survivors' 'Reintegration in Normal Living' more than one year after discharge from inpatient rehabilitation?



## **Outline of the thesis**

Because we intended to study these research questions in German-speaking Switzerland we will present a short overview of rehabilitation facilities for stroke patients in German-speaking Switzerland and describe the extent to which goal-setting and evaluation is integrated in these rehabilitation facilities (see Chapter 2).

When the idea to evaluate goal setting in rehabilitation developed we had intended to set up a longitudinal study, in which we could describe the process of goal setting and the effect of patient involvement on goal attainment during and after inpatient stroke rehabilitation. We encountered a variety of problems in realizing our study plan. In Chapter 3 we describe the lessons which could be learned from this failure. The lessons learned did help us to conduct our further research in a defined geographic region serving an urban and rural population.

Research question 1 on instruments on patient participation is answered in Chapter 4. Research question 2 on goal attainment during clinical rehabilitation is analyzed in Chapter 5, while the relationship between goal assessment in rehabilitation and post-discharge living arrangements (Research Question 3) is addressed in Chapter 6.

Chapters 7, 8, and 9 deal with informal caregiving. Evidence regarding long-term caregiver burden in the scientific literature (Research Question 4) is presented in Chapter 7. Chapter 8 describes the pattern of informal caregiving after more than one year has elapsed since inpatient stroke rehabilitation (Research Question 5), while Chapter 9 presents the psychometric qualities of a caregiver burden instrument tested on German-speaking Swiss informal caregivers of stroke patients (Research Question 6).

Chapter 10 also answers Research Question 6 but this time on 'Reintegration into Normal Living'.

The last two research questions (7 and 8) are answered in Chapter 11, which analyzes the determinants of caregiver burden in long-term caregiving, and in Chapter 12, which analyses the determinants of 'Reintegration into Normal Living' in stroke patients at least one year following discharge from inpatient rehabilitation.

The main findings of this study are summarized in the last Chapter. It also discusses the outcomes and makes recommendations for research and practice, based on the results of this study.

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## Chapter 1

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## **Rehabilitation in acute stroke patients in German-speaking Switzerland**

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## **Abstract**

**Principles:** The aim of this study was to obtain an overview of stroke-specialised rehabilitation facilities in German-speaking Switzerland, as well as the numbers of stroke patients treated. It also focused on the mode of goal setting and evaluation, and the use of instruments to assess the patient's state and progress.

**Method:** Out of 28 stroke rehabilitation facilities, 21 participated in a structured telephone interview. Of these, 18 institutions provided full data.

**Results:** The results show that the facilities (n=18) vary considerably in numbers of patients treated per year ( $\bar{X}$  124, range 7–500) and length of stay ( $\bar{X}$  40  $\pm$  17.23). Goal setting and evaluation, including the setting of short-term and long-term goals, is a common feature. They differ, however, in terms of patient involvement, processes and professions participating in goal setting and evaluation. A variety of instruments are used for patient assessment at admission and during rehabilitation. Admission to rehabilitation does not rely on standardised patient health status assessment.

**Conclusions:** Stroke rehabilitation in German-speaking Switzerland embraces a heterogeneous landscape with respect to use of instruments, goal setting and evaluation process and patient involvement. To facilitate comparison, the same core instruments for assessment and evaluation should be selected and consistently applied. Also, the admission criterion 'potential for rehabilitation' should be transformed into a universally and scientifically valid term. The effect of patient involvement in goal setting on rehabilitation outcome has not yet been investigated. Thus no recommendations can be made for the moment.

**Key words:** stroke; rehabilitation; goal setting; goal evaluation

## Introduction

Stroke is one of the leading causes of death in industrial countries [1–3]. It is the leading cause of acquired disability in adults and has an enormous socioeconomic impact on patients, their families and health services [4–6]. In Switzerland the incidence has been estimated at 150/100'000 [7]. This would mean that about 9000 people a year in Switzerland suffer a clinical first time stroke. The latest data relate to first ever ischemic stroke in a geographically defined Swiss region and show an incidence of 143/100 000 [8]. For Germany the incidence is 182/100 000 [9], while that for Austria, where no data are available due to lack of a national stroke register, is estimated at 200–300/100 000 [4]. The variations reported here are reflected in findings from other European regions [10–12] and may be explained by the differing prevalence of risk factors in the general population [13].

Stroke has an acute onset but leaves many survivors with lasting disabilities of moderate to large extent [5, 7, 14, 15] in about one third of all stroke cases [4]. Rehabilitation is considered the predominant approach to helping the individual stroke patient to return to optimal effectiveness in daily life [16–18]. There is evidence that participation in an organised multidisciplinary stroke rehabilitation unit achieves better results than the usual care provided on general wards, in outpatient services or in the community [19, 20]. Multidisciplinary team meetings are a key component in providing a forum for patient introduction to the team, multidisciplinary assessment, problem identification, setting of short-term and long-term rehabilitation goals, and decision-making [19].

The British National Guideline for Stroke recommends assessing and reassessing patients by standardised instruments. Further, meaningful short-term and long-term goals should be set which involve the patient

and his family if appropriate <sup>[21]</sup>. These recommendations are in line with the US Clinical Practice Guideline No. 16 Post-Stroke Rehabilitation<sup>1</sup> <sup>[22]</sup>. Unfortunately no national guideline is available to provide information on existing recommendations in Switzerland.

For German-speaking Switzerland no data have been found on the number of stroke-specialised rehabilitation institutions and the annual number of acute stroke patients who are rehabilitated in these facilities. Likewise, no details exist regarding the use of instruments to measure the course of rehabilitation, nor on established rehabilitation practice in goal setting and goal evaluation. The aim of this study was to shed light on this topic by posing the following questions:

- 1 How many facilities rehabilitate stroke patients in German-speaking Switzerland and what are the figures regarding patient numbers and length of stay?
- 2 What assessment systems are used to evaluate the patient's state?
- 3 Are goal setting and goal evaluation applied in stroke rehabilitation?
- 4 What persons are explicitly involved in this area?

### **Method**

The study has a descriptive design using a questionnaire. It was set up as a telephone interview of the nursing directors of rehabilitation centres with a structured questionnaire.

### **Research population**

Each stroke-specialised rehabilitation facility in German-speaking Switzerland formed part of the research population. At first an extensive web

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<sup>1</sup> This guideline is currently outdated, see: <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat6.chapter.27305>, last retrievals 29. Dec. 2005; 10. Jan. 2013

search was done to identify all neurological rehabilitation facilities in general. Search engines utilised were 'Google' (CH Version) and 'Metager'. The following search terms were used: 'rehabilitation' (AND 'neurology' OR 'stroke'). When using 'Metager' the search was limited to Switzerland. Two websites in particular provided key information: [www.krankenhaus.ch](http://www.krankenhaus.ch) and [www.vrks.ch](http://www.vrks.ch)<sup>2</sup>. All links (leading to rehabilitation facilities and acute hospitals) were screened for rehabilitation.

The individual institutions' web sites were then screened for neurological rehabilitation and figures. If the web site contained clues to neurological rehabilitation this institution was included. Where the information was ambiguous, the institution was included for further clarification during the initial contact. The preliminary list of rehabilitation facilities was then checked for completeness with four professionals in neurological rehabilitation and acute settings. They found the list to be complete.

### **Sample**

By searching the internet and interviewing key persons, 38 institutions were identified in German-speaking Switzerland which most probably give treatment to this group of patients. 28 institutions confirmed that they rehabilitate acute stroke patients. Of these, five declined to participate in the survey, citing in particular the disclosure of sensitive organisational data involved. Two more did not reply despite reminders. Data of 21 facilities was collected. Since three facilities had no authority to give full particulars, complete data from 18 institutions were eventually obtained and analysed (Figure 1).

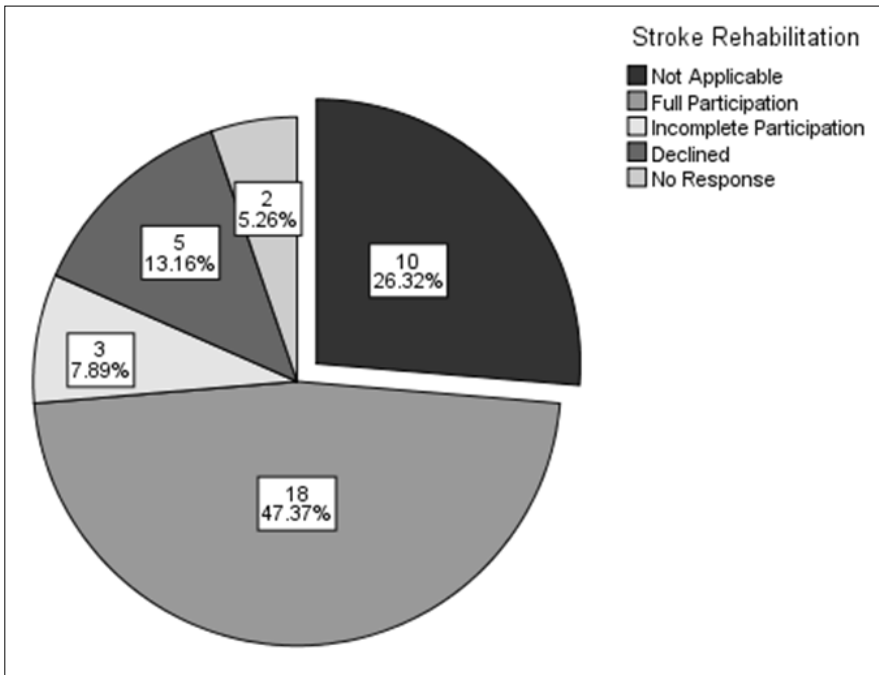
Rehabilitation takes place either in specialised rehabilitation clinics (n=11) or in specialised departments attached to acute hospitals (n=7).

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<sup>2</sup> altered into [www.swiss-reha.com](http://www.swiss-reha.com), Last retrieval 23. Jan. 2013

While stroke patients are rehabilitated on designated wards in rehabilitation clinics, the majority of rehabilitation facilities (n=11) embrace a variety of patient groups (e.g. cardiological, orthopaedic, geriatric, traumatology groups).

**Figure 1 Distribution of facilities inquired (n=38/100%)**



### **Interview and questionnaire**

A 14-item questionnaire was constructed (Table 1) and then presented to four professionals in nursing management for face validity. They considered the questions complete and clearly worded.

**Table 1: Interview questions (English and German wording)**

1. How many stroke patients did you rehabilitate in 2003?
2. What was the average length of stay of this patient group in 2003?
3. Where did these patients come from? (particular canton)
4. How were these patients distributed to the particular canton?
5. Which admission criteria must stroke patients fulfil to be admitted to your institution for rehabilitation? (e. g. severity of stroke, certain extent of functional and/or cognitive abilities)
6. Do you set rehabilitation goals in your clinic?
7. Are the set goals rather short-term and/or long-term goals? (short-term: within the next 4 weeks, long-term: within the next 3 months)
8. Could you please give us two examples for short and long-term goals each?
9. Which professional group sets the goals with whom? (Professional directly with the patient concerned, within a specific professional group, in the interdisciplinary team etc.)
10. Who starts and guides this process?
11. If several professionals set goals, how are the goals coordinated and by whom?
12. Do you evaluate the goals? (Who, when, how and how often?)
13. Which instruments do you use to assess stroke patients at admission? (e.g. NIHSS; FIM etc.)
14. Which instruments do you use to evaluate the patient's progress?

1. Wie viele Patientinnen und Patienten mit einem Schlaganfall wurden in Ihrer Klinik im Jahr 2003 rehabilitiert?
2. Wie lange war die durchschnittliche Aufenthaltsdauer dieser Patientengruppe im Jahr 2003?
3. Aus welchen Kantonen kamen diese Patientinnen und Patienten zu Ihnen?
4. Wie viele Patientinnen und Patienten waren das pro Kanton?
5. Welche Aufnahmekriterien müssen Schlaganfallpatientinnen und -patienten erfüllen, um in Ihrer Klinik zur Rehabilitation aufgenommen zu werden? (z.B. Schweregrad des Schlaganfalls, bestimmtes Ausmass an körperlichen und/oder kognitiven Fähigkeiten usw.)
6. Werden in Ihrer Klinik Rehabilitationsziele festgelegt?
7. Handelt es sich bei den festgelegten Zielen eher um kurzfristige und/oder langfristige Ziele? (Kurzfristig: innerhalb der nächsten 4 Wochen; langfristig: innerhalb der nächsten 12 Wochen)
8. Können Sie uns bitte je zwei Beispiele für festgelegte kurz- und langfristige Ziele nennen?
9. Welcher Fachbereich legt die Ziele mit wem fest? (Fachperson direkt mit den Betroffenen, innerhalb einer Berufsgruppe, miteinander im interdisziplinären Team usw.)
10. Wer beginnt und wer leitet diesen Prozess?
11. Falls verschiedene Fachpersonen Ziele festlegen: werden die Ziele koordiniert und von wem?
12. Werden die Ziele evaluiert? (Von wem, wann, auf welche Weise und wie häufig?)
13. Mit welchen Instrumenten arbeiten Sie zur Beurteilung von Schlaganfallpatienten bei Eintritt? (z.B. NIHSS, FIM usw.)
14. Welche Instrumente verwenden Sie zur Beurteilung des Verlaufs?



The nursing directors in each rehabilitation facility were contacted by mail. Information on the survey was provided and the questionnaire attached. The letter announced a telephone contact to check whether stroke patients were rehabilitated in the institution. On confirming this, they were invited to participate in the survey and an appointment for the telephone interview was made. If the nursing director judged another professional in the facility to be more qualified to give this information a reference was given. All interviewees drew on internal data and statistics. The questions regarding statistics generated unequivocal answers. However, answers to questions regarding procedures had to be clarified and differentiated in most cases during the interview. It became clear that much information was identically worded but differed in meaning or vice versa, and varied from place to place <sup>[23]</sup>, e.g. there was no unique definition of the term 'rehabilitation potential'. On the other hand, 'rehabilitation conference' and 'interdisciplinary discussion' meant the same, the periodical meeting of professionals involved in the individual patient's rehabilitation process. The mode of the telephone interview facilitated dialogue and allowed clarification of the answers. The telephone interviews were conducted by the two researchers involved, who were familiar with the research questions and background of the study. During analysis they discussed the interview results in detail.

The average number of rehabilitated stroke patients was 124 in the year 2003, ranging from 7–500 a year in the individual facility. Eleven facilities (61.1%) rehabilitate up to 100 patients a year. Three institutions (16.6%) treat up to 200 patients and four facilities (22.2%) between 200 and 500 patients.

Length of stay was 40 days on average, ranging from 10–90 days (SD 17.23). The differences in length of stay can be explained by the type of rehabilitation. One facility provided short-term rehabilitation only, while

another concentrated on patients with neuropsychological disorders requiring a longer stay.

### **Admission criteria**

For admission no institution uses standardised assessment instruments. Half of the participant institutions employ the admission criterion 'rehabilitation potential' of the patients concerned. There is no standardised definition of this term. The other half does not quote on 'rehabilitation potential' and admits patients on the basis of medical conditions, e. g. 'stable cardiovascular condition' or 'spontaneous respiration'.

### **Process of goal setting, coordination and evaluation**

The goal setting approach is employed by each institution in an analogous manner. Goals are set within two different time frames, and are termed short-term goal or long-term goal respectively. Short-term goals are set stepwise to be attained during the inpatient period. Long-term goals refer to the time after discharge and correspond to the various short-term goals.

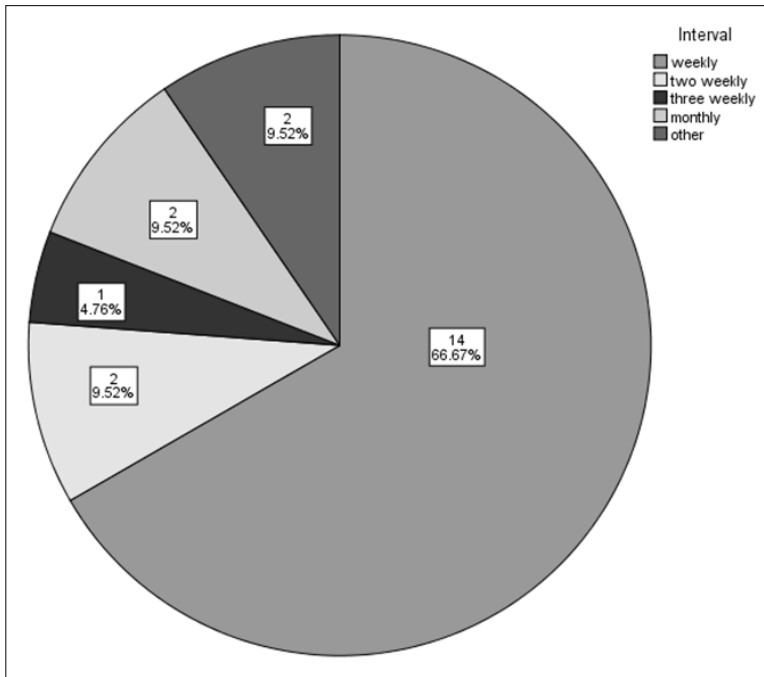
In all participant settings (n=18) short-term goals are in line with activities of daily living. Functional abilities and skills are most important, focusing on mobility, personal hygiene, elimination and nutrition.

In all cases (n=18) long-term goals focus on discharge to the patient's place of provenance whenever possible. The informants stated that patients must acquire functional abilities that are geared to their domestic environment, e.g. climbing stairs, independent bathing and dressing. The domestic environment will be adapted to the patient's functional potential and devices are supplied. Personnel resources will be evaluated and if necessary recruited. This relates to significant others and outpatient care.

A multidisciplinary approach to set the rehabilitation goals is standard practice in all settings (n=18). The procedure in setting, coordinating and evaluating rehabilitation goals differs between facilities. Responsibility for this process attaches to physicians except in two facilities. In these the process is linked to the position of a rehabilitation coordinator or to a nurse. The following professions at the minimum are involved in the process of goal setting and goal evaluation in all settings: nurses, physicians, physiotherapists, occupational therapists and speech therapists (n=3). In other institutions one (n=4) or more (n=11) professions are involved. These are neuro-psychologists and/or social workers.

The stipulated rehabilitation goals are periodically evaluated in every institution. The evaluation intervals are between one and several weeks (Figure 2).

In contrast to the multidisciplinary goal setting activities, the current practice of goal evaluation follows a monodisciplinary, profession-specific approach. The process of goal evaluation is within the province of each profession in charge, e.g. physiotherapy for mobility training. To evaluate progress each profession uses its specific assessment instruments. All results are then fed back to the multidisciplinary team for possible adaptation.

**Figure 2: Interval of goal evaluation (n=18/100%)**

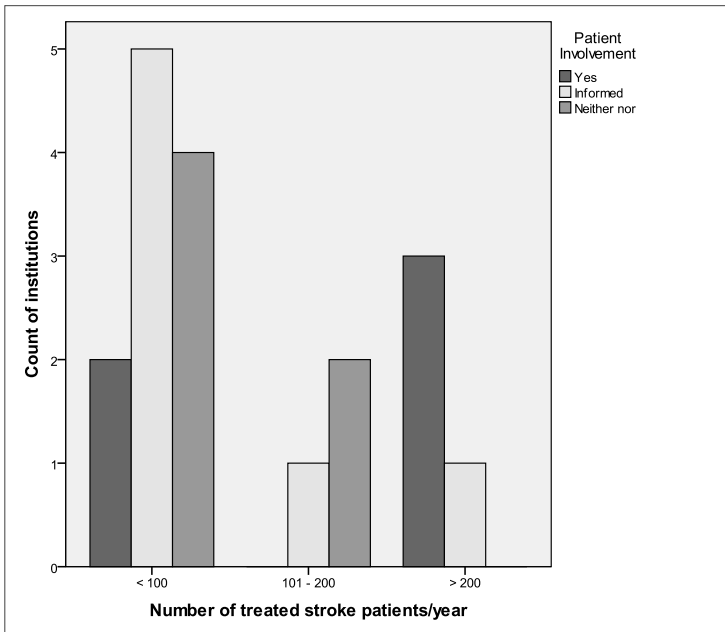
### **Involvement of patients and significant others**

In five facilities patients are directly involved in the goal setting process. In a further seven institutions they are explicitly informed of the goals set by the professionals beforehand. The third option (n=6), in which patients are neither directly involved in goal setting nor informed afterwards, seems to be more commonly practised in settings with a patient ratio <200/year. On the other hand, there is no direct patient involvement in facilities with a patient ratio between 100 and 200 patients/year (Figure 3).

Thus the number of stroke patients treated per year cannot be unequivocally related to the mode of patient involvement practice. Significant others are directly involved in goal setting simultaneously with the

patient in only two facilities. In a further six facilities, they will be informed while patients themselves are either directly involved or informed of stipulated goals (Table 2).

**Figure 3: Patients’ involvement and number of treated stroke patients/year**



**Table 2: Involvement of patients and significant others**

|                                   |                   | Patient Involvement |          |             | TOTAL |
|-----------------------------------|-------------------|---------------------|----------|-------------|-------|
|                                   |                   | Directly involved   | Informed | Neither nor |       |
| Involvement of Significant Others | Directly involved | 2                   | 0        | 0           | 2     |
|                                   | Informed          | 2                   | 3        | 0           | 5     |
|                                   | Neither nor       | 1                   | 4        | 6           | 11    |
| TOTAL                             |                   | 5                   | 7        | 6           | 18    |

## Assessment systems

The patient's status at admission and during rehabilitation is assessed with various instruments (Table 3). They can be grouped into four domains: functionality, severity of stroke, quality of life, profession-specific tests. The most used instrument to assess functionality is the 'functional independence measure' (FIM) (n=11). Other institutions use the Barthel Index (BI) and/or the Extended Barthel Index (EBI) for this purpose. The International Classification of Functionality (ICF), though developed for classification, is often used (n=6) but always combined with one of the instruments mentioned above. Only five facilities reassess the severity of stroke (Rankin Scale, NIHSS), and only two assess quality of life (SF 36). For profession-specific rating the choice of instruments varies. Except for nursing-specific instruments (AEDL, LEP, Nursing Diagnosis), which are applied in a standardised way, i.e. with each patient, the application of all other profession-specific instruments is not standardised but depends on the individual case and the appraised necessity.

**Table 3: Assessment systems**

|                       | Applied at admission only | Applied during course only | Applied at admission and during course |
|-----------------------|---------------------------|----------------------------|----------------------------------------|
|                       | frequency                 | frequency                  | frequency                              |
| FIM                   |                           |                            | 11                                     |
| BI                    |                           |                            | 3                                      |
| EBI                   |                           |                            | 5                                      |
| ICF                   |                           |                            | 6                                      |
| Rankin                |                           |                            | 1                                      |
| NIHSS                 | 1                         |                            | 3                                      |
| SF-36                 |                           | 1                          | 1                                      |
| Profession specific * | 2                         | 1                          | 8                                      |
| Nurse specific        | 3                         | 1                          | 4                                      |

\* e. g. Mini Mental State Exam, Tinetti, Olson Motorcup, Jesevic Hand Grip, Early Functional Assessment

## Discussion

The data collected reveal an inhomogeneous stroke rehabilitation landscape in German-speaking Switzerland, showing both common features and differences. All participant facilities reported working with rehabilitation goals adopting a multidisciplinary approach through the practice of team conferences. These issues have been introduced in the last decade in response to published recommendations.

The participant institutions differ in numbers of stroke patients treated per year and in the rehabilitation focus. The differing lengths of stay reported here cannot only be explained by the varying focus in stroke-specific rehabilitation, e.g. neuropsychological vs. functional rehabilitation, but probably also by varying patient profiles. Each stroke patient has unique combinations of problems and strengths which render rehabilitation an extremely complex process [23]. Patients' characteristics play a key role, not only in terms of physiological variables but also in terms of psychological characteristics, and exert a strong impact on the rehabilitation process, outcomes and quality of life [24–28]. Lengths of stay may also be strongly influenced by the local health system [29].

Multiple general instruments exist to measure aspects of health status and functional abilities, as well as stroke-specific measures. Nevertheless, admission relies on subjective evaluation of 'potential for rehabilitation' and also depends on organisational conditions. In contrast, rehabilitation outcomes are frequently evaluated with standardised instruments.

'Potential for rehabilitation' seems to be a widely used clinical term. The lack of a conceptual and operational definition implies that this term is not used consistently among health care professionals. It could be assumed to approximate to the Algorithm for Placement for Rehabilitation Care after Stroke [24], which requires a medically stable patient showing

a certain level of impairment but who can be expected to participate in therapies. The quality of judgement at this early stage of rehabilitation will depend greatly on precise information about the course of the patients' acute phase. Thus good cooperation between acute hospitals and stroke rehabilitation facilities is indispensable in enhancing comprehensive treatment strategies.

Different instruments are used to assess a patient's status on admission, progress during rehabilitation and outcome. In all institutions the focus lies on the appraisal of functional abilities and skills, and different instruments are used for this purpose. The internationally established instruments FIM <sup>[30, 31]</sup> and Barthel Index <sup>[32]</sup> or Extended Barthel Index <sup>[33]</sup> are most widely used here. Stroke has a lasting impact on the patients' quality of life <sup>[34, 35]</sup> and, in its turn, rehabilitation aims to enhance this parameter considerably. It is measured in two settings only. Both the presence of several instruments and the lack of defined admission criteria hamper scientific evaluation of stroke rehabilitation data across institutions.

The interviews show a trend towards using the 'International Classification of Functionality' <sup>[36]</sup> more often, not only to assess patient status but to organise interdisciplinary communication and cooperation with respect to goal setting and goal evaluation <sup>[37, 38]</sup>.

All participant rehabilitation institutions work with the concept of goal setting and goal evaluation. There is no insight yet into whether the concept is consistently understood and applied. What is known from the survey is that the individual goal setting processes are alike in their multidisciplinary approach and main procedures: assessment, goal setting, reassessment, and goal adaptation. Remarkably, physicians predominantly coordinate the main procedures. However, the mode and



frequency of patient assessments during rehabilitation vary between institutions. The statement as one sentence possibly emphasise a relation not supposed.

The direct involvement of patients and their significant others in the process of goal setting is uncommon. If involved at all, patients and their significant others are usually merely informed of the rehabilitation goals, a policy contrary to the guidelines' recommendations [21] and not in line with the concepts of patients' self-management and responsibility for themselves [39, 40].

The differences ascertained in admission criteria, use of instruments, and in the process of goal setting and goal evaluation complicate direct comparison of these aspects in rehabilitation outcomes of stroke patients. The observed lack of consensus and of standardised scientifically based approaches would indicate an urgent need for generally accepted recommendations or guidelines in stroke rehabilitation facilities of German-speaking Switzerland.

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## **Lessons Learned: Evaluation of a discontinued research project in stroke rehabilitation**

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## **Abstract**

Despite thorough conceptualization and planning, conducting a research project can pose multiple challenges which may eventually prevent its completion. Very little is reported on failed or discontinued research compared to successfully completed studies, although an evaluation of problems encountered and resolutions adopted can offer considerable opportunity for learning. In this article we would like to share the experiences we had with a prematurely terminated research project. Our aim is to make our findings accessible to other researchers, thus contributing to a culture that is lending more significance to communicating and discussing the failures and problems that arise in research projects.

## **Introduction**

In literature, only research projects with reliable outcomes are widely reported. There is a lack of published material concerning projects that do not lead to the anticipated findings, or that had to be prematurely discontinued due to complications while being conducted. Even in studies that have been well thought through and carefully prepared, problems and challenges may occur that bring the continuation of the study into question (Netta-Turner, Bucher, Dixon & Layton, 2008) or that even lead to its cessation (Weinrieb et al., 2001). This can occur with experienced (Brim and Schoonover, 2009) as well as inexperienced researchers (Smith, Buckwalter, Kang, Schultz & Ellingrod, 2008). There are descriptions in the literature of difficulties encountered in the course of conducting a study that have originated in the study design, in the research field as well as in the dynamics between the two.

In setting up studies, for example, the applicability of the method or condition of the research population can be misestimated, or inclusion and exclusion criteria can be wrongly chosen. After successfully carrying out a research project, West and Hanley (2006) intended to interview a study group via email since they were unable to personally interview the participants as they had in the original study. In comparison to the personal interviews, the authors were able to obtain only a fraction of the information required through the email survey. As their method proved to be ineffectual, they had to discontinue their study (West and Hanley, 2006). For data gathering, Brim and Schoonover (2009) demanded that data be routinely recorded electronically and copied to their research protocol. The duplicate documentation resulted in incomplete data sets almost without exception (Brim and Schoonover, 2009). Mohtadi et al. (2006) overestimated the size of their population after participating facilities provided incorrect information (Mohtadi,



Hollinshead, Ceponis, Chan & Fick, 2006). Ehrlich et al. (2002) intended to evaluate a surgical procedure. However, only during the course of the study did it emerge that its performance had not yet been sufficiently established relative to the procedure (Ehrlich et al., 2002). Testing a post liver transplant intervention, the relevance of which had been shown in the literature, Weinrieb et al. (2001) assumed a particular time-point for the intervention that, in retrospect, proved to be premature (Weinrieb et al., 2001). Guhian et al. (2007) based their research design upon a pilot study. However, in the new setting patients were discharged significantly earlier, which meant that a fundamental inclusion criterion did not apply and consequently not enough patients could be recruited (Guhian et al., 2007). Narrowly defined exclusion criteria likewise can hinder recruitment (Mohtadi et al., 2006).

In the research field, different characteristics conceal potential challenges. Purpose and possible benefits of a study may not be comprehensible to key persons and potential participants. Relevant information may be misinterpreted, framework requirements may change and eventual third party hindrances may occur.

The research project needs to be comprehensible to the research field stakeholders ensuring that the relevant information's scope of interpretation is as narrow as possible. Brim and Schoonover's (2009) study, aimed at examining the use of various wound dressing materials, illustrates this. In their case the nursing staff viewed the study as a personnel examination and opposed the project. Another study (Duffy and Hoskins, 2008) intended to survey all patients over 65 years of age. The recruiting nursing staff independently decided that a 93-year-old patient was too old to participate. Additionally, regardless of randomization, patients were assigned to those groups whose corresponding intervention most appealed to the recruiting nursing staff (Netta-Turner et

al., 2008). A critical health status may hinder the recognition of the possible usefulness of a study by patients or significant others, thus resulting in refusal to participate (Duffy and Hoskins, 2008; Netta-Turner et al., 2008). Substitution of key individuals in the research field may adversely affect the course of the study. In an institution for residents with dementia, the nursing director changed repeatedly. This led to relatives, whose approval for study participation was required, lost faith in the institution and declined participation (Smith et al., 2008). Nursing staff trained for a specific intervention in the care of heart failure patients left their positions. In addition to the rehiring process, the new staff then had to be trained intensively for this specific intervention (Duffy and Hoskins, 2008).

The greater the number of interfaces that have to be considered when conducting a research project, the more accident-sensitive the project becomes. Recruitment and data collection frequently are not performed by the principal investigators themselves but by a third party. To conduct the study successfully, the significance and relevance of the study are crucial for those actually collecting the data. When research activity has to be executed in addition to daily tasks in the clinical field, the clinical tasks are often perceived as more pressing (Duffy and Hoskins, 2008; Brim and Schoonover, 2009). Research fatigue may occur when a setting is frequently involved in research projects; this manifests itself in slow recruitment and insufficient data collection (Vaidya, 2004). If the course of the study extends over an extended period of time, daily business may take precedence and eclipse the research project (Duffy and Hoskins, 2008). All of these challenges may increase in multicenter studies due to prerequisites and conditions differing in each facility (Dedhia et al., 2008).

Furthermore, a research project may be jeopardised by unexpected circumstances. For example, Vaidya (2004) could not complete his study

as his population was concurrently requested to partake in a similar project where participation was financially compensated. In another study, Brim and Schoonover (2009) allowed the salespersons involved to demonstrate the proper handling of the products being tested. They undermined the research project by claiming that scientific evidence already indicated the advantages of their product (Brim and Schoonover, 2009).

The challenges described do not occur in isolation, either in the conception of the research, in interfaces or in the research field but are instead encountered in multiple areas (Weinrieb et al., 2001; Ehrlich et al., 2002; Dedhia et al., 2008; Netta-Turner et al., 2008). Many authors have tried with varying degrees of success to solve problems that have arisen (Vaidya, 2004; Duffy and Hoskins, 2008; Netta-Turner et al., 2008; Smith et al., 2008).

In our case, we had to prematurely discontinue our research project as we were undermined by the extent and the dynamics of the problems encountered and as our problem-solving efforts failed to succeed. In this article, we would like to outline our analyzed experiences with the aim of making our findings available to other researchers and in this way contribute to a culture that is lending more significance to communicating and discussing the failures and problems encountered in research projects.

### **Research project description**

We were interested in how the goal-setting process was implemented in detail in multidisciplinary rehabilitation. Furthermore, we wanted to know if there is a relationship between the goal setting process and individual goal attainment or quality of life.

We intended to empirically examine the potential relationship described above in a multicenter research project with clinical first-time, hemispheric, ischemic stroke patients. The research question was: “Taking personal traits into account, does a certain goal-setting procedure affect goal attainment and quality of life in individual patients during and after inpatient stroke rehabilitation?”

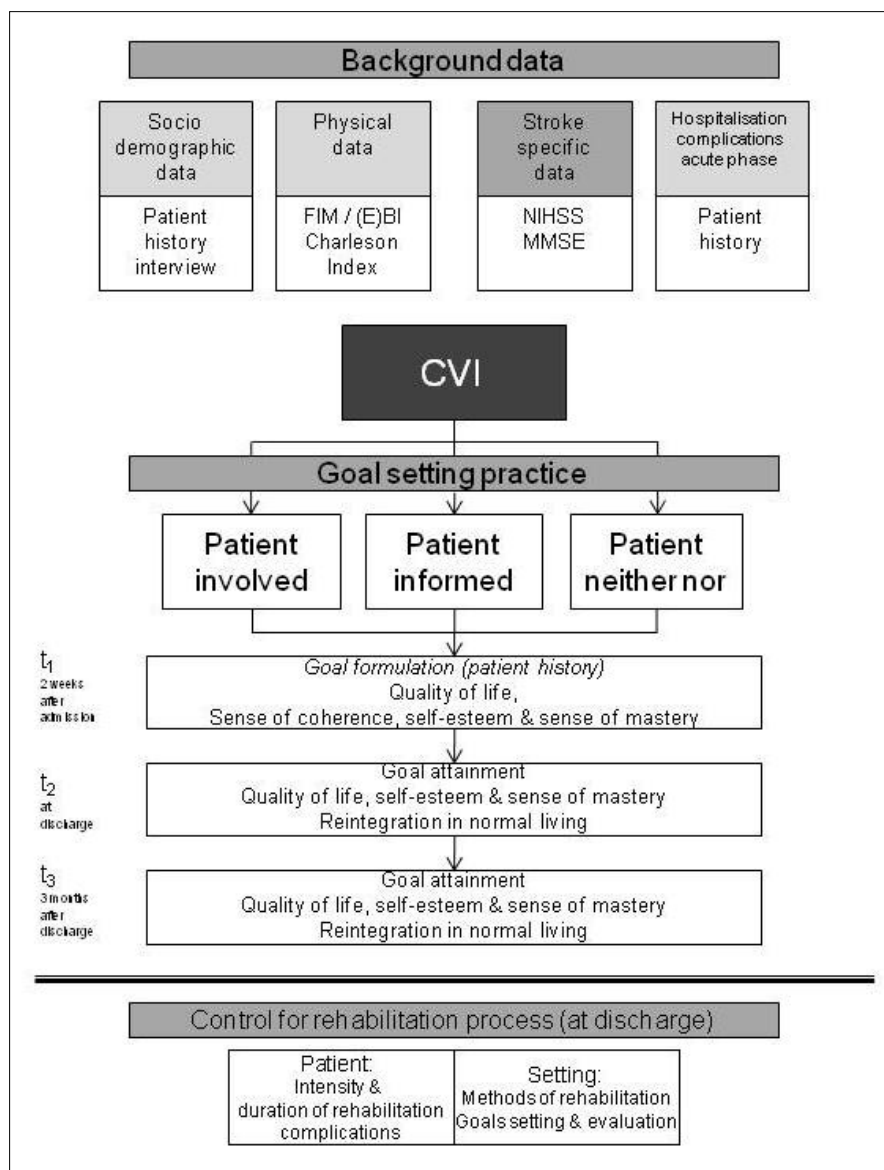
The research design envisaged multidimensional longitudinal data collection. The approach called for the participating patients to answer questionnaires administered on three separate occasions. In addition, the corresponding rehabilitation facilities were supposed to gather disease-specific patient data and details about the goal-setting procedure (Figure 1).

For data collection on the patient level, one questionnaire set was prepared for each measurement. Each questionnaire set was comprised of validated instruments for goal attainment, for health-related quality of life and for the following personal traits: sense of coherence, sense of self-esteem and sense of mastery (Table 1).

**Table 1: Instruments in questionnaire set for patients**

| Variable                                                              | Instrument                       | Source                                                         |
|-----------------------------------------------------------------------|----------------------------------|----------------------------------------------------------------|
| Goal attainment                                                       | Goal Attainment Scale            | (Kiresuk and Sherman, 1968)                                    |
| Health-related quality of life                                        | Stroke Impact Scale              | (P. W. Duncan, Wallace, Studenski, Lai & Johnson, 2001)        |
| Quality of life with regard to adaptation to the domestic environment | Reintegration into Normal Living | (Wood-Dauphinee and Williams, 1987)                            |
| Sense of coherence                                                    | Sense of Coherence Scale         | (Nilsson, Axelsson, Gustafson, Lundman & Norberg, 2001)        |
| Self-esteem                                                           | Rosenberg Self-esteem Scale      | (Badura et al., 1987) (Dantas, Motzer, & Ciol, 2002)           |
| Sense of mastery                                                      | Sense of Mastery Scale           | (Froelicher, Li, Mahrer-Imhof, Christopherson & Stewart, 2004) |

**Figure 1: Data collection protocol**



One questionnaire set comprised up to 101 items. The first two surveys were planned to be administered after admission to rehabilitation and before discharge respectively; the third was planned for three months after discharge.

We tested questionnaire set 1 on ten nursing home residents who met the study's inclusion criteria. By completing the questionnaire alongside the residents, we obtained information regarding feasibility, comprehensibility, applicability and time expenditure. Generally, the questions were clearly intelligible and the participants considered them relevant. Completing the questionnaire took 30-40 minutes, which the residents did not perceive as tedious or wearisome. Based on this information we left the questionnaire sets unaltered.

For data gathering in the clinical setting, a study protocol was compiled. This included details about the goal-setting procedure, about goals set and their evaluation, as well as demographic data, type and severity of the stroke, co-morbidity and duration of hospital stay. Furthermore, information about functional and cognitive assessment of the participating patients was collected.

In each facility a person responsible for the intern project coordination was to be appointed. This person's responsibilities included patient recruitment, study protocol conduct as well as distribution and collection of the first two questionnaire sets. We estimated a coordination effort of approximately two hours per participating patient. The research team was to have performed post-discharge data collection. We estimated an overall time frame for data collection of approximately two years. We intended to apply for research funds as soon as the first results were available.

## **Recruitment and project progression**

At an early stage of the project, we conducted a survey in the German-speaking part of Switzerland in order to ascertain the number of in-patient stroke rehabilitation facilities and to gather information about their goal-setting procedures. We identified 28 rehabilitation facilities eligible as research fields for our project (Geschwindner et al., 2007). Written participation requests were issued to all medical managers (n=28) and the project description, the three questionnaire sets and a synopsis of the results obtained in the mentioned survey were enclosed.

Within the first six weeks after sending the written request the situation was as follows:

- Two facilities spontaneously agreed to participate
- Seven facilities expressed their interest in participating. Three of them were gathered in a group of clinics
- Four facilities informed us that their patient profile had changed fundamentally since the survey and thus they were no longer eligible for participation
- One facility indicated that its geriatric stroke patients were not eligible as a research population for our project
- Eight facilities declined due to a lack of capacity
- One facility declined because similar data gathering was being implemented internally
- One declined with no reason for refusal provided
- Four facilities did not reply

In the two facilities that spontaneously agreed to participate, we discussed the clinics' strategies for patient recruitment and data gathering

with the medical manager. It was agreed that we were to provide regular assistance. After the respective ethics committees gave their approval the data gathering commencement was determined.

We re-approached the seven facilities considering participation. In three facilities we had the opportunity to personally present our concern to the chief physicians. Eventually, no facility accepted. One reason was because comprehensive restructuring and reorganization was being planned and/or being implemented at the time. A lack of human resources was another reason for declining. Participation would only have been agreed to if we had funded the study coordination. When speaking with the chief physicians, it was mentioned several times that a national study was in the process of being planned. At that time, except for compulsory participation, no further details were known to the facilities.

To the four facilities that had not replied, we sent an email reminder to the chief physicians. In the absence of any reply, we attempted to clarify the situation in these clinics by inquiring by phone or through personal contact with third parties. In three cases, all attempts remained unsuccessful. One facility communicated that the appointment of a new chief physician was imminent. At an appropriate moment we took advantage of the changed circumstances and attempted a new inquiry, which was also unsuccessful. One year later, at a specialist conference, the Swiss National Coordination and Information Body for Quality Assurance<sup>1</sup> (KIQ) introduced its pilot project on the goal-agreement process as a relevant quality indicator in neurological rehabilitation. Thirteen facilities were under an obligation to participate. In contrast to our project, the aim was solely 'documentation of the goal-setting process based on the goals set and the corresponding goal attainment' during inpatient

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<sup>1</sup> Changed to: 'National Association for Quality Development in Hospitals and Clinics' (ANQ)



rehabilitation (Diserens et al., 2008). The focus was on the clinics' process quality, while we aimed to correlate the current practice of the goal-setting process to patient outcomes. In retrospect, it emerged that the national project was in competition with our participation inquiry.

Eventually, the parameters of our more extensive, multicenter research project were narrowed to the participation of two facilities. We knew that in one clinic only a few stroke patients were being rehabilitated and thus the expected participation in the overall data collection period would be moderate. According to our calculations, in this case, study coordination and data gathering did not require great effort. In the second clinic, after an initially good start, significant organizational modifications occurred that massively increased the workload of the study coordinator. A year on, the termination of the reorganization process was not in sight. Furthermore, in this period many patients did not meet the inclusion criteria. Hence, in conjunction with the clinic, we decided to prematurely discontinue participation. With repeated efforts to enlist the participation of more facilities failing, the situation forced us to suspend the entire project.

When the project was abandoned, five patients had completed the three questionnaire sets, which we evaluated qualitatively. Based on the three completed questionnaire sets at each point of measurement, we came to the conclusion that answering 100 items each was reasonable for patients. The utilized instruments allowed delineation of emerging changes during the course of rehabilitation. This confirmed our selection of instruments. However, difficulties in mapping the goal-setting processes and their evaluation were encountered, as the formulations' abstraction and detailing were subject to changes. Furthermore, the patients set new priorities after being discharged from the rehabilitation facilities.

## **Discussion**

From our literature review it became apparent that a trend has developed in various disciplines over the last few years of publishing articles that report difficulties in research projects. Since the extent of this phenomenon remains unclear, these articles are of anecdotal nature. A systematic evaluation and publication of challenges encountered in conducting research projects will have to wait, until the concept becomes established and these experiences can be summarized in reviews. These findings are relevant for the scientific community and crucial for the development of research expertise. Helping researchers to deal with potential difficulties in the planning phase will enable challenges to be mastered efficiently during the implementation phase.

According to the literature, challenges in research projects, do not occur in isolation, but rather, multiple simultaneous and, moreover, inter-linked occurrences are possible (Smith et al., 2008). In comparing publications, three potential problem areas become apparent: in the conception of the research, in the research field and in the dynamics between the two (Netta-Turner et al., 2008). Likewise, in evaluating our prematurely discontinued research project, we identified interlinked difficulties in all three problem areas. However, it was not always possible to unequivocally assign any one difficulty to any specific problem area. Given that the problem areas suggest an emerging pattern, we have decided to maintain this structure in the following discussion and evaluation of our research project.

## **Research concept**

There is currently no scientific evidence proving the efficacy of goal setting (Levack et al., 2006a; Levack, Dean, Siebert & McPherson, 2006b). Nevertheless, the active involvement of stroke rehabilitation patients

and/or their relatives in the goal-setting process is explicitly recommended (Intercollegiate Stroke Working Party, 2008). Our research revealed that this procedure is implemented, to varying degrees, in rehabilitation clinics in the German-speaking part of Switzerland (Geschwindner, Rettke, van den Heuvel, Haalfens & Dassen, 2007) whereby the established practice sometimes contradicted recommendations. In our research conception, the crucial explanatory variable was represented by the approach implemented in the goal-setting process. The documentation required in this process could have been interpreted as a personnel examination, which would explain the disapproving attitude towards participation (Brim and Schoonover, 2009). In contrast to Ehrlich (2002), we were aware of the discrepancy between theory and practice. However, we underestimated the possible impact of the discrepancy on the willingness to participate in the study.

On the one hand, conducting a pilot study can help to avoid unexpected obstacles that may hinder progress with the project (Netta-Turner et al., 2008). It allows for identification of potential recruitment difficulties (van Teijlingen, Rennie, Hundley & Graham, 2001; Beebe, 2007). On the other hand, along with the data generated, research assumptions can be confirmed (Kearney and Simonelli, 2006; Beebe, 2007) and funding applications can be justified (van Teijlingen et al., 2001; Beebe, 2007). In the clinics, the extent of the questionnaire sets raised questions about their appropriateness for the patients, which our pre-test was able to refute. Another point of discussion was the effort required for the study coordination which we initially estimated at two hours per patient. This was considered too high to be accomplished without too much effort given their own personnel and/or financial resources. In hindsight, the experience gained during the project showed that the coordination effort was given too high on estimation. Having pre-tested the questionnaire sets, we felt we had chosen the right measuring in-

struments and inclusion criteria. However, we had not taken into consideration that we had tested the measuring instruments but not the recruitment and the data gathering in the research field. In doing so, we erroneously equated instrument applicability to study implementation feasibility.

### **Research field**

For clinical facilities, participating in a research project brings with it the implication of additional work (Sullivan-Bolyai et al., 2007). Our interlocutors in the clinics conveyed their non-participation by explaining that internal reorganizations and restructuring were imminent. Processes of change greatly affect an organization and restrain its capabilities, making it problematic to take on additional tasks. This did in fact emerge in our project.

Key persons in the research field have the potential to make a significant contribution to a study's implementation. For this to occur they need to comprehend the aim of the research (Brim and Schoonover, 2009), to reliably perform their tasks (Duffy and Hoskins, 2008; Netta-Turner et al., 2008) and to fulfill their role in the organization consistently (Smith et al., 2008). Furthermore, research activity is not included in the prime responsibilities of those active in the clinical field. Hence its implementation is given a lower priority and risks being disregarded completely (Duffy and Hoskins, 2008; Brim and Schoonover, 2009). In one of the two participating facilities, we experienced how participation acceptance does not guarantee success. Because of unforeseen reorganization, the key person was forced to neglect her tasks in our project. Third party funding of the study coordination would have allowed participation in interested facilities. An added factor was our failure in the conception phase of the study to include scheduling a test run, such as a pilot study. Instead, we intended to request research funds only after the first results became available.

### **Additional factors**

The first and second authors have not worked in the field of stroke rehabilitation and did not have personal contact with key persons and stakeholders in the research field. This impeded the development of the necessary dynamics of conceptual support and recommendations by third parties (Duncan & Haigh, 2007). Our research question is of interest to a multidisciplinary field. The research plan required insight into the structure and procedures of working in a multidisciplinary collaboration. The development of the research question and of the further research concept was eventually carried out solely by nursing science researchers. If the research plan had been developed jointly with at least one of the facilities that had been asked to participate, a viable cooperation and partnership would have been established (Slatin, Galizzi, Mawn & Devereaux Melillo, 2004; Sullivan-Bolyai et al., 2007). Furthermore, the project would have been technically and interdisciplinarily underpinned with regard to content (McCallin, 2006; Grey and Conolly, 2008). This would have enabled the critical points in the research conception and the hindrances in the research field to be detected earlier. Fundamentally this procedure could have counteracted the skeptical attitude, as it is described in the literature, towards a research project led by nursing science (Slatin et al., 2004; Sullivan-Bolyai et al., 2007).

The Swiss Health Care Insurance Act (KVG) requires that quality be verifiable (KVG, 1996). Consequently, for many of the rehabilitation facilities, the invitation to participate in the KIQ “pilot project regarding the goal-setting process as a relevant quality indicator in neurological rehabilitation” (Diserens et al., 2008)(p 1022), was of a compelling nature. The participation decision was also probably based on the ‘strong argumentation’ of the competing project (Vaidya, 2004), which decided the outcome of our research project.

## Lessons learned

A paradigm shift would require reporting not only successful projects, but also those hindrances encountered on the path to success, because they represent golden teaching opportunities. “The path to expertise comprises failure, acknowledging failure and the courage to discuss it publicly in order to understand it.” (Grütters, 2006)(p 496)

Analyzing our prematurely discontinued project allowed us to learn from the difficulties and failures encountered and to implement the knowledge gained in new research projects.

- All parties involved must share the same research interests
- Key persons on a technical and organizational level must be actively involved from the very outset of the planning phase
- Joint project development must allow for cooperation, through which joint project concretization becomes possible
- An exchange of knowledge, abilities and resources gives rise to a win-win-situation

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## Chapter 3

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**Assessment of patient participation in  
physical rehabilitation activities.  
A systematic review**

Manuscript submitted as: **Rettke, H**; Geschwindner, HM; van den Heuvel, WJA. Assessment of patient participation in physical rehabilitation activities. A systematic review

## **Abstract**

**Purpose:** Rehabilitation is a complex and multidisciplinary process with benefit to the patient as a primary aim and key outcome. Given the number of variables that can influence both structure and process, neither the amount and intensity of interventions delivered nor the extent of therapy attendance is sufficient to fully explain outcomes. This systematic review presents an overview of instruments measuring patient participation in physical rehabilitation activities. The psychometric qualities of the identified instruments are assessed and their content and usefulness in clinical settings are described.

**Design:** Systematic review

**Methods:** Pubmed, CINAHL, PsycInfo, Embase, and Cochrane Library database were searched for instruments published between 1976 and July 2012. When identified, first authors' names and instrument titles were used for a secondary full-text search. In addition, reference lists of articles retrieved were scanned separately for relevant publications. All articles were included that provided information about the development, validation, or application of an instrument designed to assess the degree of patient participation in the field of physical rehabilitation activities. The first two authors, working independently, selected the articles, extracted key data and assessed methodology.

**Findings:** Fourteen articles reporting on three instruments were found. The instruments differ with regard to their underlying theoretical concepts. Each instrument was tested in medical inpatient rehabilitation settings. For all instruments, information on target population, reproducibility, and criterion validity are reported.

**Conclusions:** Each of the instruments appears to be useful for assessing specific aspects of patient participation in rehabilitation activities. More theoretical work is needed to clarify the underlying concepts.

**Clinical Relevance:** The instruments are not yet ready for clinical application.

## **Introduction**

Rehabilitation is intended to restore optimal functioning for people with injuries or illness. Rehabilitation is a complex and multidisciplinary process (Wade & de Jong, 2000). Benefit to the patient is the key outcome and universal aim. (Cameron, 2010). Given the number of variables that can influence both structure and process (Keith, 1997), neither the amount and intensity of interventions delivered nor the extent of therapy attendance is sufficient to fully explain outcomes. There is long-standing research interest in process variables that would better explain or predict rehabilitation outcomes (Lequerica & Kortte, 2010) as well as a growing interest in a clearer understanding of what works in rehabilitation, and why (Keith, 1997; Wade & de Jong, 2000). In this context, patient adherence to rehabilitation interventions has been suggested as an area of consideration (Cameron, 2010). Adherence suggests that the extent to which patients partake in rehabilitation activities might help to explain outcomes. Furthermore, adherence might serve as a starting point to facilitate and foster participation.

A specific dimension in rehabilitation nursing is translating newly acquired patient knowledge and skills from exercise lessons into complex and socially meaningful situations (Kirkevold, 1997). That is, nurses have access to unique patient care situations which have the potential to involve patient participation. For example, a female patient, aged 74, hospitalised with a first ever hemispheric stroke ten days previously is expecting her neighbor for a short visit. Since she has never before visited with her neighbor in a night gown and ungroomed, the nurse helps her to transfer to a wheelchair and to straighten her hairstyle. By doing this the nurse will draw on the transfer skills the patient has acquired in physiotherapy lessons and on the self-care skills acquired in occupational therapy lessons. That is, the nurse helps the patient to adopt

these skills to achieve a personally meaningful result that lies beyond exercise lessons. Knowledge about a patient's level of participation would help nurses to encourage patients and to foster their efforts in contributing to and benefitting from the rehabilitation process.

For this reason, instruments are needed to determine the degree of patient participation in rehabilitation activities. Patient participation has been discussed (Cahill, 1998; Pritchard, 1981) and advocated (Brownlea, 1987; Haidet, Kroll, & Sharf, 2006; Mansell, Poses, Kazis, & Duefield, 2000; Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007) in direct patient care over the years. The World Health Organization's International Classification of Functioning, Disability and Health (ICF) views participation as a core concept (Heinemann, 2010), defined as 'involvement in a life situation' (World Health Organization, 2001). In contrast to the broad domains depicted above, our review focuses solely on the patient's active part in the process of physical rehabilitation activities. We aim to present an overview of instruments designed to assess the degree of patient participation in physical rehabilitation activities, their underlying theoretical concepts, psychometric properties, and their use in clinical practice.

This paper will address the following research questions:

1. Which instruments are reported in the literature as quantifying the extent of patient participation in physical rehabilitation activities?
2. What are the psychometric qualities of these instruments?
3. To what extent have the instruments been used in further research or in clinical practice?

## **Method**

### **Search strategy**

A systematic literature search was performed in several electronic databases: MEDLINE (Pubmed), CINAHL, PsycInfo, and EMBASE, and included articles published between January 1976 and July 2012. January 1976 was chosen as a starting point since publications on patient participation in a broad sense had started being published in the early 1980s. The following keywords were used for MEDLINE: Patient Participation AND Rehabilitation AND (Instrument OR Measurement OR Treatment Outcome) and were adapted to the specific thesaurus of each database (CINAHL: Consumer Participation AND Rehabilitation AND [Research Instruments OR Treatment Outcomes]; PsycInfo: Client Participation AND Rehabilitation AND [Measurement OR Treatment Outcomes]; EMBASE: Patient Participation AND Rehabilitation AND [Instrument OR Measurement OR Outcome Assessment]; Cochrane Library: Patient Participation AND Rehabilitation).

To capture all relevant publications, additional searches were conducted using the authors' names or the instrument titles. Furthermore, reference lists in the retrieved articles were scanned for relevant publications.

### **Inclusion and exclusion criteria**

Articles were included if they:

- addressed patient participation in the field of physical rehabilitation activities;
- provided information about the development, validation, or application of an instrument designed to assess the degree of patient participation in this field; and
- were published in English or German.

Articles were excluded if they:

- focused on patient participation in fields different from physical rehabilitation activities (e.g., decision-making or social participation); and
- dealt with other domains of health care than physical rehabilitation (e.g., mental rehabilitation, substance abuse, acute hospital care, general practice).

### **Selection procedure**

The first two authors, working independently, reviewed the abstracts of all the articles resulting from the search for inclusion or exclusion based on the predefined criteria. When unclear, articles were deemed eligible for further inspection. From this initial stage, full-text versions were retrieved of all selected articles and again independently assessed for definite inclusion as suggested elsewhere (Reeves, Koppel, Barr, Freeth, & Hammick, 2002). The first two authors met at the end of each stage to discuss their findings.

### **Data abstraction and synthesis**

The first two authors reviewed the articles independently and extracted data relating to instrument title and first author, setting and sample characteristics, validity (content/criterion/construct) and reliability (internal consistency/reproducibility). Disagreement was resolved by discussion. Articles reporting on instrument development and initial testing are summarized in Table 1. Articles reporting on instrument application are summarized in a separate table (Table 2).



**Table 1: Overview of instruments designed to assess patient participation in physical rehabilitation activities**

| Instru-<br>ment<br>First<br>author                                          | Study Design                                                                                                                                                                                                                                                                              | Setting & Population                                                                                                                                                                                                                                                                                                            | Validity<br>Content                                                                                                        | Construct                                                                                                                                                                                                                                     | Criterion                                                                                                                                                                                                                                                            | Reliability<br>Internal<br>Consistency                                                                                      | Reproduci-<br>bility                                                                                                                                                                              |
|-----------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>PRPS</b><br>Lenze<br>2004<br>(E. Lenze,<br>et al.,<br>2004)              | Prospective observational<br>design<br>Convenience sample<br>Inclusion criteria:<br>not explicitly reported<br>Exclusion criteria:<br>primary diagnosis of trau-<br>matic brain injury or spi-<br>nal cord injury                                                                         | University-associated<br>freestanding rehabilita-<br>tion hospital, 2 units<br>242 patients with<br>neurological disorders<br>(n=60)<br>orthopaedic disorders<br>(n=93)<br>other (n=73)<br>other (n=16)<br>Age: 20 - 96 yrs<br>(70.8 ± 14.8);<br>Gender: 64% female;<br>Race: 22% African<br>American, 78% Cauca-<br>sian White | Face valid-<br>ity not<br>reported;<br>develop-<br>ment based<br>on expert<br>opinion                                      | Not applicable                                                                                                                                                                                                                                | Predictive valid-<br>ity: Pearson<br>correlation:<br>age with change<br>in motor FIM<br>r = .24 and with<br>LOS r = .19<br>Multivariate<br>regression 'mean<br>PRPS Score'<br>with change in<br>motor FIM<br>[p<.0001]<br>with age<br>[p<.0001] with<br>LOS [p<.006] | Not applica-<br>ble                                                                                                         | Intraclass<br>correlation<br>coefficient<br>[ICC]<br>.91 (OT)<br>.96 (PT)                                                                                                                         |
| <b>RTES</b><br>Lequerica<br>2006<br>(A. Le-<br>querica,<br>et al.,<br>2006) | Retrospective observa-<br>tional design<br>Convenience sample<br>Inclusion criteria:<br>not explicitly reported<br>Exclusion criteria:<br>not explicitly reported<br>Administered during first<br>week of admission to reha-<br>bilitation facility, scored by<br>PT and OT independently | Urban rehabilitation<br>facility, brain injury<br>unit<br>75 patients<br>brain injury (n=52)<br>neurophysiological<br>event (n=24)<br>Age: 17 - 86 yrs<br>(45.7±16.8)<br>Gender: 37.9% female<br>Race: 66.7% African<br>American, 28% Cauca-<br>sian White, 5.3% oth-<br>ers                                                    | Not re-<br>ported,<br>reference<br>made to<br>develop-<br>ment based<br>on rehabili-<br>tation re-<br>search<br>literature | Principal com-<br>ponent analysis:<br>first factor ex-<br>tracted 88.9% ,<br>Rasch analysis:<br>comparatively<br>unidimensional<br>construct<br>Further explora-<br>tion needed in<br>terms of discrimi-<br>nant and con-<br>vergent validity | Predictive valid-<br>ity (2 step hier-<br>archical regres-<br>sions): RTES<br>accounts for<br>variance in<br>injury severity<br>and progress in<br>FIM cognitive<br>domain [p=.016]<br>and progress<br>in FIM motor<br>domain [p=.009]                               | Cronbach's $\alpha$<br>.97 PT,<br>.99 OT<br>Modest<br>correlation<br>between PT<br>and OT<br>rating<br>[r = .56;<br>p<.001] | Interrater<br>reliability<br>correlation<br>r = .56,<br>p<.001<br>(interpreted<br>as estimate<br>of cross-<br>contextual<br>consistency)<br>Intraclass<br>correlation<br>coefficient<br>[ICC] .71 |

| Instrument First author                                                                       | Study Design                                                                                                                                                                                                                                                      | Setting & Population                                                                                                                                                                                                                                                                                      | Validity Content                                                | Construct                                                                                                                                                                                                                                                                                                                       | Criterion                                                                                                                                                                                                                 | Reliability Internal Consistency           | Reproducibility                         |
|-----------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------|-----------------------------------------|
| <b>HRERS</b><br>Kortte 2007<br>(K. Kortte, L. Falk, R. Castillo, D. Johnson, S. Weeger, 2007) | Cross sectional correlational design<br>Inclusion criteria: First rehabilitation admission<br>Mini Mental State Examination >21<br>Exclusion criteria: not reported<br>Single summary assessment at end of rehabilitation stay, scored by OT and PT independently | Three local hospitals providing inpatient rehabilitation programmes<br>206 patients spinal cord injury (n=105)<br>stroke (n=37)<br>orthopaedic (n=40)<br>amputation (n=24)<br>Age: 18 - 91 yrs (56.7 ± 17.52);<br>Gender: 45.1% female;<br>Race: 41.8% African American, 56.3% Caucasian White, 2% others | Not reported, reference made to experts involved in development | Supported by factor analysis (single factor loadings from .77 to .95)<br>Positive correlations:<br>functional state (p<.01)<br>level of functioning 3 months post discharge (p<.01)<br>positive affective state (p<.001)<br>Negative correlations:<br>depression (p<.01)<br>denial (p<.001)<br>negative affective state (p<.01) | Different HRERS score categories show different clinical outcomes with:<br>FIM efficacy (p.04)<br>Total therapy absence rate (p<.001)<br>Therapy refusal absence rate (p<.001)<br>Therapy non refusal absence rate (p.02) | Cronbach's $\alpha$<br>0.92 PT,<br>0.91 OT | Intraclass correlation coefficient .733 |

**Table 2: Overview of further reports on instrument application**

| First Author                                            | Instrument | Study Design                                                                                                                                                                                     | Setting & Sample                                                                                                                                                                                                                                                                                                                                                          | Findings                                                                                                                                 | Comments                                                                                                                                          |
|---------------------------------------------------------|------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------|
| Lenze 2004<br>[E. J. Lenze, M. C. Munin, et al., 2004a] | PRFS       | Identical study to [E. J. Lenze, M. C. Munin, et al., 2004a]                                                                                                                                     | Identical sample                                                                                                                                                                                                                                                                                                                                                          | Higher scores in PRFS correlate with improvement in functional outcome (change in motor FIM)<br>(ANOVA $F_{2,239} = 6.84$ , $p < .001$ ) |                                                                                                                                                   |
| Lenze, M. C. Munin, et al., 2004b)                      |            |                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                           |                                                                                                                                          |                                                                                                                                                   |
| Munin 2005<br>[Munin, et al., 2005]                     | PRFS       | Prospective observational design<br>Convenience sample<br>Inclusion criteria: ability to provide informed consent<br>Points of measurement as in study [E. J. Lenze, M. C. Munin, et al., 2004a] | 12 inpatient rehabilitation facilities (IRF) and<br>8 skilled nursing facilities (SNF) [no description of community characteristics]<br>76 hip fracture patients<br>IRF (n=42): Age 61- 94 yrs (80.2 ± 8.4),<br>Gender: 83.3% female;<br>Race: 95.2% Caucasian White<br>SNF (n=34): Age: 63 -105 yrs (83.9 ± 9.4)<br>Gender: 79.4% female;<br>Race: 88.2% Caucasian White | PRFS scores predicted functional outcome (motor FIM)<br>[OR 3.38; 95%CI 1.11-10.32, p.032]                                               | PRFS served as patient characteristic [beside length of stay, medical complexity, cognitive function, depression social network]                  |
| Munin 2006<br>[Munin, et al., 2006]                     | PRFS       | Prospective observational design<br>Convenience sample<br>Inclusion criteria: community-dwelling pre-fracture<br>Measurements: baseline in acute care, 2 and 24 weeks post-acute                 | University affiliated tertiary care hospital referring patients to identical IRF and SNF settings as described in [Munin, et al., 2005]<br>97 hip fracture patients<br>IRF (n=58): Age: 80.06 yrs (± 8.4);<br>Gender: 81.3% female;<br>Race: 94.83% Caucasian White<br>SNF (n=39): Age: 84.16 yrs (± 9.18);<br>Gender: 82.05% female;<br>Race: 92.31% Caucasian White     | No difference in PRFS scores between IRF and SNF<br>[t 1.20 df 86 p.23]                                                                  | Participation (PRFS) served as patient characteristic [beside length of stay, medical complexity, cognitive function, depression, social network] |

| First Author                                | Instrument | Study Design                                                                                                                                                                                                                                                                                                                                         | Setting & Sample                                                                                                                                                                                                                       | Findings                                                                                                                                                                  | Comments                                                                                                                               |
|---------------------------------------------|------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------|
| Lenze 2009<br>[Lenze, et al., 2009]         | PRFS       | Prospective observational design<br>Convenience sample<br>Inclusion criteria: 60+ yrs, ability to provide informed consent, no metastatic cancer<br>Measurements: baseline in acute care (P), 2, 12 and 26 weeks in post-acute care                                                                                                                  | Acute hospital<br>126 hip fracture patients post surgery<br>Age: 63 - 107 yrs (83.0 ± 9.0);<br>Gender: 82% female;<br>Race: 92.9% Caucasian White                                                                                      |                                                                                                                                                                           | PRFS served as explanatory variable for functional outcome [motor FIM] in hip fracture patients showing symptoms of apathy at baseline |
| Talkowski 2009<br>[Talkowski, et al., 2009] | PRFS       | Prospective observational design<br>Convenience sample<br>Inclusion criteria: community dwelling pre hip fracture<br>Measurements: actigraph accelerometer and PRFS on 5 consecutive days after each therapy session                                                                                                                                 | Inpatient rehabilitation facilities [IRF] and skilled nursing facilities [SNF]; number not reported<br>18 hip fracture patients [IRF n=16; SNF n=2]<br>Age: 78.6 (± 8.95) yrs; [IRF 78; SNF 86 yrs]<br>Gender: 72.2% female;           | Concurrent validity of PRFS with physical activity [accelerometer]<br>Pearson r = .30;<br>p=.045                                                                          |                                                                                                                                        |
| Skidmore 2010<br>[Skidmore, et al., 2010]   | PRFS       | Secondary analysis of prospective interventional [drug] study<br>Convenience sample<br>Inclusion criteria: ischemic stroke, impairment in attention, cognition or executive functions<br>Measurements: PRFS after each therapy session (t = unknown)<br>Functional Independence Measure baseline + 12 weeks, cognitive & affective deficits baseline | Two stroke inpatient rehabilitation facilities [IRF] [university affiliated]<br>44 patients<br>Age: 73.6 (± 7.9) yrs;<br>Gender: 45% female;<br>Race: 85% Caucasian White;<br>donepezil [n=14]<br>galantamine [n=20]<br>no drug [n=10] | Impairment in executive functions [controlled for baseline disability] was an independent predictor of PRFS<br>[F <sub>1,33</sub> =9.35; R <sup>2</sup> = .54,<br>p<.001] |                                                                                                                                        |

| First Author                                      | Instrument | Study Design                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | Setting & Sample                                                                                                                                                                                                                                                                                                        | Findings                                                                                                                                                                                                                                         | Comments                                                                                                                                                                |
|---------------------------------------------------|------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Skidmore et al., 2011<br>(Skidmore, et al., 2011) | PRPS       | <p>Single case study</p> <p>Inclusion criteria: acute stroke, impairment in executive function</p> <p>Exclusion criteria: pre-existing disabling neurological conditions and/or cognitive impairments</p> <p>Intervention: 'Cognitive Orientation to daily Occupational Performance' + self-selection of activity based goals</p> <p>Measurements: PRPS administered during each therapy session (11 therapy days); Functional Independence Measure and PRPS at admission &amp; discharge</p>                                                                                                                                                                 | <p>Inpatient rehabilitation facility (not specified)</p> <p>1 patient</p> <p>Age: 34 yrs</p> <p>Gender: male</p> <p>Race: European American</p>                                                                                                                                                                         | <p>PRPS values increased from '3 to 4, 9' as did FIM and 'Performance Assessment of Self-Care Skills (PASS) values while self-selected goals were mostly attained</p>                                                                            | <p>The feasibility of the 'Cognitive Orientation to daily Occupational Performance' intervention was of primary concern</p>                                             |
| Paolucci et al., 2012<br>(Paolucci, et al., 2012) | PRPS       | <p>Prospective, observational design</p> <p>Convenience sample</p> <p>Inclusion criteria: disabling sequelae of cerebrovascular (stroke) or orthopaedic event (limb amputation or hip fracture)</p> <p>Exclusion criteria: hemorrhagic stroke, brain traumatic injuries, bilateral amputation, no health condition contraindicative to physical therapy</p> <p>Measurements: PRPS daily in week 1 + 2, weekly for remaining length of stay; Activities of Daily Living, Barthel-Index, Rivermead Mobility Index, Beck Depression Inventory, Milan Overall Dementia Assessment at admission</p> <p>Barthel-Index and Rivermead Mobility Index at discharge</p> | <p>Inpatient rehabilitation center</p> <p>362 patients</p> <p>45.3% first ever stroke (n=164)</p> <p>54.7% hip fracture or limb amputation (n=198)</p> <p>Drop-out: 3.9% (n=10), no group specific details given</p> <p>Age: 19-75 yrs (59.41 ± 12.85)</p> <p>Gender: not stated</p> <p>Race: 98.9% Caucasian White</p> | <p>Higher proportion of low participation compared to Lenze et al. (E. J. Lenze, M. C. Munin, et al., 2004b) (33.88% vs. 20.66%)</p> <p>Greater participation strongly correlates with higher percentages of improvement in ADL and mobility</p> | <p>Differentiation between early vs. late participation</p> <p>PRPS served as explanatory variable for functional outcome (mobility), depression and length of stay</p> |

| First Author                                                      | Instrument | Study Design                                                                                                                                                                                                                                                                             | Setting & Sample                                                                                                                                                                                                                                                                                                                                                     | Findings                                                                                                                                                                                                                 | Comments                                        |
|-------------------------------------------------------------------|------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------|
| Lequenca [Lequerica, et al., 2007]                                | RTES       | Cross sectional correlational design<br>No information on sampling<br>Inclusion criteria not reported<br>Administered during first week of admission to rehabilitation facility, scored by PT and OT independently. Parallel assessment of confusion and agitation by neuro psychologist | Traumatic brain injury unit in rehabilitation hospital<br>69 patients<br>brain injury (n=53)<br>neurophysiological event (n=16).<br>65.2% were in acute period of confusion at admission, 15.9% continued to be disoriented at discharge<br>Age: 18-79 yrs [24.2 ± 15.3];<br>Gender: 29% female;<br>Race: 62.3% African American, 31.9% Caucasian White, 5.7% others | Strong inverse relation of agitation with RTES (beyond patients' acute period of confusion), accounting for 37.5% of variance in RTES<br>R <sup>2</sup> = .38, F <sub>2,68</sub> = 19.9, p < .001                        |                                                 |
| Skolaszky 2008 [Skolaszky, Mackenzie, Wegener, & Riley III, 2008] | HRERS      | Prospective observational design<br>Inclusion criteria: 18+ yrs; ability to provide informed consent, no previous spinal cord surgery<br>HRERS applied at week 6 (last visit) by PT (attendance was self-reported weekly)                                                                | Academic spine centre<br>65 patients with degenerative lumbar spinal stenosis - post surgery<br>Age: 58 yrs (± 15);<br>Gender: 58% female;<br>Race: 85% Caucasian White                                                                                                                                                                                              | Patient activation correlated with measures of attendance and HRERS scores. Patient activation accounting for 28% of variance in attendance (r = .53, p < .001) and 56% of variance in HRERS scores (r = .75; p < .001). |                                                 |
| Kortte 2009 [Kortte, Veiel, Batsten, & Wegener, 2009]             | HRERS      | Prospective observational design<br>Inclusion criteria: 1st rehabilitation admission<br>Exclusion criteria: MMSE ≤ 21<br>HRERS applied during inpatient rehabilitation (it not specified) by PT and OT independently<br>Follow up at 3 months post discharge (not for HRERS)             | Three acute hospital inpatient rehabilitation units<br>139 patients:<br>spinal cord dysfunction (n=82)<br>stroke (n=23)<br>amputation (n=16)<br>hip or knee replacement (n=18)<br>Age: 18 - 92 yrs [54.90 ± 18.72];<br>Gender: 39.6% female;<br>Race: 53.2 % Caucasian White                                                                                         | Inverse relation of avoidance with HRERS scores (r = -.22, p < .010)<br>Internal consistency for HRERS: Cronbach's α = .92                                                                                               | HRERS was used to validate measure of avoidance |

PPRS: Pittsburgh Rehabilitation Participation Scale; RTES: Rehabilitation Therapy Engagement Scale; HRERS: Hopkins Rehabilitation Engagement Rating Scale

## Quality assessment

For quality assessment we followed the recommendations of Terwee et al. (2007) regarding criteria for assessing psychometric properties of health status questionnaires. We evaluated articles that reported on instrument development and initial testing (Table 3).

**Table 3: Quality assessment of instrument properties**

|                                       | <b>PRPS<br/>Lenze et al.,<br/>2004</b> | <b>RTES<br/>Lequerica et<br/>al., 2006</b> | <b>HRERS<br/>Kortte et<br/>al., 2007</b> |
|---------------------------------------|----------------------------------------|--------------------------------------------|------------------------------------------|
| Description of underlying concepts    | 0                                      | +                                          | +                                        |
| Description of target population      | +                                      | +                                          | +                                        |
| Description of instrument development | 0                                      | +                                          | =                                        |
| Internal consistency                  | not applicable                         | +                                          | +                                        |
| Reproducibility                       | +                                      | +                                          | +                                        |
| Content validity                      | =                                      | ?                                          | ?                                        |
| Construct validity                    | not applicable                         | 0                                          | +                                        |
| Criterion-related validity            | +                                      | +                                          | +                                        |
| Responsiveness                        | +                                      | ?                                          | ?                                        |

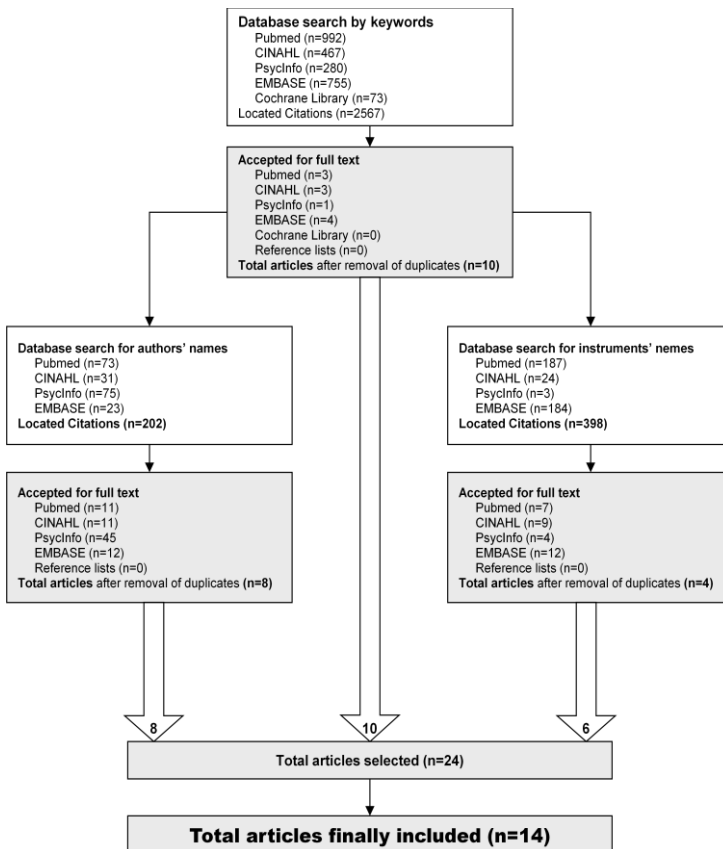
Rating: + = positive; 0 = intermediate; - = poor; ? = no information available

In assessing quality, we did not provide an overall score for two reasons. First, a sum score would give equal importance to all psychometric properties. With respect to instrument development, information about content validity is of greater importance (Terwee et al., 2007). Second, quality assessment depends on the availability of information and on the quality of reporting (Farquhar & Vail, 2006). Newly developed instruments are probably neither fully validated nor reported on in studies where multiple outcomes are assessed (Terwee, et al., 2007).

## Results

The key word search in the electronic database yielded 1634 articles (Figure 1). After reviewing the abstracts the vast majority were excluded. A predominant reason was the focus on patient participation in fields other than physical rehabilitation activities (e.g., decision-making, goal setting, and social participation). Another reason was a focus on other domains in health care (e.g., substance abuse). Nine articles passed the criteria for inclusion.

**Figure 1: Search strategy**





Based on these findings two additional full-text database searches were conducted. Here, the first authors' names (202 citations) or the instruments' titles (398 citations) were used. After a review of abstracts, twelve more articles were added (eight from search for authors' names; six from search for instruments' titles), resulting in a total of 24 articles. Ten were excluded after retrieval of the full text, for the following reasons:

- Four studies assessed other than physical activities in rehabilitation (Ashe, Eng, Miller, & Soon, 2007; Battersby et al., 2009; Kayes et al., 2010; Post et al., 2012)
- Three studies dealt with therapeutic sessions (Chan, Lonsdale, Ho, Yung, & Chan, 2009; Logsdon, McCurry, Pike, & Teri, 2009; Sal-tapidas & Ponsford, 2007)
- Three articles contained incomplete (Lenze, Munin, Dew, et al., 2004) or no data (Lequerica, 2005; Lequerica, Donnell, & Tate, 2009)

### **Pittsburgh Rehabilitation Participation Scale**

The Pittsburgh Rehabilitation Participation Scale (PRPS) assesses patients' participating behavior in rehabilitation activities at the end of each occupational and physical therapy session (Lenze, Munin, et al., 2004a). It was developed based on observations made by occupational and physical therapists and by the authors. No further definition of the term participation is offered. Initially, Lenze et al. (2004a) aimed to operationalize 'motivation for rehabilitation', but chose participation as a surrogate measure instead. The PRPS is a single item instrument appraising the individual extent of participation on a 6-point Likert-type scale. The rating points consider therapy attendance, patients' stamina and effort in therapy, as well as interest in exercises and future therapy. These different aspects are not scored simultaneously but are added stepwise. While

the lowest score refers to therapy attendance only, the highest score considers all aspects.

Eight other articles report on the PRPS (Lenze et al., 2009; Lenze, Munin, et al., 2004b; Munin, Begley, Skidmore, & Lenze, 2006; Munin et al., 2005; Paolucci et al., 2012; Skidmore et al., 2011; Skidmore et al., 2010; Talkowski, Lenze, Munin, Harrison, & Brach, 2009) (Table 2). The instrument was used predominantly in hip fracture populations (Lenze, et al., 2009; Munin, et al., 2006; Munin, et al., 2005; Talkowski, et al., 2009). From the information given it is difficult to judge whether independent samples or subsamples of major studies were assessed. Two studies examined a stroke population (Skidmore, et al., 2011; Skidmore, et al., 2010). The PRPS was used during inpatient rehabilitation only.

### **Rehabilitation Therapy Engagement Scale**

Lequerica et al. (2006) developed the Rehabilitation Therapy Engagement Scale (RTES) based on rehabilitation research literature as a response to quality assurance issues. Its purpose is to document a patient's level of engagement in rehabilitation therapy to identify problem areas that could be targeted for intervention. Engagement is defined as the deliberate effort and commitment to working toward the goals of rehabilitation therapy (Lequerica et al., 2006). The instrument consists of 15 items assessing "attitudes, perceptions, and expectations that influence engagement and performance" (Lequerica et al., 2007)(p 180). It rates on a 4-point-Likert scale, although its wording is not reported. The authors associate a high level of engagement with increased participation in rehabilitation activities (Lequerica & Kortte, 2010). The RTES was tested in populations with brain injury (n=105) or neurophysiological event (n=40) admitted to inpatient rehabilitation (Table 1, 2).

### **Hopkins Rehabilitation Engagement Rating Scale**

The Hopkins Rehabilitation Engagement Rating Scale (HRERS), developed by Kortte et al. (2007), is based on a co-author's unpublished rehabilitation participation measure. The authors define participation as the degree or extent to which a subject partakes in rehabilitation activities. They extend the construct of participation beyond therapy attendance and motivation into engagement. This term is defined "as an interest in, and an intentional effort to, work toward the rehabilitation goals" (Kortte, Falk, Castillo, Johanson-Greene, & Wegener, 2007)(p 878). The instrument consists of five items within the single domain of 'engagement' capturing therapy attendance, attitude towards rehabilitation, and participating behavior. Therapists rate their observations on a 6-point Likert scale. The HRERS was applied during inpatient rehabilitation to spinal cord populations (n=252) mainly after primary or secondary surgery. Other populations consisted of post-stroke patients (n=58), patients with hip or knee replacement (n=58), or amputation (n=41) (Table 1, 2).

### **Discussion**

This systematic review identified three instruments designed to measure patient participation in physical rehabilitation activities. All demonstrate a fair degree of psychometric properties and show clinical usefulness but exhibit variations in underlying concepts. In developing the instruments, the authors aimed at quantifying specific behaviors that represent the patient's contribution to the rehabilitation process. The authors label this behavior either 'participation' (Lenze, Munin, et al., 2004a) or 'engagement' (Kortte, et al., 2007; Lequerica, et al., 2006). This requires patient involvement (Brownlea, 1987) which is acknowledged implicitly (Lenze, Munin, et al., 2004a) and explicitly (Kortte, et al., 2007; Lequerica, et al., 2006) by all authors. In principle, motivation

is considered of major importance. Lenze (Lenze, Munin, et al., 2004a) employs participation as a surrogate measure of motivation, while Lequerica (Lequerica, et al., 2006) and Kortte (Kortte, et al., 2007) view motivation as an indispensable prerequisite for patient participation. They consider patient engagement a significant means to contribute to the rehabilitation process.

In a subsequent publication the latter authors describe participation as a "separate but related construct" (Lequerica & Kortte, 2010)(p 416) of engagement. Here, they constitute the term therapeutic engagement and offer a theoretical model that depicts the constitution and flow of patient engagement. It incorporates communication with professionals in the rehabilitation process and pinpoints areas for interventions (Lequerica & Kortte, 2010). The discussion of participation and engagement could be looked at alternatively: if patient participation reflects the observable behavior, it might be easily assessed as Lenze et al. suggest (Lenze, Munin, et al., 2004a). If patient engagement reflects motivation put into action, engagement would precede participation, thereby offering points for intervention to increase participation.

Patient participation appears to be a construct with multiple facets that cannot be simply summarized as a single item. This is shown in the way the PRPS has operationalized participation (Lenze, Munin, et al., 2004a). The patient's behavior is rated by stepwise augmenting factors that do not necessarily represent a linear increase. This would impede the identification of starting points for targeted interventions to support individual participation. On the other hand, participation can change over time. Neither RTES (Lequerica, et al., 2006) nor HRERS (Kortte, et al., 2007) were designed or tested to track changes over the course of rehabilitation, which would be necessary to evaluate improvement in

participation. However, the need to track participation has been acknowledged by Lequerica (Lequerica, et al., 2006).

Although all three instruments demonstrate a fair degree of usefulness, more theoretical work is needed to further clarify the conceptual and operational definitions. Lequerica's and Korttes's recent publication (Lequerica & Kortte, 2010) could indicate that this is on its way. It must be noted that all three instruments were developed, tested and applied by two of the professions on the otherwise multidisciplinary rehabilitation team, i.e. physiotherapists and/or occupational therapists. This does not bring into question their suitability to inform nurses of an individual patient's level of participating in physical rehabilitation activities during physiotherapy or occupational therapy sessions. However, the instruments' potential might be too limited for application in nursing practice, since the instruments' wording does not or only rudimentarily reflect complex nursing care situations as described above. Here, the question arises as to whether physical rehabilitation activities take place in exercise sessions exclusively or whether they also occur outside these parameters. In order to assess the phenomenon in question within the context of complex nursing care situations, the present instruments must be adapted or instruments will have to be specifically developed. However, an instrument able to measure patient participation in physical rehabilitation activities across professional boundaries and in various patient situations would facilitate communication within the multiprofessional team when assessing the progress of a patient in rehabilitation.

Two limitations apply with respect to the completeness of our findings. The exclusion of studies in languages other than English and German might result in missing articles. As far as Romanic languages are concerned, the titles screened did not imply that any relevant instrument

had been missed. The key words selected did not produce all articles included in this review. Only information gained from the first results (i.e., first authors' names and instruments' titles), used in a subsequent full-text search, resulted in the final number of studies. Using Pubmed's function to list 'related articles', we counter-checked for a broad range of publications, which did not produce additional studies for inclusion.

In conclusion, the relevance of assessing patient participation in the field of physical rehabilitation activities has gained attention. As for the instruments developed and tested so far, current evidence does not yet encourage application in practice.

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## **Standardized goals for post-discharge 'living arrangement' from inpatient stroke rehabilitation**

Manuscript submitted as: **Rettke, H**; Geschwindner, HM; Rentsch, HP; van den Heuvel, WJA. Standardized goals for post-discharge 'living arrangement' from inpatient stroke rehabilitation

## **Abstract**

**Objective:** To assess the degree of goal attainment in the domain of 'living arrangements' at discharge from inpatient stroke rehabilitation in comparison to goals set at admission by the multidisciplinary team.

**Design:** Retrospective cross-sectional study

**Setting:** Swiss neurorehabilitation facility

**Participants:** Post-stroke patients (n=287) who completed inpatient rehabilitation from a consecutive sample.

**Interventions:** Not applicable.

**Main outcome measures:** Goal attainment in terms of 'living arrangements' and 'Functional Independence Measure' (FIM) values at discharge from inpatient stroke rehabilitation compared to goal setting and FIM values at admission as assessed by the multidisciplinary team. Goals were standardized based on the International Classification of Functioning, Disability and Health (ICF).

**Results:** In 231 (80%) patients the rehabilitation goals pertaining to the degree of independent living were achieved at the time of discharge. There were 22 patients (8%) who exceeded the established goals while 32 (11%) patients did not meet them. Gender and cognitive functioning were the most important variables relating to the discrepancy between goals set and attained in 'living arrangements'.

**Conclusions:** The multidisciplinary team set attainable goals in the majority of cases. Little improvement in cognitive functioning during rehabilitation is correlated to dependence in living arrangements at discharge. To what degree patients maintain rehabilitation goals post-discharge remains largely unknown and warrants further examination.

## **Introduction**

Goal setting is regarded as 'best practice' in rehabilitation treatment (Levack et al., 2006; Siegert & Taylor, 2004) and is instrumental to optimising rehabilitation outcomes (Chin, Ng, & Cheung, 2008; Lawson, 2005; Playford, Siegert, Levack, & Freeman, 2009). Despite the importance of goal setting in rehabilitation, evaluations are scarce and effects are disputed (Lawson, 2005; Levack, et al., 2006; Sivaraman Nair, 2003; Wade, 2009). This may partly be due to problems in designing evaluation studies as well as in recruiting a sufficient number of participants (Dalton et al., 2011; Taylor et al., 2011). In addition, the theoretical basis for goal setting and planning is weak (Scobbie, Dixon, & Wyke, 2011; Siegert & Taylor, 2004). The need for involving patients and their families in rehabilitation goal setting is evident and is strongly recommended in literature (Leach, Cornwell, Fleming, & Haines, 2010). However, involvement requires intensive interaction between care professionals, patients, and patients' families (Lawson, 2005; Playford, et al., 2009).

From the professional perspective, two important goals in rehabilitation are restoring a patient's functionality and being discharged to an appropriate post-rehabilitation environment. From the patient perspective, self-functionality is a priority goal (Lawson, 2005; Sivaraman Nair, 2003). This finding is neither surprising nor new. In a survey of stroke patients two decades ago, independent movement, dressing and toileting, i.e. independent living, were found to be important activities (Chiou & Burnett, 1985). What is new is the understanding that goals have to be 'fine-tuned' to each patient. Rehabilitation goals have to be framed within a patient's life goals (Barnard, Cruice, & Playford, 2010; Sivaraman Nair, 2003). At the same time, goals have to be agreed upon by the rehabilitation team in order to be realistic. Discrepancies in 'realistic goals' between a patient and professionals may undermine the patient's motivation (Wade, 2009).

Goal setting and planning is a complex, multidisciplinary process. In the case of stroke, disease-related factors (type of stroke, cognitive and physical functioning, co-morbidity), social factors (social network and support, living arrangements, life style), and psychological factors (coping style, mastery, motivation) all play a role (Bradley, Bogardus Jr., Tinetti, & Inouye, 1999; Graham et al., 2010; Heruti et al., 2002; Kwakkel, Wagenaar, Kollen, & Lankhorst, 1996; Ween, Alexander, D'Esposito, & Roberts, 1996). After goals have been set, the healthcare team and the patient monitor the progress in goal achievement until the time of discharge (Rentsch et al., 2003). Literature findings indicate various factors that are related to the degree of goal attainment at discharge: gender, age, length of stay in acute care and rehabilitation facility, functional status, cognitive functioning, living arrangements, and social support (Bradley, et al., 1999; Graham, et al., 2010; Heruti, et al., 2002; Kwakkel, et al., 1996; Vincent, Alfano, Lee, & Vincent, 2006). As indicated above, goals pertaining to 'living arrangements' are crucial for patients as well as for health care professionals and are therefore the focus of this analysis. It is noteworthy that the Swiss National Organisation for Quality Management in Hospitals (ANQ) is introducing goal setting as a major factor in the quality of neurological and musculoskeletal rehabilitation. To this end the ANQ adopted the concept of goal categories which are referenced in this article. From 2013 on, data on goal setting and goal attainment will be collected in all Swiss neurorehabilitation centers (ANQ, 2012; Diserens et al., 2008).

This article describes those goals pertaining to 'living arrangements' that were established for stroke patients admitted to inpatient rehabilitation upon transfer from an acute care hospital and the degree to which these goals were achieved at discharge from the rehabilitation facility. Additionally, patient-related factors which may be associated with discrepancies in goal attainment are explored based on the goals set at admission.

## **Methods**

### **Setting**

We conducted a retrospective data analysis of patients discharged from inpatient stroke rehabilitation in a major Swiss neurorehabilitation center, a 32-bed facility co-located with a regional non-university medical center (Rentsch, et al., 2003). This facility was chosen because the health care team followed a systematic, structured process for goal setting, planning, evaluation, reporting, and documentation. The process of goal setting and evaluation was shaped and implemented in 2003 (Rentsch, et al., 2003; Rentsch & Kaufmann, 2008) and is represented in a team conference protocol. This protocol directs the assessment, evaluation and reporting of the specific domains of the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001) by each health care professional involved in each patient's care (Figure 1).

### **Goal assessment, evaluation and team conference procedures**

At admission to the neurorehabilitation center, all patients undergo a medical examination at the same time as therapeutic interventions and rehabilitative nursing care are implemented. Within the first week each member of the multidisciplinary rehabilitation team will have individually assessed the patient's functions, activities, and contextual factors according to designated responsibilities of each team member. In addition, every team member individually asked the patient or the significant other about his or her own goals post-discharge (Rentsch, et al., 2003). Assessment procedures were supported by the use of various established instruments, whereas the Functional Independence Measure (FIM) (Granger, Hamilton, Linacre, Heinemann, & Wright, 1993) served as common base of shared understanding when quantifying a patient's functional status. At the first team conference, the assessment, rehabilitation goals were

formulated on the basis of the patient’s individual goals and in consideration of the shared assessment results.

**Figure 1: Multiprofessional team conference protocol**

| Steps               | Admission                                             | Follow-up                                                                                          | Lead            |
|---------------------|-------------------------------------------------------|----------------------------------------------------------------------------------------------------|-----------------|
|                     | Introduction                                          | Goals of the meeting                                                                               | CP              |
| <b>Assessment</b>   | <i>Body functions / Body structures</i>               |                                                                                                    |                 |
|                     | Medical diagnosis<br>Body structures / Body functions |                                                                                                    | MD              |
|                     | General impression                                    | Previously defined intermediate goals<br>Follow-up information<br>Evaluation<br>General impression | MD<br>NP<br>all |
|                     | <i>Activities / Participation</i>                     |                                                                                                    |                 |
|                     | Interpersonal interactions and relationships          |                                                                                                    | N/NP            |
|                     | Mobility                                              |                                                                                                    | PT/OT           |
|                     | Self care                                             |                                                                                                    | N               |
|                     | Communication                                         |                                                                                                    | ST/N            |
|                     | Learning and applying knowledge                       |                                                                                                    | OT              |
|                     | Domestic life                                         |                                                                                                    | OT              |
|                     | General tasks and demands                             |                                                                                                    | OT              |
|                     | Major life areas                                      |                                                                                                    | all             |
|                     | Community, social and civic life                      |                                                                                                    | all             |
|                     | Functional Independence Measure (FIM)                 |                                                                                                    | N               |
|                     | <i>Contextual factors</i>                             |                                                                                                    |                 |
|                     | Personal factors                                      |                                                                                                    | MD              |
|                     | Environmental factors                                 |                                                                                                    | N               |
|                     | <i>Problems of major importance</i>                   |                                                                                                    |                 |
|                     | Impairments                                           |                                                                                                    | all             |
|                     | Activity limitations / Participation restrictions     |                                                                                                    | all             |
|                     | Barriers and hindrances                               |                                                                                                    | all             |
|                     | Facilitators / Resources                              |                                                                                                    | all             |
| <b>Goal setting</b> | Participation goals of the patient                    |                                                                                                    | all             |
|                     | Participation goals of the rehabilitation team        |                                                                                                    | all             |
| <b>Planning</b>     | Prerequisites to reach participation goals            |                                                                                                    | all             |
|                     | Setting of intermediate goals and plans               |                                                                                                    | all             |
|                     | Orders and agreements                                 |                                                                                                    | CP              |
|                     | Agenda (next conferences, discharge etc.)             |                                                                                                    | CP              |

Additional information from all participating team members, where applicable

**Abbreviations:** CP = chair person, MD = medical doctor, NP = neuro-psychologist, N = nurse, PT = physiotherapy, OT = occupational therapy, ST = speech therapy

At this neurorehabilitation center, team conferences on individual stroke patients take place one week after admission to assess goals in terms of 'living arrangements', 'socio-cultural participation,' and 'employment'. Three steps (assessment, goal setting, and planning) provide the structure for the assessment conference, which lasts 30 minutes. Goal categories were operationalized by formulating core requirements in the ICF components of 'body functions and structures', 'activity and participation', and 'contextual factors' with regard to goals at the level of participation (Rentsch, et al., 2003). In consecutive evaluative team conferences, held every four to five weeks, new information or changes concerning the ICF components of 'body functions and structures', 'environmental and personal factors' and 'activities and participation' were reported. Having evaluated the goals, necessary adaptations in goal setting and the rehabilitation plan were made, as required (Rentsch, et al., 2003). Patients and their families were invited to participate in a team conference for shared goal setting three to six weeks following admission, but not earlier. This was to protect them from additional stress at a time when they were not yet ready for joint decision-making.

In this analysis we focused on the goal categories of 'living arrangements' as presented in Figure 2. The six categories comprise living in an institution, living at home with help, and living at home independently without help. Since the majority of stroke patients are past retirement age (Truelsen et al., 2006), the 'employment' goal categories only apply to a small number of post-stroke patients. Also, the goal categories in 'socio-cultural participation' refer only to either assisted or independent participation in outside home activities (Luzerner Kantonsspital Rehabilitation, 2007).



**Figure 2: Goal categories ‘living arrangements’**

| 1                                                                  | 2                                 | 3                                                                               | 4                                                  | 5                            | 6                                                             |
|--------------------------------------------------------------------|-----------------------------------|---------------------------------------------------------------------------------|----------------------------------------------------|------------------------------|---------------------------------------------------------------|
| Integration into a nursing home (preservation of health condition) | Assisted living in an institution | Living at home with the support of related persons living in the same household | Living at home independently with external support | Living at home independently | Living at home independently with additional responsibilities |

**Study design**

We conducted a retrospective data analysis of patient data at admission and discharge. Prior to data access and analysis the approval of the local ethics committee was obtained. All stroke patients admitted for inpatient rehabilitation between 2005 and 2008 were considered. Inclusion criteria were: confirmed medical diagnosis of first-ever ischemic or hemorrhagic stroke and completed inpatient rehabilitation. Exclusion criteria were: premature termination of rehabilitation irrespective of reason or admission to inpatient rehabilitation due to a medical diagnosis other than ischemic or hemorrhagic lesion. In two cases no records were available for either goal setting or goal attainment. Both were excluded from this part of data analysis.

The first two authors extracted the data from medical records. These included demographic variables (age, gender), type of stroke, length of stay in both acute and rehabilitation settings, ‘Functional Independence Measure’ (FIM) scores, and goal categories for post-discharge ‘living arrangements’ at admission and discharge. The FIM has been shown to validly indicate the degree of disability post-stroke at admission and to reflect changes in functional status over the course of rehabilitation (Chummney et al., 2010; Karges & Smallfield, 2009; Ponte-Allan & Muir Giles, 1999).

Descriptive statistics were summarized for sample characteristics. Mann-Whitney-U tests were used to check for differences between pa-

tient characteristics and one sample t-tests to demonstrate changes in FIM values between admission and discharge. Exploratory data analysis was performed to investigate associations between patient characteristics, FIM values, and goal attainment. For data analysis SPSS version 20.0 was used (SPSS Analytics, IBM Inc., Armonk, NY, USA).

## Results

### Sample characteristics

The sample consisted of 287 post-stroke patients (170 men, 117 women) who completed inpatient rehabilitation between 2005 and 2008 in a major Swiss neurorehabilitation center (Table 1). The majority suffered from ischemic stroke. Mean age was 68 and average motor and cognitive FIM scores at admission were 58 and 24. Both improved significantly ( $p < .001$ ) during inpatient rehabilitation (Table 2). Mean length of rehabilitation stay was 47 days.

**Table 1: Sample characteristics**

| Type of stroke                                    | Ischemic<br>Hemorrhagic | 253<br>34             |
|---------------------------------------------------|-------------------------|-----------------------|
| Gender                                            | Male<br>Female          | 170<br>117            |
| Mean age (SD)                                     |                         | 68.29 ( $\pm 13.97$ ) |
| Mean days in acute hospital                       |                         | 21.0 ( $\pm 12.74$ )  |
| Mean days in rehabilitation facility              |                         | 47.24 ( $\pm 32.76$ ) |
| Mean FIM total at admission in rehabilitation     |                         | 82.19 ( $\pm 26.73$ ) |
| Mean FIM motor at admission in rehabilitation     |                         | 58.41 ( $\pm 22.09$ ) |
| Mean FIM cognitive at admission in rehabilitation |                         | 23.75 ( $\pm 6.95$ )  |

The largest group of patients ( $n=130$ ) was assessed at attaining goal category 3 (Living at home with the support of a person living in the same household). The second largest group ( $n=58$ ) was placed in goal category 4 (Living at home independently with external support). There

were 26 patients who were assessed as requiring nursing home care at discharge, goal category 1.

**Table 2: Differences in FIM values between admission and discharge stratified for gender**

|           |        |         | Admission     |        | Discharge      |        | Difference    |        |
|-----------|--------|---------|---------------|--------|----------------|--------|---------------|--------|
|           |        |         | Mean (SD)     | Range  | Mean (SD)      | Range  | Mean (SD)     |        |
| total FIM | All    | (n=287) | 82.19 (26.73) | 18-126 | 98.38 (23.43)  | 21-126 | 16.19 (15.68) | p<.001 |
|           | Male   | (n=170) | 85.78 (24.52) | 18-126 | 100.77 (21.73) | 31-126 | 14.99 (14.99) |        |
|           | Female | (n=117) | 76.97 (28.97) | 18-125 | 94.91 (25.39)  | 21-126 | 17.93 (16.53) |        |
| motor FIM | All    | (n=287) | 58.41 (22.09) | 13-91  | 72.11 (18.85)  | 13-91  | 13.70 (13.87) | p<.001 |
|           | Male   | (n=170) | 61.38 (20.59) | 20-91  | 74.18 (17.68)  | 20-91  | 12.81 (13.45) |        |
|           | Female | (n=117) | 54.09 (23.52) | 13-91  | 69.10 (20.15)  | 13-91  | 15.01 (14.41) |        |
| cogn FIM  | All    | (n=287) | 23.75 (6.95)  | 5-35   | 26.28 (6.34)   | 5-35   | 2.53 (3.17)   | p<.001 |
|           | Male   | (n=170) | 24.34 (6.52)  | 5-35   | 26.64 (5.96)   | 10-35  | 2.31 (2.86)   |        |
|           | Female | (n=117) | 22.91 (7.48)  | 5-35   | 25.76 (6.84)   | 5-35   | 2.85 (3.57)   |        |

In 81% of the study patients (n=231) the goal set at admission was achieved at discharge, while 11% (n=32) of patients did not attain that goal. There were 22 patients (8%) who exceeded the goal. Decided improvement in goals pertaining to living arrangements were recorded for two patients who were expected to live in a nursing home but at discharge were able to return home with support. Significant negative divergence from goals occurred for 12 patients who were unable to

achieve the goal of living at home independently with external support. Instead they were discharged to a nursing home (Table 3).

**Table 3: Concordances in goal categories ‘living arrangement’ between goal setting at admission and goal attainment at discharge. In low categories: trend for under estimation of goal attainment**

|                                                                     |   | Goal attainment “living arrangement“<br>at discharge (t <sub>1</sub> ) |          |            |           |           |           | Total |
|---------------------------------------------------------------------|---|------------------------------------------------------------------------|----------|------------|-----------|-----------|-----------|-------|
|                                                                     |   | 1                                                                      | 2        | 3          | 4         | 5         | 6         |       |
| Goal setting “living arrangement“<br>at admission (t <sub>0</sub> ) | 1 | <b>24</b>                                                              | <b>0</b> | <b>1</b>   | <b>1</b>  | <b>0</b>  | <b>0</b>  | 26    |
|                                                                     | 2 | <b>2</b>                                                               | <b>4</b> | <b>2</b>   | <b>1</b>  | <b>0</b>  | <b>0</b>  | 9     |
|                                                                     | 3 | <b>8</b>                                                               | <b>2</b> | <b>109</b> | <b>4</b>  | <b>7</b>  | <b>0</b>  | 130   |
|                                                                     | 4 | <b>12</b>                                                              | <b>2</b> | <b>2</b>   | <b>39</b> | <b>1</b>  | <b>2</b>  | 58    |
|                                                                     | 5 | <b>1</b>                                                               | <b>0</b> | <b>1</b>   | <b>1</b>  | <b>37</b> | <b>3</b>  | 43    |
|                                                                     | 6 | <b>0</b>                                                               | <b>0</b> | <b>0</b>   | <b>0</b>  | <b>1</b>  | <b>18</b> | 19    |
| Total                                                               |   | 47                                                                     | 8        | 115        | 46        | 46        | 23        | 285   |

### Factors explaining deviations in goal attainment

Age as well as motor and cognitive FIM scores showed a significant relationship to the goal level assessed regarding ‘living arrangements’ at admission. That is, patients of older age (-0.02 (95% Confidence Interval) (-.030 to -0.10)  $p=.001$ ) were more often assessed to live in settings requiring institutional care. In contrast, higher physical (0.03 (0.02 to 0.03)  $p<.001$ ) and cognitive functioning scores (0.04 (0.02 to 0.06)  $p<.001$ ) were associated with post-discharge living at home.

Univariate regression was used to analyze associations between factors which may be related for those patients who did not attain their goals at discharge. These patients were more often female (OR 2.88 (1.36 to

6.12)  $p=.006$ ). We saw a trend for older patients (OR 1.03 (0.99 to 1.06)  $p=.091$ ), while a longer stay in the neurorehabilitation center (OR 1.02 (0.99 to 1.04)  $p=.144$ ) and less improvement in cognitive function (OR 0.92 (0.81 to 1.05)  $p=.210$ ) showed weaker improvement. Amongst the 22 patients who exceeded goal attainment at discharge we found a trend for positive changes in cognitive functioning (-2.33 (-4.79 to 0.12)  $p=.061$ ) in male patients.

## **Discussion**

Stroke patients who had experienced a serious brain attack (as reflected by FIM scores at admission to the rehabilitation center) were assessed as having less chance of living independently. These patients also stayed longer in the acute care hospital. Overall at discharge, stroke patients admitted from the acute care hospital to inpatient rehabilitation largely attained the goal 'living arrangements' assessed at admission. However, every fifth stroke patient did not attain this goal. In the literature, older age and female gender are related with unfavourable rehabilitation outcome (Graham, et al., 2010; Ween, et al., 1996) which is supported by the findings of this study. An important finding is that cognitive function is related to adverse outcomes when it comes to 'living arrangements' (Heruti, et al., 2002; Rabadi, Rabadi, Edelstein, & Peterson, 2008). In particular, it is the lack of progress in cognitive functioning during rehabilitation that threatens independent living (Saxena, Ng, Koh, Yong, & Fong, 2007). This suggests that rehabilitation professionals have to pay a great deal of attention to cognitive rehabilitation measures for patients following stroke.

Goal setting is an exacting process requiring appropriate expertise (van de Weyer, Ballinger, & Playford, 2010). Although the manifold contributions of health care professionals were accounted for, the way the con-

tributions were incorporated into the process of arriving at a specific goal remains part of a 'black box' that could be best termed as 'expert opinion'. The team conference structure and quality have been carefully implemented (Rentsch, et al., 2003; Rentsch & Kaufmann, 2008) but the processes of goal setting and evaluation might still be driven by team dynamics rather than by objective measures. This aspect needs further research.

Another aspect which needs further consideration is direct patient involvement. Goals were carefully set and evaluated collectively by the members of the multidisciplinary team but without patients or family members being directly present at the team conference. Instead, their goal expectations were represented by members of the multiprofessional team. Direct patient involvement in goal setting is strongly advocated in the literature (Leach, et al., 2010) but not well implemented in stroke rehabilitation practice in German-speaking Switzerland (Geschwindner, Rettke, van den Heuvel, Halfens, & Dassen, 2007) or in other Western countries (Levack, Siegert, Dean, & McPherson, 2009). An important factor in understanding goal attainment is the extent to which patients understand and agree with the goals set by the multidisciplinary team. Additionally, the relationship between patients and professionals is likely to impact rehabilitation outcomes. Thus, more research is needed in this regard.

The issue of ideal timing and the method of patient involvement are debatable. In the setting described here, patients or families were interviewed one-on-one by different members of the multidisciplinary team to share their goal expectations. When setting goals during the initial team conference, patient goal expectations were taken into consideration. Shared goal setting between patients or families and the multidisciplinary team was not scheduled until three to six weeks following admis-

sion. One might ask whether this is far too late to start joint decision-making. However, an early confrontation with a large team of rehabilitation specialists might provoke more anxiety and uncertainty than confidence.

In general, research in goal setting is sparse (van de Weyer, et al., 2010) and this study adds to the body of knowledge regarding this important aspect of rehabilitation. This study has a rather unique component in that goal setting and attainment is based on the ICF framework. The multidisciplinary team has been well trained to make specific contributions according to a designated protocol. The protocol itself offered the structure for coordination that is needed in team-based approaches to goal setting (Duff, 2009).

### **Study limitations**

Since there is no comparable neurorehabilitation facility in German-speaking Switzerland in terms of working structure and goal categories, our study is limited to a single facility.

The need for more research has been argued before, particularly as regards the goal-setting process within a multidisciplinary team and understanding the role of patient participation in rehabilitation activities. Given the focus of the ANQ on the goal-setting process in neurological and musculoskeletal rehabilitation there is reason to hope for obtaining new insights in the near future (ANQ, 2012).

### **Conclusions**

Despite the limitations of this study, we may conclude that multidisciplinary rehabilitation teams set attainable goals based on the team's specific expertise and explicit protocols. Cognitive function plays an intervening role in goal attainment, since non-improvement in cognition

shows a negative effect on goal attainment as regards 'living arrangements'. Even with the demand for more research in the rehabilitation process, another perhaps more important question is to what degree patients can maintain their goals in 'living arrangements' after discharge from inpatient rehabilitation.



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## Chapter 5

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**Goal assessment in rehabilitation and independent living more than one year after inpatient stroke rehabilitation**

Manuscript submitted as: **Rettke, H**; Geschwindner, HM; Rentsch, HP; Bucher, PO; van den Heuvel, WJA. Goal assessment in rehabilitation and independent living more than one year after inpatient stroke rehabilitation

## Abstract

**Objective:** To explore the extent to which, one to three years after completing inpatient rehabilitation, stroke patients achieved 'living arrangement' goals set at discharge by a multidisciplinary team, as well as to determine factors related to goal attainment.

**Methods:** Medical data were extracted from patient records of a consecutive sample of 278 patients following a first-ever stroke, all of whom had subsequently completed inpatient rehabilitation. Data collection included age, gender, cause of stroke, length of stay in acute and rehabilitation setting, and physical and cognitive functioning at admission and discharge. During the rehabilitation process patients were assessed regarding goals relating to post-discharge 'living arrangements'. Goal attainment was assessed at discharge and a long-term goal set for future 'living arrangements'. Participants were contacted one to three years post-discharge by means of a mailed questionnaire in order to assess their level of goal attainment.

**Results:** The questionnaire was completed by 174 participants. Of these, 91 (52.3%) attained the long-term goal set at discharge; 73 (42.0%) did not attain their goals and the remaining 10 (5.7%) exceeded goal attainment. Non-attainment was related to lower motor FIM values at discharge ( $p=.002$ ), provision of help from family members or other persons, ( $p<.001$ ) and performance of continued therapies immediately after discharge ( $p=.039$ ) Negative changes in life situations that occurred post-discharge also contributed to non-attainment of the long-term goal ( $p=.005$ ).

**Conclusion:** Post-discharge goal attainment points toward the sustainability of rehabilitation outcomes. However, other factors mediate this outcome. Longitudinal research is needed for a better understanding of factors contributing to outcomes in long-term goal attainment.

## **Introduction**

Stroke presents a global health problem (World Health Organization, 2003), one that is likely to increase markedly until 2025 (Truelsen et al., 2006). Stroke frequently leaves patients with lasting disabilities (Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002). Rehabilitation has been shown to be effective in reducing dependence and improving post-stroke functional outcomes (Teasell et al., 2009). Returning home after discharge represents an important goal in the rehabilitation process from a patient's perspective (Frank, Conzelmann, & Engelter, 2010). From a professional perspective, rehabilitation activities aim at assisting patients to achieve independence at discharge and thereafter (Brandstater, 2011). Although the perceptions of patients and professionals may diverge substantially in terms of valuable rehabilitation outcomes (McKevitt, Redfern, Mold, & Wolfe, 2004), living as independently as possible could well be an objective both groups can agree on.

Goal setting is held to be best practice in rehabilitation (Levack et al., 2006; Siegert & Taylor, 2004), since it assists the multidisciplinary team in planning and coordinating therapeutic interventions (Playford et al., 2000; Struhkamp, 2004; Wade, 2009). Goal setting is linked to self-efficacy and performance (Duff, 2009) and thus may help to improve patient outcomes (Langhorne, Bernhardt, & Kwakkel, 2011; Ponte-Allan & Muir Giles, 1999). Setting long-term goals that project beyond discharge is a well established practice in rehabilitation (Playford, Siegert, Levack, & Freeman, 2009). Long-term goals are believed to be valuable for patients' future motivation and guidance after discharge (Young, Manmathan, & Ward, 2008).

A multidisciplinary team of professionals in neurological rehabilitation performed well in predicting short-term goal attainment during inpatient rehabilitation (Rettke, Geschwindner, Rentsch, & van den Heuvel, submitted), working closely with individual patients, assessing status

and monitoring progress during the rehabilitation process. This study addresses the question of whether professional assessments of long-term goals are in line with the patient situation one year or more after discharge.

Patients may not achieve the long-term goals set at discharge because post-discharge factors may interfere with goal attainment. The first month at home is reported to be a transition period (Pringle, Hendry, & McLafferty, 2008) that introduces major challenges (Kirkevold, 2010; Wohlin Wottrich, Aström, & Löfgren, 2012). The process of getting back to 'real living' and reintegrating into community is often an on-going challenge (Wood, Conelly, & Maly, 2010) and patients' health may deteriorate (Haacke et al., 2006) or their social network may diminish over time (Lynch et al., 2008).

The purpose of this study was to explore, to what extent stroke patients achieved the goals pertaining to 'living arrangements' one to three years after completing inpatient rehabilitation when the goal was set at discharge by a multidisciplinary team. Factors that might contribute to the extent of goal attainment (i.e., under- or overestimation of patient improvement) were examined. Based on a review of the literature, these factors include age and gender (Graham et al., 2010), length of stay in care settings, and physical (Brock et al., 2009) and cognitive functioning (Heruti et al., 2002). Also, changes in health and social context that occur post-discharge have to be examined as intervening factors (Haacke, et al., 2006; Lynch, et al., 2008)

### **Methods**

Patients who, having completed inpatient rehabilitation (following their first-ever stroke) at a major neurorehabilitation center, were contacted one to three years later by means of a mailed questionnaire. Local ethics

committee's approval had been obtained before the study commenced. The center is a 32-bed facility co-located with the largest non-university hospital in German speaking Switzerland. It serves both an urban and a rural population.

The multidisciplinary team at this neurorehabilitation center had developed and implemented a team conference protocol that is explicitly based on the International Classification of Functioning, Disability, and Health Framework (ICF) (World Health Organisation, 2001). The protocol structures each team member's specific contributions to an individual patient's assessment, goal setting, intervention planning, and evaluation of goal attainment to allow for necessary adaptations during inpatient rehabilitation (Rentsch et al., 2003). The team conference procedure is described in more detail elsewhere (Rettke, Geschwindner, Rentsch, & van den Heuvel, submitted). Likewise, standardized goal categories had been defined at the ICF level of 'participation' for patient post-discharge living arrangements (Rentsch, 2005)(p 322ff). The goal categories encompass a range from institutionalized to independent living (Figure 1). Requirements for goal attainment were operationalized into 'key problems' (Rentsch, et al., 2003). For example, the difference between living at home with external support and living at home with support from a person sharing the same household is designated as a key problem by the term 'mastering the night alone' (see Figure 1).

The multidisciplinary team applies these goal categories systematically when following the conference protocol for each patient (Rentsch, et al., 2003). At admission, a goal for 'living arrangements' while the patient is at the rehabilitation facility is set, based on the multidisciplinary team's assessment results that were assembled during the team conference. Each member of the team is assigned specific key aspects in assessing patients and thus contributes to the team conference on the same level.



For instance, physiotherapists report on state of mobility, nurses and speech therapists discuss communication issues, and physicians will draw on medical diagnosis. The perspectives and personal goals of the patient and significant others are collected by team members in individual sessions and then shared during the initial team conference. At discharge the level of achievement of the inpatient goal set at admission is evaluated, i.e. whether the goal has been achieved or not. Based on this evaluation, each patient is then assigned a long-term goal for post-discharge 'living arrangements' which considers the patient's course and progress during the rehabilitation stay and corresponds with the goal attainment as evaluated at discharge.

For this study, all patients who were admitted to inpatient rehabilitation from January 2005 onwards, had a confirmed diagnosis of first-ever neurovascular disorder due to either ischemic or hemorrhagic lesion, and were 18 years and older, were eligible for inclusion. The exclusion criterion was incomplete inpatient stroke rehabilitation irrespective of reason.

The first two authors extracted the data from medical records. These included: age, sex, type of stroke, lengths of stay in acute care and rehabilitation settings, both 'Functional Independence Measure' (FIM) values (Granger, Hamilton, Linacre, Heinemann, & Wright, 1993), goal categories for 'living arrangements' at admission and discharge (Figure 1), and information whether therapies were continued and/or informal or formal care was planned post-discharge. These data represent the known facts about patient status and goals when discharged from inpatient rehabilitation.

**Figure 1: Goal categories ‘living arrangements’**

| 1                                                                  | 2                                                 | 3                                                                                            | 4                                                                   | 5                                                          | 6                                                                            |
|--------------------------------------------------------------------|---------------------------------------------------|----------------------------------------------------------------------------------------------|---------------------------------------------------------------------|------------------------------------------------------------|------------------------------------------------------------------------------|
| Integration into a nursing home (preservation of health condition) | Assisted living in an institution                 | Living at home with the support of related persons living in the same household <sup>I</sup> | Living at home independently with external support                  | Living at home independently <sup>II</sup>                 | Living at home independently with additional responsibilities <sup>III</sup> |
| All care needs are met by professionals                            | <i>Mastering to be on one's own by the hour *</i> | Mastering to be on one's own by the hour                                                     |                                                                     |                                                            |                                                                              |
|                                                                    |                                                   | <i>Mastering the night *</i>                                                                 | Mastering the night alone                                           |                                                            |                                                                              |
|                                                                    |                                                   | <i>Use of toilet*</i>                                                                        | Unassisted use of toilet                                            |                                                            |                                                                              |
|                                                                    |                                                   |                                                                                              | <i>Washing and dressing *</i>                                       | Washing and dressing oneself                               |                                                                              |
|                                                                    |                                                   |                                                                                              | <i>Interacting with others *</i>                                    | Interacting with others                                    |                                                                              |
|                                                                    |                                                   |                                                                                              | <i>Managing financial matters *</i>                                 | Managing financial matters                                 |                                                                              |
|                                                                    |                                                   |                                                                                              | <i>Acquisition of vital goods / simple tasks in house-keeping *</i> | Acquisition of vital goods / simple tasks in house-keeping |                                                                              |
|                                                                    |                                                   |                                                                                              | <i>Using means of transport *</i>                                   | Using means of transport                                   |                                                                              |

\* Here, the extent of physical and emotional support others (e3) and their attitudes (e4) according to the ICF apply.

<sup>I</sup> With and without external support

<sup>II</sup> Included all activities, directed to the own person

<sup>III</sup> All activities not directed to the own person

To assess the extent of goal attainment in terms of 'living arrangements' one to three years after discharge a questionnaire was constructed by the authors. It encompassed all 'key problems' (Figure 1) that are considered necessary to attain a specific goal category. For example, the key problem of 'mastering the night alone' was reflected in the questionnaire by the following two statements: "During the night I more often than not need help from another person" and "Throughout the night I do not need any help from another person". Agreement on either statement served as the criterion to classify participants into either goal category 3 (living at home with the support of related persons living in the same household) or 4 (living at home independently with external support). Also, changes in health (i.e., newly diagnosed severe illness or new stroke) and social context (i.e., separation/divorce, severe illness, or death of a close family member) that had occurred after discharge were explored. The questionnaire was sent to participants by mail with a pre-paid return envelope. If needed, a reminder was mailed after approximately six weeks asking the participant to return the questionnaire.

When the completed questionnaires were received, all answers to items addressing 'key problems' were manually recoded by the third author (HPR) into the respective goal categories. However, a change between two goal categories did not always reflect a clinically relevant change regardless of personal meaning that might have been attached to this by patients. We therefore re-grouped the six goal categories into three: living in an institution, living at home with help, and living at home independently (Figure 2).

A descriptive statistic approach was applied to patient characteristics and length of stay in acute care and rehabilitation settings. Respondents were compared to non-respondents (based on the medical data extracted from the overall sample) with regard to differences in goals set

at discharge from inpatient rehabilitation, for age, sex, length of stay in acute care and rehabilitation facility, and FIM values. Since variables were not normally distributed, Mann-Whitney-U tests were conducted. To identify parameters associated with goal attainment post-discharge, a stepwise logistic regression (backward selection) was bootstrapped 100 times. Parameters that were selected at least 70 out of 100 times were used for the final model<sup>iv</sup>. These were: age, gender, cause of stroke (ischemic or hemorrhagic), length of stay in acute care and rehabilitation facility, motor and cognitive FIM subscales at admission and discharge, long-term goals set at discharge, obtaining formal or informal help, and receiving continued therapies. Similarly, parameters associated with non-goal attainment were identified in a second logistic regression model. The Statistical Package for Social Sciences, Version 20 (SPSS Analytics, IBM Inc., Armonk, NY, USA), and the Stata 11.1 statistical software package (Copyright 1996-2011, StataCorp LP, 4905 Ladeway Krive, College Station TX 77845, USA) were used.

**Figure 2: Re-grouping of goal categories for clinical relevance**

| 1                                                                  | 2                                 | 3                                                                               | 4                                                  | 5                            | 6                                                             |
|--------------------------------------------------------------------|-----------------------------------|---------------------------------------------------------------------------------|----------------------------------------------------|------------------------------|---------------------------------------------------------------|
| Integration into a nursing home (preservation of health condition) | Assisted living in an institution | Living at home with the support of related persons living in the same household | Living at home independently with external support | Living at home independently | Living at home independently with additional responsibilities |
| <b>Living in an institution</b>                                    |                                   | <b>Living at home with help</b>                                                 |                                                    | <b>Living independently</b>  |                                                               |
| <b>1</b>                                                           |                                   | <b>2</b>                                                                        |                                                    | <b>3</b>                     |                                                               |

<sup>iv</sup> Boot-strapping for variable selection was solely executed on Stata 11.1

## Results

From January 2005 to the study date, a total of 287 stroke patients were admitted to inpatient rehabilitation; all were sent a questionnaire by mail. Of these, 174 (60.6%) returned completed questionnaires. Follow-up data were not collected from 113 patients (39.4%): 9 were deceased, 28 were lost to follow-up and 66 did not reply. Goals set for post-discharge 'living arrangements' differed significantly between respondents and non-respondents. Respondents were more often assessed as sufficiently recovered at discharge to be ready for independent living. For their part, non-respondents were more often assessed as needing to live in an institution ( $p < .001$ ). There were no statistically significant differences in sex, type of stroke (i.e., ischemic vs. hemorrhagic) or lengths of stay in acute care and rehabilitation. However, respondents were younger ( $p = .009$ ) and had higher motor and cognitive FIM values at admission ( $p < .001$ ) and discharge ( $p < .001$ ) (Table 1).

**Table 1: Comparison between respondents and non-respondents**

| Variable                                    | Mann-Whitney-U test statistics | p-value |
|---------------------------------------------|--------------------------------|---------|
| <b>Age</b>                                  | (U=8044.000, Z=-2.602)         | p=.009  |
| <b>Sex</b>                                  | (U=9266.500, Z=-.965)          | p=.334  |
| <b>Type of stroke</b>                       | (U= 9632.000, Z=-.518)         | p=.605  |
| <b>Length of stay acute hospital</b>        | (U=9407.500 , Z=-.617)         | p=.537  |
| <b>Length of stay rehabilitation center</b> | (U=9034.500, Z=-1.160)         | p=.246  |
| <b>Motor subscale FIM at admission</b>      | (U=7231.000, Z=-3.786)         | P<.001  |
| <b>Cognitive subscale FIM at admission</b>  | (U=7434.500 Z=-3.493)          | p<.001  |
| <b>Motor subscale FIM at discharge</b>      | (U=6418.500, Z=-4.971)         | p<.001  |
| <b>Cognitive subscale FIM at discharge</b>  | (U=7301.500, Z=-3.689)         | p<.001  |

Of the 174 participants, 91 (52.3%) attained, 10 (5.7%) exceeded and 73 (42.0%) did not attain long-term goals (Table 2). Five patients decreased substantially from 'independent living' at discharge to 'institution'. These participants were not characterized by any outliers in terms of

age, length of stay, or FIM values at admission and discharge. First, we looked at factors known at time of discharge. Regression analysis showed that respondents who did not attain long-term goals were negatively characterized by lower motor FIM values ( $p=.002$ ), receiving help from family members or other persons ( $p<.001$ ) and having continued therapies after discharge ( $p=.039$ ). The only defining characteristic for exceeding goal attainment one to three years post-discharge was male gender ( $p=.036$ ).

**Table 2: Goal attainment ‘living arrangement’ at 1-3 years post-discharge**

|                                 |                              | Long-term goal attained 1-3 years post-discharge |                          |                              | Total |
|---------------------------------|------------------------------|--------------------------------------------------|--------------------------|------------------------------|-------|
|                                 |                              | Living in an institution                         | Living at home with help | Living at home independently |       |
| Long-term goal set at discharge | Living in an institution     | 7                                                | 2                        | 1                            | 10    |
|                                 | Living at home with help     | 13                                               | 43                       | 7                            | 63    |
|                                 | Living at home independently | 5                                                | 55                       | 41                           | 101   |
| Total                           |                              | 25                                               | 100                      | 49                           | 174   |

We then looked at factors that emerged post-discharge. Regression analysis showed that non-attainment of the long-term goal in ‘living arrangements’ could be explained by changes in social context (i.e., separation/divorce, severe illness, or death of a close family member) ( $p=.005$ ) and by the presence of informal or formal help at the time of answering the questionnaire ( $p<.001$ ). No informal or formal help indicates a trend towards improvement by exceeding goal attainment ( $p=.057$ ) (Table 3).

**Table 3: Regression analyses**

| <b>Variables at time of discharge from inpatient rehabilitation</b>           |                           | <b>β- coefficient</b> | <b>OR</b> | <b>95% CI</b>   | <b>p-value</b> |
|-------------------------------------------------------------------------------|---------------------------|-----------------------|-----------|-----------------|----------------|
| <b>If goal not attained</b>                                                   | Motor FIM                 | .043                  | 1.044     | 1.016 - 1.072   | .002           |
|                                                                               | Continuation of therapies | -1.129                | .323      | .111 - .943     | .039           |
|                                                                               | Informal or formal help   | -2.199                | .111      | .035 - .355     | <.001          |
| <b>If goal exceeded</b>                                                       | Male gender               | -.1524                | .218      | .053 - .218     | .036           |
| <b>Variables at time of questionnaire completion 1-3 years post-discharge</b> |                           |                       |           |                 |                |
| <b>If goal not attained</b>                                                   | Changes in social context | 1.230                 | 3.420     | 1.444 - 8.098   | .005           |
|                                                                               | Informal or formal help   | 3.272                 | 26.361    | 5.865 - 118.483 | <.001          |
| <b>If goal exceeded</b>                                                       | Informal or formal help   | -1.581                | .206      | .040 - 1.049    | .057           |

## Discussion

This study explored goal setting and expectations of independent living at the time of discharge from inpatient stroke rehabilitation as well as goal attainment one to three years later. The most striking outcome is that despite a careful goal-setting process during inpatient rehabilitation and at discharge for 174 stroke patients, almost half experience a divergence in their actual living arrangements one to three years later. Severity of stroke, that is, the extent of effect on mobility, is a determining factor in whether patients do much better than expected at discharge and are able to live independently one to three years post discharge. However, changes in social context after discharge as well as the need for additional therapies are related to negative changes in living arrangements as compared to expectations at discharge. The latter indicates that external factors do have adverse effects on living independently after stroke despite positive perspectives at the time of discharge from the rehabilitation facility.

In comparison to setting realistic and attainable short-term goals during inpatient stroke rehabilitation (Rettke, et al., submitted), setting equivalently attainable long-term goals appears to be much more challenging for the multidisciplinary team. Some authors argue that health professionals have a tendency to err on the side of caution when setting rehabilitation goals in this phase of inpatient rehabilitation (Levack, Dean, Siegert, & McPherson, 2011). Overcautious judgment may also extend to the setting of long-term goals at discharge which would inevitably result in a large number of patients attaining higher goals than originally set. In our sample, we did not observe this. The quality of the goal-setting process during multidisciplinary team conferences in this neuro-rehabilitation center (Rentsch, et al., 2003) might have avoided underestimating the patients' potential for goal attainment.

Even 'slightly disabled' stroke survivors report persevering problems and limitations five years later (Teasdale & Engberg, 2005). Higher levels of functioning correspond to a higher level of goal attainment (Brock, et al., 2009). In turn, functionality is shown to decline over time independent of age, stroke severity, marital status (as marker of social support) and co-morbidities (Dhamoon et al., 2009). A similar decrease in functionality might also have contributed to non-attainment in our sample. In our sample, the over-attainment of goals was characterized by male gender. This information applies only to a small group (n=10). Gender-related outcomes are controversial when discussed in literature. Nevertheless, age differences between males and females (Gall, Tran, Martin, Blizzard, & Srikanth, 2012) or poor physical functioning prior to stroke (Lai, Duncan, Dew, & Keighley, 2005) might account for differences in outcome. A recent study also failed to confirm gender as an explanatory variable for outcomes in the rehabilitation process (Mizrahi, Waitzman, Arad, & Adunsky, 2012).



Cognitive functioning has been shown to predict functional outcome post-stroke at six months (Saxena, Ng, Koh, Yong, & Fong, 2007) and 13 months (Wagle et al., 2011) from onset and to indicate discharge destination (van der Zwaluw, Valentijn, Nieuwenhuis-Mark, Rasquin, & van Heugten, 2011). During inpatient stroke rehabilitation, an improvement in cognitive functions has been shown to be linked to better outcomes at discharge (Rettke, et al., submitted). However, our findings do not support this at a later time period, i.e., at one to three years post-discharge.

The presence of significant others in the home facilitates independent living (Frank, et al., 2010; Ween, Alexander, D'Esposito, & Roberts, 1996) and as such, they are a valuable resource. Nevertheless, their role in informal caregiving should be viewed critically. In our study, help from family members or other persons after discharge was counterproductive to post-discharge goal attainment. Informal caregivers can be over-protective (Wood, et al., 2010) which in turn can hamper goal attainment post-discharge (Pound, Gompertz, & Ebrahim, 1998).

There are limitations that have to be considered. If discharged patients were moved to an institution at some point after discharge, some were likely to be lost to follow-up, as happened with 28 patients in this sample. This would indicate a selection bias in that patients who did not attain long-term goals will not have been included in the results. The generalizability of our results is limited by data being collected in one center only. Nevertheless, it is the only neurorehabilitation center in German-speaking Switzerland that has introduced this type of goal-setting approach on a systematic basis and gathered experience in its application. Hence, the outcomes can be seen as representative for this type of approach.

Post-discharge goal attainment points toward the sustainability of rehabilitation outcomes. However, other factors mediate this result. Longitudinal research is needed for a better understanding of factors contributing to outcomes in long-term goal attainment. Persons likely to be involved in post-discharge care should be informed that over-protection might hinder goal attainment. They should be carefully instructed in how to provide supportive care that allows room for patients' efforts toward stability or improvement.

Direct involvement of patients and/or significant others in the goal-setting process is a crucial element of defining goals that are equally relevant to patients and to professionals. When defining long-term goals that extend beyond discharge, patients and significant others should be instructed as to which challenges and barriers are to be expected and informal caregivers should be educated in providing support for long-term goal attainment.

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**Long-term burden in informal caregivers of stroke survivors or persons suffering from dementia. A systematic review**

Manuscript submitted as: **Geschwindner, HM**; Rettke, H; van den Heuvel, WJA. Long-term burden in informal caregivers of stroke survivors or persons suffering from dementia. A systematic review

## **Abstract**

The care of persons suffering from stroke or dementia living at home is usually provided by informal caregivers. Informal caregivers experience subjective burden while caring for people with either a stable or progressive chronic condition over an indefinite period. This literature review focuses on long-term burden of informal caregivers and its changes over time. A literature search has been conducted using the electronic databases Medline, CINAHL, Embase and PsycInfo for the period of January 2000 to December 2011. Eight articles have been identified presenting results of longitudinal studies with a minimum duration of 18 months, three focusing on informal stroke caregivers and five caregivers of demented people. Informal caregivers of both chronic conditions report on high burden soon after onset of care. While caregiver burden decreases in stroke caregivers over time, informal caregivers of demented people show both increase and decrease. One important finding is the persistence of caregiver burden regardless of time span or chronic disease cared for. The impact of long-term burden for informal caregivers is substantial. A longitudinal approach is frequently applied to investigate caregiver burden, but hardly longer than one year. Since informal caregiving is provided much longer this should be considered in designing further studies.

## Introduction

Stroke survivors and persons with dementia living at home are usually cared for by informal caregivers (Brodaty & Donkin, 2009; Mayor, Ribeiro, & Paul, 2009; Saban, Shewood, DeVon, & Hynes, 2010; Wrubel, Richards, Folkmann, & Acree, 2001). Informal care of patients with these chronic conditions comprises a substantial burden to next of kin caring for them and could even affect the caregivers' health. Although stroke is a major cause of lasting disability in adults (Jungbauer, von Cramon, & Wilz, 2003; Saban, et al., 2010; Wolfe, 2000) the disease process after the sudden onset is comparatively stable in long-term perspective in contrast to dementia (J. Gaugler, Zarit, & Pearlin, 2003; King, Hartke, & Houle, 2010). Suffering from dementia results in an irreversible deterioration of mental and physical abilities (J. Gaugler, et al., 2003) frequently causing lasting rearrangements of the family patterns, the role of each family member and relationships in the home environment (Braun, et al., 2009; Schoenmakers, Buntinx, & Delepeleire, 2010). Caring for either stroke or dementia patients entails a long-lasting perspective (Draper, Poulos, Cole, Poulos, & Ehrlich, 1992; Saban, et al., 2010; Thommessen, et al., 2002). Several factors add to an increasing demand for informal caregiving. Advancements in medical care and increasing life expectancy lead to a growing prevalence of chronic diseases. Additionally, the societal and political expectations foster the idea of old frail people and persons with chronic diseases living at home as long as possible. This creates more and even longer-lasting informal caregiving situations (Braun, et al., 2009; Greenwood & Mackenzie, 2010; Jungbauer, et al., 2003; Kesselring, et al., 2001). Early discharge home of acute hospital patients is strongly advocated leaving further care needs to be met by informal caregivers and/or home care professionals (DeFries, McGuire, Andresen, Brumback, & Anderson, 2009).



Informal caregiving refers to "activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves" (Pearlin, Mullan, Semple, & Skaff, 1990)(p 583). Caregiving onset varies considerably. If a next of kin experiences an acute disease, such as stroke, informal caregiving starts abruptly and completely unprepared soon after (J. Gaugler, et al., 2003; King, et al., 2010). In the case of an evolving chronic disease such as dementia, caregiving may be introduced gradually or when diagnosis is ascertained (J. Gaugler, et al., 2003). Irrespective of its starting point, informal caregiving remains unfamiliar and challenging to the family member (J. Gaugler, et al., 2003; Thommessen, et al., 2002).

Caregiver burden is a frequently reported phenomenon in informal caregivers (van Heugten, Visser-Meily, Post, & Lindeman, 2006; J. M. A. Visser-Meily, Post, Riphagen, & Lindeman, 2004). The concept of caregiver burden itself is not uniquely defined, but many authors refer to the works of Montgomery (Montgomery, Gonyea, & Hooyman, 1985) and Pearlin (Pearlin, et al., 1990). Pearlin (1990) states that under chronic conditions and prolonged impairment, caregiving can come to the point where the help, affection and assistance become unidirectional and can exert a stressful impact. Caregiver stress or burden should neither be understood as a transitional event nor as a consistent phenomenon (Pearlin, et al., 1990). Instead, it is seen as a "multidimensional response to physical, psychological, emotional, social and financial stressors associated with the care giving experience" (Vrabec, 1997)(p 384) while giving care for a family member or friend (Zarit, Reever, & Bach-Peterson, 1980). Caregiver burden represents the caregiver's load experienced as a result of undertaking the caregiving role (Rigby, Gubitz, & Phillips, 2009).

Some authors distinguish between objective and subjective burden (Braithwaite, 1992; Montgomery, et al., 1985). Objective burden refers

to the degree of dependency of the person needing care, the amount of time spent and the amount of caregiving tasks provided by the caregiver (Montgomery, et al., 1985; van Exel, Brouwer, van den Berg, Koopmanschap, & van den Bos, 2004). Furthermore, care recipients' characteristics often are used as an objective indicator explaining the negative outcomes of informal caregiving. In this case, measures of cognitive and/or physical impairment, and behavioral problems might be applied (Lyons, Zarit, Sayer, & Whitlatch, 2002).

While objective burden refers to external factors, subjective burden corresponds to the caregiver's own feelings and emotional reactions as a consequence of the experiences while fulfilling the caregiving role (Reinardy, Kane, Huck, Thiede Call, & C.T., 1999; Rigby, et al., 2009; van Exel, et al., 2004; Vrabec, 1997). Informal caregiving may result in positive and negative experiences (J. Gaugler, et al., 2003; Mayor, et al., 2009). Finding meaning and gratification in the caregiving role can be seen as a positive effect (Kesselring, et al., 2001; Lyons, et al., 2002). In research, however, the focus frequently lies on negative effects such as strain/burden, depression, health deterioration and social changes (Brodaty & Donkin, 2009; J. E. Gaugler, 2010; Van Durme, Macq, Jeanmart, & Gobert, 2012).

Publications reporting on caregiver burden mostly elucidate a time frame of one year or less although informal caregiving is provided over a by far longer period in time. Often lifelong care is required. Especially the effects of informal care of stroke patients on the unprepared family caregivers are investigated over the period of the first months after discharge from hospital. Although dementia is known as a slowly progressing disease that results in the need of informal caregiving longitudinal studies investigating the long-term effect are scarce. That's why little is known whether the extent of caregiver burden alters after one year or longer, and about its long-term consequences for the informal caregiv-

ers. A better understanding of long-term burden in informal caregivers of stroke survivors and of demented people is of particular importance to healthcare professionals in providing early support to minimize the caregivers' risk of health problems and poor quality of life due to burden. In this systematic review, we set out to find and appraise evidence of long-term consequences of and changes in subjective burden over time experienced by informal caregivers caring for patients with stroke or dementia for a period of 18 months and longer.

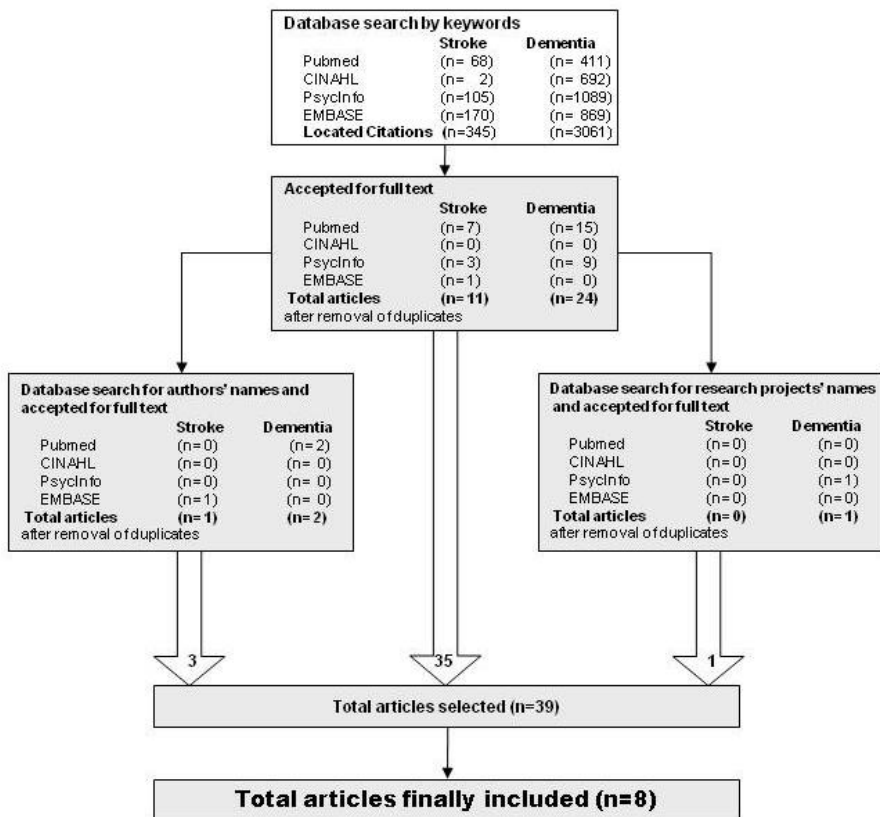
## **Method**

A literature search has been conducted using the electronic databases Medline (Pubmed), CINAHL, Embase, and PsycInfo for the period of January 2000 to December 2011. The following search terms were used for Medline: caregiver OR family caregiver; caregiver burden OR caregiver strain OR caregiver stress, cerebrovascular disorders OR stroke; dementia OR Alzheimer's disease. The results of the first two search terms were combined with stroke or dementia respectively. Searching the further databases, the respective MeSH terms from the Thesaurus were used. To make sure all relevant articles have been identified further searches for the author's names and research projects' names have been conducted. Additionally, the reference lists of identified articles have been screened for further relevant articles.

The citations' titles and abstracts were screened for the inclusion by the first two authors. A set of inclusion and exclusion criteria was defined beforehand for this systematic review. Included were articles reporting on persons suffering from stroke or dementia living at home and receiving care delivered by informal caregivers. Further inclusion criteria were longitudinal studies with repeated measures of caregiver burden, reporting the use of validated instruments, and presenting results of at least one measure at  $\geq 18$  months. In addition, intervention studies were included

if the control group received exclusively care as usual. Excluded were articles published in languages other than English or German, articles presenting cross-sectional data of longitudinal studies only, secondary analyses with lack of comprehensibility to the original data, and qualitative studies.

**Figure 1: Search strategy**



The search resulted in a total of 3406 articles (Figure 1). Of these 345 articles focused on informal stroke caregivers and 3061 on informal dementia caregivers. The articles' titles and abstracts were screened for

possible inclusion. If the abstract of an article in question did not offer relevant information to allow for definite inclusion or exclusion, the full article was retrieved. During this initial screening 39 articles were included (stroke n=12, dementia n=27). Next, full text of these articles was retrieved and judged by the first author for definite inclusion. In the case of uncertainty, the particular article was discussed with the both other authors to reach an agreement for inclusion. Eight articles met the criteria and were included in the review. During the following process, the first two authors independently reviewed these eight articles.

### **Quality assessment**

There is no gold standard for methodological quality assessment of systematic reviews. The quality of studies included should refer to population and sample criteria, internal and external validity as well as to statistical criteria (Sinha & van den Heuvel, 2011; van der Mei, et al., 2006).

The quality criteria applied for this specific review are based on the criteria lists of van der Mei (2006) and Sinha (2011), which have been tested in the population of kidney transplant patients (van der Mei, et al., 2006) and lower limb amputees (Sinha & van den Heuvel, 2011). For this review, the following criteria were considered appropriate for quality assessment: type of study population, information on dropouts, validated (burden) measures, appropriate statistical tests, and data presentation of burden outcome measure. The criterion response rate of the antecedent lists has been modified. Since longitudinal studies with a length of several months or years within the respective population result in a high dropout rate, this criterion has been newly defined as response rate at t1 as lowest common denominator. After this, the final list of quality criteria focused on source population and methodological characteristics (see Table 1). The overall quality was calculated as a sum score where 20 resp. 100% represented the maximum score.

**Table 1: Results of quality assessment of included articles**

| Criteria                                                         | Scores                                                                                              | Adriaansen et al., 2011 | Froelich et al., 2009 | Gaugler et al., 2008 | Mausbach et al., 2008 | Moretti et al., 2006 | Tibaldi et al., 2007 | Visser-Meilyet al., 2009 | White et al., 2003 |
|------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------|-------------------------|-----------------------|----------------------|-----------------------|----------------------|----------------------|--------------------------|--------------------|
|                                                                  | Author names                                                                                        |                         |                       |                      |                       |                      |                      |                          |                    |
| <b>Focus</b>                                                     | Stroke (s), Dementia (d)                                                                            | s                       | d                     | d                    | d                     | d                    | d                    | s                        | s                  |
| <b>Source population (SP)</b>                                    |                                                                                                     |                         |                       |                      |                       |                      |                      |                          |                    |
| Description of source population                                 | Not available (0), Ambiguous (1), Available (2)                                                     | 2                       | 2                     | 2                    | 1                     | 1                    | 2                    | 2                        | 2                  |
| Description of inclusion and/or exclusion criteria for caregiver |                                                                                                     | 2                       | 0                     | 1                    | 2                     | 0                    | 0                    | 2                        | 0                  |
|                                                                  | Score SP                                                                                            | 4                       | 2                     | 3                    | 3                     | 1                    | 2                    | 4                        | 2                  |
|                                                                  | %                                                                                                   | 100                     | 50                    | 75                   | 75                    | 25                   | 50                   | 100                      | 50                 |
| <b>Methodological characteristics (MC)</b>                       |                                                                                                     |                         |                       |                      |                       |                      |                      |                          |                    |
| Representative population                                        | Not clear (0), Partially (1), Yes (2)                                                               | 1                       | 0                     | 1                    | 0                     | 0                    | 0                    | 1                        | 0                  |
| Study design / study type                                        | Not clear (0), Cross sectional design (1), Retrospective / Mixed design (2), Prospective design (3) | 3                       | 3                     | 3                    | 3                     | 3                    | 3                    | 3                        | 3                  |
| Population selection                                             | Non randomized (0), Randomized / NA (1)                                                             | 1                       | 1                     | 1                    | 1                     | 1                    | 1                    | 1                        | 1                  |
| Instruments used                                                 | Non-validated (0), Partially validated (1), Validated (2)                                           | 2                       | 2                     | 2                    | 2                     | 2                    | 2                    | 2                        | 2                  |
| Statistical methods for measures                                 | Non-appropriate (0), Partially appropriate (1) Appropriate (2)                                      | 2                       | 2                     | 2                    | 2                     | 2                    | 1                    | 2                        | 2                  |
| Control for confounding variables                                | Not considered (0), Partially considered (1), Fully considered (2)                                  | 2                       | 1                     | 2                    | 2                     | 0                    | 0                    | 2                        | 2                  |
| Response rate vs. dropout (at t <sub>i</sub> )                   | < 60% / Not mentioned (0), 60-80% (1), >80% (2)                                                     | 2                       | 1                     | 2                    | 2                     | 2                    | 1                    | 2                        | 2                  |
| Characteristics of dropouts                                      | Not reported (0), reported (1)                                                                      | 1                       | 1                     | 1                    | 0                     | 1                    | 1                    | 1                        | 1                  |
| Relevant outcome measure                                         | Not well-defined (0), Well-defined (1)                                                              | 1                       | 1                     | 1                    | 1                     | 1                    | 1                    | 1                        | 1                  |
|                                                                  | Score MC                                                                                            | 15                      | 13                    | 15                   | 13                    | 12                   | 10                   | 15                       | 14                 |
|                                                                  | %                                                                                                   | 93.7                    | 81.2                  | 93.7                 | 81.2                  | 75                   | 62.5                 | 93.7                     | 87.5               |
|                                                                  | <b>Quality sum score</b>                                                                            | <b>19</b>               | <b>15</b>             | <b>18</b>            | <b>16</b>             | <b>13</b>            | <b>12</b>            | <b>19</b>                | <b>16</b>          |
|                                                                  | %                                                                                                   | <b>95</b>               | <b>75</b>             | <b>90</b>            | <b>80</b>             | <b>65</b>            | <b>60</b>            | <b>95</b>                | <b>80</b>          |

The two first authors independently scored the included articles. Differences in scoring were discussed extensively until consensus was reached. The last author was involved in the final agreement to achieve consensus for one single study.

## **Results**

Eight articles report on a longitudinal course of subjective burden and its changes over time, i.e. 18 months or more. Of these, three articles report on informal stroke caregivers and five on dementia caregivers. In general, subjective caregiver burden is investigated in combination with other concepts such as depression, physical health, coping strategies, and quality of life. Detailed information on the articles included is presented in Table 2.

Overall, the longitudinal studies investigating informal dementia caregivers (Froelich, et al., 2009; J. Gaugler, Roth, Haley, & Mittelman, 2008; Mausbach, et al., 2008; Moretti, Torre, Antonello, & Cazzato, 2006; Tibaldi, et al., 2007) more often present a larger sample size and longer duration of study than those investigating informal stroke caregivers (Adriaansen, van Leeuwen, Visser-Meily, van den Bos, & Post, 2011; A. Visser-Meily, et al., 2009; White, Mayo, Hanley, & Wood-Dauphinee, 2003). Longitudinal studies in stroke survivors and/or their caregivers seldom last more than up to three years. In contrast, studies concerning dementia are planned for a research period longer than three years, one even more than 10 years. Two studies investigated burden of informal caregiving in stroke patients on a national level (Adriaansen, et al., 2011; A. Visser-Meily, et al., 2009) as did one study in caregivers of dementia patients (J. Gaugler, et al., 2008). Another study in informal dementia caregivers was conducted on an international level (Froelich, et al., 2009).

Table 2: Overview on articles included

| Author                 | Focus    | Aim of study                                                                                                                                                                                                                                                 | Points of measurement                                                                                                        | Sample and Dropout                                                                                                                                                                                                                                                                                                                                                                             | Instruments applied                                                                                                                  | Changes over time and related factors                                                                                                                                           |
|------------------------|----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Adriaansen et al. 2011 | Stroke   | Description of the course of social support in spouses of stroke patients during the period two months post stroke until three years. Furthermore the examination of direct and indirect factors related to life satisfaction.                               | t <sub>1</sub> 2 months after discharge from rehabilitation, t <sub>2</sub> 1 year and t <sub>3</sub> 3 years post stroke    | Dyads of stroke patients and their spouses n=180<br>Dropout reasons are stated (death, severe illness, divorce, refused). Participation over the total study period n=113, at t <sub>1</sub> and t <sub>2</sub> n=180.                                                                                                                                                                         | Social Support List<br>Life Satisfaction Questionnaire<br>Caregiver-Strain Index                                                     | An increase of caregiver burden over time is reported as well as a decline of social support. Despite this social support remains positively associated with life satisfaction. |
| Froelich et al. 2009   | Dementia | The researchers want to observe in real life settings the effects of standard care of persons suffering from a mild to moderate Alzheimer's Disease (AD) and their outcomes. The impact of informal caregiving is investigated in terms of caregiver strain. | t <sub>0</sub> and every 6 months<br>t <sub>1</sub> - t <sub>4</sub> up to 24 months                                         | Patients with mild to moderate AD and their primary informal caregivers who regularly see the patients (at least 2 visits a week)<br>Recruitment in 12 European countries; n=2288.<br>60.4% of patients completed. Reasons: loss for follow-up, care recipient ineligible to continue, inability of caregiver to complete questionnaire, care recipient living alone and discontinued [p. 006] | Zarit Burden Interview (ZBI),<br>distress using (part of Neuropsychiatric Inventory NPI)<br>time spent caring<br>service utilisation | Burden increased significantly over time [p < 0.0001]                                                                                                                           |
| Gaugler et al. 2008    | Dementia | An intervention of enhanced counselling and support should be tested if it helps to reduce caregiver burden and depressive symptoms in spouse caregivers of persons with Alzheimer's Disease                                                                 | Baseline t <sub>0</sub> and every 4 months during the first year, then every 6 months<br>t - t <sub>4</sub> up to 15.9 years | Spouses of persons with AD n=406, n=203 each for treatment and control group (=care as usual)<br>n=385 completed data collection for analysis (in average over a period of 3-5 years). Follow up data of 10 years are available from 48 participants.                                                                                                                                          | Zarit Burden Interview (ZBI)<br>Geriatric Depression Scale (GDS)<br>Nursing Home Admission                                           | Burden and depressive symptoms were significantly higher in spouses caregivers as in usual group (control group).                                                               |



| Author               | Focus    | Aim of study                                                                                                                                                                                                                                                                                                                    | Points of measurement                                                     | Sample and Dropout                                                                                                                                                                                                                              | Instruments applied                                                                                                                                                         | Changes over time and related factors                                                                                                                                                                                                                                |
|----------------------|----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Mausbach et al. 2008 | Dementia | The study aims at investigating the longitudinal relationships between caregiver stress, personal mastery strategies, and the $\beta_2$ adrenergic receptor sensitivity over time in spouses of persons with Alzheimer's Disease                                                                                                | Baseline $t_0$ and every 12 months up to 5 years ( $t_1$ - $t_5$ )        | Spouse caregivers of Patients with AD n=115<br>Participants at $t_0$ n=115; $t_1$ n=97; $t_2$ n=74; $t_3$ n=34, and $t_4$ n=11                                                                                                                  | Pearlin Role Overload Scale + Pearlin Problem Behavior Scale<br>Pearlin Mastery Scale<br>Hamilton Depression Scale<br>Interim Medical History Questionnaire<br>Blood sample | Caregiver stress is negatively and mastery positively associated with receptor sensitivity over time. Within person variance of stress is significant over time [all points of measurement ( $p < .001$ ), 51.4 % of stress variability is within the single person. |
| Moretti et al. 2006  | Dementia | The eventual differences of behaviour alterations in the two distinct types of vascular dementia (subcortical, multi-infarct) shall be defined. The possible influence of these differences on patients' cognitive aspects and global daily living performances as well as on informal caregivers' stress is investigated, too. | Baseline measure and at 3, 9, 12, 15, 18, 21 and 24 months; $t_0$ - $t_7$ | Dyads informal caregivers of patients with vascular (Group A) or multi-infarct dementia (Group B)<br>In total n=240, n=120 per group<br>Group A 5 patients died,<br>Group B 2 patients died and 2 left study caused by independence limitations | Relatives' Stress Scale                                                                                                                                                     | Informal caregivers of persons suffering from multi-infarct dementia report on an increase of caregiver stress over time. Contrariwise these caring for persons with subcortical dementia report on a decrease of stress.                                            |
| Tibaldi et al. 2007  | Dementia | An evaluation of mortality, functional and cognitive impairment of demented people and caregiver stress at a 2-year follow-up after admission to a geriatric ward                                                                                                                                                               | $t_1$ at admission, $t_2$ at discharge, $t_3$ at follow-up.               | Demented patients and their family caregivers n=82<br>25 participants completed survey                                                                                                                                                          | Relatives' Stress Scale                                                                                                                                                     | During the 2 years period the stress level decreased slightly but remains high.                                                                                                                                                                                      |

| Author                   | Focus  | Aim of study                                                                                                                                                                                                                                                                                          | Points of measurement                                                                                                                                                | Sample and Dropout                                                          | Instruments applied                                                                                                                                                         | Changes over time and related factors                                                                                                                                                                         |
|--------------------------|--------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Visser-Meily et al. 2009 | Stroke | Evaluation of changes in psychosocial functioning of stroke patients' spouses in terms of burden, depressive symptoms, relationship and social relations over the period of 3 years after inpatient rehabilitation as well as the identification of predictors of the course of patients' functioning | after stroke onset<br>$t_1$ after admission to rehabilitation facility,<br>$t_2$ 2 months after discharge,<br>$t_3$ 1 year post stroke,<br>$t_4$ 3 years post stroke | Stroke patients and their spouse caregivers<br>$n=211$<br>$n=121$ completed | Utrecht Coping List (UCL)<br>Goldberg Depression Scale<br>Caregiver Strain Index<br>Interactional Problem Solving Inventory<br>Social Support List                          | Over time burden, relationship and social relations decreased significantly ( $p < 0.01$ ). In contrast depressive symptoms increased. All criteria are closely related to the caregivers' coping strategies. |
| White et al. 2003        | Stroke | The research aims to describe family caregivers' health related quality of life and their overall quality of life during the first 2 years following stroke onset.                                                                                                                                    | $t_1 \approx 7$ months after stroke onset,<br>$t_2 \approx 23$ months after stroke onset                                                                             | Dyads of stroke patients and their family caregivers<br>$n=97$              | List presence of physical symptoms experienced over the last 30 days with dichotomous answers<br>(Zarit) Burden Index<br>SF-36 plus<br>Single item referring to overall QoL | Family caregivers report on a higher burden after 24 months. Scores of HRQoL and overall QoL remain stable over time                                                                                          |

The total quality score of the articles included in this systematic review was judged 60% to 95% (Table 1). Three articles were scored 90% and above. Representativeness of population was mostly judged low. This is because of studies concerning caregiver burden often focus primarily on patients for recruitment. Next of kin were asked to participate in the study if they are eligible. While patient sampling approximated a representative proportion of the population under study, this does not necessarily apply for the sample of next of kin.

The population of informal caregivers is heterogeneous and involves spouses, children, close relatives, friends, neighbors and other persons. Included studies focusing on stroke or dementia caregivers investigated either samples of spouses only or samples of informal caregivers not further specified. Considering the gender aspect in the studies reviewed, the proportion of female caregivers is considerably higher than that of male caregivers. For one study (Moretti, et al., 2006) no information on caregivers' sex is provided. The remaining seven mention a proportion of 60 to 80 % females.

All the studies included report on a high dropout rate over time in participants either caring for people after stroke or people with dementia. The reasons for dropout are stated clearly for care recipients as well as for caregivers. Care recipients dropped out due to death or admission to institutional care. Caregiver dropout is caused by deterioration of own health, own death, change of living site, or they refused further participation in later follow-up measures. The studies included show an increasing dropout rate over time. Those investigating informal caregiving in stroke patients show a dropout of about 1/3 after three years. The dropout in dementia caregivers is divergent. In one case, 40% of the participants dropped out after two years (Froelich, et al., 2009), in another study, the dropout was only 3% (Moretti, et al., 2006). Follow-

up data of 5 years (Mausbach, et al., 2008) and up to 10 years (J. Gaugler, et al., 2008) are available for 10% of the participants.

As an overall result, all articles included report on changes in caregiver burden over time. Different trends are stated, such as increase and decrease. Irrespective of an increase or decrease, informal caregivers either caring for stroke survivors or persons suffering from dementia experience some persistent amount of subjective burden.

### **Caregiver burden in informal stroke caregivers**

Two of the three articles reporting on caregiver burden in informal stroke caregivers refer to a single national study conducted in the Netherlands (Adriaansen, et al., 2011; A. Visser-Meily, et al., 2009). White (White, et al., 2003) report on a Canadian study. The study population of Adriaansen (Adriaansen, et al., 2011) and Visser-Meily (A. Visser-Meily, et al., 2009) were stroke patients and their spouses. The subjects were recruited during inpatient rehabilitation in nine Dutch rehabilitation facilities. White's (White, et al., 2003) sample of stroke survivors and their informal caregivers was recruited during hospital stay. Spouses represent 60% of this sample.

Only the two instruments 'Zarit Burden Interview' (Zarit, et al., 1980) and 'Caregiver Strain Index' (Robinson, 1983) were applied to measure burden in informal stroke caregivers. This makes the results comparable. While White (White, et al., 2003) reports on a marginal increase in caregiver burden after 2 years, Adriaansen (Adriaansen, et al., 2011) and Visser-Meily (A. Visser-Meily, et al., 2009) report a decrease (Table 3). The subjective burden decreased slightly in this sample during the first year after stroke onset. The third burden measure 3 years after onset shows a further decrease but still remains at a high level.

### Caregiver burden in informal dementia caregivers

The five articles reporting on caregiver burden in informal dementia caregivers refer to sample sizes between 82 participants (Tibaldi, et al., 2007) and 2288 participants (Froelich, et al., 2009). Two studies (J. Gaugler, et al., 2008; Mausbach, et al., 2008) included only spouses, while the others included all informal caregivers. Since dementia has no distinct point of onset, the point of time of measuring burden varies considerably, as do recruitment and inclusion.

To measure subjective caregiver burden in informal dementia caregivers, three instruments were applied, i.e. Zarit Burden Interview (Zarit, et al., 1980), Relative Stress Scale (Greene, Smith, Gardiner, & Timbury, 1982), and the Pearlin Role Overload Scale (Pearlin, et al., 1990).

**Table 3: Course of caregiver burden over time: informal stroke caregivers**

| Author, publication year | Instrument               | Baseline measure | ≤ 6 months | 12 months     | 18 months | 24 months | 3 years and more |
|--------------------------|--------------------------|------------------|------------|---------------|-----------|-----------|------------------|
| Adriaansen et al. 2011   | Caregiver Strain Index   |                  | 7.1        | -             |           |           | -                |
| Visser-Meily et al. 2009 | Caregiver Strain Index   |                  | 7.1        | -<br>(p=.040) |           |           | -<br>(p=.000)    |
| White et al. 2003        | Burden Interview (Zarit) | 24.0             |            |               | (+)       |           |                  |

**Legend:** measure of burden: = kept unchanged; - decreased; (-) decreased marginally; + increased; (+) increased marginally

When caring for a person suffering from dementia, the informal caregivers in general experience a significant increase of burden over time. An exception is reported in two smaller samples. Moretti reports on a decrease in the subsample of subcortical dementia caregivers (n=120) after 24 months, while caregivers providing care to persons with vascular

dementia (n=120) experience an increase of burden (Moretti, et al., 2006). Tibaldi's sample shows a slight decrease in burden after the period of 2 years, too (Tibaldi, et al., 2007) (Table 4).

**Table 4: Course of caregiver burden over time: informal dementia caregivers**

| Author, publication year | Instrument                  | Baseline measure                | ≤ 6 months    | 12 months      | 18 months      | 24 months | 3 years and more |
|--------------------------|-----------------------------|---------------------------------|---------------|----------------|----------------|-----------|------------------|
| Froelich et al. 2009     | Zarit Burden Interview      | 26.0                            | +<br>(p<.045) | +<br>(p<.0001) | +<br>(p<.0001) | +         | 26.0             |
| Gaugler et al. 2008      | Zarit Burden Interview      | 28                              |               |                |                |           | +                |
| Mausbach et al. 2008     | Pearlin Role Overload Scale | 9.3                             |               | +              |                | +         | +                |
| Moretti et al. 2006      | Relative Stress Scale       | Group A <sup>o</sup> :<br>39.12 |               |                |                | -         |                  |
|                          |                             | Group B <sup>o</sup> :<br>44.72 |               |                |                | +         |                  |
| Tibaldi et al. 2007      | Relative Stress Scale       | 36.6                            |               |                |                | (-)       |                  |

**Legend:** measure of burden: = kept unchanged; - decreased; (-) decreased marginally; + increased; (+) increased marginally

<sup>o</sup> Group A: subcortical vascular dementia; Group B: multi-infarct dementia

## Discussion

This systematic review aims at identifying trends and patterns of informal caregivers' subjective burden in long-lasting informal care situations in patients suffering from stroke or dementia. Such a distinct

trend could be found in neither informal stroke caregivers nor in informal dementia caregivers.

One finding was consistent throughout the electronic literature search: The huge amount of articles reporting on caregiver burden, published during the last decade (2000 - 2011) is remarkable. It raises the question whether it is related to the societal interest in providing informal care to persons living at home with chronic conditions. Also it might be related to the economic interest to cut on length of stay in acute hospital care by transferring caregiving to the next of kin.

A longitudinal approach is conducted frequently to investigate caregiver burden, but the time frame of the studies is limited to 6 to 12 months. Giving informal care to a person suffering from stroke with persistent disabilities or from dementia with deteriorating functional and cognitive abilities encompasses a much longer time span than is frequently investigated (Bakas & Burgener, 2002; Kesselring, et al., 2001; Simon, Kumar, & Kendrick, 2009). The number of longitudinal studies conducted longer than one year is small.

The concept of caregiver burden has been of growing interest during the last 30 years. Concepts of caregiver burden in the context of dementia (Braithwaite, 1992; Montgomery, et al., 1985; Pearlin, et al., 1990) and instruments measuring the burden of informal caregivers were developed in the early 1980s (Pearlin, et al., 1990; Zarit, et al., 1980). Zarit's Burden Interview is the widest precursor still frequently applied today measuring caregiver burden in the context of several diseases. The 'Zarit Burden Interview' has been applied in three articles included (Froelich, et al., 2009; J. Gaugler, et al., 2008; White, et al., 2003). Further instruments have been developed relying on these most common concepts of caregiver burden. The instruments developed for application in de-

mentia caregivers have been tested in other populations, or they were developed specifically for caregivers providing care to persons with other health conditions. The remaining five articles included reports on three further instruments. Adriaansen et al. (2011) and Visser-Meily et al. (2009) applied the 'Caregiver Strain Index' (Robinson, 1983), Moretti (2006) and Tibaldi (2007) the 'Relatives Stress Scale' (Greene, et al., 1982), and Mausbach (2008) the 'Pearlin Role Overload Scale' (Pearlin, et al., 1990). While the two measures 'Caregiver Strain Index' and 'Relatives Stress Scale' are commonly used in diverse populations (J. M. A. Visser-Meily, et al., 2004), the 'Pearlin Role Overload Scale' is mainly used in dementia populations.

Due to the fact that only four instruments measuring caregiver burden have been applied in the studies reviewed here, the results are comparable. Nevertheless none of the studies included relies on a specific concept of caregiver burden or stress even when the primary outcome measure is burden.

The term caregiver used in research literature is broadly defined and relates to spouses, children, not further specified family members or persons from the social or living context (Brodaty & Donkin, 2009; Simon, et al., 2009). The articles included refer to spouse caregivers or to not specified informal caregivers. This observation applies to the majority of caregiver burden studies in general (McCullagh, Brigstocke, Donaldson, & Kalra, 2005). In terms of caregivers' sex, the eight articles included report on a majority of female caregivers participating in the studies. Comparable gender proportions are reported in other studies of both populations, too (King, et al., 2010; McCullagh, et al., 2005).

Gaugler et al. (2003) observed that the change in burden depends on the entry in the caregiving role. In the case of informal caregiving to



patients with dementia, there is no clear starting point of giving care. Adopting the role as informal caregiver is often a gradual process and not explicitly linked to the particular time of diagnosis (J. Gaugler, et al., 2003). That is why the time-point of baseline measures investigating the course of caregiver burden in dementia caregivers varies considerably, thus hampering comparisons between study results. The longitudinal pattern of changes in burden referring to all five dementia articles reviewed here is inconsistent. Indeed, dementia literature reports on various patterns of burden over time. Caregivers who provided care prior to diagnosis show a greater longitudinal decrease in burden and role overload than those with diagnosis-dependent entry (J. Gaugler, et al., 2003).

In contrast to informal caregiving for stroke patients, our results show high burden at the first point of measurement within the first 3 to 6 months after stroke onset. In stroke literature, a period of high burden after a sudden onset of caregiving with a gradually decrease of burden over time has been hypothesized (van Puymbroeck & Rittman, 2005; A. Visser-Meily, Post, Schepers, & Lindeman, 2005). Overall, our findings confirm this hypothesis as did other studies (Ostwald, Bernal, Cron, & Godwin, 2009; Tooth, McKenna, Barnett, Prescott, & Murphy, 2005).

However, some authors did not find any association between duration of caregiving and subjective burden experienced by the informal caregiver (Poll & Gaugler, 2009). They refer to the greater impact of other factors on caregiver burden such as the patient's behavioral changes, personal relationship or social support.

The aim of this review is to identify particular patterns of change in caregiver burden over a longer period of time or differences in disease-

related caregiver burden. This could be partly achieved. One important finding of this review is the persistence of a certain amount of caregiver burden, regardless of time span or chronic disease cared for by informal caregivers. The degree of caregiver burden may decrease over time, but it never will be extinguished or be rated as inexistent (Forsberg-Wärleby, Möller, & Blomstrand, 2004; Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998). However, different patterns of the course of caregiver burden in dementia and stroke caregivers were found, which is contradictory to the finding of similar levels of burden in spouses caring for patients with stroke, dementia or Parkinson's disease (Thommessen, et al., 2002). A bias is likely to be introduced by the divergent time points of baseline measurement and in frequency and time points of repeated measurement when comparing burden between studies.

The results of this systematic review call for further research. The study designs need improvement in terms of representativeness, selection criteria and methodology, validated instruments, measurement times and follow-up. For example, in stroke caregiving baseline data were collected soon after stroke onset, but in the case of dementia baseline measure could have been conducted at any point in time during the course of disease. The inclusion or exclusion criteria mostly consider the care recipient and not the caregiver. The primary caregiver has been recruited if available. To improve representativeness, the recruitment procedures of caregivers should be done independently of the care recipient's recruitment. More long-term studies are needed to reliably reflect the experience of informal caregiving and the amount and course of caregiver burden over time. A minimal time span of 18 to 24 months should be considered.

We found evidence that the long-term burden for informal caregivers in patients with stroke and dementia is substantial, although the burden decreases in stroke caregivers over time. Due to the fact that the need of informal care in chronic conditions will remain over a much longer period of time than commonly investigated its long-term effect on caregiver burden has especially been studied insufficiently so far. This review points to a lack of longitudinal studies on burden in informal caregivers more than 12 months. It also shows the need for improved study designs.

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## Chapter 7

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**Pattern of informal caregiving provided in the post-rehabilitation phase of stroke survivors. A prospective cross-sectional study**

Manuscript submitted as: **Geschwindner, HM**; Rettke, H; Gabriel, C; van den Heuvel, WJA. Pattern of informal caregiving provided in the post-rehabilitation phase of stroke survivors. A prospective cross-sectional study



## **Abstract**

**Purpose:** Little is known about the pattern of long-term informal care at home provided to stroke survivors at least one year after discharge from inpatient rehabilitation.

**Methods:** A cross-sectional study has been conducted on a sample of patients (n=287) suffering from first-ever stroke one to three years post-discharge and their informal caregivers. We examined how many persons are involved, their relationships to the care receiver, and the individual stroke survivor's abilities and limitations requiring daily care. Beside descriptive statistics, we constructed an index referring to the different combinations of informal caregiving.

**Results:** In total, 103 dyads of stroke survivors and their informal caregivers participated. Five patterns of informal caregiving could be identified involving one or more persons differing in relationship to the care receiver. An overall trend was found; stroke survivors being cared for by a single person are more independent than those cared for by several. If functional or cognitive limitations call for care all day long, informal care is provided by close family members, while friends provide support in financial matters and social activities. Regarding time since discharge, the proportion of partners providing care alone decreases continuously after one year.

**Conclusion:** The findings strengthen the importance of informal caregiving for stroke survivors after discharge home. Since stroke survivors require informal care for an undetermined period of time, the potential informal caregivers should already be counseled by health professionals during inpatient rehabilitation.

**Key words:** stroke, informal caregiving, long-term care, cross-sectional

## **Introduction**

Stroke rehabilitation is meant to enable the stroke patients to restore functions and to return to normal living. In the majority, the most important rehabilitation goals set by patients and health professionals refer to living independently at home (Frank, Conzelmann, & Engelter, 2010). However, for many stroke patients these goals are not fully attainable. The majority of stroke survivors will not recover to their former level of functional and social independence after rehabilitation (Dewey, et al., 2002; Koyama, Sako, Konta, & Domen, 2011). For those stroke patients, this frequently means lifelong living with disabilities and having a demand of daily assistance for an undetermined period due to physical, cognitive or behavioral problems (Bakas & Burgener, 2002; Greenwood, Mackenzie, Cloud, & Wilson, 2009; Koyama, et al., 2011). Stroke patients can be discharged home depending on the extent of stroke sequelae, subsequent care needs, and the quality of social context (King, Hartke, & Houle, 2010; Nguyen, Page, Aggarwal, & Henke, 2007; Opara & Jaracz, 2010). In western countries, a high proportion of stroke patients return home after treatment in a hospital and/or rehabilitation facility. That proportion ranges between 62.2% and 87.7% (Frank, et al., 2010; Koyama, et al., 2011). As stroke survivors deal with physical, cognitive and social limitations, access to informal caregiving is essential for many of them to be able to live as independently as possible at home (Franzén-Dahlin, Larson, Murray, Wredling, & Billing, 2007; Stoltz, Udén, & Willman, 2004). Informal caregiving is described as actual care and support provided by partner, child, other family member and/or others (i.e. friends, neighbors) (Eldred & Sykes, 2008; Roche, 2009). It includes supporting activities in daily living, household chores, psychosocial support and social contacts (DeFries, McGuire, Andresen,

Brumback, & Anderson, 2009; van Eeden, van Heugten, & Evers, 2012). Informal caregiving for stroke patients is also essential for cost control in the care of chronically ill people (di Carlo, 2009; Hickenbottom, et al., 2002; Low, Payne, & Roderick, 1999; Saka, Serra, Samyshkin, McGuire, & Wolfe, 2009; van Heugten, Visser-Meily, Post, & Lindeman, 2006).

Social expectations towards informal caregiving vary considerably depending on political and/or religious beliefs and cultural context, e.g. urban compared to rural environment, lower class compared to middle class. These underlying values and attitudes towards each other determine the role of the family and especially of women as potential caregivers (Döhner, Kofahl, Lüdecke, & Mnich, 2007; McKeivitt, Redfern, Mold, & Wolfe, 2004). From such a point of view, informal caregiving would not be a question of feasibility or willingness of the care provider (Kerr & Smith, 2001). The main motivational factor to adopt the role as informal caregiver is the close emotional relationship to the care recipient. Further reasons are conscientiousness and moral obligation (Döhner & Kofahl, 2005).

While adopting the caregiver role, the next of kin experience several life changes (Bhagal, Teasell, Foley, & Speechley, 2003). Because of the sudden onset of stroke, most of them have to deal with the new role, new responsibilities and problems not yet experienced (Draper, Poulos, Cole, Poulos, & Ehrlich, 1992; Johnson, 1998; King, et al., 2010). The informal caregivers often report being unprepared for their new task of caregiving (Grant, Glandon, Elliott, Giger, & Weaver, 2006; King, et al., 2010; O'Connell & Baker, 2004; Ski & O'Connell, 2007) or having little social support (Simon, Kumar, & Kendrick, 2009), which has a negative impact on the caregiver's health and wellbeing (Andersen, Linto, & Ste-

wart-Wynne, 1995; Tellier & Rochette, 2004) as well as that of the stroke survivor's (Cameron, Cheung, Streiner, Coyte, & Stewart, 2011). Crucial for informal caregivers' decision to adopt the caregiver role and function are, beside willingness, the potential informal caregiver's age and gender, family relationship and living arrangement as well as the extent of informal care to be given (Han & Haley, 1999; Tiegs, et al., 2006; van Heugten, et al., 2006). The transition phase for patients living at home after discharge from a rehabilitation facility and its challenges are well investigated and documented (Pringle, Hendry, & McLafferty, 2008), as is the impact of informal caregiving for the stroke survivor in the first months (Ski & O'Connell, 2007; Tooth, McKenna, Barnett, Prescott, & Murphy, 2005). The impact of caregiving on the informal caregivers is widely recognized as threatening. However, caregiving may also result in positive effects, such as increased well-being and life satisfaction (Bacon, Milne, Sheikh, & Freeston, 2009; McKevitt, et al., 2004; Poulin, et al., 2010). Nevertheless, research on negative impacts predominates (Al-Janabi, Frew, Brouwer, Rappange, & van Exel, 2010). Research has identified that stroke caregivers perceive higher caregiver burden/strain and often suffer from depression (Bäckström & Sundin, 2009; van Heugten, et al., 2006; Visser-Meily, Post, Riphagen, & Lindeman, 2004). On the other hand, patterns of informal caregiving and the consequences of long-term care by informal caregivers are rarely described in the literature (J. Gaugler, 2010; Geschwindner, Rettke, & van den Heuvel, submitted).

The extent of informal care provided on a daily base is closely related to the stroke patients' disabilities and long-lasting dependencies (Bugge, Alexander, & Hagen, 1999). An individualized program of therapeutic interventions (physiotherapy [PT], occupational therapy [OT]) is often

continued after discharge from inpatient rehabilitation to foster patients' progress over a middle and long-term perspective. Information on long-term progress is sparse. While approximately 50% of stroke patients maintained or improved their goals set at discharge and their skills up to three years post-discharge, others deteriorate (Rettke, Geschwindner, Rentsch, Bucher, & van den Heuvel, submitted). This implies a long-lasting need of daily help and support of informal caregiving.

The purpose of this study is to describe the pattern of care and support provided by informal caregivers at home, i.e. the number of persons involved and their relationship to the stroke survivor with respect to the individual's abilities and limitations at least one year after discharge from inpatient rehabilitation.

## **Method**

A prospective cross-sectional study with a sample of stroke survivors and their significant others has been conducted at the neurorehabilitation unit of a regional non-university medical center in German-speaking Switzerland with an urban and rural catchment area. The purpose of the study was to investigate patients' long-term outcome in respect of living arrangement and patients' actual health situation one to three years post-discharge from inpatient stroke rehabilitation. In this context, the individual need of daily social support and informal caregiving were essential variables to investigate. Also information on this topic gathered from the next of kin has been of interest.

One questionnaire each for the discharged patients and for their next of kin was composed. The patient questionnaire assesses the actual living arrangement, changes in social context and health situation, formal and informal care and therapies received and provided by whom immediately

after discharge and at the time of data collection. Due to the fact that physical functioning is one of the most important outcome measures in rehabilitation therapy, we were interested in information on the patient's actual state of functioning abilities and limitations. In the rehabilitation facility, patients were assessed using the Functional Independence Measure (FIM) (Granger, Hamilton, Linacre, Heinemann, & Wright, 1993). Because FIM is a proxy measure assessed by health professionals, we decided to use a surrogate measure. Therefore, we constructed items reflecting the physical, cognitive and social abilities/skills, which were also close to the criteria used in the rehabilitation facility to assess goal attainment. Applying a factor analysis to these items identified four factors explaining 69% of variance. These factors refer to the dimensions activities of daily living (ADL), mobility, instrumental activities of daily living (IADL), and communication skills. Based on this, we grouped the items into four categories and calculated a sum score for each.

The informal caregiver's questionnaire surveys socio-demographic data, information on family relationship, living arrangement, employment and the number of persons involved in informal caregiving. Both questionnaires were sent to a cohort of stroke survivors ( $n=287$ ) who had completed inpatient rehabilitation in 2006 to 2008. For study inclusion, the patient must have suffered from a first-ever ischemic or hemorrhagic stroke and understand German. Each stroke survivor was asked to pass a letter explaining the objective of the study and the questionnaire to his next of kin. No further inclusion and exclusion criteria for these were assigned. The study was approved by the local ethics committee before data selection started.

To describe who provides care at home one to three years after discharge from the rehabilitation setting, we decided to construct an index

of the informal care pattern. We focused primarily on informal caregivers but also accounted for formal care services, if any. Different combinations of care providers at home were reported by the informal caregivers, as were various relationships to the stroke survivor. At least one person was involved, but more often several persons provide care. Because each of the three variables related to persons involved in care – ‘other family members’, ‘friends and neighbors’, and ‘formal homecare services’ – were small in numbers, these were put together and named ‘others’ for further analysis.

We constructed the Pattern of Informal Care Index (PIC) referring to five categories to accentuate the involvement of close family members in long-term informal caregiving, i.e. partner, children or grandchildren. These categories encompass care provided by one or more persons. The five PIC categories are defined as a) PIC 1: partner and close family member (and others), b) PIC 2: partner or close family member and others, c) PIC 3: partner alone, d) PIC 4: close family member alone, and e) PIC 5: others only, those including further relatives, friends and neighbors, and homecare services in which either one person alone or at least two of this group provide care.

The statistical program SPSS 20.0 (SPSS Analytics, IBM Inc., Armonk, NY, USA) was used for data analysis. Descriptive statistics were applied for analysis of sample characteristics, stroke patients’ limitations and care pattern. Differences between groups were checked by nonparametric tests, i.e. Mann-Whitney-U test, Chi-Square test and Kruskal-Wallis test.

## **Results**

### **Description of sample**

From the initial population of stroke patients (n=287), 177 (62%) participated in the study. Patients' dropout can be distinguished as 19 patients (7%) deceased, 28 (10%) moved, and 63 (22%) who did not respond at all. Also, 136 significant others responded and were identified as informal caregivers. Four informal caregivers could not be matched to patients and were therefore excluded, resulting in 132 dyads. Another 29 dyads had to be excluded because nine stroke survivors had meanwhile been admitted to a nursing home, and another 20 (15%) no longer needed any informal help or support. Hence, the sample consists of 103 dyads of patients and their informal caregivers. Due to missing data three dyads automatically were excluded in some analysis executed. The characteristics of patient and caregiver dyads included (n=103) are shown in Table 1 in contrast to the total number of dyads (n=132) participating. Comparing the included (n=103) and excluded (n=29) dyads, the Mann-Whitney-U test shows significant differences only in patients' age ( $p=.041$ ), i.e. patients without need of informal care are younger (median 60.00 years) than patients still receiving informal care (median 68.00 years). No statistical differences in informal caregivers' characteristics were found.

### **Pattern of informal care**

In total, 103 stroke survivors needed assistance and care on a daily base. Even three years after discharge from inpatient rehabilitation, 30 patients were in regularly need of informal caregiving. At least one person was involved in caregiving to cover the individual stroke survivor's care demands. More often, additional persons were involved, too.



**Table 1 Characteristics of stroke survivors and their next of kin**

|                                                 |                        | All responding dyads              | Dyads of patients needing informal care |
|-------------------------------------------------|------------------------|-----------------------------------|-----------------------------------------|
| Sample size                                     |                        | n=132                             | n=103                                   |
| Stroke survivor                                 |                        |                                   |                                         |
| Sex                                             | Female:                | 45 (34%)                          | 34 (33%)                                |
|                                                 | Male:                  | 87 (66%)                          | 69 (67%)                                |
| Age                                             |                        | 66.25 ± 13.524<br>(24 - 92) years | 67.08 ± 13.085<br>(27 - 92) years       |
| Stroke                                          | Ischemic               | 116 (88%)                         | 92 (89%)                                |
|                                                 | Hemorrhagic            | 16 (12%)                          | 11 (11%)                                |
| Time since discharge from stroke rehabilitation | 1 year                 | 49 (37%)                          | 36 (35%)                                |
|                                                 | 2 years                | 43 (33%)                          | 37 (36%)                                |
|                                                 | 3 years                | 40 (30%)                          | 30 (29%)                                |
| Next of kin                                     |                        |                                   |                                         |
| Sex                                             | Female:                | 97 (73%)                          | 73 (71%)                                |
|                                                 | Male:                  | 35 (27%)                          | 30 (29%)                                |
| Age                                             |                        | 55.76 ± 15.129<br>(22 - 93) years | 56.62 ± 14.887<br>(27 - 93) years       |
| Degree of relationship                          | Spouse / partner       | 79 (60%)                          | 66 (64%)                                |
|                                                 | Child or family member | 39 (30%)                          | 28 (27%)                                |
|                                                 | Friends                | 4 (3%)                            | 2 (2%)                                  |
|                                                 | Others                 | 10 (7%)                           | 7 (7%)                                  |
| Living with the stroke survivor                 |                        | 84 (64%)                          | 68 (66%)                                |
| Employment (yes)                                | Before stroke          | 78 (59%)                          | 59 (64%)                                |
|                                                 | At time of survey      | 65 (50%)                          | 47 (46%)                                |

Partner, children and other family members as well as friends were in charge of caring for the stroke survivor (Table 2). Most often ( $\approx 90\%$ ), informal care was provided by partner and close family members, e.g. children. Regardless of the number of persons involved, partners or children constitute the primary caregivers. Caregiving partners were

aged 60.95 ( $\pm 13.308$ ) yrs. on average, close family members 44.80 ( $\pm 12.738$ ) yrs. and others 64.50 ( $\pm 6.364$ ) yrs. While almost all partners ( $n=62$ ) were living in the same household with the stroke survivor they care for, only five close family members are living in the same house or flat. In total, eleven informal caregivers quit their job after stroke onset. Of these, six family members aged 30 – 59 quit their job to care for the stroke survivor. The caregivers who quit their jobs were one child and five partners, one of them male. Five caregivers retired after the onset of stroke.

**Table 2: Caregivers involved in long-term care at home after 1 to 3 years post-discharge from rehabilitation**

| Care at home provided by |                  | Involved in caregiving at home |                      |                      |                       |                    | Number of cases |
|--------------------------|------------------|--------------------------------|----------------------|----------------------|-----------------------|--------------------|-----------------|
|                          |                  | Partner/Spouse                 | Close family member* | Other family members | Friends and neighbors | Home-care services |                 |
| One single person        | Count            | 27                             | 16                   | 1                    | 0                     | 2                  | <b>46</b>       |
| Two persons              | Count            | 21                             | 25                   | 7                    | 2                     | 11                 | <b>33</b>       |
| Three persons            | Count            | 8                              | 20                   | 11                   | 3                     | 9                  | <b>17</b>       |
| Four persons             | Count            | 4                              | 4                    | 2                    | 2                     | 4                  | <b>4</b>        |
| Total                    | Count of Entries | 58                             | 65                   | 21                   | 7                     | 26                 | <b>100</b>      |

Legend: \* involves children, grand children and siblings

In the majority, informal care is delivered by a single person ( $n=46$ ). Different combinations of caregivers could be identified when two or more persons provide care. Maximum four persons were involved, for example partner and children provide care with support of friends and/or formal care services. The absolute numbers of the five categories of the Pattern of Informal Care Index (PIC) are presented in Table 3.

**Table 3: Pattern of Informal Caregiving Index (PIC) in Swiss stroke patients 1 – 3 years post-discharge**

|                 | <b>PIC 1<br/>Partner<br/>AND close<br/>family<br/>member<br/>(and oth-<br/>ers)</b> | <b>PIC 2<br/>Partner<br/>OR close<br/>family<br/>member<br/>and oth-<br/>ers</b> | <b>PIC 3<br/>Partner<br/>alone</b> | <b>PIC 4<br/>Close<br/>family<br/>member<br/>alone</b> | <b>PIC 5<br/>Others<br/>only</b> | <b>Total</b> |
|-----------------|-------------------------------------------------------------------------------------|----------------------------------------------------------------------------------|------------------------------------|--------------------------------------------------------|----------------------------------|--------------|
| Number of cases | 34                                                                                  | 16                                                                               | 27                                 | 16                                                     | 7                                | 100          |

Formal homecare services were also called in, in almost a quarter of the cases (n=26). In two cases, the homecare services were the only care provider. Otherwise, the homecare services were giving care in combination with a single (n=11), two (n=9) or three (n=4) informal caregivers.

The overall patterns do not differ statistically significant when comparing the time since discharge from inpatient rehabilitation ( $X^2$  8.337,  $p=.059$ ). However, concerning the proportion of partners giving care alone (PIC 3) is lower when years after discharge increase. At the same time, the proportion of PIC 1 and PIC 2 increases (Table 4).

**Table 4: Pattern of Informal Caregiving Index - distribution regarding time post-discharge**

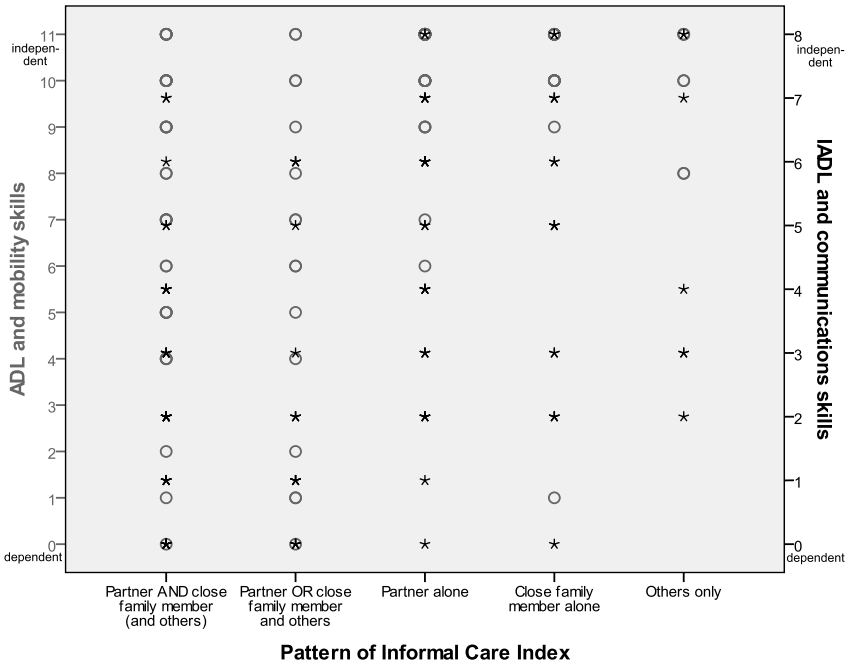
| Pattern of Informal Caregiving Index                       | 1 year post-discharge | 2 years post-discharge | 3 years post-discharge | Total |
|------------------------------------------------------------|-----------------------|------------------------|------------------------|-------|
| <b>PIC 1:</b> Partner AND close family member (and others) | 9 (26%)               | 13 (37%)               | 12 (40%)               | 34    |
| <b>PIC 2:</b> Partner OR close family member and others    | 3 (9%)                | 5 (14%)                | 8 (27%)                | 16    |
| <b>PIC 3:</b> Partner alone                                | 13 (37%)              | 9 (26%)                | 5 (18%)                | 27    |
| <b>PIC 4:</b> Close family member alone                    | 7 (20%)               | 6 (17%)                | 3 (10%)                | 16    |
| <b>PIC 5:</b> Others alone                                 | 3 (9%)                | 2 (6%)                 | 2 (7%)                 | 7     |
| Total                                                      | 35                    | 35                     | 30                     | 100   |

**Stroke survivors' characteristics**

Stroke survivors cared for by partner or a close family member with support from other persons (PIC 1 & PIC 2) were older on average (73 years) than those cared for by a partner alone (62 years). More male stroke patients (n=22) are cared for by the partner alone than female stroke patients (n=5). No statistically significant differences were found between the PIC categories in age, sex, changes in health and in social context. With respect to the stroke survivor's functional, social and cognitive abilities and limitations, we found statistically significant differences between the five PIC categories, for ADL, IADL, mobility and communication ( $p < .001$  resp.  $p = .004$ ). The stroke survivors in our sample show a relatively high degree of independence according to the mean scores and median of ADL and mobility dimensions. By contrast, the stroke survivors report on severe limitations with respect to the IADL and communications skills, as reflected in lower means and medians.

An overall trend is found in contrasting the different Pattern of Informal Care Indexes with the patients' degree of independence/dependence. Stroke survivors, who are cared for by partner and/or close family members and others (PIC 1 & PIC 2) are more dependent than those who are cared for by partner or close family members alone (PIC 3 & PIC 4). Living at home and being cared for by others only (PIC 5), i.e. friends or homecare services, indicates certain independence and an adequate recovery from the stroke (Figure 1).

**Figure 1: Overview on dependence of stroke survivors with respect to the Pattern of Informal Care Index**



Legend: ★ = referring to IADL and communication,  
 ○ = referring to ADL and mobility

In our sample, patients indicated a huge amount of limitations regarding IADL (n=251) and communication skills (n=176), whereas 109 or 137 were stated with respect to ADL skills and mobility, respectively. That is, each stroke survivor reported to be dependent in at least two IADL skills, e.g. ‘managing financial and economic matters’. Although these statements reflect the presence of serious limitations for the patients and may require informal care on a daily basis, they are not only unevenly distributed among the five PIC categories but also show particular dispositions (Table 5). If a (functional or cognitive) limitation calls for support all day long, the appropriate care is given by the partner and close family mem-

bers, hardly ever by others. Stroke survivors categorized in PIC 3 are for the most part limited in their skills referring to the instrumental activities of daily living, i.e. managing the household chores or financial matters, and in their communication skills which may result in assistance provided by their partners. In PIC 1 and PIC 2 the stroke survivors stated dependencies in almost all of the four dimensions calling for informal care and support, while friends (PIC 5) are predominantly involved when limitations in communication and social activities show up.

**Table 5: Proportion of patient limitations related to the Pattern of Informal Care Index**

|                                                           | <b>PIC 1</b><br>Partner<br>AND<br>close<br>family<br>member<br>(and<br>others)<br><b>n=34</b> | <b>PIC 2</b><br>Partner<br>OR close<br>family<br>member<br>and<br>others<br><b>n=16</b> | <b>PIC 3</b><br>Partner<br>alone<br><b>n=27</b> | <b>PIC 4</b><br>Close<br>family<br>member<br>alone<br><b>n=16</b> | <b>PIC 5</b><br>Others<br>only<br><b>n=7</b> |
|-----------------------------------------------------------|-----------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|-------------------------------------------------|-------------------------------------------------------------------|----------------------------------------------|
| Mastering being on one's own for a certain amount of time | 32%                                                                                           | 44%                                                                                     | 0                                               | 6%                                                                | 0                                            |
| Using the toilet                                          | 32%                                                                                           | 38%                                                                                     | 4%                                              | 6%                                                                | 0                                            |
| Washing and dressing oneself                              | 59%                                                                                           | 69%                                                                                     | 15%                                             | 6%                                                                | 42%                                          |
| Use of public transports                                  | 79%                                                                                           | 88%                                                                                     | 41%                                             | 44%                                                               | 42%                                          |
| Independently moving around the living quarters           | 47%                                                                                           | 69%                                                                                     | 4%                                              | 19%                                                               | 0                                            |
| Managing household chores                                 | 76%                                                                                           | 50%                                                                                     | 63%                                             | 50%                                                               | 29%                                          |
| Managing financial and economic matters                   | 79%                                                                                           | 81%                                                                                     | 44%                                             | 38%                                                               | 57%                                          |
| Participating in social activities                        | 88%                                                                                           | 81%                                                                                     | 48%                                             | 69%                                                               | 71%                                          |
| Following a conversation with several people              | 59%                                                                                           | 56%                                                                                     | 44%                                             | 38%                                                               | 29%                                          |
| Writing skills                                            | 68%                                                                                           | 75%                                                                                     | 48%                                             | 25%                                                               | 57%                                          |

## **Discussion**

For the majority of patients, suffering a stroke means living with persistent impairment and need of daily help and support, in our sample 85% (n=112), one to three years after discharge from inpatient rehabilitation. We found the daily support and care in the half of our sample provided by at least one informal caregiver, whereas the other half is cared for by groups of up to four persons (Pattern of Informal Care Index). The proportion of daily care given by formal homecare services was unexpectedly low with 26%.

Of the caregivers participating in the current study, 73 (71%) women adopted the role as informal caregivers. This is a proportion comparable to that reported in other studies (Döhner, et al., 2007; Höpflinger, Bayer-Oglesby, & Zumbrunn, 2011; King, et al., 2010; Krevers & Öberg, 2011; McCullagh, Brigstocke, Donaldson, & Kalra, 2005). In the majority, partners are the primary informal caregivers (n=58) followed by close family members, i.e. children. The involvement of close family members in informal care and their role as primary caregivers is a general finding reported in research literature (Blake & Lincoln, 2000; McCullagh, et al., 2005; Tooth, et al., 2005). These results also are in line with models of informal caregiving described by Lyons and Zarit (Lyons & Zarit, 1999). These authors refer to the hierarchical compensatory model by Cantor (Cantor in (J. E. Gaugler, Zarit, & Pearlin, 2003) which suggests caregiving preferences are based on social relationship. Hence care should be provided by the person closest and most accessible and available to the care receiver. As a result of this, partners are the first choice for informal caregivers. The care receivers' children are second choice. Following the hierarchy downwards, other family members, friends and formal care services are at the very end. Also combinations of formal and informal caregiving are assumed depending on skills needed and/or time when care has to be provided. At that point of time when health

care professionals adopt caregiving, informal caregivers remain involved but with a new role, e.g. as the manager of informal care. The majority of the propositions made in the different models described above could be recognized and confirmed in the Pattern of Informal Care Index introduced in this article. The partner or spouse as primary caregiver supported by children, sibling and friends is a typical and widely occurring phenomenon not only in the context of stroke survivors (Blake & Lincoln, 2000; Perrig-Chiello, Höpflinger, & Schnegg, 2010).

Caring for a family member who suffers from stroke is a long-lasting task equal to caring for a person with another chronic condition as well (Wright, Hickey, Buckwalter, Hendrix, & Kelechi, 1999). Several studies report a period of approximately three years regarding the duration of informal caregiving (Bakas & Burgener, 2002; Kesselring, et al., 2001). We studied the informal care pattern one to three years post-discharge from inpatient rehabilitation to gain more insight about this objective. Reasons for the need of assistance and care over such a long period are not only caused by impairment in physical functioning but also by need of assistance in cognitive tasks and social interaction. Indeed, these are functions informal caregivers usually perform and assist (Hankey, 2004; Holst & Edberg, 2011). Especially assistance in cognitive tasks and social interaction call for the informal caregivers because they rarely are performed by formal care services. Höpflinger et al. (2011) differentiate between need of help and need of care. While help refers to support around living and household chores, care is tendered to meet the person's physical requirements. Help and care services are delivered complementary by both informal caregivers and professional care services and can be arranged individually (Simon, et al., 2009). Formal care services provide care regarding the physical needs in particular, whereas family members, friends and neighbors are more often involved in support of social needs and tasks. These statements are confirmed by our findings.



Our results point to a shift towards the involvement of more persons in informal caregiving over time. While the partner is often the only caregiver in the early period after discharge home, a trend to call in other people for support is visible in the long term. The need for informal care also increases with increasing age and unaltered or deteriorating health status (Holst & Edberg, 2011; Höpflinger, et al., 2011).

Giving care to a family member is attended by social changes for the informal caregiver. In our sample, six younger caregivers quit their job to care for the stroke survivor. Literature considers an increase of perceived burden when working and giving care to a family member at the same time (Nowotny, Dachenhausen, Stastny, Zidek, & Brainin, 2004; Woittiez & Van Gameren, 2007). Döhner (Döhner & Kofahl, 2005) reports on 15% of informal caregivers who had to reduce their employment status because of providing care, thereby accepting a financial loss.

The study conducted shows some limitations. The main limitation of our study is that data were collected in a sample of inpatient rehabilitation patients of a single rehabilitation facility, so patients only receiving outpatient rehabilitation have been ignored. Thus the representativeness and generalizability of the results are limited. Because only one rehabilitation facility has been involved, a related limitation is that the population of investigation lives in a Catholic-oriented and rather traditional urban and rural district of German-speaking Switzerland, and the people's attitude might reflect the willingness to adopt the caregiver role. Thus the results may be taken as representative for such a specific population but might differ from the results of a distinct urban population.

The construction of a surrogate measure to assess patients' physical, cognitive and social abilities and limitations strengthens the reliability of such a measure, but at the same time it creates some vagueness, i.e. which specific aspect is at stake in each pattern of informal care. The

relationship between Pattern of Informal Care Index and the explicit amount and kind of care and assistance needed by the stroke survivors on a daily basis can be hypothesized only because more specific information on these facts is lacking. However, rudimentary trends can be shown referring to stroke survivors' physical and cognitive/social dependencies.

However, this is one of a few articles which try to describe the pattern of informal caregiving as it exists in reality more than one year after discharge from inpatient stroke rehabilitation.

## **Conclusions**

The results of this study show that the family is still important for the stroke survivor, who has been discharged home. Long-term informal caregiving for stroke survivors after discharge from rehabilitation does persist, not only for the first months after discharge but still after some years. This raises the question of involvement of family members in an early stage of the rehabilitation course to prepare them for the long-term maintenance of needs of assistance and care. This emphasizes the importance of a patient and informal caregiver centered approach. Family members and persons potentially providing informal care to stroke survivors should be carefully informed about the impact of caregiving, the amount of care daily provided concerning the stroke survivors limitations, and the indefinite period of caregiving. Also the impact of caregiving on the informal caregivers should be highlighted early, e.g. experience of burden, changes in one's own health and quality of life. Health professionals should closely counsel and prepare the next of kin while adopting the caregiver role during inpatient rehabilitation. This counseling and support should not be limited to the time of discharge. That is why a follow-up program for informal caregivers should be established to support them in their caregiver role in the time after discharge.

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**Psychometric qualities of a caregiver burden instrument in German-speaking Swiss caregivers of stroke patients**

Manuscript submitted as: **Geschwindner, HM**; Rettke, H; van den Heuvel, WJA. Psychometric qualities of a caregiver burden instrument in German-speaking Swiss caregivers of stroke patients

## **Abstract**

**Background:** Stroke has long lasting consequences for the patient and for the next of kin. To enable patients to return home after stroke rehabilitation next of kin are asked to undertake informal caregiving. The impact of informal caregiving is well investigated and documented. However, not all instruments applied in practice to assess burden in informal caregivers have been correctly translated and additionally tested.

**Objective:** To evaluate the validity and reliability of a caregiver burden instrument in informal caregivers of stroke patients in German-speaking Switzerland.

**Method:** In this cross-sectional study informal caregivers of stroke survivors were recruited one to three years after patients' discharge home from rehabilitation facility. In total 132 informal caregivers completed the questionnaires and could be linked to a patient. The psychometric properties of the scale were tested for reliability and validity including construct, convergent and concurrent validity.

**Results:** Factor analysis using principal component analysis with Varimax rotation produced a 5-factor solution of which one component includes one item. Reduced to a 4-factor solution this explains 59.9% of the variance. Overall the scale showed that five items are multidimensional. Cronbach's alpha coefficient for the total sum score of the instruments was .912.

**Discussion:** The caregiver burden instrument is important in care practice and if applied in time it helps to better support the informal caregiver to prevent negative effects for the caregiver himself as well as for the patient.

## **Introduction**

Stroke has far-reaching consequences for patients and their social environment (Bäckström & Sundin, 2009; Bergström, Eriksson, von Koch, & Tham, 2011; di Carlo, 2009; van den Heuvel, 2002). Because stroke has a sudden onset, partner, children and/or other family members may be poorly prepared to take over the role as a caregiver (Grant, Glandon, Elliott, Giger, & Weaver, 2006; O'Connell & Baker, 2004) and so their personal needs may remain unaddressed (Tellier & Rochette, 2009). Not being prepared for the caregiving role or having little social support has a negative impact on the health and wellbeing of both caregivers and stroke survivors (King, Hartke, & Houle, 2010; Simon & Kumar, 2009). Besides detriment to physical health the long-lasting demanding role as caregiver often leads to financial and social loss as well as decreasing quality of life (Bakas & Burgener, 2002). The impact of caregiving for a stroke survivor is well investigated and documented. Research has identified that stroke caregivers perceive higher caregiver burden/strain and often suffer from depression (Bäckström & Sundin, 2009; van Heugten, Visser-Meily, Post, & Lindeman, 2006). Assessment of the caregiver burden is crucial for the possibilities of interventions to prevent/reduce the burden of caregiving (Han & Haley, 1999; Jones & Riazi, 2011; van Heugten, et al., 2006).

## **Caregiver burden and its measures**

The concept of caregiver burden deals with the reactions of informal caregivers, who take care of a patient under chronic conditions and prolonged impairment (Pearlin, Mullan, Semple, & Skaff, 1990). Caregiving intends to support, assist and help, based on love, affection and compassion. Sometimes caregiving is also based on duty and necessity. Whatever the reasons, caregiving may have a stressful impact on the caregiver. Caregiving is a multidimensional concept, including physical,

psychological, emotional, social and financial aspects related to various experiences in the caregiving process (Vrabec, 1997). In this way, caregiver burden is a subjective concept. It refers to the caregiver's feelings and emotional reactions as a consequence of the experiences while fulfilling the caregiving role (Reinardy, Kane, Huck, Thiede Call, & Shen, 1999; Rigby, Gubitz, & Phillips, 2009; van Exel, et al., 2004; Vrabec, 1997).

Various instruments have been developed and tested to assess caregiver burden, such as the Caregiver Burden Inventory (24 items), Caregiver Burden Scale (18 items), Caregiver Strain Index (12 items), Caregivers' Stress Scale (15 domains), Perceived Caregiver Burden Scale, Revised (13 items), Zarit Burden Interview (22 items) (Berg, Palomäki, Lönnqvist, Lehtihalmes, & M., 2005; British Columbia Psychogeriatric Association & Government of Canada; Elmstahl, Malmberg, & Annerstedt, 1996; Novak & Guest, 1989; van Exel, et al., 2004; Zarit, Reever, & Bach-Peterson, 1980). All caregiver burden instruments are meant to identify the risks of unhealthy impacts and the needs for support and help in caregivers. Most instruments specify, at least conceptually, various domains, however a valid instrument is mostly constructed based on one general index. Most instruments measuring caregiver burden were developed to assess caregiver burden related to a specific disease, such as dementia. After being established in health care and/or nursing settings these instruments were applied and tested in caregiver populations other than the original target group (Visser-Meily, Post, Riphagen, & Lindeman, 2004).

As mentioned, caregiver burden instruments are often used as a one-dimensional construct in practice, but theoretically and conceptually they are designed as multidimensional instruments (Bartolo, et al., 2010; Caserta, Lund, & Wright, 1996; Chou, Chu, Tseng, & Lu, 2003;

Marvardi, et al., 2005; Novak & Guest, 1989). For example the Caregiver Burden Inventory (CBI) originally contained five dimensions (time burden, physical burden, personal developmental burden, emotional burden and social burden), but in further research these dimensions are not identified per se (Bartolo, et al., 2010; Caserta, et al., 1996; Marvardi, et al., 2005). Research from various countries shows the psychometric qualities of caregiver burden instruments (Caserta, et al., 1996; Grunfeld, et al., 2004; Kim & Schulz, 2008; Marvardi, et al., 2005; Novak & Guest, 1989; Raccichini, Castellani, Civerchia, Fioravanti, & Scarpino, 2009). The CBI is also used frequently in health care practice in various countries and cultures.

## **Background**

In daily care practice, various instruments are used to assess caregivers' burden, often based on 'officially-validated burden assessment instruments'. Such validated original versions of instruments may be adapted over time based on experience in daily practice. If no suitable instrument is available in the required language, the instruments of interest are translated as well as possible and applied in practice without testing the translation and the psychometric properties. Nurses working in the field frequently do not possess knowledge of the importance and significance of a correct translation process and the reapplication of validation tests. Those instruments introduced in practice might assess the clients' state as better or worse without being recognized by the health care professionals.

A caregiver burden instrument based on the Caregiver Burden Inventory (Novak & Guest, 1989) has been used in practice for some time in German speaking Swiss health care institution care for demented or frail, old and dependent persons. A "Caregiver Burden Inventory – Zurich Version" is widely accepted and has been frequently applied in community long-

term care services, and outpatient health care services e.g. memory clinic, respite settings, as well as counselling services, in the city of Zurich (Switzerland) for many years. The phrasing was adapted to German reflecting the Swiss cultural background. It appears to be very close to the English original and contains all 23 items. However, the source of translation and the exact procedures remain unknown. The frequent use in practice, as well as now in research, raises the question about the validity of the instrument. Therefore, the aim of this paper is to explore its validity. Such a validation contributes to the international discussion on the meaning and components of caregiving burden.

### **Objectives**

This article aims to analyze the psychometric qualities of the caregiver burden instrument as used to assess the burden of stroke patient caregivers in practice by German-speaking care providers of stroke patients in Switzerland. The research question is: what are the validity and reliability of the caregiver burden instrument in German-speaking Swiss caregivers of stroke patients? More specifically, the construct validity, the internal consistency, and the convergent and concurrent validity will be analyzed.

### **Method**

A cross-sectional study has been conducted in a sample of stroke survivors one to three years after stroke rehabilitation. The purpose of the study was to investigate patients' long-term outcome in respect to living arrangement and patients' actual health situation one to three years post-discharge from stroke rehabilitation. The outcome of informal care was also to be surveyed. Focussing on the topic of informal caregiving, next of kin were questioned regarding the amount of hands-on care and the burden experienced.



## **Data collection procedures**

A sample of stroke survivors, rehabilitated in a neurorehabilitation unit of a major Swiss hospital, was taken one to three years after discharge from the stroke rehabilitation unit. The number of stroke patients included from the registration of the clinic was 287. A questionnaire was sent by mail to all of them. Also the patients were asked to name a person relevant in their informal care process, and to hand over an envelope with a letter inviting this particular person to participate in the research on caregiver burden. The envelope contained a questionnaire form and also a stamped envelope to send back the completed questionnaire. The approval for study conduction was obtained from the local Ethics Committee before mailing the questionnaires to the designated potential participants.

## **Measures**

As mentioned the Caregiver Burden Inventory (Novak & Guest, 1989) was used as main source for this caregiver burden instrument applied in health care practice. Formulations were, however, sometimes adapted (for example 'I don't have a minute's break from my caregiving chores' became 'I do not have time for myself' and 'I feel emotionally drained due to caring for my care receiver' was reformulated as 'I feel exhausted due to my role as caregiver'). Another item ('I resent him/her') was left out because it was considered to be inappropriate to ask for such a statement. Two other items were expanded, i.e. 'or with my parents' was added to 'I have had problems with my marriage', because the instrument often was used in adult children who give care to a parent. The second item 'I don't do as good a job at work as I used to' has been expanded with 'or in housekeeping'. The German language caregiver burden instrument had 23 items. The items could be answered on a 3-point scale (yes, repeatedly; yes, often; no, not at all), where 'yes, repeatedly'

was rated with 2 and 'no, not at all' with 0. Thus the maximum possible total sum score is 46.

Besides the questions about caregiver burden, the questionnaire consisted of demographic data, information on family relationships, living arrangements, employment, persons involved in informal caregiving, and the "Sense of Mastery Scale" (Pearlin, et al., 1990). Furthermore, two single item questions were included concerning the amount of personally-delivered caregiving and the amount of subjective burden. Both items were rated on a VAS with the range 0 to 100.

### **Procedures for data analyses**

The psychometric qualities of the caregiver burden instrument, used in practice in German-speaking Switzerland, were assessed as follows.

The construct validity was explored through principal component analysis (eigenvalue >1.0) with varimax (Kaiser Normalisation) rotation. Since a subsample of stroke patients did not need any care on a daily basis while other patients did, we additionally performed the 'known group technique'. The assumption behind this patient characteristic was that informal caregivers of stroke patients without any care needs will experience a lower degree of subjective burden, while those of patients who need daily care experience a higher degree.

Based on this first step in the analysis, convergent (or criterion-related) validity was determined by the correlation between the scores on the caregiver burden instrument (one or more domains) and the amount of subjective burden as test variable for convergence. We consider a correlation of > .70 as criterion for convergence.

Concurrent (or discriminatory) validity was tested by comparing the caregiver burden instrument scores (one or more domains) between the

amount of care given ('giving daily support' and 'the amount of personally-delivered care') according to the caregiver (McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998; Tiegs, et al., 2006). A correlation of  $> .40$  was used as criterion for concurrence.

The internal consistency and dimensions were assessed by using standardized Cronbach's alpha (criterion of consistency  $> .70$ ). SPSS Version 20 (SPSS Analytics, IBM Inc., Armonk, NY, USA) was used for data storage and all analyses applied.

## **Results**

### **Participants**

Of the 287 stroke patients, 174 (61%) returned the completed questionnaire. It is not known how many and which patients handed the envelope with invitation letter over to a next of kin. Besides the 174 completed questionnaires of the patients, we received a total of 136 completed questionnaires from next of kin. These persons are designated 'informal caregivers' below, although they did not necessarily provide any caregiving. Four of the questionnaires filled out by caregivers could not be linked to the patient questionnaire and were therefore excluded. Since we have neither information about the number of questionnaires handed out nor about characteristics of the non-responding informal caregivers, we cannot analyze bias in responding. If we compare the socio-demographic data of the patients whose next of kin respond with those of patients whose next of kin did not participate, the two groups showed no statistically significant differences in age, gender, score of motor functioning, and of cognitive functioning (Functional Independence Measure) at discharge from the rehabilitation facility.

## Validity

**Construct validity** - Principal component analysis with eigenvalue  $> 1.0$  as criterion showed a 5-component solution, which explained 63.4% of the variance. All communalities were  $>.40$ . The rotated matrix showed that five items are multidimensional (factor loadings on at least two factors  $>.40$ ). The fifth factor contained one item 'I am not getting enough sleep'. Leaving out this item resulted in a 4-component solution (eigenvalue  $> 1$ ), 59.9% explained variance, communalities  $>.40$  and five items multidimensional (Table 1). Three items were multidimensional in both solutions, i.e. 'I wish I could escape from this situation', 'I expected things would be different at this point in my life' and 'I feel exhausted due to my role as caregiver'.

Component 1 is determined by 'My health has suffered', 'Caregiving has made me physically ill', 'I don't do as good a job at work or in house-keeping as I used to do', 'My social life has suffered' and 'I am physically tired'. This component is focused on the consequences of informal caregiving experienced in personal functioning. The second component is characterised by 'My care receiver needs my help to perform many daily tasks', 'I have to help my care receiver with many basic functions', 'My care receiver is dependent on me' and 'I have to watch my care receiver constantly'. The emphasis is here on the experienced intensity of caregiving. It is interesting to note that the three items which are multidimensional, are the same as mentioned above, indicating the relationship between the components 1 and 2, but each component has another main focus.

**Table 1: Principal component analysis and factor loadings of 22 items on caregiving burden**

|                                                                         | Domains (components) |             |             |             |
|-------------------------------------------------------------------------|----------------------|-------------|-------------|-------------|
|                                                                         | 1                    | 2           | 3           | 4           |
| I don't have a minute's break from my care giving chores                | .197                 | .542        | .347        | .151        |
| My social life has suffered                                             | .706                 | .358        | .168        | .071        |
| I don't get along with other family members as I used to                | .082                 | .096        | .588        | .416        |
| I feel embarrassed over my care receiver's behavior                     | .469                 | .163        | .339        | .251        |
| My care receiver is dependent on me                                     | .265                 | .832        | .038        | .102        |
| My health has suffered                                                  | .747                 | .151        | .190        | .264        |
| I feel that I am missing out on life                                    | .636                 | .330        | .250        | .021        |
| My caregiving efforts aren't appreciated by other family members        | .082                 | .111        | .576        | .419        |
| I feel ashamed of my care receiver                                      | .358                 | .008        | -.066       | .700        |
| My care receiver needs my help to perform many daily tasks              | .151                 | .909        | .014        | .020        |
| I wish I could escape from this situation                               | .540                 | .453        | .294        | .012        |
| I expected things would be different at this point in my life           | .534                 | .408        | .021        | -.048       |
| I'm physically tired                                                    | .692                 | .183        | .203        | .131        |
| I don't do as good a job at work as I used to                           | .731                 | .109        | .276        | .058        |
| I have to watch my care receiver constantly                             | .322                 | .757        | -.008       | -.007       |
| I feel emotionally drained due to caring for my care receiver           | .650                 | .438        | .029        | .282        |
| Caregiving has made me physically sick                                  | .742                 | .098        | .065        | .114        |
| I feel resentful of other relatives who could help but do not           | .055                 | .193        | .215        | .775        |
| I feel uncomfortable when I have friends over                           | .149                 | -.077       | .682        | -.065       |
| I feel angry about my interaction with my care receiver                 | .206                 | .103        | .657        | .111        |
| I have to help my care receiver with many basic functions               | .152                 | .834        | -.044       | .222        |
| I've had problems with my marriage                                      | .355                 | -.043       | .508        | -.170       |
| <b>Cronbach's alpha .912</b><br>(22 items, 'not enough sleep' excluded) | <b>.907</b>          | <b>.889</b> | <b>.642</b> | <b>.652</b> |
| (number of items included; factor loading > .40)                        | (10)                 | (8)         | (5)         | (4)         |

**Cronbach's alpha all items** (including 'not enough sleep') **.914**

Component 3 deals with problems in social relationships: 'I feel uncomfortable when I have friends over', 'I feel angry about my interaction with my care receiver', 'I don't get along with other family members as well as I used to' and 'I have had problems with my marriage, respectively with my parents'. The fourth component mainly expresses the disappointment of the informal caregiver in bearing responsibility alone: 'I feel resentful of other relatives who could help but do not' and 'I feel ashamed of my care receiver'. The experience of each caregiver in each domain was calculated by the factor scores, which weight all items based on the factor loadings.

For further testing of the construct validity we performed the known-group technique. We tested the group of informal caregivers of stroke survivors who need daily care provision (n=112) against those informal caregivers whose stroke survivors do not need any form of care (n=20). Our tests confirmed the hypothesis that the first group of informal caregivers experience a higher degree of subjective burden. The informal caregivers of stroke survivors with need of daily care show a mean burden score of 12.21 ( $\pm$  8.225), while those of patients without care needs show lower scores (2.82  $\pm$  3.206) (Mann-Whitney-U 269.500, Z -4.718,  $p < .001$ ).

**Convergent validity** - Convergent validity as determined by comparing the strength of association between the total sum score of the caregivers' burden items and the amount of burden judged by the caregiver himself on the VAS. Pearson's  $r$  is .779 ( $p < .001$ ). Caregivers, who judge their subjective burden as (very) high also indicated a (very) high burden on the mean sum score on the caregivers' burden items, indicating a strong convergent validity.

**Concurrent validity** - Concurrent validity assesses the potential to differentiate between caregivers with (supposed) different burden. Those caregivers who did not give daily support scored significantly lower on the caregivers' burden items (Analysis of variance  $F = 26.329$ ,  $df=1$ ,  $p<.001$ ). Also a statistically significant difference was found between total sum score on the caregivers' burden items and the amount of personally delivered care (Pearson's  $r = .599$ ,  $p<.001$ ). So the caregivers' burden items do discriminate between persons who deliver a high amount of care (own judgment) as compared to those who do not.

### **Reliability**

We calculated the reliability of each domain (as found by factor analysis) by Cronbach's alpha, using the items with a factor score of  $> .40$  (see Table 1). The data show that two domains (3 and 4) do not fulfil the criterion set before. Given the lack of consistency in some domains and the multidimensionality of five items, we decided to use all 23 items to assess caregivers' burden (Cronbach's alpha  $.914$ ) for convergent and concurrent validity. The caregivers' burden items as total sum score is a reliable construct. We could calculate the total sum score for 129 respondents. The mean score was  $10.85 (\pm 8.35)$  and the range between 0 – 33.

### **Discussion**

A caregiver burden scale (23 items) is used on a regular basis in Swiss German-speaking long-term care practice. This instrument is based on the Caregiver Burden Inventory, among others, but has never been validated. Such validation is considered to be important for practice as well for research.

We tested the consistency and validity of the 23 items. Various dimensions are identified in various caregivers' burden instruments. We found

four interesting components, called here 'burden in personal functioning', 'burden by intensity of caregiving', 'burden in social relationships' and 'burden in responsibility'. These dimensions differ considerably in items and content from what is known from the literature. For example, the Caregiver Burden Inventory mentions five dimensions, called 'time burden', 'physical burden', 'personal development burden', 'emotional burden', and 'social burden' (Novak & Guest, 1989). These dimensions were not always in research found (Marvardi, et al., 2005), while other authors used a total score and accepted the dimensions as granted (Bartolo, et al., 2010). Other authors prefer – for practical or theoretical reasons – other dimensions (Savundranayagam, Montgomery, & Kosloski, 2010). So we believe we contribute to this scientific dispute with our findings which show another perspective. Our analysis shows that personal investment of the informal caregiver may lead to feelings of personal dysfunctioning. The person who is taken care of may be very demanding, resulting in intensive caregiving, which thus becomes another source of burden. Another aspect which we found, as reported in many other studies, is the effect caregiving has on social relationships (J. Adriaansen, C. van Leeuwen, J. Visser-Meily, G. van den Bos, & M. Post, 2011; J. J. Adriaansen, C. M. van Leeuwen, J. M. Visser-Meily, G. A. van den Bos, & M. W. Post, 2011; Bakas & Burgener, 2002).

The multidimensionality of caregiver burden – as we found – is not generally discussed (Bartolo, et al., 2010; Caserta, et al., 1996; Marvardi, et al., 2005; Savundranayagam, et al., 2010). But our findings did raise the question about the stability and reliability of these dimensions. We found multidimensional items and not each component proved to be a reliable measure (using Cronbach's alpha > .70 as criterion). We believe that the various dimensions in caregivers' burden are related to culture (beliefs, values, traditions), to social security (responsibilities of states, families) and health care arrangements (availability, accessibility, qual-



ity). Therefore, we strongly recommend further research on the content, reliability, and validity of caregivers' burden instruments, especially on their components. Once the validity of dimensions is confirmed, these dimensions may be very useful in developing more specific interventions.

Concurrent validity is another matter of debate in the literature. Although some authors have reported clear findings on concurrency in socio-demographic variables (McCullagh, et al., 2005; Tiegs, et al., 2006) others did not find such associations (Bartolo, et al., 2010; Scholte op Reimer, et al., 1998). However, we believe other characteristics of the informal caregiver, the patient and the social context may be more important to understand the degree of caregiver burden. The dependency of the patient, his physical and cognitive functioning, as well as his material and financial resources may play an important role as well as caregivers' characteristics like coping style, mastery of the situation and quality of social relationships (Bugge, Alexander, & Hagen, 1999; McCullagh, et al., 2005; Scholte op Reimer, et al., 1998; Tiegs, et al., 2006; van den Heuvel, 2002).

### **Limitations**

One limitation of this validation study was the restriction to a population of informal caregivers of former stroke patients discharged from a single regional neuro-rehabilitation facility. Beforehand we had no detailed information on the population of interest. The caregiver burden measure is usually applied to informal caregivers providing care of persons living at home with diverse diseases. Due to the fact that the population of informal stroke caregivers has been stressed in this study, we recommend further testing considering informal caregivers of persons suffering from diverse chronic conditions.

### **Clinical implications**

As mentioned above, the informal caregiver burden is important in care practice. A timely assessment of burden also is important to support and protect the caregiver as well as the patient from negative effects of caregiving by maintaining the stability of the informal care setting. The present study contributes to the psychometric testing of a caregiver burden instrument applied in long-term facilities and affiliated health care services. Therefore, we recommend, for the moment, the use of a sum score of caregiver burden items instead of various dimensions. We have shown the consistency and validity of such a sum score.

An important question for future research, but also for care practice, is which characteristics (personal, social, and life-span) affect (different dimensions of) caregiver burden or conversely individual gratification in undertaking the role as informal caregiver. More effective interventions to reduce caregiver burden may also be designed when these complex relationships are understood.

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**Assessment of the psychometric quality of the 'Reintegration into Normal Living' Index in German-speaking Swiss stroke patients**

Manuscript submitted as: **Rettke, H**; Geschwindner, HM; van den Heuvel, WJA. Assessment of the psychometric quality of the 'Reintegration into Normal Living' Index in German-speaking Swiss stroke patients

## **Abstract**

**Background:** The ultimate goal of rehabilitation is a return to living life as normally as possible. Reintegration into normal living is strongly related to functional independence, fewer symptoms of depression and more years of life post injury. To assess the degree of reintegration into normal living following inpatient rehabilitation in German-speaking Switzerland, the Reintegration in Normal Living (RNL) Index was translated into German keeping the Swiss cultural background in mind.

**Objective:** The aim of this study was to assess the psychometric qualities of the RNL Index for research and rehabilitation practice when applied to post-stroke patients in German-speaking Switzerland.

**Methods:** A total of 174 stroke survivors completed a questionnaire that was sent to them one to three years following discharge from inpatient stroke rehabilitation. The average age was 67 and the majority of the respondents were men (78%). The RNL Index was tested for reliability and validity including construct, criterion-related and discriminatory validity.

**Results:** Factor analysis (varimax rotation) produced a two-factor solution with four out of the eleven variables contributing to both factors. With a one-factor solution executed, given the overlap between the factors 1 and 2, the explained variance is 47%. One variable contributes little ('taking trips out of town'), another contributes only moderately ('comfortable with social self') to this solution. Criterion-related validity was strongly supported with respect to the rating of 'overall recovery of stroke' (Pearsons'  $r = .743$ ,  $p < .001$ ). Patients living at home independently scored higher on the overall index ( $p < .001$ ) than those living in an institution as well as on each item, supporting the discriminate validity. The entire scale's internal consistency Cronbach's alpha was .815.



**Discussion:** The translated version of the RNL proves to be a reliable and valid measure when used as a single index. The wording of some items should be reconsidered in order to enhance applicability in the local context. The index should also be tested in other patients with different health conditions and age.

## **Introduction**

Research on rehabilitation focuses mainly on physical functioning as the predominant measure of outcome (Baseman, Fisher, Ward, & Bhattacharaya, 2010; Cicerone, 2004; Kim & Colantonio, 2010). The ultimate goal in rehabilitation is to enable patients to live a life as 'normal' as possible after an event resulting in persistent disability (Brown, Deriso, & Tansey, 2012; Frieden & Cole, 1985). Living a 'normal' life includes autonomous decision-making, independence in self-care, and participation in society. The latter concept has gained more attention in the last decade (Whittemore, 2005). Accordingly, the World Health Organization (WHO) considers social participation an important health outcome that is reached not only through rehabilitation but also involvement of the individual, his social environment, and social assistance regulations (World Health Organization, 2001). Participation presupposes social integration, which is seen as a multidimensional concept (Cummins & Lau, 2003; Willemse-van Son, Ribbers, Hop, & Stam, 2009). To assess participation and social integration in a reliable and valid way is a challenge (Willemse-van Son, et al., 2009), with only a limited number of instruments available for this purpose. One instrument, the Reintegration into Normal Living Index (RNL Index), was developed more than two decades ago and has since been used in research and practice and validated in various contexts and languages (Rehabilitation Institute of Chicago, 2010).

The RNL Index is used to assess the degree to which individuals who have experienced traumatic or incapacitating illness achieve reintegration into normal social activities. Reintegration into normal living was defined by the authors of the RNL Index as the "organization of organic, psychological, and social characteristics of an individual into a harmonious whole so that one can resume well-adjusted living after incapaciti-

tating illness or trauma" (Wood-Dauphinee & Williams, 1987)(p 492). Other researchers have found that the RNL Index assesses satisfaction with performance in life activities as judged by the individual (May & Warren, 2002). Thus, the RNL Index may be seen as measuring more than societal participation.

The RNL Index is considered by some researchers to be an important instrument in rehabilitation practice (Bourdeau, Desrosiers, & Gosselin, 2008; Carter, Buckley, Ferraro, Rordorf, & Ogilvy, 2000). Results of studies have demonstrated that the degree of 'successful normal living' is strongly related to functional independence (Bourdeau, et al., 2008; Carter, et al., 2000; Hitzig, Escobar, Noreau, & Craven, 2012; Murtezani et al., 2009), fewer depressive symptoms (Murtezani, et al., 2009; Pang, Eng, & Miller, 2007), and a greater number of years of life post injury (Hitzig, et al., 2012). The RNL Index is seen as a predictor for quality of life (Murtezani, et al., 2009). However, although it is recommended for assessing 'ultimate rehabilitation outcomes' in stroke studies, the RNL Index is not commonly used (Carter, et al., 2000; Daneski, Coshall, & Wolfe, 2003).

The psychometric qualities of the RNL Index have been tested in individuals with various diseases, in written or oral form, as well as in different countries (Carter, et al., 2000; Hitzig, et al., 2012; McGill University, 2012; Pang, Lau, Yeung, Lin-Rong, & Chung, 2011; Rehabilitation Institute of Chicago, 2010) and on this level it has been judged a valid instrument for assessing reintegration into normal social activities (Carter, et al., 2000; Daneski, et al., 2003; Hitzig, et al., 2012; Pang, et al., 2011; Wood-Dauphinee & Williams, 1987). However, other researchers found it necessary to change the wording and rating format of the scales to improve the validity of the RNL Index (Miller, Clemson, & Lanin, 2011). In addition, some validation studies have questioned the use

of a total index (Rasch model) (Miller, et al., 2011) or subscales, such as daily functioning and self-perception (Hitzig, et al., 2012; Pang, et al., 2011). Furthermore, a scoring bias between patients and significant others is indicated in that patients score their reintegration higher than significant others do (Tooth, McKenna, Smith, & O'Rourke, 2003). Therefore, the validity of the RNL Index is still a matter of scientific debate.

The purpose of this study was to assess the psychometric qualities of the RNL Index for research and rehabilitation practice for the first time in German-speaking Switzerland. Data were collected among stroke patients who had been discharged from a neuro-rehabilitation clinic at least one year previously. The research question is intended to analyze the construct validity, internal consistency, and the convergent and concurrent validity of the RNL Index in German-speaking Swiss stroke patients.

## **Methods**

Questionnaires were sent by mail to a sample of 287 stroke survivors 1 to 3 years after discharge from a neuro-rehabilitation unit of a major Swiss hospital. Of these, 174 (61%) questionnaires were completed and returned. Of the questionnaires that were not completed, 19 patients were deceased, 28 were returned as address lost or unknown, and no answer was received from 66 patients (23%). No statistically significant differences were found between responders and non-responders in gender, type of stroke, and lengths of stay in acute care and rehabilitation. However, responders were younger and had higher (positive) Functional Independence Measure (FIM) values at admission and discharge.

The RNL Index was used to assess patient satisfaction with performance in life activities after discharge from the rehabilitation center. The RNL had been developed in English and French (Wood-Dauphinee, Opzoo-

mer, Williams, Marchand, & Spitzer, 1988) and the original English version of the RNL Index was translated into German keeping the Swiss cultural background in mind. In the absence of a standard guideline for instrument translation (Maneesriwongul & Dixon, 2004) the guideline suggested by Beaton et al. (2000) was followed in principle. This procedure aims to achieve high equivalence of the translation with the original (Beaton, Bombardier, Fuillemin, & Ferraz, 2000). The RNL Index was translated by the first two authors and a professional interpreter independently provided a second translation. Both drafts were then compared in collaboration with a physiotherapist. The first two authors and the physiotherapist constituted the panel for evaluating the German version. A consensus was reached on the best wording of items, drawn from both versions. This new draft was sent for backward translation into English to a bilingual nurse scientist who, having completed her doctoral education in North America, was currently teaching and conducting research. The retranslated draft was compared to the original version, and the wording of the German version was adapted accordingly. Once again, the adapted version was translated back. Since the retranslation did not vary in major concepts, lay persons and nurses were asked to check the German wording on this version for clarity and appropriateness, and all approved. Approval was sought and received from Sharon Wood-Dauphinee for the second version of the 'backwards' translation. She authorized the use of the German version for this study by the first two authors and the collaborating physiotherapist.

The original RNL Index answer format consists of a 10cm visual analog scale (VAS) for each item, so participants can indicate answers ranging from 'does not describe my situation' to 'fully describes my situation' (Wood-Dauphinee, et al., 1988), but other formats are used as well. These formats were evaluated with stroke patients and comprise a dichotomous response scale (disagree/agree) (Daneski, et al., 2003), a

3-point ordinal scale (Mayo, Wood-Dauphinee, Côté, Duncan, & Carlton, 2002; Mayo et al., 2000) with a category inserted as 'partially describes my situation', a 4-point ordinal scale (Murtezani, et al., 2009; Pang, et al., 2007), and a 10-point Likert scale (Stark, Edwards, Hollingsworth, & Gray, 2005). To address disability concerns, the 3-point ordinal scale was used to simplify the process. The German version in this format was a component of a larger questionnaire. It underwent two pre-tests in this form. The RNL was personally read to six geriatric post-stroke patients in long-term facilities. All stated that the wording was understandable, the statements meaningful and the answering format easy to use. Then six stroke patients were asked to complete the questionnaire. These patients were attending day rehabilitation after having completed inpatient rehabilitation. They approved the questionnaire presented as well.

The psychometric qualities of the RNL Index were assessed as follows. The construct validity was analyzed through principal component analysis (eigenvalue >1.0) with varimax (Kaiser Normalisation) rotation. The internal consistency of the RNL Index was assessed by using standardized Cronbach's alpha (criterion of consistency >.70). Based on this first step in the analysis, convergent and concurrent validity was determined by the strength of correlations between scores on the RNL Index and the selected indicators for the convergent and concurrent concepts.

Patient scores on 'recovery from stroke', a VAS scale from 0 (no recovery at all) to 100 (complete recovery), were used as an indicator for convergent (or criterion-related) validity. This question is presented at the end of the Stroke Impact Scale (SIS), a validated instrument designed to assess multidimensional stroke outcomes, including mobility, communication, and participation (Duncan, Bode, Lai, & Perera, 2003; Duncan, Wallace, Studenski, Lai, & Johnson, 2001; Kasner, 2006). It

was decided that the correlation between 'recovery from stroke' and RNL Index should be not only statistically significant but also 'clinically relevant'; therefore, a correlation of  $>.70$  was considered a validity criterion.

Concurrent (or discriminatory) validity was tested by comparing scores on RNL Index with time since rehabilitation and FIM scores (motor and cognitive) at discharge from the rehabilitation center as discriminatory criteria. Based on the literature it might be expected that reintegration would be positively related to positive FIM scores at discharge and more time elapsed since discharge from the rehabilitation center. In this study, moderate (Pearson correlations between  $.30$  and  $.60$ ) statistically significant correlations between FIM scores and RNL Index score, and a statistically significant analysis of variance (ANOVA) outcome, were expected. Another test involved the 'known-groups technique', in which data are collected on a measure from two or more groups with a known or strongly expected particular difference with respect to the variable in question. In this case, patients discharged to an institution would be expected to score considerably lower on the RNL Index than patients discharged to their homes. We used SPSS, Version 20 (SPSS Analytics, IBM Inc., Armonk, NY, USA), and the Stata 11.1 statistical software package (Copyright 1996-2011, StataCorp LP, 4905 Ladeway Drive, College Station TX 77845, USA), for data analysis.

## Results

The average age of participants was 67 years and the majority were male (78%) (Table 1). The average stay in the rehabilitation center was 46 days. The average score on 'recovery after stroke' was 61.4. Average FIM scores were 76.7 for motor functioning and 27.3 for cognitive functioning. All patients had been discharged more than one year before the study: 38% were discharged between one and two years before completing the ques-

tionnaire, 31% between two and three years, and 31% more than three years.

**Table 1: Demographic and rehabilitation data of the discharged stroke patients (average or percentages)**

|                                                  | Mean | SD    | Percentage                                            |
|--------------------------------------------------|------|-------|-------------------------------------------------------|
| Age                                              | 66.9 | ±13.6 |                                                       |
| Gender                                           |      |       | 72% men<br>38% women                                  |
| Stay in rehabilitation center (in days)          | 45.9 | ±33.8 |                                                       |
| Recovery from stroke                             | 61.4 | ±23.8 |                                                       |
| Years after discharge from rehabilitation center |      |       | 38% 1-2 years<br>31% 2-3 years<br>31% 3 years or more |
| Motor FIM score                                  | 76.7 | ±15.4 |                                                       |
| Cognitive FIM score                              | 27.3 | ±5.9  |                                                       |

Factor analysis (criterion eigenvalue >1) resulted in a two-factor solution (Table 2). Each variable contributed sufficiently to the two-factor solution (communalities >.47) and all variables showed satisfactory factor loadings (>.50). The explained variance of the two-factor solution was 57%. After varimax rotation, the following variables contributed mostly to factor 1: ‘comfortable with relationships’, ‘can deal with life events’, ‘comfortable with social self’, and ‘assume role in family’. The variables ‘moving in community’, ‘moving in own home’, and ‘taking trips out of town’ contribute mostly to factor 2. Four variables, namely, ‘comfortable with self-care’, ‘engage in activity as necessary’, ‘participate in recreation’, and ‘participate in social activities’ contributed to both factors, with factor loadings between .444 and .585.

With a one-factor solution executed, given the overlap between factors 1 and 2, the explained variance is 47%. One variable contributing little to



this solution is ‘taking trips out of town’ (communality .10; factor loading .31), while one factor that contributes moderately to it is ‘comfortable with social self’ (communality .33; factor loading .58).

**Table 2: Factor loadings for two-component solution (eigenvalue >1) and one-component solution (Principal Component Analysis) of the RNL Index**

| RNL items                        | Two-component solution with varimax rotation |       | One-component solution |
|----------------------------------|----------------------------------------------|-------|------------------------|
|                                  | 1                                            | 2     | 1                      |
| <i>Component</i>                 |                                              |       |                        |
| Moving in own home               | .331                                         | .723  | .706                   |
| Moving in community              | .346                                         | .800  | .765                   |
| Taking trips out of town         | -.124                                        | .676  | .318                   |
| Comfortable with self-care       | .503                                         | .486  | .695                   |
| Engage in activity as necessary  | .535                                         | .491  | .723                   |
| Participate in recreation        | .585                                         | .444  | .735                   |
| Participate in social activities | .542                                         | .456  | .708                   |
| Assume role in family            | .667                                         | .299  | .709                   |
| Comfortable with relationships   | .792                                         | .072  | .669                   |
| Comfortable with social self     | .751                                         | -.019 | .580                   |
| Can deal with life events        | .765                                         | .300  | .787                   |

The consistency (Cronbach’s alpha) of component 1, based on the four variables with the highest factor loadings, is .802; Cronbach’s alpha of component 2, using the three variables with the highest factor loadings, is .488, indicating insufficient reliability. If the seven variables with the highest factor loadings on component 1 are used, Cronbach’s alpha is .866; for the seven variables with the highest factor loadings on component 2, it is .722. Cronbach’s alpha is .815 when all 11 variables are tested on reliability as one scale.

Given the overlap of four variables in the two-factor solution and the insufficient reliability of component 2 (three variables), the one component solution was used for further analysis. The validity of the RNL Index was tested as one scale (including all 11 variables). Factor scores were calculated for each participant.

A strong, statistically significant relationship was found between the score on the RNL Index and the score on 'recovery from stroke' (Pearson's  $r = -.743$ ,  $p < .001$ ). This relationship supports the convergent or criterion validity of the RNL Index: persons who state they are well integrated in normal life after stroke also consider themselves to have recovered rather well from stroke.

Discriminatory validity of the RNL Index is demonstrated by the differences between patients with high and low physical and cognitive dependency (FIM scores motor and cognitive) at discharge and score on the RNL Index (Pearson correlation  $-.477$ ,  $-.474$ , respectively;  $p < .001$ ). Stroke patients who had problems in physical and cognitive functioning at discharge from the rehabilitation clinic were found to be less integrated in normal life more than one year after discharge. No statistically significant difference was found between the RNL Index score and years after discharge from the rehabilitation center. In addition, differences in RNL Index sum score and single items between patients discharged to an institution or discharged home were also examined. Patients discharged home scored higher on the overall RNL Index ( $p < .001$ ) as well as in each item. However, statistical significance was weakest in 'participate in recreational activities' ( $p = .045$ ), 'participate in social activities' ( $p = .170$ ), and in 'comfortable with social self' ( $p = .457$ ).

## Discussion

The RNL Index is intended to assess the extent of reintegration, or 'normal' participation in society, as perceived by the (former) patient. There is little doubt among practitioners, policy makers, and scientists that such a measure represents an important health care outcome, especially for rehabilitation. That is why a German version of the RNL Index was made available. The question is, based on this sample and analysis, whether the RNL Index is a reliable and valid measure to use in German-speaking Switzerland (and beyond). The answer from this analysis is, yes and no.

The structure of the RNL Index, that is, whether it is one index or two, is discussed in the literature. We found that a single index, including all 11 variables, is a reliable, consistent measure and demonstrates convergent and discriminant validity. This finding is in line with other research (Wood-Dauphinee 1987, Carter 2000, Daneski 2002).

However, some caution is needed. One of the items, 'taking trips out of town', seemed to be of marginal worth to the index. This might be due to the characteristics of the participants involved in this study. They were older patients (mean age 67 years), whose interests, combined with disease history, might make it less likely for them to take trips. The variable explicitly asks about 'taking trips out of town' and respondents may react more negatively to this phrasing. For example, most respondents answer positively to the question when it focuses on 'moving in community'. This phenomenon may be affected by generational or cultural differences. Our sample stems from both urban and rural populations, where mobility patterns may differ. For patients with other diseases or impairments, or who are of different ages, this question may convey a different meaning. Also, travelling behavior and requirements may differ in Canada from Switzerland. Finally, this could reflect inappropriate

phrasing of the German translation or even in the original version, as is discussed in literature (Miller, et al., 2011). These issues may need to be taken into account by researchers who use the RNL Index in German as well as considering the varying socio-cultural contexts in which older people live in different parts of Europe.

Based on the findings of this study, questions arise regarding the two subscales and how they are to be 'labeled'. While daily functioning and self-perception are used as two 'labels' (Pang, et al., 2011; Hitzig, et al., 2012), our findings indicate the following: one aspect (factor 2) involving on 'mobility inside and outside home' and another aspect (factor 1) relating to being able to deal with social situations ('coping'). Further theoretical and conceptual study is needed to identify proper dimensions for an index on integrated living.

The two-factor solution, found in principal component analysis with eigenvalue  $>1$  as criterion, did not result in two clearly different dimensions. Therefore, the use of two subscales is not currently recommended. Further investigation is needed to determine whether two dimensions (social reintegration and mental reintegration) are preferable. To answer this question the experiences of patients, families, and care professionals must be taken into account.

It is important to note that in the one-component solution the two highest factor loadings deal with the two different aspects mentioned above, specifically, mobility by 'moving in community' (.765) and coping by 'can deal with life events' (.787). Thus, the two 'subscales' are strongly connected in the one-factor solution. We believe that further testing of the validity (and perhaps phrasing) of the RNL Index is important, but not without a further, qualitative exploration involving patients, families, and care professionals.

Our findings generally confirm the validity (convergent and concurrent) of the RNL Index. One interesting finding is the absence of a relationship between RNL Index score and time since rehabilitation. This could indicate that 'reintegration into normal living' occurs shortly after discharge, or that reintegration is already 'determined' when these patients are discharged from the rehabilitation clinic. This idea is underlined by the significant association between the FIM scores and RNL Index scores. Nevertheless, for patients with other diseases this process may have a rather different time frame. Therefore, the lack of correlation between RNL Index and time since rehabilitation may be an inappropriate indicator for concurrent validity in this patient group.

At the same time, one could argue that the absence of an association between time since rehabilitation and the extent of reintegration into normal life reveals something about rehabilitation (Carter, et al., 2000; Bourdeau, et al., 2008). The extent of reintegration is apparently a direct outcome of rehabilitation. If so, it raises the question of which aspects must be included in the rehabilitation process to ensure integration into normal living. By understanding this relationship, rehabilitation may make more of a contribution not only to reintegration, but also to quality of life. As shown in the literature, a high score on integration is related to better quality of life scores (Murtezani, et al., 2009). When the rehabilitation process contributes effectively to successful integration in normal living, it also contributes to the quality of life of the rehabilitation patient.

This research focused on stroke patients, which carries limitations in terms of outcomes. As suggested, for patients with other diseases and for other age groups the outcomes might have been different in terms of relationships between RNL Index and time after rehabilitation. Another limitation of this study is that patients with higher FIM scores were

overrepresented in this analysis. However, FIM scores themselves affected the reintegration into normal life, so they are a determinant for 'normal reintegration'.

Based on this analysis, we recommend further study of the validity of the RNL Index. We believe it should be altered although not necessarily into two dimensions. But instead toward adaptation of some of the 11 indicators, to be formulated on a more general level. Such adaptations would be worthwhile because participation and integration are important, societal health outcomes with wide-ranging impact. Rehabilitation guidelines and standards of care increasingly emphasize integration with regard to family, social roles and community involvement (Canadian Stroke Strategy, 2006). The RNL Index is a useful and reliable instrument to be used to implement these guidelines in clinical practice.

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## **Determinants of caregiver burden in long-term stroke caregiving**

Manuscript submitted as: **Geschwindner, HM**; Rettke, H; van den Heuvel, WJA. Determinants of caregiver burden in long-term stroke caregiving

## **Abstract**

**Background:** Living with stroke means persisting disabilities and a life-long demand on care, which is frequently provided by persons close to the stroke survivor. The informal caregivers are expected to provide care on a daily base which enables the stroke survivor to live at home. Adopting the role as informal caregiver is challenging for the person who will provide care for an undefined period in time. Providing informal care comprises a substantial burden. The purpose of this study is to identify factors which determine caregiver burden.

**Method:** A cross-sectional study was conducted with a sample (n=132) of stroke survivors one to three years post-discharge from rehabilitation facility and their informal caregivers. To measure caregiver burden an adapted version of the Caregiver Burden Inventory has been applied. Descriptive analysis and multiple linear regression analysis have been executed.

**Results:** Our results showed a rather low extend of burden reported by the informal caregivers. Two determining factors were identified: caregivers' Sense of Mastery score and caregivers' employment at the time of stroke onset. Characteristics of the stroke survivors did not show a strong relation to caregiver burden. The final regression model explains >50% of variance.

**Conclusions:** We found Sense of Mastery as a salient determining factor of caregiver burden. This information may contribute to developing interventions that strengthen the informal caregiver when providing care for an indefinite time period, thus resulting in informal caregivers experiencing lower burden and better well-being.

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## Introduction

Suffering from stroke often results in living with disabilities and quite often in lifelong demand of care and assistance on a daily basis (Nguyen, Page, Aggarwal, & Henke, 2007). For many stroke patients the most preferred rehabilitation goal is to return back to pre-stroke life and live at home as independently as possible (Stoltz, Udén, & Willman, 2004). To put this into practice, the social context and the family system are indispensable for the stroke survivor. Moreover informal caregiving is expected by society and as an essential element of the general health care system (DeFries, McGuire, Andresen, Brumback, & Anderson, 2009). The informal caregivers are expected to provide daily care which enables the dependent stroke survivor to return home (McKevitt, Redfern, Mold, & Wolfe, 2004; Sit, Wong, Clinton, Li, & Fong, 2007; Ski & O'Connell, 2007). The majority of informal care is provided by close family members (Blake & Lincoln, 2000; Eldred & Sykes, 2008). Partner/spouse are the first choice for the caregiver role, followed by children and grandchildren and further relatives and friends (Han & Haley, 1999). Beside the relationship factors, the proportion of female informal caregivers is greater than of males (Mnich & Balducci, 2006; Sit, et al., 2007). Several changes in the actual life situation are implied for those next of kin adopting the caregiver role (Bhogal, Teasell, Foley, & Speechley, 2003). In literature (Brereton & Nolan, 2002; White, Poissant, Côté LeBlanc, & Wood-Dauphinee, 2006) the course of informal caregiving is differentiated in three phases: adopting the caregiver role, continuing in the role as caregiver and at last relinquishing the caregiving role. Each of these phases is challenging in itself but additionally confronts the caregiver with a huge amount of tasks and responsibilities. Already at the very beginning of informal caregiving, it is challenging for the persons close to the patient to deal with the new tasks and the new role as caregiver, just as it is challenging for the care recipient, because he has

to abandon his pre-stroke role (Bhugal, et al., 2003; Jungbauer, von Cramon, & Wilz, 2003). Providing informal care comprises a substantial burden to next of kin and could even affect the well-being and health of the caregiver (Bakas & Burgener, 2002; Han & Haley, 1999; Rigby, Gubitza, & Phillips, 2009), and that of the care recipient, too (Jungbauer, Döll, & Wilz, 2008).

Caregiver burden is known as a general phenomenon in informal caregiving regardless whether the care recipients suffer from an acute or chronic disease, or of a meliorating or deteriorating health situation (Roche, 2009; Wright, Hickey, Buckwalter, Hendrix, & Kelechi, 1999). The diverse definitions of caregiver burden emphasize the multidimensionality of stressors and their impact associated with the experience of giving care to a next of kin (Vrabec, 1997). Caregiver burden and its consequences for the caregiver are well investigated concerning patients with different diseases, e.g. dementia, cancer, or stroke (Schumacher, Stewart, & Archbold, 2007; Wright, et al., 1999). But the period under investigation is frequently limited to several months up to one year (Geschwindner, Rettke, & van den Heuvel, submitted-a). On the other hand, caring for persons under chronic conditions entails a long-lasting perspective of informal caregiving and of the course of caregiver burden (White, et al., 2006). Zarit (Zarit, Reever, & Bach-Peterson, 1980) states that caregiving comes to the point when the help and assistance shifts to the unidirectional, and from that point in time providing informal care becomes stressful. Reports on the long-term course of caregiver burden and its effects are rare (Jungbauer, et al., 2003).

The role of the informal caregiver has been investigated in different contexts and with a variety of populations. Besides assessing the burden experienced, studies usually asked caregivers about their health and emotional status, coping strategies, and quality of life (Han & Haley,

1999; Rigby, et al., 2009). Since researchers frequently quest for factors explaining the extent of caregiver burden, specific patient characteristics are investigated in addition to the caregivers' variables. Patient characteristics often refer to socio-demographic variables, physical and cognitive functioning, disabilities and limitations, emotional constitution and the course of disease, e.g. activities of daily living, depression, behavioral problems (Blonder, Langer, Pettigrew, & Garrity, 2007; Holst & Edberg, 2011; Rigby, et al., 2009).

The sudden stroke onset affects not only the stroke patient but the family members (Bäckström & Sundin, 2009), who may be overwhelmed by the vague situation. The future informal caregiver is largely unprepared for this situation. Even when systematically prepared before the patient is discharged, e.g. by receiving information on the future tasks, the informal caregivers are still concerned about their poor preparation and uncertainty (Lutz, Young, Cox, Martz, & Creasy, 2011; Ski & O'Connell, 2007). When adopting the caregiver role, it is difficult for the significant other person to foresee the whole extent of consequences of the stroke for both the stroke survivor and the caregiver (Elkwall, Sivber, & Hallberg, 2004; McKeivitt, et al., 2004). Whereas the next of kin consider the physical impairment of the stroke patient as stressful during the hospital stay, the cognitive restrictions become prominent and demanding after discharge home (Forsberg-Wärleby, Möller, & Blomstrand, 2004). Furthermore, stroke has a strong impact on the family system. Dependant on residual impairments, the stroke survivor probably will not perform his pre-stroke role in the family system (Bhokal, et al., 2003; Glass, et al., 2004; Rodgers, Francis, Brittain, & Robinson, 2007). The complex adaptation to the new role of each family member is challenging and characterized as heterogeneous and various (McKeivitt, et al., 2004; Simon, Kumar, & Kendrick, 2009).

The impact of informal caregiving is widely considered to be demanding and wearing, hence the consequences investigated refer to negative effects (Van Durme, Macq, Jeanmart, & Geobert, 2012). Despite that, providing care may be a positive experience for some informal caregivers, resulting in increased well-being and life satisfaction (Bacon, Milne, Sheikh, & Freeston, 2008; McKeivitt, et al., 2004; Poulin, et al., 2010). Less is known about how informal caregivers deal with the challenges of the caregiving role in the long run and whether they experience a lesser or higher degree of caregiver burden and negative health impacts. Therefore, the aim of this study is to describe the caregiver burden of informal caregivers, who take care of stroke patients one to three years after discharge from clinical rehabilitation, and to determine which factors are related to the extent of caregiver burden.

### **Method**

A cross-sectional study of stroke survivors one to three years after stroke rehabilitation and their next of kin has been conducted. All 287 former patients of a neurorehabilitation unit of a regional medical centre in German-speaking Switzerland who suffered from a first-ever ischemic or hemorrhagic stroke and completed inpatient rehabilitation in 2006 to 2008 were asked by mail for study participation. The stroke survivors were also asked to hand over a letter explaining the objective of the study and the questionnaire to their next of kin. The study was approved by the local ethics committee before data collection started.

Both questionnaires, the patients' and the informal caregivers' form, were developed in cooperation with clinical experts from the rehabilitation unit, i.e. the rehabilitation physician, the neuropsychologist, a physical therapist and a nurse were involved in checking on the one hand if all topics of interest are included, and on the other hand the



relevance of the single items. Before conducting the study, the questionnaires were tested in two small samples of stroke survivors receiving day rehabilitation and living in nursing homes.

The patient questionnaire focuses on the living arrangement after discharge, changes in social context, changes in health, information on physical and cognitive functioning, recovery from stroke, reintegration into normal life, need of therapy and informal care immediately after discharge and “today”, i.e. one to three years post-discharge. While the functionality was assessed during inpatient rehabilitation by the Functional Independence Measure (Granger, Hamilton, Linacre, Heinemann, & Wright, 1993) which is applied by professionals, we used a surrogate measure for self-assessment. This measure refers to the dimensions ‘activities of daily living’ (ADL), ‘mobility’, ‘instrumental activities of daily living’ (IADL), and ‘communication’. So we gained information on the patients’ physical abilities and impairments, and their social-communicative skills and limitations. A high score refers to a high independence. Recovery from stroke has been assessed on a visual analogue scale from 0 to 100, in which 0 represents no recovery and 100 recovered completely.

Additionally, the first two authors extracted patient data from the patient records. These data include socio-demographic information (age, gender), type of stroke, lengths of stay in acute hospital and in inpatient rehabilitation, scores of motor and cognitive FIM both at admission and discharge, as well as short and long-term goals set during rehabilitation and the degree of goal attainment at discharge.

For data collection, the next of kin had to complete a separate questionnaire. Beside socio-demographic data, information on family relationship, living arrangement, employment, and pattern of informal caregiving provided at home, and an adapted version of the “Caregiver Burden

Inventory" (Novak & Guest, 1989) and the "Sense of Mastery Scale" (Pearlin, Mullan, Semple, & Skaff, 1990) composed the main part of this questionnaire.

The Caregiver Burden Inventory (CBI) (Novak & Guest, 1989) is a 23-item instrument to assess the burden perceived by the informal caregiver. Conducting this study we applied an adapted version which is regularly applied in long-term care facilities in German-speaking Switzerland, the so called Caregiver Burden Inventory Zurich Version (CBI ZH). The CBI ZH proved to be reliable and valid; the use of total sum score is recommended (Geschwindner, Rettke, & van den Heuvel, submitted-b).

The Sense of Mastery scale (SoM) was developed by Pearlin in 1978 (Pearlin, et al., 1990) to assess a person's ability to manage everyday life and to which degree a person sees him/herself as in control of (unexpected) situations that affect life. The first measure includes seven items, later versions like the German version by Badura (Badura, et al., 1987) only four or five items. We applied the 5-item German version with ratings on a 4-point scale from strongly disagree (1) to strongly agree (4). The higher scores refer to better mastery, i.e. an individual believes to be able to deal with arising life situations by herself/himself.

Descriptive analyses were used to summarize socio-demographic information on stroke patients and their next of kin and to compute the various sum scores, i.e. CBI, SoM, ADL, IADL, mobility and communication. To identify parameters related to caregiver burden, we executed a multiple linear regression analysis with CBI ZH sum score as dependent variable. Independent variables were entered consecutively with respect to their timely occurrence. Informal caregivers' data were entered at the first step, i.e. age, gender, relationship to stroke survivor, living with stroke survivor, employed before stroke onset. In the second

step, patients' variables concerning information that was available at time of discharge, i.e. age, gender, cause of stroke, length of stay in acute care and in rehabilitation facility, motor and cognitive FIM scores and goal attainment in living arrangement were entered. In the next step, data on changes in health situations and in social context (e.g. divorce, death of partner) were entered. Then variables reflecting the stroke survivors' status at the time of data collection followed (i.e. ADL, IADL, mobility, and communication sum scores, living arrangement, and state of recovery). In the final step, informal caregivers' information reflecting that point in time was entered, i.e. currently employed, pattern of informal care, and Mastery sum score. SPSS, Version 20 (SPSS Analytics, IBM Inc., Armonk, NY, USA) was used for analysis.

## Results

In total, 174 stroke patients (61%) participated in the study. 19 patients (6.6%) died and 28 (9.7%) moved, 63 (22%) did not respond. Besides 136 (47 %) were obtained from next of kin identified as informal caregivers. Of these, four could not be matched to a patient because of the patient's non-response. Thus, in total, 132 dyads (46%) of informal caregivers and stroke survivors participated in the study. 26% of the informal caregivers were male: the proportion of male stroke survivors was 66%. The majority of stroke survivors suffered from an ischemic stroke (n=116, 88%). The stroke survivors' average age was 66 years, that of the informal caregivers 56 years. The majority (90%) of the informal caregivers were partners or children and close family members. In general, the stroke survivors lived at home independently (27%) or with help (59%), only 18 (14%) were living in an institution (assisted living, nursing home). The participating dyads were evenly distributed to the time cohorts post-discharge. An overview of the independent variables (distribution in percentage or mean and standard deviation) is presented in Table 1.

**Table 1: Independent variables: descriptive statistics or distribution**

|                                             | <b>N</b> | <b>Mean</b>    | <b>Standard deviation</b> |
|---------------------------------------------|----------|----------------|---------------------------|
| Sense of Mastery sum score                  | 123      | 15.25          | 3.098                     |
| Caregiver's age                             | 125      | 55.76          | 15.129                    |
| Stroke survivor's age                       | 132      | 66.25          | 13.524                    |
| Length of stay in acute care                | 132      | 20.73          | 12.349                    |
| Length of stay in rehabilitation facility   | 132      | 49.97          | 35.886                    |
| FIM motor score at discharge                | 132      | 75.92          | 16.469                    |
| FIM cognitive score at discharge            | 132      | 27.07          | 6.080                     |
| ADL sum score                               | 132      | 3.92           | 1.663                     |
| IADL sum score                              | 132      | 1.51           | 1.501                     |
| Mobility sum score                          | 132      | 4.58           | 17.56                     |
| Communication sum score                     | 132      | 2.33           | 1.531                     |
| State of recovery                           | 132      | 60.06          | 23.608                    |
|                                             |          |                |                           |
|                                             |          | <b>Percent</b> |                           |
| Caregiver's gender                          |          |                |                           |
| Female                                      | 97       | 74 %           |                           |
| Male                                        | 35       | 26 %           |                           |
| Caregiver's relationship to stroke survivor |          |                |                           |
| Spouse /Partner                             | 79       | 60 %           |                           |
| Child                                       | 39       | 30 %           |                           |
| Friends                                     | 4        | 3 %            |                           |
| Others                                      | 10       | 7 %            |                           |
| Caregiver living with stroke survivor       |          |                |                           |
| Living together                             | 84       | 64%            |                           |
| Caregiver's employment before stroke onset  |          |                |                           |
| Being employed                              | 78       | 59%            |                           |
| Stroke survivor's gender                    |          |                |                           |
| Female                                      | 45       | 34 %           |                           |
| Male                                        | 87       | 66 %           |                           |
| Type of stroke                              |          |                |                           |
| Ischemic                                    | 116      | 88 %           |                           |
| Hemorrhagic                                 | 16       | 12 %           |                           |

|                                                            | <b>N</b> | <b>Mean</b> | <b>Standard deviation</b> |
|------------------------------------------------------------|----------|-------------|---------------------------|
| Goal attainment 'living arrangement' at discharge          | 13       | 10 %        |                           |
| living in an institution                                   | 79       | 60 %        |                           |
| living at home with help                                   | 39       | 30 %        |                           |
| living independently                                       |          |             |                           |
| Changes in social context (e.g. divorce, death of partner) | 125      | 98 %        |                           |
| yes                                                        |          |             |                           |
| Changes in health (e.g. another stroke, further diseases)  | 59       | 45 %        |                           |
| yes                                                        |          |             |                           |
| Living arrangement at time of data collection              | 18       | 14%         |                           |
| living in an institution                                   | 78       | 59 %        |                           |
| living at home with help                                   | 36       | 27 %        |                           |
| living independently                                       |          |             |                           |
| Caregiver's employment at time of data collection          | 65       | 49 %        |                           |
| Being employed                                             |          |             |                           |
| Pattern of Informal Care Index                             |          |             |                           |
| Partner AND close family member (and others)               | 34       | 31 %        |                           |
| Partner OR close family member (and others)                | 16       | 14 %        |                           |
| Partner alone                                              | 27       | 25 %        |                           |
| Close family member alone                                  | 16       | 14 %        |                           |
| Others only                                                | 16       | 14 %        |                           |

Executing the multiple linear regression analysis in the first two steps, informal caregivers' and patients' data known at discharge were entered. Regarding informal caregivers' data, none of the variables was statistically significant. From patients' data, the cognitive FIM score was statistically significant ( $p=.004$ ), i.e. caregiver burden is more experienced when taking care of patients who had cognitive problems at discharge from the rehabilitation clinic. Other patient-related factors like age, length of stay in care or goal attainment during rehabilitation are not related to caregiver burden. Adding the variables that report on changes between discharge from the rehabilitation facility and time of question-

naire completion, FIM cognitive sum score remains the only statistically significant variable ( $p=.003$ ). Changes in context and in patient's health as assessed do not affect burden. When including data referring to patients' actual status, the ADL sum score is statistically significantly related to caregiver burden ( $p=.039$ ), i.e. caregiver burden is higher when patients are more ADL dependent. When introducing the variables on patients' actual status, the relationship between cognitive FIM score and caregiver burden is no longer statistically significant ( $p=.091$ ). In the final step, when actual caregiver data were introduced, the result changed. None of the patient variables are statistically significantly related to caregiver burden. The mastery sum score shows a statistically significant ( $p<.001$ ) relation to caregiver burden, as does caregivers' employment at stroke onset ( $p=.041$ ) (Table 2). The pattern of informal care does not influence the extent of burden. The final model explains 64.7% (corrected  $r^2=.515$ ) of variance.

Sense of Mastery sum score is the salient factor related to caregiver burden. As mentioned in Table 1, the informal caregivers scored their mastery on average on 15.25 ( $\pm 3.098$ ), ranging from 0 – 20 (maximum score). Higher scores indicate better mastery. Informal caregivers who experienced a lower burden ( $<15$ ) show a SoM score on average 16, whereas those with a high burden (CBI  $>27$ ) scored 10 on average.

At the time of data collection 50% of the informal caregivers were employed and combined caregiving for the stroke survivor with their vocational work. The results demonstrate that caregivers who quit their job after stroke onset perceive a higher degree of subjective burden (mean 18.67,  $p=.001$ ). No statistically significant differences on CBI sum score was found between informal caregivers who were currently employed at time of stroke onset or not, or between those who were employed at time of data collection or not.

**Table 2: Regression analysis – final model**

|                                                   | $\beta$ -<br>coefficient | OR    | 95% CI  |        | p-value     |
|---------------------------------------------------|--------------------------|-------|---------|--------|-------------|
| (constant)                                        | 35.781                   |       | 10.125  | 61.438 | .007        |
| Caregiver's age                                   | .063                     | .114  | -.073   | .199   | .358        |
| Caregiver's gender                                | 2.171                    | .125  | -1.186  | 5.528  | .201        |
| Caregiver's relationship to stroke survivor       | -.335                    | -.050 | -1.651  | .981   | .612        |
| Caregiver living with stroke survivor             | .903                     | .054  | -3.045  | 4.850  | .649        |
| Caregiver's employment before stroke onset        | -5.334                   | -.327 | -10.431 | -.237  | <b>.041</b> |
| Stroke survivor's age                             | -.034                    | -.058 | -.182   | .114   | .647        |
| Stroke survivor's gender                          | 1.497                    | .090  | -1.795  | 4.789  | .367        |
| Type of stroke                                    | -1.381                   | -.052 | -6.214  | 3.453  | .570        |
| Length of stay in acute care                      | .007                     | .011  | -.103   | .117   | .902        |
| Length of stay in rehabilitation facility         | -.026                    | -.121 | -.072   | .019   | .251        |
| Motor FIM at discharge                            | -.030                    | -.063 | -.213   | .153   | .745        |
| Cognitive FIM at discharge                        | -.235                    | -.179 | -.559   | .088   | .151        |
| Goal attainment 'living arrangement' at discharge | -.108                    | -.012 | -1.852  | 1.635  | .902        |
| Changes in social context                         | 7.295                    | .134  | -2.157  | 16.747 | .128        |
| Changes in health                                 | 1.739                    | .108  | -1.360  | 4.837  | .266        |
| Recovery status                                   | .016                     | .047  | -.065   | .096   | .699        |
| ADL sum score                                     | -1.084                   | -.234 | -2.749  | .581   | .198        |
| IADL sum score                                    | -1.140                   | -.190 | -2.854  | .573   | .188        |
| Mobility sum score                                | 1.091                    | .253  | -.638   | 2.820  | .212        |
| Communication sum score                           | -.119                    | -.022 | -1.555  | 1.317  | .869        |
| Living arrangement at data collection             | -1.175                   | -.088 | -4.198  | 1.848  | .440        |
| Caregiver's employment at data collection         | 4.238                    | .263  | -1.222  | 9.699  | .126        |
| Pattern of Informal Care Index                    | -.316                    | -.057 | -1.360  | .728   | .547        |
| Sense of Mastery sum score                        | -1.545                   | -.602 | -2.022  | -1.068 | <b>.000</b> |

## **Discussion**

In the current study we investigated to what extent informal caregivers experience burden when providing long-term care to a stroke survivor, i.e. at least for one year after discharge from inpatient rehabilitation. As outcome measure we used an adapted German version of the Caregiver Burden Inventory, (Novak & Guest, 1989) the CBI ZH for the first time in research. Because the original CBI version and the CBI ZH differ considerably in wording and rating format, we deliberately avoided to comparing results with other studies. As far as we know, the CBI seldom has been applied in populations other than dementia (Chou, Chu, Tseng, & Lu, 2003; Ferrara, et al., 2008; Tooth, McKenna, Barnett, Prescott, & Murphy, 2005).

About 70% of the informal caregivers report on a rather low extent of caregiver burden. The extent of burden of informal care does not differ between those who provide care for just one year and those up to three years. Literature reports on changes in caregiver burden over time (Bhagal, et al., 2003; Forsberg-Wärleby, et al., 2004; Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998). But also increasing and decreasing trends have been reported (Gaugler, 2010; Wright, et al., 1999). Irrespective of time and any direction of change, a certain extent of burden persists (Geschwindner, et al., submitted-a). This might explain why informal caregivers did not rate zero even when the stroke survivors meanwhile lived independently without any type of help and assistance. Furthermore, it is known that an informal caregiver continues to experience burden when coordinating and managing tasks for the informal care at home, but the actual hands-on care is provided by others and several persons (O'Connell & Baker, 2004). In our study the pattern of informal care, i.e. a single person or several persons caring for one stroke survivor, did not impact caregiver burden.



We identified two parameters relating to burden of informal stroke caregivers and determined the individual caregiver's degree of experienced subjective burden. Surprisingly, only caregiver variables were identified, namely, the Sense of Mastery sum score and caregiver's employment at the time of stroke onset. While at first patient variables (cognitive FIM score resp. ADL sum score) contributed to the regression model, these variables were overruled when the mastery sum score was introduced. Determining factors of caregiver burden post-stroke are well investigated. The findings are heterogeneous and contradictory. Either antecedent characteristics of stroke survivors and informal caregivers, e.g. age, gender, or factors occurring post-stroke, e.g. impairments or amount of care provided, were assumed to contribute to burden (Blake & Lincoln, 2000; Rigby, et al., 2009). Some studies found that functional dependency, impaired cognitive function, or depressive symptoms influence caregiver burden (Bakas & Burgener, 2002; Bugge, Alexander, & Hagen, 1999; Thommessen, et al., 2002; Visser-Meily, Post, Schepers, & Lindeman, 2005). There are contradictory reports on the influence of patient's post-stroke factors like functional and cognitive impairment, and mental health. In contrast, the impact on caregiver burden with respect to caregiver related factors, i.e. amount of care, health and mental status, is reported more consistently (Blonder, et al., 2007; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Tooth, et al., 2005), whereas employment or social support does not seem to determine burden (Rigby, et al., 2009).

In the current study we found a positive relationship between sense of mastery and caregiver burden, i.e. a high sense of mastery contributes to a lower degree of experienced burden. Sense of mastery is a well established concept referring to an individual's ability to control and manage certain situations and deal with life circumstances. Individuals with a low sense of mastery are prone to distress and are unable to cope.

Because sense of mastery is understood as a characteristic trait, it is relatively stable over time (Badura, et al., 1987). Pearlin (Pearlin, et al., 1990) connected sense of mastery closely to informal caregiving, which in his view is a stressful experience affiliated with negative (emotional) health consequences for the caregiver. But he also proposes that there are many additional aspects of the family and the care situation that can affect caregiver outcomes, e.g. stressors and psychosocial resources. Sense of mastery is one of these psychosocial resources.

Our finding of sense of mastery as related factor to caregiver burden is supported by recent research. Some studies report on a decrease in negative effects of informal caregiving, like depression (Smith, Egbert, Dellman-Jenkins, Nanna, & Palmieri, 2012), and burden (Cameron, Cheung, Streiner, Coyte, & Stewart, 2011; Gitlin, et al., 2008) when mastery increased or has been stable over time. Furthermore, it is stated that mastery is positively correlated with informal caregivers' well-being (Singh & Cameron, 2005) and quality of life (Smeets, van Heugten, Geboers, Visser-Meily, & Schepers, 2012). It is important to note from literature findings that mastery may change over time. This opens perspectives for intervention to influence caregiver burden more effectively.

The impact of informal caregiving on employment and vice versa is well reported frequently in the context of economic burden (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; Döhner, Kofahl, Lüdecke, & Mnich, 2007). Providing informal care is time consuming and thus often incompatible with vocational work. Figures on time spent for informal care vary from approximately 8 to 20 hours a week (Heitmueller, 2007; Hick-enbottom, et al., 2002). Taking time spent for informal care into account full-time employment causes further stress, which is why many informal caregivers leave their job or work part time (Nowotny, Dachenhau-

sen, Stastny, Zidek, & Brainin, 2004; Rodgers, et al., 2007). Informal caregiving and vocational work may impact each other. On one hand caring reduces job performance and career, on the other hand persons with poor jobs will probably engage in informal caregiving. Study results refer to the relation between the amount of care to be provided and employment: the more hours proportionally spent for caregiving, the more like caregivers are to give up or reduce paid employment (Andlin-Sobocki, Jönsson, Wittchen, & Olesen, 2005; Woittiez & Van Gameren, 2007). If providing informal care only for some hours a week, informal caregivers combine both care providing and employment. Maintaining work may help the informal caregiver to better cope with the care situation, resulting in less burden and better health status (Colombo, et al., 2011).

### **Limitations**

The current study has some potential limitations. First, the generalizability and replication of our findings is limited because data has been collected from a single sample of stroke patients of only one regional neurorehabilitation unit in German-speaking Switzerland. Secondly the recruitment of informal caregivers was left to the stroke survivors. This might have biased the informal caregivers' sample. We have no information if the responders differ from non-responders. Conducting a cross-sectional study to collect data on long-term outcomes has limited the analyses to comparing the groups with respect to time post-discharge. The assumption that the three cohorts were even with regard to elementary characteristics has been confirmed by statistical tests, nevertheless, results may be different when collected at different times of measurement with a longitudinal approach.

### **Implications for practice**

When planning the stroke patient's discharge, the next of kin's involvement is essential not only to organize care but also to make the informal caregivers aware of the possible effects of caregiving over time. There is a lack in knowledge and information about the future prospects of both the stroke survivor and the informal caregiver. To become a responsible caregiver, the informal caregiver has to understand the tasks and difficulties that arise when providing informal care. Professionals can support the discharge preparation in providing detailed information on the course of the disease and its consequences for both stroke survivors and informal caregivers in general and applied to the individual stroke patient's situation. Furthermore, the future informal caregivers need information to understand their own role in the context of informal caregiving and its short and long-term impacts and consequences. Strengthening the individual caregiver's mastery would be beneficial for both caregivers and care receivers.

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**Determinants of long-term outcome in reintegration into normal living after inpatient stroke rehabilitation**

Manuscript submitted as: **Rettke, H**; Geschwindner, HM; van den Heuvel, WJA. Determinants of long-term outcome in reintegration into normal living after inpatient stroke rehabilitation

## **Abstract**

**Background:** Lasting disabilities from acute stroke can represent considerable barriers to reintegrate into normal living following discharge from inpatient rehabilitation. Rehabilitation focuses on regaining functions impaired by stroke, enabling patients to return home whenever possible.

**Method:** A sample of 174 stroke survivors returned the 'Reintegration into Normal Living' Index that was sent to them one to three years post-discharge. A 3-point ordinal answering format was used with a maximum sum score of 22. A multivariate regression analysis was executed to identify factors related to reintegration in normal living. Patient variables were entered along the timeline from discharge until the time when the questionnaire was completed.

**Results:** Respondents scored 15.88 ( $\pm 5.37$ ) on average, ranging from 0 to 22. Those living in an institution scored statistically significantly lower than those living independently. No differences in mean score were found related to time after discharge. Regression analysis showed that mobility ( $p=.006$ ) and communication ( $p=.002$ ), assessed at time of questionnaire completion were strongly related with the outcome

**Conclusion:** Rehabilitation traditionally has a strong focus on restoring physical functioning. More emphasis should be given to communication skills, because they are equally important for reintegrating into normal living when it comes to social activities.

## **Introduction**

Reintegration to normal patterns of social and community life is a key idea in rehabilitation (Youngkhill, McCormick, & Austin, 2001). This conform with patients' notion that reintegration to community life represents the end point of their rehabilitation process (Lord & Rochester, 2005). But, stroke patients' experience of life after the event is characterized by existential aspects of suffering and loss (Pilkington, 1999; Secrest & Thomas, 1999). Stroke is considered to be a life-transforming event by those it affects (Brauer, Schmidt, & Pearson, 2001). Much has been reported on patients' post-discharge limitations in physical (de Wit et al., 2007), cognitive (Wagle et al., 2011), and emotional functioning (Bergersen, Frey Froslic, Stibrant Sunnerhagen, & Schanke, 2010; Herrmann, Black, Lawrence, Szekely, & Szalai, 1998). Stroke sequelae are often enduring (Hankey, Jamrozik, Broadhurst, Forbes, & Anderson, 2002) regardless of age (Wilkinson et al., 1997) and stroke severity (Teasdale & Engberg, 2005). Also, reduction in community and leisure activities (Holbrook & Skilbeck, 1983), and isolation (Rittmann, Boylstein, Hinojosa, Sherna Hinojosa, & Haun, 2007) are observed. The latter implies that the effects of stroke are more social than physical (Burton, 2000) and represent major obstacles on the way 'back to real living' (Wood, Conelly, & Maly, 2010).

At the threshold to reintegration into normal living, that is at discharge from inpatient stroke rehabilitation, patients leave a therapy setting that is characterised by a multiprofessional team focussing on shared patient-centered goals and working together with patients towards goal attainment. Post-discharge, patients might continue gaining physical functioning and independence (Wood, et al., 2010) while their focus will shift from physical to social concerns (Reed, Harrington, Duggan, & Wood, 2010). Back in a domestic setting, health care is provided by

individual professionals and informal caregivers often lacking a shared focus to coordinate care and support to assist discharged patients in managing their altered health situation (Hickey, Horgan, O'Neill, & McGee, 2012). Of course, such a situation will never be stable. Functionality in stroke survivors can decrease over time (Dhamoon et al., 2009), their health status may change with new or recurring health problems (Haacke et al., 2006), and their social context may alter (Lynch et al., 2008) in that a couple gets divorced or a significant other is affected by disease or dies.

Stroke patients strive to return to their pre-stroke lives (Doolittle, 1992; Hafsteinsdottir & Grypdonck, 1997) or at least to resume valued activities (Cott, Wiles, & Devitt, 2007; Folden, 1994). Rehabilitation, in turn, aims at restoring functional independence (Mayo et al., 2000) and thus significantly contributes to patients' living independently. As Burton (2000) states, the essential patient work load is translating what has been learnt in the rehabilitation setting to the discharge environment (Burton, 2000). Notwithstanding the fact that patients may have regained a certain level of functioning, most patients cannot return home without informal care and the support of a social network (Meijer et al., 2004). The immediate post-discharge period is described as difficult, demanding (Pringle, Hendry, & McLafferty, 2008) and stressful (Ostwald, Bernal, Cron, & Godwin, 2009), and greatly marked by uncertainty (Brauer, et al., 2001; Burton, 2000; Carlsson, Möller, & Blomstrand, 2009). It is probably only at home that patients and their families will fully understand the consequences imposed by stroke (Olofsson, Andersson, & Carlberg, 2005).

This study aims at describing the extent to which persons having completed inpatient stroke rehabilitation reintegrate in normal living more than one year post-discharge. Furthermore, determinants will be ana-

lysed that affect the degree of reintegration in normal living. This knowledge would inform clinicians which factors may contribute to support patients in better reintegrating in normal living. Such factors may become important aspects of treatment, rehabilitation and care arrangements of stroke patients.

## **Method**

A consecutive sample of 287 patients was included after completing inpatient stroke rehabilitation in a neurorehabilitation facility adjacent to a major hospital in German-speaking Switzerland. Inclusion criterion was rehabilitation following a first-ever ischemic or hemorrhagic stroke. Patient records provided information on demographic data, lengths of stay in acute care and rehabilitation facility, functionality as measured by the Functional Independence Measure (FIM) (Granger, Hamilton, Linacre, Heinemann, & Wright, 1993) and discharge destination. Functionality was recorded at admission and discharge. Discharge destination categories were broadly defined as 'living in an institution' (i.e. nursing home or assisted living), 'living at home with help' (i.e. help from someone living in the same household or external), and 'living at home independently'. The approval of the local ethics committee was obtained before accessing patient data and contacting patients by mail as described below.

A questionnaire was developed to evaluate long-term outcomes in terms of stability of discharge destination, general functioning and participation in community and social life. The questionnaire was sent by mail to all 287 patients one to three years after discharge. To assess functioning, questions were termed capturing physical, cognitive and social functioning and overall mobility. Questions were framed within activities of daily living (ADL) (e.g. 'I can eat on my own' vs. 'I need somebody to

help me with eating'), instrumental activities of daily living (IADL) (e.g. 'I can do the household chores on my own' vs. 'I need help with doing the household chores'), communication (e.g. 'Reading is of no difficulty for me; I read newspapers, notes or letters' vs. 'I have difficulties with reading'), and mobility (e.g. 'At home I move around without help from another person' vs. 'I need help from another person when I move around at home').

Community and social participation was specifically assessed by the Reintegration in Normal Living Index (RNL) (Wood-Dauphinee, Opzoomer, Williams, Marchand, & Spitzer, 1988). The index assesses the degree to which patients successfully reintegrate into community after incapacitating illness or severe trauma (Wood-Dauphinee & Williams, 1987).

Addressing disability concerns in our sample (Clarke, Black, Badley, Lawrence, & Williams, 1999), we chose the 3-point ordinal scale (Mayo, et al., 2000) to simplify the answering format and to increase response rate. According to the original answering format (Wood-Dauphinee & Williams, 1987), we allocated '0' to disagree and '2' to strongly agree with each item. Applied in a stroke population post-discharge, the index shows good psychometric properties (Rettke, Geschwindner, & van den Heuvel, 2012), a finding which is in line with other publications with regard to the original English version (McGill University, 2012). This is the first time the German version has been used and evaluated in research.

Descriptive statistics were used to summarize patient characteristics, limitations in ADL, IADL, mobility, and communication and sum scores in RNL. Chi<sup>2</sup>-statistics were applied to test for differences in limitations (ADL, IADL, mobility, and communication) and RNL sum scores between living arrangements. To investigate which factors contribute to reinte-



gration into normal living, a multiple linear regression analysis was executed, using the enter method. With RNL as the dependent variable, variables were entered as they occurred along the timeline from discharge from inpatient rehabilitation until completion of the questionnaire. At first, patient data were entered that were available at discharge (i.e., age, gender, cause of stroke, length of stay in acute care and rehabilitation facility, motor and cognitive FIM subscores at discharge, and the long-term goal set for 'living arrangement' at discharge). Then, 'receipt of help', and 'continued therapies' immediately post-discharge were entered. Next, data on changes in health or social context that occurred after discharge and completion of the questionnaire were introduced. Finally, all data emerging at the time point when the questionnaire was completed were entered (i.e., received help and continued therapies, sum scores of ADL, IADL, mobility and communication, as well as goal attainment in 'living arrangement').

SPSS, Version 20 (SPSS Analytics, IBM Inc., Armonk, NY, USA), was used for analysis.

## Results

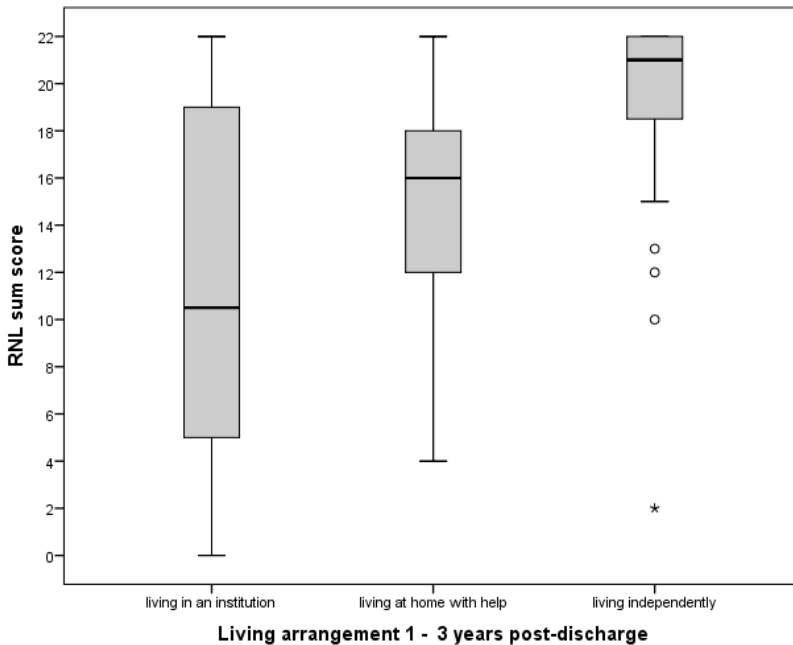
Out of 287 eligible patients, 174 (61%) returned the completed questionnaire. 19 patients (7%) had died, 28 (10%) had moved, and 63 (22%) did not respond. Characteristics of the responders, time since discharge and the long-term goal set at discharge and attained at time of questionnaire completion are shown in Table 1.

RNL scores were available from 170 patients, since 4 patients left this part of the questionnaire blank. The RNL mean sum score is 15.88 ( $\pm 5.37$ ), ranging from 0 to 22 (maximum score), that is, 70 (41%) respondents scored below the mean value, while 100 (59%) scored higher. No statistically significant difference is found between RNL scores and

time from discharge, but respondents differ statistically significantly with respect to the actual goal attainment in 'living arrangement' (see Figure 1). Respondents living at home independently were much better reintegrated as assessed by RNL than those living in an institution. Besides, bivariate analysis showed strong correlations between RNL on the one hand and length of stay in the rehabilitation center ( $r=-.225$ ), motor FIM at discharge (.415), cognitive FIM at discharge (.384), long-term goal attainment at discharge (.356), help after discharge (.277), therapy today (-.224), help today (-.443), long-term goal attainment today (.522), ADL (-.518), IADL (-.279), communication (-.589), and mobility (-.393).

**Table 1: Patient characteristics**

|                                  |                                      |
|----------------------------------|--------------------------------------|
| <b>Variables</b>                 |                                      |
| Age (mean)                       | 66.92 ( $\pm 13.42$ )<br>(24-92 yrs) |
| Gender                           |                                      |
| <b>male</b>                      | 107 (61%)                            |
| <b>female</b>                    | 67 (39%)                             |
| Cause of stroke                  |                                      |
| <b>ischemic</b>                  | 152 (87%)                            |
| <b>hemorrhagic</b>               | 22 (23%)                             |
| Length of stay                   |                                      |
| <b>in acute care</b>             | 20.63 ( $\pm 12.74$ )                |
| <b>in rehabilitation setting</b> | 46.42 ( $\pm 33.98$ )                |
| FIM at discharge                 |                                      |
| <b>motor</b>                     | 76.73 ( $\pm 15.55$ )                |
| <b>cognitive</b>                 | 27.40 ( $\pm 5.87$ )                 |
| Time since discharge             |                                      |
| <b>1 year</b>                    | 66 (38%)                             |
| <b>2 years</b>                   | 54 (31%)                             |
| <b>3 years</b>                   | 54 (31%)                             |
| Long-term goal set at discharge  |                                      |
| <b>living in an institution</b>  | 10 (6%)                              |
| <b>living at home with help</b>  | 63 (36%)                             |
| <b>living independently</b>      | 101 (58%)                            |
| Long-term goal attained          |                                      |
| <b>living in an institution</b>  | 25 (14%)                             |
| <b>living at home with help</b>  | 100 (58%)                            |
| <b>living independently</b>      | 49 (28%)                             |

**Figure 1: RNL sum scores when questionnaire was completed**

In the first step of the multiple linear regression analysis, all patient data available at discharge were entered. The cognitive FIM score was statistically significant ( $p=.037$ ). None of the variables that correlate with RNL in the bivariate analysis impacted anywhere near a significant level. Cognitive functioning at discharge is the most as compared to other data we collected during inpatient rehabilitation to be related to post-discharge reintegration following discharge. When the next two variables were entered, i.e. 'help' and 'continued therapies' provided immediately after discharge, the influence of the cognitive FIM decreased ( $p=.065$ ). This continues in the third step where changes in health and in social context were taken into account (cognitive FIM  $p=.77$ ). In the final step, when those data were included that were present at the time of questionnaire completion, the cognitive FIM has no impact on reintegration ( $p=.587$ ). In this step length of stay in rehabilitation shows an asso-

ciation ( $p=.080$ ) with reintegration. Two variables clearly contribute to reintegration in normal living. These are limitations in ‘mobility’ ( $p=.006$ ) and in ‘communication’ ( $p=.002$ ) (Table 2). This would mean that stroke patients having good mobility and communication skills one to three years following discharge from inpatient rehabilitation are well integrated into normal living. The final model explains 52.4% of the variance. The model also demonstrates that data assessed during inpatient rehabilitation are not related to reintegration when data for actual functioning were introduced. While mobility and communication were strongly related to reintegration, ADL and IADL were not.

**Table 2: Regression analysis**

|                                  | $\beta$ -<br>coefficient | OR    | 95% CI |        | p-value     |
|----------------------------------|--------------------------|-------|--------|--------|-------------|
| (constant)                       | 23.436                   |       | 8.940  | 37.933 | .002        |
| Age                              | .043                     | .125  | -.020  | -.107  | .178        |
| Gender                           | .991                     | .098  | -.55   | 2.540  | .207        |
| Cause of stroke                  | .194                     | .013  | -2.20  | 2.595  | .873        |
| Length of stay in acute care     | -.023                    | -.049 | -.098  | .052   | .539        |
| Length of stay in rehabilitation | .023                     | .170  | -.003  | .050   | .080        |
| Motor FIM at discharge           | -.015                    | -.042 | -.121  | .091   | .777        |
| Cogn FIM at discharge            | .060                     | .060  | -.159  | .280   | .587        |
| Long-term goal at discharge      | .538                     | .067  | -1.252 | 2.329  | .552        |
| No therapy at discharge          | -.013                    | -.001 | -2.39  | 2.364  | .991        |
| No help at discharge             | .204                     | .018  | -1.886 | 2.294  | .847        |
| Changes in social context        | -.759                    | -.069 | -2.424 | .907   | .368        |
| Changes in health                | .164                     | .016  | -1.367 | 1.696  | .832        |
| Therapy today                    | -.478                    | -.049 | -2.154 | 1.199  | .573        |
| Help today                       | -1.524                   | -.148 | -4.492 | 1.444  | .311        |
| ADL sum score                    | -.477                    | -.126 | -1.436 | .482   | .326        |
| IADL sum score                   | .313                     | .109  | -.287  | .913   | .303        |
| <b>Mobility sum score</b>        | -.717                    | -.442 | -1.227 | -.208  | <b>.006</b> |
| <b>Communication sum score</b>   | -1.140                   | -.306 | -1.852 | -.429  | <b>.002</b> |
| Goal attainment today            | .094                     | .012  | -2.122 | 2.310  | .933        |

## Discussion

We investigated to what extent stroke survivors reintegrated in normal living, i.e. live a normal life as far as their disabilities permit, and reintegrate into the community one to three years after discharge from inpatient rehabilitation. As outcome measure we used the German version of the original Reintegration in Normal Living Index (Wood-Dauphinee & Williams, 1987). To allow for comparison with other study results where the RNL was used with stroke patients, we adjusted our 3-point ordinal scoring results to the original answering format introduced by Wood-Dauphinee et al. (1988). They applied a visual analogue scale with a maximum sum score of 100 representing the highest level of reintegration (Wood-Dauphinee, et al., 1988). Thus we accordingly transformed the RNL mean sum score from our study results into a score of 72. We applied this procedure to all other RNL study reports unless the original scoring format had been used.

In three studies, the RNL was assessed at a single point in time. Mean sum scores reported were 83 (Pang, Eng, & Miller, 2007), 84 (Tooth, McKenna, Smith, & O'Rourke, 2003), and 62 (Murtezani et al., 2009). In the study of Murtezani et al. (2009) the sample of stroke patients showed a low score of reintegration into normal living. Participants were comparatively young, i.e. 50 years on average. The sample was recruited from a rehabilitation facility and included many patients with severe deficits in performing activities of daily living. This might explain the low RNL mean score. In turn, Tooth et al. (2003) point out that their sample had low levels of physical deficits which, in their view, explain the high level in RNL scoring. The results reported here differ somewhat from ours, which may be due to different designs. The various scoring systems might also have an impact (Hitzig, Escobar, Noreau, & Craven, 2012). That is, more comparable studies are needed to understand which factors would relate to reintegration.

One study evaluated the RNL against an intervention. Mayo et al. (2000) evaluated 'early supported discharge', an intervention meant to assist stroke patients in readapting to the home environment. They assessed RNL at one and three months post-discharge (Mayo, et al., 2000). The average age was 70. All patients were in need of informal care post-discharge due to motor deficits. The overall RNL score was 73 at one and 82 at three months in those who were supported at discharge. The overall RNL score in the non-supported control group did not differ (72 respectively 84). Apparently, the intervention for readapting into the home environment did not affect RNL.

Our study results demonstrate that mobility and communication skills are significantly related to reintegration in normal living. Clinical rehabilitation therapies contribute to physical and cognitive functioning. As such, they might add to reintegration. Patients discharged home will, in the absence of professionals, gradually try out functions and abilities in their own 'natural environment' (Kirkevold, 2002). They will consolidate their regained independence (Wood, et al., 2010) and continue recovery (Doolittle, 1992). The question is, in which specific way rehabilitation could contribute to increased reintegration. Rehabilitation has a strong focus on restoring physical functioning. More emphasis should be given to communication skills to facilitate social integration.

Some limitations to our findings have to be acknowledged. The sample originates from a single setting which constrains generalizability. Only inpatient rehabilitation was considered. We have no information about the RNL outcome when patients attended outpatient rehabilitation only. Due to the cross-sectional design, our results give no information about any sequelae related to reintegration over time. Further longitudinal research is needed to observe changes in levels of reintegration over time.

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## CHAPTER 13

# General Discussion

## **Introduction**

The objectives and the research questions of this PhD thesis were formulated in Chapter 1. In Chapters 4 – 12 we answered these questions. However, we started to describe stroke-rehabilitation facilities in German-speaking Switzerland, focusing on the way goal setting was applied and evaluated in the facilities. This was meant to be a first step in a multidisciplinary longitudinal study conducted at multiple study sites to evaluate goal setting and goal attainment in stroke patients admitted to a rehabilitation center after a first stroke.

However, we found that goal setting was not systematically applied in rehabilitation practice in German-speaking Switzerland and that protocols of goal setting and evaluation were lacking. In turn, validated instruments to assess patients' status were applied. But there is no consistent choice of instruments across rehabilitation settings.

Generally, evaluations of the effects of patient participation are scarce, although patient participation in rehabilitation is strongly advocated. In addition, systematic evaluation of goal attainment in rehabilitation is seldom reported in the literature.

This study is meant to offer 'building stones' which might be important to future evaluation of goal attainment and which are useful when assessing rehabilitation outcomes in German-speaking Swiss rehabilitation practice. We concentrated on examining long-term rehabilitation outcomes, i.e. one to three years following discharge from inpatient rehabilitation.

Discharged from clinical rehabilitation, stroke survivors are often cared for at home. This is important to maintain independence. Care needed is frequently provided by persons close to the stroke survivor. Providing

informal care is a demanding task and may negatively affect not only the caregiver but also the stroke survivor himself or herself and the whole family system.

The main findings of this study will be presented in this final Chapter followed by a general discussion. We end with recommendations for future research and for rehabilitation practice.

## **Main findings**

### **Systematic reviews**

Two systematic literature reviews were executed (Research Questions 1 and 4): one review related to instruments for assessing patient participation in clinical rehabilitation and one review describing the longitudinal course of caregiver burden in informal stroke and dementia caregivers.

Patient participation is unquestionably essential in rehabilitation, and particularly needed in goal setting and goal attainment (Turner-Stokes & Wade, 2004). The systematic review of instruments for assessing patient participation showed it to be a complicated concept. In clinical rehabilitation, the number of validated instruments is very limited. The few validated instruments that exist show serious shortcomings conceptually and operationally, when applied in rehabilitation practice and especially in nursing practice.

Long-term caregiving for persons suffering from stroke or dementia or other chronic diseases, is often provided by informal caregivers (Brodaty & Donkin, 2009; Saban, Shewood, deVon, & Hynes, 2010; Wrubel, Richards, Folkmann, & Acree, 2001). Surprisingly, little is known about the long-term effect on caregiver burden as disclosed by our systematic

literature review. Although the caregiver burden in informal caregivers of stroke patients or persons suffering from dementia changed unequivocally over time in the few studies available, the change was in either direction. The review showed that a certain degree of caregiver burden persists over time and has a substantial impact on informal caregivers.

### **Validation studies**

We executed two validation studies (Research Question 6) to assess the validity of outcome measures used in rehabilitation and long-term care for stroke patients: reintegration into normal life and burden in informal long-term caregivers. The psychometric properties of both instruments had not yet been tested in German-speaking Switzerland.

The Reintegration in Normal Living (RNL) Index, including all 11 variables, is a reliable, consistent measure and has proven to have good to sufficient construct and criterion-related validity and internal consistency.

The Caregiver Burden Inventory Zurich Version, was largely based on the Caregiver Burden Inventory of Novak (Novak & Guest, 1989) and is used in German-speaking Swiss long-term health care practice. The overall index, comprising 23 items, showed satisfactory good to sufficient construct and criterion-related validity and internal consistency.

### **Study population**

The outcomes of our PhD project are based on a partly retrospective, partly cross-sectional study of stroke patients and their informal caregivers. All first-ever stroke patients who completed inpatient rehabilitation between 2006 and 2008 in a neurorehabilitation facility of a major non-university affiliated hospital in German-speaking Switzerland constituted the study population. We used scientific literature, clinical data

registered systematically in a neurorehabilitation facility, and data from questionnaires, completed by stroke patients and their informal caregivers. Study participation one to three years after discharge from clinical rehabilitation was satisfactory. Respondents were younger, had better scores on physical and cognitive functioning and were therefore more often assessed as able to live independently after discharge as compared to non-respondents. This finding reflects clinical practice; older patients and patients with serious functional and cognitive limitations are more often discharged to an institution and lost to long-term follow-up. Of all the patients who participated in the study, two thirds were discharged home with help or assistance on a daily base. In the majority of cases of patients who responded, informal caregivers could be identified. These were mostly women (spouse or partner) and younger than the stroke patient.

### **Goal attainment during and after clinical rehabilitation**

The assessment of the goal 'living arrangements', i.e. the extent of living independently after rehabilitation, was studied during and after clinical rehabilitation (one to three years following discharge) and associations between goal attainment, patient characteristics and (in the case of long-term goal attainment) changes in social context and in health of patients after discharge were sought (Research Questions 2 and 3).

A multidisciplinary team set goals at admission to be reached during inpatient rehabilitation. These goals were evaluated regularly in team meetings. Goal attainment at discharge was evaluated and long-term goals were set, i.e. goals meant to be achieved after discharge. In this study, we analyzed the extent of goal attainment with respect to 'living arrangements' as assessed during inpatient rehabilitation.

Four out of five patients did attain the goal as evaluated at the end of clinical rehabilitation. Of the remaining 54 patients, 22 did better than the goal set at admission and 32 did not attain it. Older patients were more often held to need to live in an institutional care setting, while patients with a relatively better score on physical and cognitive functioning were more often assessed as able to live at home as independently as possible. Binary logistic regression analysis confirmed these results.

One to three years after discharge from the clinical rehabilitation facility the same patients were contacted again by means of a questionnaire for further information on living arrangement, life events, health situation, overall functioning, and on reintegration into normal living. More than half of the 174 responding patients attained the long-term goal as set at discharge; 6% exceeded this goal and 42% did not attain it. Stepwise logistic regression analysis showed that non-attainment is related to limitations in patients' physical functioning at discharge, to receipt of informal and/or formal help, to performance of continued therapies immediately after discharge as well as to a narrowing of the social context following discharge.

### **Patterns of informal care of stroke patients one to three years after inpatient rehabilitation**

The stroke patients, who were approached one to three years following discharge from inpatient rehabilitation, were asked to give a separate questionnaire to their next of kin. In total 132 completed questionnaires were returned with 103 cases receiving some kind of informal care at home. Different patterns of informal care emerged. Half of the patients received informal care from their spouse or partner alone, from a close family member alone or from a combination of several persons. Stroke survivors cared for by a single person were less dependent than those



receiving informal care from more than one person. In addition to informal care, 26 patients had formal home care. Of these, in 2 cases formal home care was the only care provider involved. The data showed that, at one year post-discharge, a larger number of survivors were cared for by the spouse or partner alone. This number changed when care was provided two or three years post-discharge. In cases requiring 24-hour care, more than one informal caregiver was involved. In these instances, for the most part it was family members who were engaged. Informal care provided by friends or neighbors often had to have recourse to assistance in instrumental and social activities.

### **Caregiver burden in informal stroke caregivers one to three years after clinical rehabilitation**

The maximum score on CBI Zurich Version is 46. The informal caregivers in this study scored 11 on average when caring for a stroke survivor for at least one year following discharge from inpatient rehabilitation. This score is not related to years after discharge. A smaller degree of subjective caregiver burden is strongly related to a pronounced sense of mastery. Besides mastery, employment of the informal caregiver at the time of stroke onset is a second determining factor of caregiver burden.

### **Reintegration into Normal Living (RNL) of stroke patients one to three years after clinical rehabilitation**

The maximum score on RNL is 22. The stroke patients in this study scored 16 on average, one to three years after clinical rehabilitation. This score is not related to years after discharge. Better reintegration is related to greater independence in mobility and less affected communication capabilities.

## **Discussion**

In this paragraph we discuss the results of our study. We organized the discussion along the main research questions mentioned in Chapter 1.

### **Goal setting and goal attainment in rehabilitation**

Goal setting is given importance in rehabilitation and is the essence of multidisciplinary, rehabilitative expertise (Holliday, Antoun, & Playford, 2005; Playford, Siegert, Levack, & Freeman, 2009). Patient participation should also extend to goal setting (Wade, 2009a). In order to set goals, patients' objectives and preferences must be taken into account. However, the goals must be adapted in accordance with the individual's potential for rehabilitation and the rehabilitation interventions as available at the facility.

Therefore, the fact, as the systematic literature review has shown, that instruments assessing patient participation are largely lacking in rehabilitation practice is astonishing. It is not said that patients do not participate in clinical practice. Rather, that the extent of patient participation is not validly measured or systematically assessed in daily practice, either by therapists or by nurses.

Goal setting is a systematic, skilful process which requires appropriate expertise and protocols (Evans, 2012; Siegert & Taylor, 2004; Wade, 2009b). Although it is strongly advocated, goal setting is seldom put into practice the way that it should be (Holliday, et al., 2005). In Switzerland, one rehabilitation facility has developed a systematic, multidisciplinary procedure (based on ICF) for assessing goals in stroke patients. Despite a careful goal-setting process during inpatient rehabilitation and another careful evaluation at the time of discharge, we found goals were not always attained. The proportion of non goal attainment was

smaller in the short-term (during the rehabilitation process) as compared with the long-term outcome one to three years after discharge.

Other than the time span and the 'controlled' rehabilitation setting, the short-term concordance between goal setting and attainment may be biased by team dynamics (Baxter & Brumfitt, 2008). Individual opinions can easily have a prevailing influence in team decision-making. On the other hand, this assumption is at odds with the positive reporting on team conference quality (Rentsch et al., 2003). However, the available data did not allow for an investigation of these explanations.

Furthermore, it was not clear in which way participation of patients and their families was realised during the goal-setting process. The way that patients and families are involved in goal setting may influence goal attainment during rehabilitation (Barnard, Cruice, & Playford, 2010) and will have a considerable impact on the course of events after discharge.

Theoretically, patients attain their rehabilitation goals and health care professionals direct all rehabilitation interventions towards that goal attainment. A multidisciplinary team approach is characteristic of rehabilitation (Momsen, Rasmussen, Nielsen, Iversen, & Lund, 2012). Therefore, it is important to understand the roles of both patient and care professional and the interactions between them. In the case of health care professionals the matter is complicated by the fact that each discipline may have its own roles and objectives. Each team member has a professional view regarding assessing and treating a stroke patient specific to his or her discipline. Physicians focus on medical conditions in terms of diagnostics and medical therapy. Cognitive functioning lies in the field of the neuropsychologist. Physiotherapists and occupational therapists are concerned with motor functioning. Speech therapists will

address swallowing and verbal expression (Miller et al., 2010). Nurses, in turn, concentrate on restoring patients' self-care abilities (Robinson-Smith & Pizzi, 2003). The common denominator shared by the various professional concerns is the individual stroke patient and his or her individual rehabilitation goals.

Direct involvement of patients and family members in the goal-setting process is regarded as indispensable to defining goals that are relevant for patients and professionals alike (Holliday, Ballinger, & Playford, 2007; Northen, Rust, & Nelson, 1995). It is for this reason that they must be meaningful and realisable. This is supported by goals defined in a specific, measurable, achievable, relevant and timed format ("SMART") (Wade, 2009a). When defining long-term goals beyond discharge, patients and those who may be caring for them should be even more involved given that they are the ones who will have to realise these goals.

Post-discharge goal attainment supports the sustainability of rehabilitation outcomes. But other factors also take on importance. For example, after discharge there may be more changes to the patient situation than anticipated. This leads to the question of which factors could possibly be anticipated or in which cases intervention might be undertaken already at the time of rehabilitation? Generally, the severity of stroke, i.e. limited physical and cognitive functioning, have an impact on daily living after discharge (Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002). However, it is also an important factor in maintaining the ability to live independently in the ensuing years.

In our research, receipt of informal or formal help, continued therapies, negative changes in social context, as well as decreased health were related to deterioration in living arrangements in comparison to clinical

assessment at discharge. This finding indicates that negative external factors do have adverse effects on living independently after stroke despite positive perspectives at the time of discharge on the part of the rehabilitation facility.

This raises the question of which factors rehabilitation and care professionals should be taking into account when assessing which long-term goals can realistically be attained post-discharge. Our data are not sufficient to answer this question in detail, but the results indicate that the availability of informal caregivers is a key factor. As is found in other research, the presence of family members or friends facilitates discharge home (Frank, Conzelmann, & Engelter, 2010; Ween, Alexander, D'Esposito, & Roberts, 1996) and as such, they are a valuable resource.

However, we also found that help from family members or other persons after discharge could be counterproductive to post-discharge goal attainment. Informal caregivers are at risk of being over-protective (Wood, Conelly, & Maly, 2010) and this behaviour is contrary to goal attainment post-discharge (Pound, Gompertz, & Ebrahim, 1998). Here the positive effects of informal caregiving may apply (Poulin et al., 2010). Giving informal care not only presents negative outcomes, but can reinforce life satisfaction.

### **Informal caregiving and care patterns**

Informal caregiving is an important condition for care recipients to live independently. It also is an essential issue of the public health system, albeit not yet fully acknowledged (DeFries, McGuire, Andresen, Brumback, & Anderson, 2009). Therefore we studied the informal care given by family members or friends of stroke patients. Informal care complements the formal services in health care (DeFries, et al., 2009) and helps to sustain care that has to be provided at home around the clock,

i.e. all day long and during the night (Döhner & Kofahl, 2007). It is a common societal expectation that family members adopt the role of informal caregivers. Most often, female spouses or partners provide the bulk of informal caregiving (Mnich & Balducci, 2006).

In our study we have identified patterns of informal caregiving one to three years following discharge from a rehabilitation facility. These care patterns refer to the number of persons involved and the degree of disability and dependence of the stroke survivor being cared for. In many cases, if the degree of disability and dependence allows, informal care is executed by one person only. This is usually the person closest to the stroke survivor. However, if dependence increases and the care demand becomes exhausting, more persons are called in. Our findings show that the proportion of care patterns with more than one person providing care is larger when the duration of caregiving is longer. The type of disability and dependence indicates the category of informal caregiving. At the point at which a person is physically independent but needs occasional support with societal activities, e.g. managing financial matters etc., the caregiver is more likely to be someone outside of the core family. The wide range of issues of informal care and their organisation related to the impact of stroke on the care recipient is often reported (McKevitt, Redfern, Mold, & Wolfe, 2004). Regardless of the care pattern the aim of informal caregiving remains ensuring the best quality of care. Particularly in the very beginning of providing care the informal caregivers often have to learn by trial and error (Bhogal, Teasell, Foley, & Speechley, 2003). Both the stroke survivor and the informal caregiver may experience uncertainty about the diseases trajectory, its possible implications on the stroke survivor and the care interventions necessary (Sit, Wong, Clinton, Li, & Fong, 2004).

The sudden onset of stroke affects not only the patient but also the entire family system. This new and unexpected situation embodies a life-threatening health condition with an unpredictable course of recovery. Persistent disabilities necessitate caregiving for an undefined period of time. Caring for a stroke survivor is a demanding task. Adopting this role and its new tasks is challenging and can cause role stress (Forsberg-Wärleby, Möller, & Blomstrand, 2004; Pearlin, Mullan, Semple, & Skaff, 1990), not only for the caregiving person. The stroke also alters the family structure in that the survivor has to abandon his or her pre-stroke role and come to terms with being dependent. The consequences of stroke on the family system cannot be prevented. Family functioning is assumed to be an important factor to provide care and to support the stroke survivor in restoring functioning and being able to live as independent as possible. In turn, poor family functioning might result in deterioration and poor patient outcomes (Bhagal, et al., 2003).

For informal caregivers providing care to stroke survivors is not always easy. For this reason we assessed the extent of caregiver burden experienced. We applied an instrument based on the Caregiver Burden Inventory (Novak & Guest, 1989). The instrument has been translated into German and adapted to the Swiss cultural background. No information is available on the translation process. Nevertheless it is of standard use in urban long-term care settings.

Although frequently used, the instrument has not yet been validated. Therefore, we tested its psychometric qualities. Test results for construct validity point towards the multidimensionality of some of the items. Notwithstanding, the resulting validity is satisfactory. Consistency was excellent when testing the entire scale as mentioned before. The psychometric quality is comparable with that of the original instrument reported in several studies.

However, further development and validation is needed. First, no information on the instrument's translation is available. It seemed to be an open translation and not to be executed forwards and backwards. That is why the wording should be reconsidered in order to make results comparable with other studies where the original CBI was used. Then, the various dimensions (time burden, personal developmental burden, emotional burden, physical burden, and social burden) within the concept of caregiver burden should be identified. It is important that these dimensions be distinguished because they indicate more precisely which aspects of the caregiving process are stressful and will therefore offer ways to develop specific interventions to reduce or prevent caregiver burden.

We applied this instrument to the informal caregivers identified by the stroke survivors who participated in our study. The degree of caregiver burden experienced in our sample was rather low on average with reference to the maximum score. Duration of caregiving of either one, two or three years did not have an impact. Differences in burden were found with respect to the living situation and need for care. When the stroke survivor was able to live independently, and did not need any care or support, caregiver burden was scored low. However, when care and support had to be provided regularly, caregiver burden was scored higher. There was no difference found between the extent of caregiver burden when the stroke survivor was living at home together with the informal caregiver or when the stroke survivor being cared for in an institution. These results are in line with research on nursing home transitions. Informal caregiver experience burden further, even though they stopped providing hands-on-care (Gaugler, Roth, Haley, & Mittelman, 2008).



We found that a strong sense of mastery is a salient characteristic that seems to offer protection from experiencing high levels of caregiver burden. Sense of mastery refers to a person's self-perception of being in control of everyday life, also in unexpected situations. In our statistical model, sense of mastery overruled all competing variables, e.g. motor and cognitive functioning. Burden is suggested to be an emotionally laden factor. Some personal characteristics may contribute to better dealing with such stressors (Blake, 2007). Pearlin (1990) and Badura (1987) added sense of mastery to these beneficial characteristics (Badura et al., 1987; Pearlin, et al., 1990).

Both our findings of patterns of informal caregiving and the degree of subjective caregiver burden indicate that involving family members in an early stage of the rehabilitation course prepares them for the long-term maintenance of assistance and care. Persons providing informal care to stroke survivors should be informed about the lasting consequences of stroke, the resulting care demands for an indefinite period of time, and the unknown complications that might arise (Adriaansen, van Leeuwen, Visser-Meily, van den Bos, & Post, 2011; Brodaty & Donkin, 2009; King, Hartke, & Houle, 2010; van Durme, Macq, Jeanmart, & Geobert, 2012). The consequences of caregiving on informal caregivers should be stated early, e.g. experience of burden, deterioration of the caregiver's own health and quality of life (Jungbauer, Döll, & Wilz, 2008; Ski & O'Connell, 2007). Health professionals should counsel and support the family member or friend in adopting the caregiver role (van Heugten, 2006).

### **Reintegration into normal living**

The underlying purpose of the goal-setting approach and the ultimate goal of rehabilitation are to enable patients to return as closely as possible to their 'pre-stroke' life, i.e. to live as normally as possible or to reintegrate into normal living. In the international research field a specific

instrument was developed to assess reintegration into normal life, the Reintegration into Normal Living Index (RNL) (Wood-Dauphinee, Opzoomer, Williams, Marchand, & Spitzer, 1988). But it had not yet been validated in German-speaking Switzerland. In our research the RNL proved to be a reliable and valid instrument when the total score is used. We believe the total score of RNL is a significant and valid outcome measure for rehabilitation. Despite being recommended in stroke studies (Carter, Buckley, Ferraro, Rordorf, & Ogilvy, 2000; Daneski, Coshall, & Wolfe, 2003) and its assumed potential (Bourdeau, Desrosiers, & Gosselin, 2008; Carter, et al., 2000) the RNL Index is not yet frequently used to assess 'ultimate rehabilitation outcomes'. There is, however, a scientific debate about the need to distinguish various dimensions within RNL, especially between the mobility aspect and the coping aspect. This debate should be continued because it is not only scientifically relevant, but also may bring forward ideas about new, specific interventions in the rehabilitation process.

We found that RNL scores are not affected by the number of years following discharge from clinical rehabilitation. It is important to establish whether these findings will be found in other studies or not. Our findings suggest that reintegration into normal living may be 'settled' shortly after discharge from the rehabilitation facility or even during inpatient rehabilitation. If so, this would underline the importance of goal setting and goal attainment during rehabilitation. The RNL items operationalize the process of reintegration by addressing relevant domains and illustrate the field of patient activities and interactions with their context necessary for achieving reintegration to normal living. As such, the RNL items might provide the basis for a shared understanding of the concept of reintegration between professionals, stroke patients and their families. This is important because the understanding of ultimate rehabilitation outcomes and the means by which they are achieved have been

found to differ between professionals and stroke patients (McKevitt, et al., 2004). A shared understanding would encourage patients to participate in goal setting and likewise motivate participation in rehabilitation activities. This could also have the effect of facilitating the involvement of family members in the rehabilitation process.

Furthermore, the RNL items could be deployed as a means of assessing the fields that need to be addressed for successful reintegration. Then the appropriate interventions could be implemented to support patients and their families not only in learning and practicing the appropriate skills but also in integrating these skills into everyday life.

### **Strengths and weaknesses of this study**

This study is unique in the sense that we described the outcomes of rehabilitation at a clinic where goal setting and goal attainment were introduced some years ago, based on the ICF model. To our knowledge, this rehabilitation method is still unique in German-speaking Switzerland and seldom applied in other rehabilitation facilities in Europe.

Several strong points can be emphasized: we have well-registered data regarding the functionalities of the stroke patients during clinical rehabilitation and we were able to combine these data with information received from patients and family members one to three years following discharge from inpatient rehabilitation. However, in addition we accessed clinical data that were not specifically collected for research purposes but generated in on-going clinical rehabilitation processes. We developed the questionnaires together with professionals working at the study site who were familiar with clinical processes and locality. Then we were able to look into clinical decision-making within common processes in rehabilitation. These processes involved members of various disciplines who contributed equally to decision-making irrespective

of traditional hierarchy. Furthermore, our data enabled us to describe in detail what is to be expected to patients, families and informal caregivers and to describe what has to be considered both during inpatient rehabilitation and afterwards.

Another strong point is that we validated instruments that are often used in health care research. The RNL Index has been made available for further testing and application in German speaking settings. The extent to which results from the CBI Zurich Version could be relied on was not known. By scientifically testing its psychometric properties we gained initial evidence that the scale is valid and reliable.

At this point we would like to address several weak points in our study: our access to clinical data were limited and did not allow for collecting information on marital status, education and other variables that could have been relevant in answering our research questions. We ourselves had no access to the study site and were therefore dependent on all information being provided by employees of the facility. Assessing Sense of Mastery and Reintegration in Normal Living provided strong data for our analysis. Nevertheless, use of more and better validated instruments would have lent further corroboration to our results. There was the fear that the more items presented, the less likely the questionnaire would be completed in full. An interdisciplinary approach in questionnaire development neither helped to prevent redundancy nor did it enable us to avoid complicate wording. It was only at the point of analyzing our data that we realized that we had neglected to collect data that would have supported our interpretations.

If discharged patients were moved to an institution at some point after discharge, a certain number were likely to be lost to follow-up, as were 28 patients in our sample. This would indicate a selection bias in that

patients were missed, who did not attain their long-term goal. Due to our lack of access, we could not analyze the goal-setting process, and the role of the different disciplines in this process and in goal attainment. Then, informal caregivers were not directly approached for study participation. The patients were asked to give a separate questionnaire to their next of kin. For this reason we have no information on whether responders differ from non-responders.

The generalization of our results is limited since data were collected in one facility only. Generalization is also limited by our loss of the most vulnerable patients in the follow-up measurement. On the other hand, this is the only neurorehabilitation facility in German-speaking Switzerland to systematically introduce such a goal-setting system and to have gathered experience in its application. Hence, the outcomes may be seen as representative for such an approach and in such a population.

## **Recommendations**

### **Practice**

#### **Clinical rehabilitation**

Literature reports that patients generally appreciate being involved in goal setting. However, their point of reference differs considerably from that of professionals and this cannot be disregarded when involving patients in goal setting. Literature emphasizes that professionals must strive to understand the patients' point of view and to bring this in line with their professional concerns when formulating rehabilitation goals that are both meaningful and at the same time clinically relevant.

A team-based approach in goal setting needs structure for coordination. The team conference protocol as applied at our study site suggests a structure that would support other rehabilitation teams to set realistic and attainable goals.

Goal attainment is associated with cognitive functioning. To improve patient outcomes related to living independently the rehabilitation professionals should focus on cognitive functioning. That is, cognitive functioning should be systematically assessed, monitored and, where appropriate treated.

Reintegration in normal living is associated with independent living following discharge. Reintegration requires a certain degree in physical and cognitive functioning. In our study results mobility and communication were related with the extent of reintegration. While restoring physical functioning is prominent in rehabilitation therapies, aspects that affect social interactions are less stressed. In discharge planning not only assistance in activities in daily living should be addressed. It should also be assessed to what extent support in social interactions is required for successful reintegration in normal living.

Family members are ones most often caring for stroke survivors after discharge. Being over-protective is reported to be counterproductive to long-term goal attainment. For this reason, family members should be involved early on in the rehabilitation process and carefully educated in providing adequate care.

### **Support in care at home**

Still three years after discharge from stroke rehabilitation the majority of stroke survivors were in need of daily care. Care is mostly provided by close family members. Since stroke has a sudden onset, the informal caregivers are required to adopt the caregiving role quickly. Already during inpatient rehabilitation health professionals should carefully inform the family members about the course of the disease and its consequences for both, stroke survivors and informal caregivers, the amount of care to provide in relation to the individual stroke survivor's limitations, and about the indefinite period of caregiving.

Caregiver burden is frequently observed in long-term caregiving situations. A timely assessment of caregiver burden could help to protect the caregiver and the care recipient from negative effects of caregiving. This would help to maintain the stability of the informal care setting.

Some personal characteristics may contribute to better cope with stressors and their consequences. Sense of mastery is described as a personal resource to deal with life circumstances. In our findings sense of mastery is adversely related to caregiver burden. That is why sense of mastery should be assessed in family members or potential informal caregivers to identify those who are likely to experience negative consequences of informal caregiving. Health professionals then could better prepare for the new tasks and role, and follow up to monitor the course of caregiving and its consequences.

## **Research**

The outcome of direct patient involvement in goal setting on goal attainment is not yet fully investigated. Since different versions of patient involvement in goal setting are practiced across rehabilitation facilities (patient directly involved, patient only informed, patient not informed) the outcomes could be studied in a natural setting provided that patient's variables can be matched, and rehabilitation therapies are comparable.

Patients may benefit by actively participating in clinical rehabilitation activities. The need to track participation has been acknowledged in the literature. The instruments developed so far should be improved in two directions. They should be able to demonstrate changes in patient participation over time. They also should be applicable by the majority of healthcare professionals in the multidisciplinary team to allow for comparing patient participation between therapy sessions or patient care situations.

The team-based approach to goal setting and evaluation proved to be successful during inpatient rehabilitation. However, the way information is processed and goals are determined during team conferences remains unclear. Evaluation research or a qualitative approach might be the appropriate way to shed light into this 'black box' on this area.

Reintegration in normal living is the ultimate outcome of rehabilitation. The German version of the RNL Index shows satisfactory psychometric properties. Regardless of this, the wording should be examined for better understanding as well as its multidimensionality. In this process, patients, families and care professionals should be involved. Further testing of the validity is needed and should encompass other patient groups.



As we have shown still little is known about changes in patterns of informal caregiving over time, and whether they are related to stroke survivors' and informal caregivers' outcomes, i.e. reintegration in normal living and caregiver burden. Longitudinal research is needed to detect changes in patterns over time and to test for association with stroke survivors' and informal caregivers' characteristics and outcomes.

The impact of caregiver burden on informal caregivers has been widely studied in diverse populations. Nevertheless, research on the long-term course of caregiver burden and changes over time is sparse. This information is needed to understand the relationship between duration of caregiving, changes in the care recipient's characteristics, and burden experienced by the informal caregivers. Such insight would be helpful to develop appropriate interventions that explicitly include the long-term perspective of informal caregiving.

The Caregiver Burden Inventory, Zurich Version showed to be valid and reliable when used in a German-speaking Swiss sample giving informal care to stroke survivors. Further validity testing is needed to demonstrate psychometric properties when applied to informal caregivers of persons suffering from chronic conditions other than stroke.

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## **Summary**

## **Summary**

Medical treatment for chronic and acute diseases has advanced over the past decades to such an extent that survival rates have increased. This has also been observed for cerebrovascular accidents (strokes) and therefore stroke has become a major cause of persistent disabilities. Stroke impairs physical and cognitive functioning and affects the whole person. Stroke not only changes the lives of the individuals afflicted but also the lives of their families. Rehabilitation programs provide effective treatment for recovering impaired physical and cognitive functioning. However, many people still need care and support following discharge home after stroke rehabilitation. This care is often provided by informal caregivers such as partners, children, other relatives, friends or neighbors who are required to adopt the caregiving role for an indefinite period. Providing such care represents positive and negative challenges and can cause considerable stress.

In Chapter 1 we introduce the double focus of our research study: investigating stroke patients one to three years following discharge and their informal caregivers. This enabled us to examine aspects of stroke care from two perspectives. We first determined how goals are set and evaluated during inpatient stroke rehabilitation. Then we investigated the attainment of long-term goals one to three years following discharge. And lastly, we assessed the informal caregivers involved in caring for these patients post-discharge and the extent to which providing care was experienced as stressful.

In Chapter 2 we identify facilities in German-speaking Switzerland that specialized in stroke rehabilitation. These settings are important as they have the expertise necessary to help stroke patients regain function and independence. Goal setting is considered to contribute to the recovery of the patient and should tap a patient's potential and meet the individual

patient's needs. It is therefore important to involve the patient in setting goals. We investigated the extent to which patients and their families are directly involved in goal setting. All rehabilitation facilities involved in the study stated that goal setting is included in their program and three different variations of goal setting were identified. The first involved the patients directly. The second set goals without consulting the individual patient and then informing him/her of the outcome. The third did not involve the patient in goal setting and did not inform the patient of the established goals.

In Chapter 3 we reflect back on our original research project which was prematurely terminated. In that project we strived to investigate the effect of direct patient participation in rehabilitation goal setting on goal attainment and, at the same time, to evaluate the goal-setting process that takes place within a multidisciplinary rehabilitation team. There were several obstacles hindering the implementation of this project. And despite a positive start, we were eventually compelled to terminate. We describe the lessons learned and those needed to be kept in mind for future research endeavors. Gaining access to study sites, building networks and acquiring funding were major obstacles that we initially underestimated.

In Chapter 4 we focus on the concept of patient participation. Rehabilitation professionals work daily with patients to restore all aspects of functioning, and patients have a crucial role by actively participating in the rehabilitation activities. We were interested in how patient participation could be improved. Using the appropriate instrument would allow patient participation to be monitored and options to be identified that would support patients in achieving optimal participation. Through a systematic literature review we found three instruments that differed in their underlying conceptualization. They were developed by two of the

## Summary

professions included in the multidisciplinary rehabilitation team. Although the instruments appear to be useful in assessing specific aspects of patient participation, they are not yet ready for clinical application. We recommend further development of such instruments with an emphasis on the multidisciplinary aspects.

In Chapter 5 we assess the degree of goal attainment during inpatient rehabilitation. We worked together with a neurorehabilitation facility in German-speaking Switzerland that had established a systematic procedure for goal setting based on the International Classification of Functioning, Disability and Health (ICF). This procedure incorporates a team conference protocol that allows all professionals involved the opportunity to contribute on an equal basis to patient assessment and goal setting. We specifically assessed the goal pertaining to post-discharge living arrangements, i.e. the extent to which patients could live independently after discharge from rehabilitation. The sample consisted of 287 patients at the time of discharge from the rehabilitation facility. The majority of patients had attained this goal at the time of discharge. Non-attainment could be attributed to too little improvement in cognitive functioning during inpatient rehabilitation.

In Chapter 6 we follow these same patients to assess goal attainment with regard to independent living one to three years post-discharge. Long-term goals are frequently set during inpatient rehabilitation but goal attainment following discharge is rarely monitored. We investigated the extent to which this long-term goal was attained. We sent a questionnaire to the 287 patients described in chapter 5. Of these, 174 returned the completed questionnaire. Half of the respondents achieved their long-term rehabilitation goal. We found impaired physical functioning at discharge to be related to non-attainment of the goal of independent living. Help from family members or other persons as well as



continued therapy immediately after discharge was also associated with a failure to attain the long-term goal.

In Chapter 7 we conduct a systematic literature review to explore the long-term caregiver burden. One result of progress in medical treatment and improved outcomes is that today more people suffer from chronic diseases and require long-term care. Stroke and dementia are among the most common chronic conditions requiring long-lasting informal care. Providing care for a person suffering from either an improving or deteriorating disease has a great impact on the caregiver. Burden as a negative effect of caregiving has been well investigated, but less is known of the long-term effect of this burden on informal caregivers. The result of our literature review was disappointing due to the fact that few studies report on this topic from a long-term perspective. In addition, no common trend regarding the course of burden has been observed. The extent to which an individual experiences burden varies, at times improving and at times worsening. But it is clear that burden will never disappear completely.

In Chapter 8 we describe the patterns of care provided to stroke survivors from the perspective of informal caregivers. Two questionnaires were sent to the identified stroke survivors, one for the patient and one for the informal caregiver who was involved in their personal care and assistance. This resulted in 136 responses from informal caregivers. In 132 cases the informal caregiver could be linked with the individual patient. Because some stroke survivors no longer needed any help or assistance, 103 dyads (informal caregiver and care recipient) remained in the final analysis. We identified five patterns of informal caregiving by quantifying the degree to which caregivers are involved in relation to the limitations of the care recipient. We found that the spouse or partner primarily gives informal care either alone or together with other persons.

## Summary

For example, whenever assistance or care had to be provided around the clock, at least one more person was called in to help. Conversely, we found that the less dependent the stroke survivor is, the more often care is provided by someone less closely attached than a spouse.

In Chapter 9 we test an instrument, often used in Switzerland for long-term care, to assess caregiver burden. It is an internationally validated instrument that has been translated for the Swiss setting. No information was available regarding the validity and reliability of the Swiss version. In an effort to address the Swiss cultural background, some of the items differed in wording from the original instrument. Psychometric testing indicated satisfactory reliability and validity. In spite of this, we recommend evaluating the wording in relation to the original instrument and subjecting it to further testing.

In Chapter 10 we look at the psychometric properties of the Reintegration in Normal Living Index (RNL). This is an internationally validated instrument to determine the extent to which reintegration into everyday life is managed, according to the patient, after an illness that results in permanent disability. As indicated earlier, reintegration into normal patterns of everyday life is an important goal in stroke rehabilitation. The RNL items mainly refer to mobility and social life. We received authorization to translate the instrument from Canadian English into German for Switzerland and to test it in practice. Two dimensions have been previously identified. However, in our factor analysis we found an overlap between both dimensions and therefore applied the index as a single scale. The RNL Index proved to be a valid and reliable measure for reintegration. For the future, we recommend further investigations of the distinction between the two dimensions.

In Chapter 11 we assess perceived caregiver burden in persons caring for stroke survivors. We administered the instrument reported in chapter 9 to a sample of 132 informal caregivers who were taking care of stroke survivors one to three years following discharge from inpatient rehabilitation. The burden experienced was comparatively low. This applies both to those who had provided informal care for one year and for those giving care for three years. Regression analysis showed that patient characteristics did not relate to the degree of burden. However, when sense of mastery was introduced into the regression analysis it had an overriding impact on caregiver burden. Informal caregivers who managed to keep control in different life situations experienced less burden than those who did not.

In Chapter 12 we identify determinants of reintegration into normal life. We applied the RNL Index as described in chapter 10 as the dependent variable. Time since discharge from inpatient rehabilitation does not appear to be related to the degree of reintegration. Respondents living in an institution scored lower on the RNL Index than those living independently at home. In a stepwise regression analysis, cognitive functioning at discharge appeared to impact the degree of reintegration. In the final model, however, mobility and communication, as assessed by the questionnaire, were strongly related to reintegration into everyday life.

In Chapter 13 we present a summary of the main findings of our study. In addition, we discuss the results and give recommendations for clinical rehabilitation, for home support for stroke patients, for support for caregivers of stroke patients, and for further research.



## **Samenvatting**

## **Samenvatting**

De afgelopen decennia zijn medische behandelingen voor chronische of infauste aandoeningen zodanig verbeterd dat de overleving (zoals na een cerebrovasculair accident (CVA/beroerte)) veel vaker voorkomt dan voorheen. Een CVA/beroerte blijft echter een belangrijke oorzaak voor een blijvende beperking. Een beroerte tast het lichamelijk en cognitief functioneren aan en beïnvloedt de hele persoon. De aandoening verandert niet alleen het leven van het getroffen individu getroffen, maar ook het leven van zijn familieleden.

Revalidatie biedt effectieve behandelingen om verminderde fysieke en cognitieve functies (groten)deels te herstellen. Toch hebben veel mensen na een beroerte, nadat ze zijn ontslagen naar huis uit een revalidatiekliniek, nog zorg en ondersteuning nodig. Vaak wordt deze zorg verstrekt door informele verzorgers zoals partner, kind, andere familieleden, vrienden en/of burens (mantelzorgers). Mantelzorgers nemen daarmee de rol van zorgverlener voor onbepaalde tijd op zich. Het geven van mantelzorg is een positieve en negatieve uitdaging en kan leiden tot aanzienlijke stress.

Zoals we in hoofdstuk 1 aangeven staan in dit onderzoeksproject zowel patiënten na een beroerte als hun mantelzorgers centraal. Enerzijds wordt nagegaan in hoeverre doelstellingen tijdens de klinische revalidatie bij patiënten met een beroerte worden gerealiseerd en hoe het hen vergaat na ontslag uit de revalidatiekliniek. Anderzijds wordt beschreven welke mantelzorgers betrokken zijn bij de zorg thuis aan deze patiënten na ontslag en in hoeverre deze zorg als belastend wordt ervaren. Het onderzoek richt zich op patiënten, die een tot drie jaar eerder ontslagen zijn uit een revalidatie kliniek.

In hoofdstuk 2 beschrijven we de revalidatie instellingen, die gespecialiseerde zijn in de behandeling van beroerte, in het Duitstalige deel van Zwitserland. Deze instellingen zijn belangrijk omdat ze over de expertise (dienen te) beschikken, die nodig is om patiënten met een beroerte te helpen weer onafhankelijk te kunnen functioneren. Hiertoe stelt de revalidatie instelling specifieke doelen, die enerzijds tegemoet komen aan de individuele behoeften en wensen van de patiënt en anderzijds rekening houden met de mogelijkheden die de patiënt (nog) heeft. Het stellen van deze doelen wordt geacht bij te dragen aan het herstel van de patiënt. Daarbij is het van belang de patiënt te betrekken bij het stellen van die doelen. Wij hebben onderzocht in welke mate patiënten en hun familie direct betrokken zijn bij stellen van doelen in de revalidatie instellingen in het Duitstalige deel van Zwitserland.

Alle revalidatie instellingen die hebben deelgenomen aan het onderzoek geven aan dat zij revalidatie doelen bij patiënten stellen en deze uitvoeren.

Dit kan echter op verschillende manieren gebeuren en er zijn drie verschillende benaderingen geïdentificeerd. Sommige instellingen betrekken patiënten direct bij het vast stellen van de doelen. Andere instellingen stellen doelen zonder aanwezigheid van de individuele patiënten, maar informeren hen later over de gestelde doelen. Weer andere instellingen stellen ook doelen zonder de patiënt daar direct bij te betrekken, maar informeren daar de patiënten of familie (ook later) niet over.

In hoofdstuk 3 kijken we terug op een voortijdig afgebroken onderzoeksproject. In dat project streefden we er naar om het effect van directe deelname van de patiënt aan de revalidatie zorg via het stellen van specifieke doelen te onderzoeken. Tegelijkertijd wilden we het proces waarop de doelen binnen het multidisciplinaire revalidatieteam werden vast gesteld beschrijven. Er waren echter diverse obstakels die ons

belemmerden het project uit te voeren. Ondanks een positieve start zijn we uiteindelijk gedwongen om het project voortijdig te beëindigen. We beschrijven de lessen die hieruit te leren zijn. Deze lessen houden we in gedachten voor toekomstige onderzoeksplannen. Toegang krijgen tot de instellingen, die men wil bestuderen, het opbouwen van een netwerk in het veld, waarbinnen het onderzoek speelt, en het verwerven van financiële middelen waren de grote obstakels waar we aanvankelijk geen rekening mee hadden gehouden.

In hoofdstuk 4 komt het concept ‘patiëntenparticipatie’ aan de orde. In de revalidatie werken professionals dagelijks met patiënten om hun functioneren te herstellen. Patiënten zelf spelen een cruciale rol in hun eigen revalidatieproces door actief deel te nemen aan revalidatieactiviteiten. Met het juiste instrument in de hand, kan patiëntparticipatie worden vastgesteld en gecontroleerd en kunnen opties worden geïdentificeerd die optimale participatie van patiënten ondersteunen. Via een systematisch literatuur onderzoek vonden we drie instrumenten om de mate van patiëntenparticipatie vast te stellen. Deze drie instrumenten verschillen in hun onderliggende conceptualisering. Ze zijn ontwikkeld door twee disciplines, die werkzaam zijn binnen een multidisciplinair revalidatieteam.

Hoewel de instrumenten volgens de gerapporteerde onderzoeken bruikbaar zijn bij de beoordeling van specifieke aspecten van patiëntparticipatie, zijn ze nog onvoldoende ontwikkeld voor klinische toepassing in een multidisciplinair revalidatieteam. Wij bevelen verdere ontwikkeling van dergelijke instrumenten aan, waarbij de nadruk dient te liggen op multidisciplinaire aspecten.

In hoofdstuk 5 onderzoeken we de mate van doelbereiking tijdens klinische revalidatie. Hiertoe is samengewerkt met een revalidatie instelling in het Duitstalige deel van Zwitserland die een systematische



procedure voor het stellen van doelen heeft ingevoerd, gebaseerd op de International Classification of Functioning, Disability and Health (ICF).

De instelling hanteert een team conferentie protocol dat alle professionals die betrokken zijn bij de zorg voor de patiënt de gelegenheid geeft om – op voet van gelijkheid – een bijdrage te leveren aan beoordeling van de patiënt en het stellen van doelen. Wij hebben als belangrijkste doel de (leef)situatie na ontslag gekozen: de mate waarin men onafhankelijk kon wonen/leven na ontslag uit de revalidatie instelling. In totaal gaat het om 287 patiënten. De meerderheid van de patiënten bereikt dit doel.

Als het doel niet bereikt wordt, kan dit toegeschreven worden aan te weinig verbetering in het cognitief functioneren van de patiënt tijdens de revalidatie.

In hoofdstuk 6 worden dezelfde patiënten beoordeeld op het bereiken van het doel ‘mate van onafhankelijk leven/wonen’ een tot drie jaar na ontslag. Lange termijn doelen worden tijdens het revalidatieproces gesteld, maar doelbereiking na ontslag wordt zelden gevolgd. We hebben de lange termijn doelbereiking ‘de mate waarin men onafhankelijk woonde/leefde’ onderzocht. Hiertoe is aan alle patiënten een vragenlijst gestuurd. Van 174 patiënten (van het totaal van 287) is een ingevulde vragenlijst retour ontvangen.

De helft van de mensen met een beroerte in onze steekproef blijkt het gestelde lange termijn doel te hebben bereikt. Verminderd functioneren bij ontslag hangt samen met het niet bereiken van het lange termijn doel. Hulp van familieleden of andere personen, evenals behandelingen onmiddellijk na ontslag zijn ook geassocieerd met het niet bereiken van het lange termijn doel.

Als gevolg van de vooruitgang in medische behandeling lijden steeds meer personen aan een chronische aandoening die informele zorg voor

een onbepaalde tijd nodig maakt. Beroertes en dementie behoren tot de meest voorkomende chronische aandoeningen waarbij langdurige mantelzorg veel voorkomt. 'Caregiver burden' als een negatief effect van mantelzorg is goed onderzocht, maar minder bekend is wat de lange termijn effecten zijn op mantelzorgers. In hoofdstuk 7 onderzoeken we wat bekend is over de lasten van mantelzorgers op langere termijn via een systematische literatuur review. De resultaten zijn teleurstellend vanwege het feit dat weinig studies rapporteren over de 'burden' van mantelzorgers op langere termijn. De weinige, beschikbare onderzoekdata laten geen duidelijke trend zien in het verloop van de 'burden'; soms verbeterde de individueel ervaren belasting met de tijd, maar bij ander onderzoek verslechterde deze. Duidelijk is wel dat deze belasting nooit helemaal verdwijnt.

In hoofdstuk 8 beschrijven we de zorgpatronen aan CVA patiënten door mantelzorgers. Aan de patiënten is gevraagd een bijgevoegde vragenlijst te geven aan de persoon, die het meest betrokken was bij de zorg voor de patiënt. Dit resulteerde in 136 reacties van mantelzorgers, waarvan 132 keer patiënt en mantelzorger gekoppeld konden worden. Omdat sommige patiënten geen hulp (meer) nodig hadden of naar een zorginstelling waren verhuisd, zijn uiteindelijk 103 'koppels' in de analyse betrokken.

Vijf patronen van mantelzorg zijn geïdentificeerd. Partner of nabije familie (meestal een kind) geeft het meest frequent informele zorg en de partner doet dit ook relatief vaak alleen. Als zorg dag en nacht nodig is, dan wordt altijd een beroep gedaan op een tweede persoon of op meer personen. Omgekeerd blijkt dat hoe onafhankelijker de patiënt na de beroerte is des te vaker de partner (indien aanwezig) de zorg alleen aan kan.

In hoofdstuk 9 wordt een instrument getest dat in de praktijk in Zwitserland wordt gebruikt om de 'burden' van mantelzorgers te beoordelen. Er was geen informatie beschikbaar over de validiteit en betrouwbaarheid van deze versie. Het is een vrij vertaalde versie van een internationaal gevalideerd instrument, waarbij formuleringen en items zijn aangepast aan de Zwitserse context. Psychometrische testen tonen aan dat het instrument betrouwbaar en valide is. Desondanks bevelen we aan de formulering ten opzicht van het oorspronkelijke instrument te toetsen en vervolgens het instrument opnieuw te valideren.

De Re-integratie in Normal Living (RNL) index is een internationaal gevalideerd instrument om vast te stellen in hoeverre re-integratie in het leven van alle dag is gelukt volgens de patiënt na een ziekte met een blijvende beperking. Zoals eerder aangegeven is re-integratie in de normale patronen van alle dag na een beroerte een belangrijk doel van revalidatie. In hoofdstuk 10 beschrijven we de psychometrische eigenschappen van de RNL. De RNL vragen hebben voornamelijk betrekking op de mobiliteit en het sociale leven.

We hebben toestemming ontvangen om het instrument te vertalen van het Engels in het Duits en het in de praktijk te gebruiken. Bij factoranalyse worden twee dimensies binnen de RNL geïdentificeerd, die elkaar deels overlappen. Daarom hebben we in dit onderzoek de RNL als één schaal gebruikt. Deze schaal (RNL index) blijkt een valide en betrouwbare maat voor re-integratie te zijn. Wel bevelen we aan het onderscheid tussen de twee dimensies nader te onderzoeken.

In hoofdstuk 11 beschrijven we de ervaren lasten ('burden') van de mantelzorgers bij hun zorg voor mensen na een beroerte. Hiertoe gebruikten we het instrument gemeld in hoofdstuk 9 bij een steekproef van mantelzorgers (n=132) die zorgden voor iemand na een beroerte een tot drie jaar nadat deze persoon uit de revalidatiekliniek was ontslagen.

## Samenvatting

De ervaren last blijkt in dit onderzoek relatief laag. Dit geldt zowel voor hen die de informele zorg een jaar geven als voor hen die het drie jaar geven. De regressie analyse toont aan, dat geen van de patiëntenkenmerken gerelateerd is aan de mate van 'burden'. Echter de mate van 'mastery' heeft een significante invloed op de mate van ervaren 'burden'. Mantelzorgers, die in verschillende situaties controle weten te houden, ervaren minder 'burden' dan zij, die dat niet kunnen.

In hoofdstuk 12 identificeren we de determinanten voor re-integratie in het normale leven. Daarvoor gebruikten we de RNL index zoals vermeld in hoofdstuk 10 als afhankelijke variabele. De tijd na ontslag uit de revalidatiekliniek (een tot drie jaar) blijkt niet samen te hangen met de mate van re-integratie. Respondenten die in een instelling wonen scoren lager op de RNL index (zijn minder gere-integreerd) dan zij die zelfstandig wonen. In de stapsgewijze regressie analyse lijkt het cognitief functioneren bij ontslag uit de revalidatie instelling een effect te hebben op de mate van re-integratie. In het uiteindelijke model echter blijken de mobiliteit en de communicatie mogelijkheden na ontslag sterk gerelateerd te zijn aan re-integratie in het leven van alle dag.

In hoofdstuk 13 geven we een samenvatting van de belangrijkste bevindingen van onze studie. Daarnaast bediscussiëren we de resultaten en geven aanbevelingen voor de klinische revalidatie, voor ondersteuning thuis van mensen na een beroerte en voor verder onderzoek.

# **Zusammenfassung**

## **Zusammenfassung**

In den vergangenen Jahrzehnten hat sich die medizinische Behandlung derart verbessert, dass das Überleben von chronischen und akuten Erkrankungen weitaus häufiger vorkommt als früher. Dies trifft auch auf zerebrovaskuläre Insulte (Schlaganfälle) zu. Dennoch ist ein Schlaganfall nach wie vor eine häufige Ursache anhaltender Behinderungen. Ein Schlaganfall beeinträchtigt körperliches und kognitives Funktionieren und betrifft die gesamte Person. Er verändert nicht nur das Leben der davon betroffenen Person, sondern auch das Leben deren Angehörigen. Rehabilitationsprogramme bieten eine wirksame Behandlung zur Wiederherstellung körperlicher und kognitiver Funktionen. Gleichwohl benötigen viele Patienten<sup>1</sup> Pflege und Unterstützung auch nach ihrer Entlassung nach Hause. Diese wird oft von informell Pflegenden erbracht wie z.B. von Ehe- bzw. Lebenspartnern, Kindern, anderen Verwandten oder Personen aus dem Freundeskreis oder der Nachbarschaft. Diese Personen übernehmen die damit verbundene Rolle auf unbestimmte Zeit. Pflege und Unterstützung in diesem Kontext zu leisten birgt sowohl positive als auch negative Herausforderungen und kann erheblichen Stress verursachen.

In Kapitel 1 stellen wir den zweifachen Fokus unseres Forschungsprojekts vor: Schlaganfallpatienten ein bis drei Jahre nach Entlassung aus der stationären Rehabilitation und ihre pflegenden Angehörigen. Das erlaubte uns, Aspekte der Schlaganfallbetreuung aus zwei Blickwinkeln zu untersuchen. Zuerst ermittelten wir, wie Ziele in der Schlaganfallrehabilitation gesetzt und evaluiert werden. Dann evaluierten wir das Erreichen von langfristigen Rehabilitationszielen ein bis drei Jahre nach Austritt. Und schliesslich untersuchten wir die pflegenden Angehörigen, die

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<sup>1</sup> Zur besseren Lesbarkeit wurde nur eine Geschlechterform gewählt, es sind aber stets beide Geschlechter gemeint.

diese Patienten nach Austritt betreuen, sowie das Ausmass, in dem die Angehörigen diese Betreuung und Pflege als belastend erleben.

In Kapitel 2 beschreiben wir Einrichtungen in der Deutschschweiz, die sich auf Schlaganfallrehabilitation spezialisiert haben. Diese Einrichtungen sind von Bedeutung, weil sie über die notwendige Expertise verfügen, Schlaganfallpatienten im Wiedererlangen ihrer Alltagsfunktionen und Unabhängigkeit zu unterstützen. Das Setzen von Zielen wird als Beitrag zur Genesung der Patienten gesehen und sollte sowohl an das Potenzial der Patienten anknüpfen als auch individuelle Patientenbedürfnisse berücksichtigen. Deshalb wird der Einbezug von Patienten in den Prozess der Zielsetzung befürwortet. Wir untersuchten das Ausmass, in dem Patienten und deren Angehörige direkt am Zielsetzungsprozess beteiligt werden. Alle Rehabilitationseinrichtungen, die an dieser Untersuchung teilnahmen, gaben an, dass sie Rehabilitationsziele setzen. Jedoch fanden wir drei Varianten im Vorgehen, wie solche Ziele gesetzt werden. Einige Einrichtungen beteiligten die Patienten direkt. Andere setzten Ziele in Abwesenheit der einzelnen Patienten, informierten sie aber später über die anzustrebenden Ziele. Wieder andere Einrichtungen setzten Ziele ohne Dabeisein der Patienten und unterliessen es ausserdem, die Patienten über das gesetzte Ziel zu unterrichten.

In Kapitel 3 reflektieren wir ein vorzeitig beendetes Forschungsprojekt. Mit diesem Projekt wollten wir in verschiedenen, auf Schlaganfallrehabilitation spezialisierte Einrichtungen untersuchen, welche Wirkung eine direkte Patientenbeteiligung im Zielsetzungsprozess auf die Zielerreichung hat. Gleichzeitig wollten wir den Zielsetzungsprozess evaluieren, wie er im multiprofessionellen Rehabilitationsteam stattfindet. Einige Hindernisse vereitelten die Umsetzung unseres Projekts. Trotz eines positiven Starts sahen wir uns schliesslich gezwungen, das Projekt vorzeitig zu beenden. In diesem Kapitel beschreiben wir die Lektionen, die

wir daraus gelernt haben und jene, die wir für ein zukünftiges Forschungsunterfangen berücksichtigen wollten. Den Zugang zu Studienorten zu gewinnen, das Aufbauen von Netzwerken und das Akquirieren finanzieller Mittel waren die grössten Hürden, die wir anfänglich unterschätzt hatten.

In Kapitel 4 setzen wir uns mit dem Konzept der Patientenbeteiligung auseinander. In der Rehabilitation arbeiten Berufspersonen täglich mit Patienten, um deren persönliche Funktionsfähigkeit wiederherzustellen. Die Patienten selber spielen dabei eine entscheidende Rolle, in dem sie sich aktiv an den Rehabilitationsmassnahmen beteiligen. Uns interessierte, wie die Patientenbeteiligung verbessert werden kann. Mit einem entsprechenden Instrument könnten die Beteiligung der Patienten erfasst und Möglichkeiten identifiziert werden, um sie im Erreichen einer optimalen Beteiligung zu fördern. Mit einer systematischen Literaturübersicht identifizierten wir drei Instrumente, die sich in den ihnen zugrunde liegenden Konzepten unterschieden. Die Instrumente wurden von zwei Berufsgruppen des multidisziplinären Rehabilitationsteams entwickelt. Obwohl die Instrumente im Erfassen spezifischer Aspekte der Patientenbeteiligung nützlich sein könnten, besteht noch weiterer Entwicklungsbedarf, um sie in der klinischen Praxis einzusetzen. Wir empfehlen das weitere Entwickeln solcher Instrumente unter Berücksichtigung der multidisziplinären Aspekte.

In Kapitel 5 beurteilen wir den Grad der Zielerreichung während des stationären Aufenthalts. Wir arbeiteten mit einer Neurorehabilitationseinrichtung in der Deutschsprachigen Schweiz zusammen, die ein systematisches Verfahren zur Zielsetzung und Evaluation anwendet, welches auf der Internationalen Klassifikation der Funktionsfähigkeit, Behinderung und Gesundheit (ICF) aufgebaut ist. Das Verfahren schliesst in seinem Ablauf eine Teamkonferenz ein, die allen beteiligten Berufs-



personen die Möglichkeit einräumt, in gleichberechtigter Weise zum Einschätzen des Patientenzustands und zum Setzen von Rehabilitationszielen beizutragen. Das grundsätzliche Ziel bezieht sich auf die Lebens- und Wohnsituation nach Austritt, d.h. inwieweit Patienten nach der Entlassung aus der Rehabilitation so unabhängig wie möglich leben würden. Die Stichprobe umfasste 287 Patienten zum Zeitpunkt der Entlassung. Die Mehrheit der Patienten erreichte das gesetzte Ziel am Ende des Rehabilitationsaufenthalts. Das Nichterreichen des Ziels konnte mit ungenügenden Fortschritten im Wiedererlangen der kognitiven Leistungsfähigkeit in Verbindung gebracht werden.

In Kapitel 6 untersuchen wir dieselben Patienten, um ihre Zielerreichung ein bis drei Jahre nach Abschluss der stationären Rehabilitation zu erfassen. Langfristige Ziele werden während des Rehabilitationsaufenthaltes zwar regelmässig gesetzt, aber deren Zielerreichung nach Austritt wird selten überprüft. Mit der Befragung erhielten wir die Gelegenheit, das Ausmass zu ermitteln, zu dem die Langzeitziele tatsächlich erreicht wurden. Dazu versendeten wir an alle 287 Patienten, wie in Kapitel 5 erwähnt, einen Fragebogen. Von ihnen schickten 174 den ausgefüllten Fragebogen an uns zurück. Die Hälfte aller Antwortenden erreichte ihr langfristiges Rehabilitationsziel. Wir stellten fest, dass beeinträchtigte Funktionsfähigkeit bei Austritt mit dem Nichterreichen von Zielen in Zusammenhang steht. Ausserdem konnten negative Ergebnisse mit dem Erhalt von Hilfe durch Familienmitglieder oder anderen Personen aber auch mit dem Fortführen von Therapien, beides unmittelbar nach Austritt, in Verbindung gebracht werden.

In Kapitel 7 führen wir eine systematische Literaturstudie durch, um uns mit der Belastung pflegender Angehöriger auseinanderzusetzen. Bedingt durch die Fortschritte in der Medizin und der damit einhergehenden Verbesserung von Behandlungsergebnissen leiden zunehmend mehr

Menschen an chronischen Erkrankungen und benötigen langfristig Pflege und Betreuung. Schlaganfall und Demenz gehören zu den häufigsten chronischen Erkrankungen, die über einen langen Zeitraum Pflege erfordern. Jemanden zu pflegen, dessen Gesundheitszustand sich langfristig verschlechtert oder auch verbessert, hat einen starken Einfluss auf jene Personen, welche die Pflege leisten. Die Belastung als negative Auswirkung informellen Pflegens ist zwar breit erforscht, aber über deren Langzeitauswirkungen ist wenig bekannt. Die Resultate unserer Literaturstudie waren enttäuschend, weil nur wenige Publikationen aus einer Langzeitperspektive darüber berichten. Zudem konnte keine Tendenz ermittelt werden, wie sich die Belastung im Zeitverlauf verändert. Das Ausmass, wie die Belastung individuell erlebt wird, ist unterschiedlich. Die Belastung kann sowohl abnehmen als auch zunehmen, verschwindet jedoch niemals vollständig.

In Kapitel 8 beschreiben wir Pflegekonstellationen zur Betreuung Schlaganfallüberlebender aus der Perspektive pflegender Angehöriger. Den Schlaganfallpatienten versendeten wir zwei Fragebögen; einen für sie selbst und einen zur Weitergabe an jene Person, die in ihre persönliche Pflege und Unterstützung eingebunden war. Auf diese Weise erhielten wir 136 Antworten von pflegenden Angehörigen. In 132 Fällen konnten sie mit dem jeweiligen Patienten in Verbindung gebracht werden. Weil einige Schlaganfallüberlebende keine Pflege oder Betreuung mehr benötigten, konnten schliesslich 103 Paarkonstellationen (Dyaden, d.h. pflegender Angehöriger und Schlaganfallüberlebender) ausgewertet werden. Wenn die Anzahl der an der Pflege beteiligten Personen den Einschränkungen des Pflegeempfängers gegenübergestellt wird, zeigen sich fünf Muster informeller Pflege. Wir stellten fest, dass meistens Ehepartner oder Lebenspartner allein oder gemeinsam mit anderen Personen die Pflege erbrachten. Wenn z.B. Unterstützung oder Pflege rund um die Uhr notwendig wurde, musste mindestens eine weitere Person hinzuge-

zogen werden. Umgekehrt fanden wir, dass bei zunehmender Unabhängigkeit des Schlaganfallüberlebenden öfter eine weniger nahestehende Person als z.B. Ehepartner oder Kinder die Pflege übernimmt.

In Kapitel 9 testen wir ein Instrument, das häufig in Langzeitpflegeeinrichtungen in der Schweiz eingesetzt wird, um die Belastung pflegender Angehöriger einzuschätzen. Es ist ein international validiertes Instrument, das bereits für den Einsatz in der Deutschschweiz übersetzt worden ist. Zur Gültigkeit und Zuverlässigkeit der übersetzten Version standen keine Informationen zur Verfügung. Um dem kulturellen Hintergrund in der Deutschschweiz Rechnung zu tragen, unterscheidet sich der Wortlaut einiger Aussagen vom Originalinstrument. Die psychometrischen Tests der deutschen Übersetzung zeigten zufriedenstellende Reliabilität und Validität. Trotzdem empfehlen wir, die Übersetzung in Bezug zum Wortlaut des Originalinstruments zu prüfen und das Instrument erneut zu testen.

In Kapitel 10 untersuchen wir die psychometrischen Eigenschaften des "Reintegration in normales Leben" Index (RNL). Es ist ein international validiertes Instrument, das mittels Angaben des Patienten bestimmt, in welchem Umfang in Folge einer Krankheit mit bleibenden Behinderungen die Reintegration in den Alltag stattfindet. Wie bereits erwähnt, ist nach einem Schlaganfall die Wiedereingliederung in die normale Alltagsstruktur das übergeordnete Ziel der Rehabilitation. Das Instrument bezieht sich hauptsächlich auf Mobilität und das soziale Leben. Wir erhielten die Genehmigung, das kanadische Originalinstrument aus dem Englischen ins Deutsche zu übersetzen und in der Praxis zu testen. Die bisherige Forschung beschreibt das Instrument als zweidimensional. Wir fanden aufgrund unserer Faktorenanalyse eine Überlagerung zwischen beiden Dimensionen und verwendeten den Index deshalb als eine einzige Skala. Der Index erwies sich als gültige und zuverlässige

Messung der Wiedereingliederung in normales Leben. Wir empfehlen weitere Untersuchungen zur Unterscheidung beider Dimensionen.

In Kapitel 11 untersuchen wir die Belastung pflegender Angehöriger, die Schlaganfallüberlebende betreuen. Dazu wendeten wir das im Kapitel 9 beschriebene Instrument bei einer Stichprobe von 132 Angehörigen an, die Schlaganfallüberlebende ein bis drei Jahre nach deren Entlassung aus der stationären Rehabilitation betreuen. Die durchschnittliche Belastung wurde als verhältnismässig gering beurteilt. Dies trifft sowohl auf jene Gruppe Angehöriger zu, die seit einem Jahr einen Schlaganfallüberlebenden pflegen als auch auf die Gruppe, die seit drei Jahren diese Pflege erbringt. Die Regressionsanalyse zeigt, dass Patientenmerkmale in keinem Zusammenhang mit dem Ausmass der Belastung stehen. Sobald jedoch die Angehörigenvariable Kontrollüberzeugungen in das Modell eingebracht wurde, zeigte sich diese als Grösse, die den Einfluss aller anderen Faktoren aufhob.

In Kapitel 12 sind wir bestrebt, bestimmende Faktoren zu erkennen, die für die Wiedereingliederung in normales Leben ausschlaggebend sind. Wir verwendeten den in Kapitel 10 beschriebenen RNL Index als abhängige Variable. Die Zeitspanne seit der Entlassung aus der stationären Rehabilitation stand in keinem Zusammenhang mit der Ausprägung der Wiedereingliederung. Bei Studienteilnehmern, die in einer Einrichtung lebten, fanden wir tiefere Werte des RNL Index als bei jenen, die unabhängig zuhause wohnten. In einer schrittweisen Regressionsanalyse schienen die kognitiven Fähigkeiten bei Austritt einen Einfluss auf den Grad an Wiedereingliederung zu haben. Im abschliessenden Modell zeigte sich jedoch ein enger Zusammenhang zwischen Mobilität und Kommunikation, gemessen zum Zeitpunkt der Befragung, und dem Ausmass an Wiedereingliederung.

In Kapitel 13 präsentieren wir eine Zusammenfassung der Hauptergebnisse. Zudem diskutieren wir die Ergebnisse und geben Empfehlungen für die klinische Rehabilitation, die häusliche Unterstützung von Schlaganfallpatienten, die Unterstützung von pflegenden Angehörigen von Schlaganfallüberlebenden und für weitere Forschung ab.



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