University of Applied Sciences Hamburg - Faculty of Life Sciences

Health Sciences degree

Experiences with a new therapeutic concept applied at the patient’s home

Master thesis

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Abstract

Physical and occupational therapy have a significant role in the motoric rehabilitation after a stroke; thus research on therapeutic interventions is important in order to find out the best evidence based practice. In the cluster randomized controlled trial HOMECIMT, the efficacy of a new therapeutic concept ("Cimt at home") for chronic stroke patients, who have an impaired hand and arm function is tested. Central elements of "Cimt at home", which is a modified form of the constraint-induced movement therapy, are the implementation of the therapy at the home environment of the patient as well as the inclusion of non-professional coaches (NPCs) in the therapy. It is the aim of this master thesis to investigate the experiences of stroke patients and NPCs with the new therapeutic concept in order to gain information about the practical implementation of "Cimt at home".

A qualitative study design connected with the conduction of in-depth interviews with stroke patients and NPCs were applied. As qualitative approach the hermeneutic phenomenology of Max van Manen was chosen. This approach aims at the description of the common experiences and meanings of a phenomenon for several individuals. The experiences of patients and NPCs with the new therapeutic concept were understood in this thesis as the phenomenon of interest. The experiences of thirteen stroke patients and nine NPCs were included in the qualitative analysis.

By the hermeneutic phenomenological analysis overall 275 significant statements about the experiences of the stroke patients and 194 significant statements about the experiences of the NPCs with "Cimt at home" have been extracted. From these statements seven respectively five main themes about the experiences with "Cimt at home" arose in the analysis. Almost all stroke patients and NPCs perceived improvements through the implementation of "Cimt at home". However, the evaluation of these improvements varied among the patients. The coordination of everyday life and "Cimt at home" was experienced differently by the interviewees. Whereas some patients and NPCs experienced the implementation of "Cimt at home" as manageable there were other interviewees, who experienced difficulties. The practice between patients and NPCs contained positive experiences (e.g. more time spend together), but also difficult experiences (e.g. NPC too strict during the practice).

Through this thesis the perspective of patients and NPCs has been integrated in the research of the new therapeutic concept. Based on the experiences of the interviewees recommendations for a future practice and further development of "Cimt at home" in the ambulant care of stroke patients with physical and occupational therapy were formulated. Furthermore, ideas for further investigations of the new therapeutic concept are provided.

Content

Content of tables

Content of figures

List of abbreviations

CIMT	Constraint-induced movement therapy
DEGAM	Deutsche Gesellschaft für Allgemeinmedizin und Familienmedizin (German College of General Practitioners and Family Physicians)
DGNR	Deutsche Gesellschaft für Neurorehabilitation (German Society of Neurorehabilitation)
ESPro	Erlanger Schlaganfall Projekt (Erlangen Stroke Project)
GEK	Gmünder ErsatzKasse
HOMECIMT	Acronym of the cluster randomized controlled trial in which the new therapeutic concept ("Cimt at home") for the ambulant care of chronic stroke patients is tested.
ICF	International Classification of Functioning, Disability and Health
IQPR	Institut für Qualitätssicherung in Prävention und Rehabilitation (Institute of Quality Assurance in prevention and rehabilitation)
ITT	Intention-to-treat (analysis)
LOCF	Last observation carried forward
mCIMT	Modified constraint-induced movement therapy
n	Sample size
NIDCP	National Institute on Deafness and Other Communications Disorders
NPC/NPCs	Non-professional coach/Non-professional coaches
PNF	Proprioceptive neuromuscular facilitation
RCT	Randomized controlled trial
RKI	Robert Koch-Institut (Robert Koch-Institute)
ZVK	Deutscher Verband für Physiotherapie (ZVK) e.V. (German Association for Physical Therapy)

1 Introduction

In Germany each year approximately 262.400 people are hit by a stroke. Even though the mortality rate in Germany is below the average compared to the European Union since 1990s; a stroke is the most common reason for acquired disabilities among adults. Furthermore, it is the most common reason for adults requiring care in Germany (Heuschmann et al. 2010, Robert Koch-Institut 2006, p. 27).

According to the International Classification of Functioning, Disability and Health (ICF) stroke survivors suffer from restriction in their activities of daily living, their participation and their bodily functions depending on the severity of the stroke (Geyh et al. 2004).

After acute medical treatment, the rehabilitation often takes an important part in the recovery after a stroke. The aim of the neurological rehabilitation is to improve disability and impairment and to achieve as primary goal participation in working and social life as well as to allow an independent and self-determined life (DEGAM 2012, p. 95-98, Kompetenznetz Schlaganfall 2013a, Gutenbrunner 2007, p. 114-134).

In the in-patient rehabilitation process as well as in the ambulant care of stroke patients physical- and occupational therapy play a significant role in achieving the rehabilitation goals (Bauder et al. 2001, p. 13, Kompetenznetz Schlaganfall 2013a, DEGAM 2012, p. 99-106). Consequently, research on physical and occupational therapeutic interventions for stroke patients is essential in order to find out the best evidence based practice for the motoric stroke rehabilitation (Kompetenznetz Schlaganfall 2013 a, b, Höppner 2010, p. 124).

One of the first randomized controlled trials (RCT) with therapy practices in Germany is the recently started HOMECIMT trial in which a new physical and occupational therapeutic concept for the ambulant care of chronic stroke patients is tested. The applied therapy, which is called “Cimt at home”, is based on a modified form of the constraint-induced movement therapy. The aim of the HOMECIMT trial is to investigate the efficacy of this new therapeutic concept for chronic stroke patients, who have an impaired hand and arm function after their stroke (Barzel et al. 2013).

Central elements of “Cimt at home” are the implementation of the therapy at the home environment of the stroke patients as well as the inclusion of non-professional coaches (NPCs) in the therapy with the patient. The main tasks of the NPCs, which are often close family members of the patient, are the guidance and support of the stroke patient with the daily exercises over a period of four weeks under the supervision of a physical or occupational therapist (Barzel et al. 2013, 2009).

The primary aim of the HOMECIMT trial is to investigate the efficacy of “Cimt at home”. But it is also of interest to know what experiences are made by the stroke patients and NPCs with the implementation of this new therapeutic concept at their home environment.

At this point the present master thesis starts.

1.1 Aim of this master thesis

In addition to the objectives of the HOMECIMT trial, the subject of this master thesis is to investigate the experiences of stroke patients, who took part in the new therapeutic concept “Cimt at home”, applied at their home environment. Furthermore, this thesis will explore the experiences of participating NPCs, who play an important role in the new therapeutic concept “Cimt at home”. Through the investigation of the experiences of stroke patients and NPCs detailed information about the practical implementation of the new therapeutic concept will be gained.

Moreover, it is the aim of this thesis to give recommendations for the future practice of the new therapeutic concept based on the experiences of the stroke patients and NPCs.

The aim of this thesis is realized by the application of a qualitative research design connected with the conduction of in-depth interviews with stroke patients and NPCs. This approach can add the perspective of stroke patients and NPCs to the results of the randomized controlled trial and will thereby allow a deeper insight in the applied new therapeutic concept “Cimt at home”.

1.2 Research questions

With respect to the aims of this master thesis, two research questions were formulated:

- **What are the experiences of chronic stroke patients with the new therapeutic concept “Cimt at home” applied at their home environment?**

- **What are the experiences of non-professional coaches with the new therapeutic concept “Cimt at home”?**

1.3 Structure

In the second chapter the theoretical background of this thesis is provided. Subsequently the methods, which were followed to answer the research questions, are presented in chapter three.

Thereafter, chapter four contains the results of this master thesis. First, the interviewees on whom the analysis is based are introduced as well as a short description of the current life of the stroke patients and NPCs after the stroke is given. Chapter 4.4 and 4.5 contain a comprehensive description of the experiences of the stroke patients and NPCs with the new therapeutic concept "Cimt at home" implemented at their home environment.

The results of this thesis are discussed in chapter five. The first section discusses main findings in terms of the experiences of the patients and NPCs with the new therapeutic concept. In the second section methodological considerations and limitations of this thesis are described

Finally, the last chapter contains recommendations for a future practice of "Cimt at home" and presents perspectives for further investigations.

2 Theoretical background

It is the aim of this chapter to provide firstly a short overview over the stroke disease and its consequences for the stroke affected person. Furthermore, information about the family caregivers of stroke patients is given because all of the interviewed NPCs were caring relatives of stroke patients. The third part of this chapter provides information about the neurological rehabilitation and physical and occupational therapy within. After the provision of the general framework of this thesis, the HOMECIMT trial in which the new physical and occupational therapeutic concept is tested is introduced. The fifth and sixth part contains then detailed information on constraint-induced movement therapy and the new therapeutic concept “Cimt at home”. This is a modified form of the constraint-induced movement therapy.

2.1 Stroke and its consequences

The general term stroke refers to ischemic infarcts, spontaneous intra-cerebral hemorrhages and subarachnoid hemorrhages, whereas the ischemic infarct occurs with 80% most commonly. The ischemic infarct belongs to the most common diseases of the neurological discipline (Back 2010, p. 272).

An ischemic infarct with damage to a certain area of the brain is caused by an arterial circulatory disorder e.g. thrombus or embolus (Back 2010, p. 172). Hemorrhagic infarcts differentiate in intra-cerebral and subarachnoid hemorrhages and are in only 15-20% of the cases the reason for a stroke. Common causes for intra-cerebral hemorrhages are high blood pressure or congenital or acquired malformations of the brain arteries. The cause of subarachnoid hemorrhages is most common (85-90%) the aneurysm (Meyer 2010, p. 308-318).

According to the RKI (2006), 85% of all strokes in Germany occur above the age of 60 years (RKI 2006, p. 27). Because stroke is considered a disease of the older age, it is expected that in Germany the number of people suffering from a stroke will rise in the next years. Reasons are the increase of the older population and at the same time an only slight declining rate of new stroke cases (RKI 2006, p. 27, Heuschmann et al. 2010, p. 334).

German incidence rates for strokes are calculated on the data basis of the Erlangen Stroke Project (ESPro). Accordingly, there are 196.000 first-time strokes and approximately 66.000 secondary strokes within a year in Germany. This means that each year approximately 262.000 people suffer from a stroke (Heuschmann et al. 2010, p. 334). In 2011 approximately 21.600 people died due to a stroke. Thus stroke was one of the main reasons for death in Germany (rank four). However, the number of people dying after a stroke is decreasing (Statistisches Bundesamt 2012, Heuschmann et al. 2010).

A detailed and uniform description of the symptoms of a stroke affected person is not possible because the symptoms and the severity of the symptoms are depending on the localization of the stroke, not on the type of stroke. This means that each stroke patient can vary in terms of her or his symptoms and the severity of the symptoms (Sitzer & Steinmetz 2011, p. 117, 124). Besides that, characteristic symptoms of stroke can be described and are listed below (Back 2010, p. 272 ff., Mattle & Mumenthaler 2013, p. 103 ff.):

- Hemiparesis
- Coordination disorders
- Sensory disturbance
- Facial palsy
- Speech disorders
- Diplopia
- Reduced consciousness
- Neuropsychological impairments e.g. language disorders apraxia, spatial-constructive disorders, neglect, memory disorders (Sitzer & Steinmetz 2011, p. 52-49)
- Dysphagia

Long term effects of a stroke might be the development of dementia and depression (Sitzer & Steinmetz 2011, p. 145-146).

A study conducted by Lawrence et al. (2001) showed that the acute symptom, which occurs most often after a stroke is with 77, 4% a motoric deficit of the upper limbs. It is followed by motoric deficits of the lower limbs (72, 4%) (n = 1259).

Broeks et al. (1999) investigated long-term outcomes of arm function of 54 patients suffering a stroke for the first time. One result showed that after four years, 27 patients had a fair to good functional ability in the paretic arm. The other half of the patients had a non-functional arm[1]. Furthermore, they found out that 37 out of 54 patients, also patients, who already have achieved a fair to good functional ability, reported that they still experience nonuse or disuse of the impaired arm as a major problem.

Fundamentally, it needs to be noticed that despite the decrease of the mortality rate stroke is the most common reason for acquired disability among adults in Germany (Heuschmann et al. 2010, p. 334) and referring to Freitas et al. (2005) “more disabling than lethal” (Freitas et al. 2005, p. 1).

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[1] For the assessment of the arm function the action research arm test was applied (cf. IQPR 2010).

The consequences of a stroke on the affected person are diverse. Stroke can affect physical and cognitive functions, activities of daily living, the ability for participation as well as the quality of life of these patients (Geyh et al. 2004, Sturm et al. 2004, Haacke et al. 2006, Carod-Artal & Egido 2009). With respect to factors, which might influence the quality of life of stroke patients four years after a stroke, Haacke et al. (2006) showed that physical impairments, cognitive functioning and depression are associated with a low health-related quality of life. Similar findings were made by Sturm et al. (2004) two years after the onset of stroke.

2.2 Family caregivers of stroke patients

Family members of stroke patients play an important role in the rehabilitation and life of a stroke affected person. Many stroke patients, who return to their home environment after an acute stroke, still require depending on the severity of their stroke support of other persons in terms of care and/or their management of everyday life. Mostly this care and support is provided by a spouse or partner of the patient (DEGAM 2012, Visser-Meily et. al. 2009, Anderson et al. 1995).

Besides the consequences of a stroke for the stroke victim, the care and support of and life with a stroke affected relative can be a considerable burden for the caring family members (Rigby et al. 2009). In the study of Jungbauer et al. (2003) changed roles in the partnership, increased workload, changes in the daily routine, disabilities and personality changes of the partner were identified as burdening aspects for spouses of stroke patients in their life after an incidence of stroke.

In a study by Anderson et al. (1995) family caregivers reported one year post-stroke that the illness of the partner and the associated caregiving had particular a negative impact on their emotional health, their social life, their leisure time and also on the family life.

The caregivers burdens that may arise after the stroke of a relative can particularly lead to adverse effects of the caregivers’ psychological health and well-being. Physical problems may appear as well. Furthermore, the quality of life of family caregivers might be reduced (Jungbauer et al. 2003, Anderson et al. 1995, Visser-Meily et al. 2009). Anderson et al. (1995) found that particular behavioral changes and dementia of the stroke patient may be associated with emotional illness of the family caregiver whereas physical impairments of the stroke patient may not have such a great influence. Similar results were described by Cameron et al. (2011). They also described that behavioral changes, but also psychological well-being of the stroke patient, had an influence on the mental health of the caregiver.

2.3 Rehabilitation after stroke

After the acute medical treatment of a stroke often a subsequent rehabilitation is necessary for the recovery of the stroke affected person. It is the overall aim of the neurological rehabilitation and of rehabilitation in general to enable the stroke affected person to return back into her or his previous social environment and professional life and to allow participation, independence and self-determination. In Germany, the ICF, which was developed and revised by the World Health Organization, is the central basis for the rehabilitation. The legal basis for rehabilitation is predominantly the Social Security Code IX (DEGAM 2012, p. 97-98, Kompetenznetz Schlaganfall 2013a, for more detailed information about rehabilitation in Germany see e.g. Gutenbrunner 2007, p. 114-134, Deutsche Rentenversicherung Bund 2009).

To achieve the above mentioned rehabilitation aims respectively to reach the overall rehabilitation aims as close as possible, it is on one hand the task of the neurological rehabilitation to improve the functional impairments and disabilities that arose after a stroke and on the other hand to support and motivate the stroke patient in recovering her or his everyday life competencies. An important aspect of rehabilitation, which is also required by law, is the integration of the stroke patients agreed individual rehabilitation goals. If possible, also close relatives of stroke patients should be integrated in this process (Gutenbrunner 2007, p. 119, Kompetenznetz Schlaganfall 2013a, DEGAM 2012, p. 97-98).

In Germany, the medical rehabilitation after a stroke can be implemented in the in-patient and out-patient setting as well as by ambulant rehabilitation measures. The in- and out-patient medical neurological rehabilitation often takes place in specialized rehabilitation clinics, which have a strong focus on rehabilitation measures using different professional groups (e.g. physicians, nursing staff, physiotherapists, occupational therapists, speech therapists and neuropsychologists) (Gutenbrunner 2007, p. 127-129, Kompetenznetz Schlaganfall 2013a).

After the medical rehabilitation or directly after the acute treatment when a medical rehabilitation is not considered necessary, the continuing care of stroke patients with rehabilitation measures takes place in an ambulant setting. Therapies for the ambulant rehabilitation are organized by resident doctors (mainly general practitioners) through the prescription of non-physician care (e.g. physical and occupational therapy, speech therapy) (GEK 2007, p. 75, DEGAM 2012, p. 104-106). Referring to the “GEK- Heil- und Hilfsmittel-Report 2007”, it is important for maintaining the achievements of the medical rehabilitation that a subsequent care with for example physical or occupational therapy is organized without a break (GEK 2007, p. 75-76).

2.4 Physical and occupational therapy in the motoric rehabilitation after stroke

Because of the high frequencies of motoric problems after a stroke, physical and occupational therapy have in the acute as well as in the chronic phase after a stroke an important significance in the rehabilitation and recovery of motoric functions (Langhorne et al. 2009, Hesse & Liepert 2004, p. 74, GEK 2007, p. 74, Bauder et al. 2001, p. 13-14).

Nowadays various neurological physical and occupational therapeutic approaches are available for the treatment of motoric problems. The Bobath concept is a therapeutic concept, which is applied most frequently by physical and occupational therapists in the neurological rehabilitation after a stroke. The concept was developed by Berta and Karel Bobath through observations and clinical experiences in the nineteen-forties. In this group of the so called traditional and long-established neurological approaches also belongs the Vojta concept or the proprioceptive neuromuscular facilitation (PNF) (Hesse & Liepert 2004, p. 74-75, Kompetenznetz Schlaganfall 2013c, d, e). The neurophysiological concepts have in common that by a specific tactile input of the therapist movements and activities of the stroke patient are facilitated and promoted. Therefore, these concepts are also called “hands-on” concepts (Diener & Weimar 2012, p. 1054, Hömberg 2005, p. 4). Bobath, PNF and Vojta are the only neurological therapeutic concepts, which are listed in the German Remedy Catalogue (Gemeinsamer Bundesausschuss 2011).

Because of the increased demand of evidence based therapies, the traditional approaches increasingly are questioned because they are not based on the newest knowledge of neurophysiology. Moreover, there is no evidence for the superiority of these traditional concepts compared to other therapies thus far (cf. Hömberg 2005, p. 4, Hummel et al. 2012, p.1178, van Peppen et al. 2004, Kollen et al. 2009, Platz 2009, Kompetenznetschlaganfall 2013c, d, e).

New results in the field of neurophysiological and neuroimaging research in the last 20 years have caused developments of new therapeutic concepts (e.g. task-oriented training, constraint-induced movement therapy, robotics, mental practice) (Hauptmann 2008, p. 41, Hömberg 2005, p. 4). These new therapies have in common that they consider the principles of motor learning, which means for example that a training of movements should be active, task specific and repetitive. Furthermore, a patient should be motivated during the course of the training and a feedback should be given in terms of the performed movements or activities (Hömberg 2005, p. 4-5). In contrast to the traditional concepts, these concepts are called “hands-off” therapies because the patients’ active movement is in the focus (Diener & Weimar 2012, p. 1055). For some of these new therapies promising treatment effects have been described (see for an overview Platz 2009, Langhorne et al. 2009, 2011). Referring to the reviews of Langhorne et al. (2009, 2011) and Platz (2009) particular for constraint-induced movement therapy good evidence of therapeutic results for the improvement of the upper limbs are available.

2.5 The HOMECIMT project

The HOMECIMT project with the working title “Enhancing participation of stroke patients in primary health care by constraint-induced movement therapy” is funded by the German Federal Ministry of Education and Research with the announcement of “Patient-oriented research - chronic diseases and patient orientation”. The project is scheduled for the length of three years and has been taking place in the period of 01.01.2011 - 31.12.2013. The primary aim of the HOMECIMT project is to investigate the efficacy of a new therapeutic concept for the upper extremities of stroke patients in contrary to conventional ambulant physical and occupational therapy with respect to the ability to participate in everyday activities. The new therapeutic concept is called “Cimt at home”. The following flow chart gives an overview about the course of the HOMECIMT project.

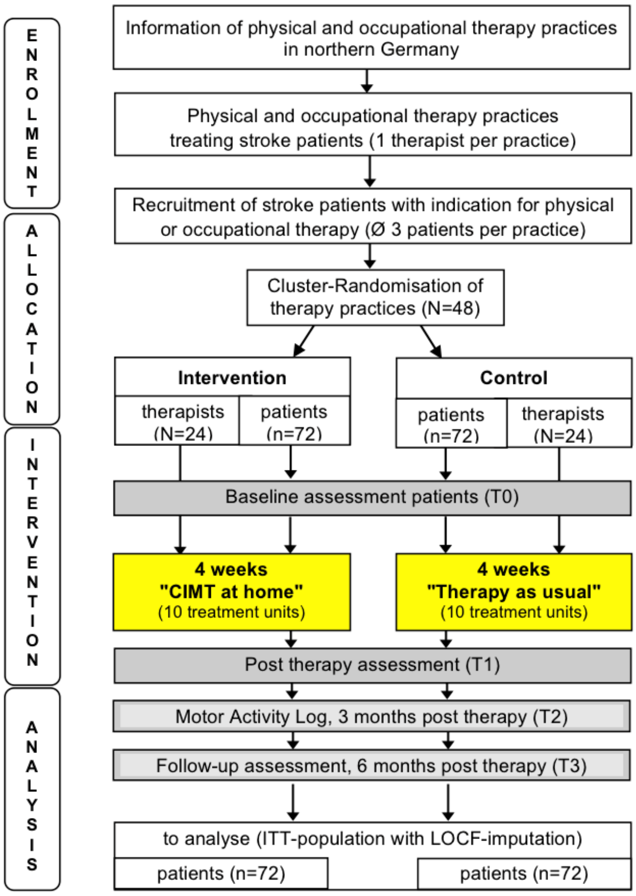

Figure 1: Flow-chart of the HOMCIMT project (Barzel et al. 2013), abbreviations: ITT = intention to treat; LOCF = last observation carried forward

The HOMECIMT study is designed as a cluster randomized controlled trial with physical and occupational therapy practices as clusters. To answer the primary research question a minimum sample size of 48 therapy practices and 144 stroke patients were calculated.

Physical and occupational therapy practices were recruited via information sessions about the project in five regions in northern Germany. Practices could participate in the study if the interested therapist from the particular practice had a qualification for the treatment of stroke patients (Bobath, PNF or Vojta) and at least one stroke patient, who would fulfill the below mentioned inclusion criteria, was treated in the practice. After the inclusion of the practice, the stroke patients were recruited via the particular therapy practice. Following inclusion and exclusion criteria were defined for the stroke patients:

Inclusion criteria

- Indication for physical or occupational therapy
- Age above 18 years
- Stroke at least 6 months ago
- Impairment of the motoric arm and hand function with minimal hand function[2]
- Support through a non-professional coach would be possible
- Informed consent

Exclusion criteria

- Lack of German language skills
- Severe impairment of speech and understanding
- Severe neurocognitive deficits
- Inability to consent
- Severe and/or life-limiting disease
- Participation in another therapeutic trial

After the patient/s has/have signed the consent form, the therapy practices were allocated either to the intervention or control group. The patients of the particular therapy practice received the associated four-week therapy, which means that patients from an intervention group practice received the new therapeutic concept “Cimt at home” and patients from a control group practice got “therapy as usual”. The intervention respectively control therapy was carried out by the participating therapist. The therapists of the intervention group were trained in “Cimt at home” in advance. The one-day training included background information about the new therapeutic concept and its origin as well as the general procedures of “Cimt at home” and information about the implementation.

The conduction of the assessments was done in a pre, post and follow-up design. The patients were tested before, directly after as well as three and six months after the four-week therapies. The assessments were done by blinded physiotherapeutic respectively occupational therapist study staff at the patients’ home. Each stroke patient was visited by the same study staff (Barzel et al. 2013).

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[2] Minimal hand function is definend as at least 10° hand extension, the ability to slightly open the affected hand and the ability to slightly abduct the thumb (Barzel et al. 2013).

2.6 Constraint-induced movement therapy (CIMT)

CIMT is a therapy particular for chronic stroke patients, which are affected by a hemiparesis and have an impaired hand arm function with a simultaneous minimal hand function. Besides the main focus of CIMT on the upper extremities of stroke patients, there are also approaches where CIMT is applied to improve the affected lower extremity after a stroke (Billinger et al. 2010, Hamzei et al. 2012) and it is also used with other neurological diseases (e.g. multiple sclerosis) (Taub 2012). The general aim of CIMT is to promote an increased and improved use of an impaired and neglected extremity in the everyday life (Bauder et al. 2001, p. 24, Morris et al. 2006).

2.6.1 Theory behind CIMT

The theoretical background of CIMT was developed by the psychologist Edward Taub and his research group in the nineteen-sixties and -seventies on a theory, which they called "learned non-use". The theory originates from behavioral observations of monkeys (Bauder et al. 2001, p. 19-20, Taub 2012). The mechanism of the learned nonuse is based on the assumption that besides a neurological damage, which leads to an impairment of the upper and lower extremity also a learned behavior leads additionally to a nonuse of the affected extremity. The learned behavior results from negative experiences (e.g. pain, unsuccessful and exhausting movements) in using the affected paretic extremity in the first months after the stroke and positive experiences by using the unaffected and functional extremity. Through the successful and effective use of the healthy extremity the usage of the healthy extremity is reinforced and the use of the paretic extremity decreases. The acquired learned nonuse refuses possible activities of the affected extremity (Taub et al. 2002, p. 229, Bauder et al. 2001, p. 19-23). Figure 2 illustrates the mechanism "learned nonuse".

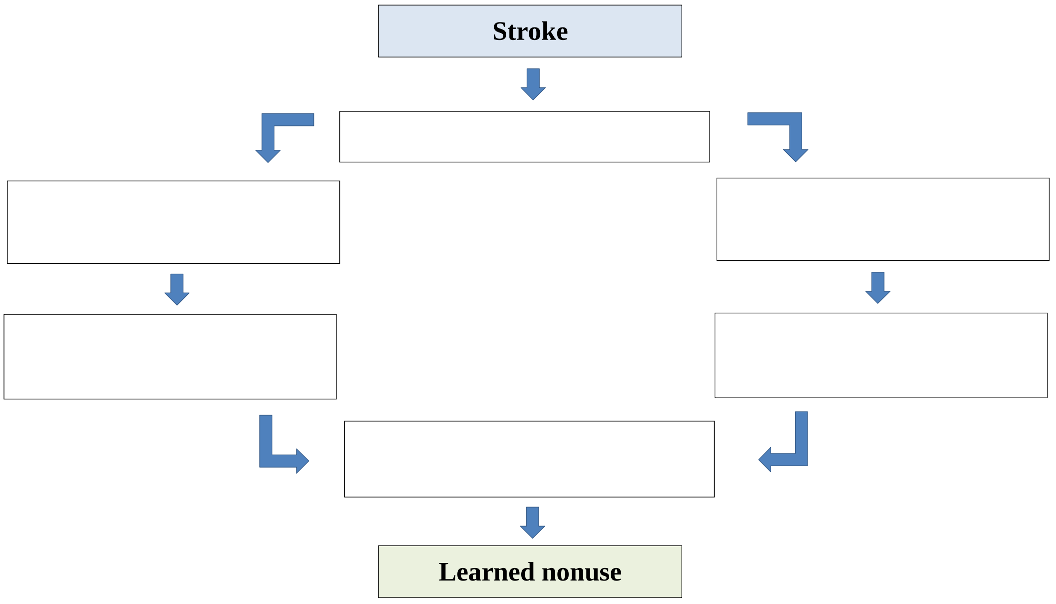

Figure 2: Schematic illustration of the mechanism learned nonuse (adapted from Bauder et al. 2001, p. 22)

Based upon its theoretical considerations, CIMT has the aim to break the mechanisms of the learned nonuse by promoting an increasing use of the affected extremity (Bauder et al., p. 23-24, Taub et al. 2002). The core elements of CIMT are the restriction of the less affected or healthy extremity and an intensive motoric and active training of the affected extremity (Bauder et al., p. 24-25). By the restriction of the healthy extremity the motivation to use the affected extremity increases and additionally the enhanced usage of the impaired extremity is reinforced through the intensive motoric training. Figure 3 schematically shows how to overcome the learned nonuse.

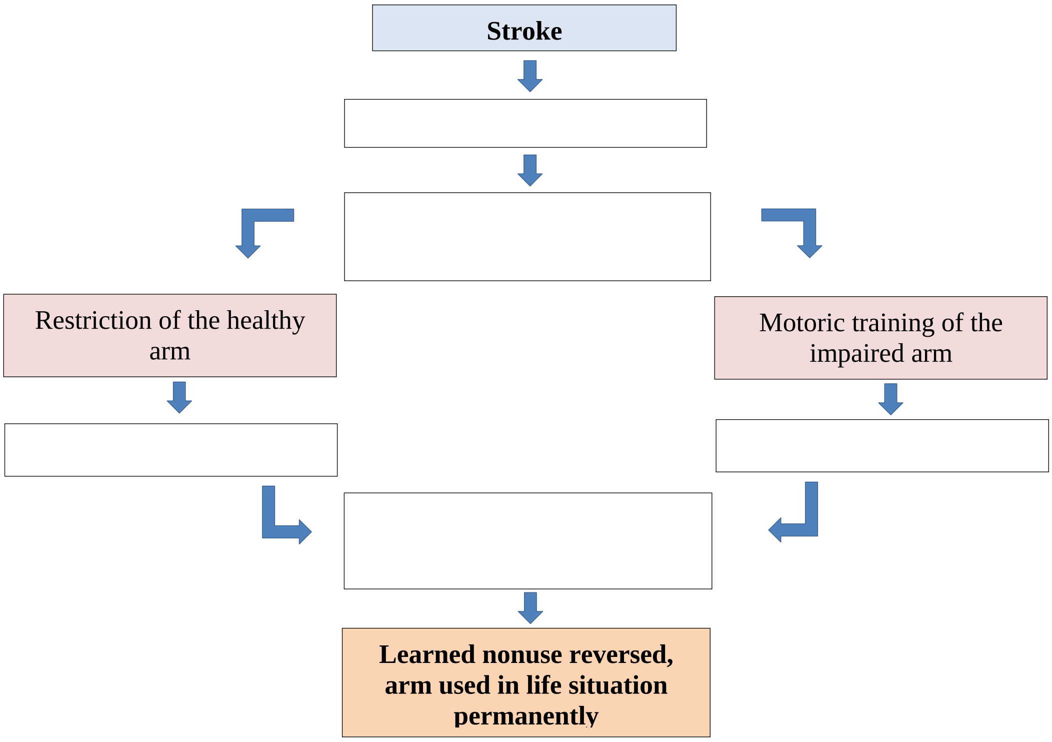

Figure 3: Schematic illustration of the mechanism how to overcome the learned nonuse (adapted from Bauder et al. 2001, p. 23)

2.6.2 Therapy components of CIMT

Besides restriction and repetitive, intensive training, the core elements of CIMT, it is the aim of CIMT to involve the patient actively in the therapy and to promote the transfer of learned activities into the everyday life (Morris et al. 2006, Bauder et al. 2001). In order to achieve these aims, different techniques and strategies can be applied in CIMT. These strategies are summarized by Morris et al. (2006) and Taub (2012) under the heading “transfer package”. In the following section an overview about the three main components of CIMT is given.

1. The intensive motoric training of CIMT is characterized by a repetitive, task-oriented practice, which is done on several consecutive days (Bauder et al. 2001, p. 24). An important element of the training is the consideration of shaping principles. At the beginning of CIMT simple movements are trained with the patient. It is important that these exercises are measurable so that directly positive feedback can be given and success is seen clearly.

Furthermore, it is important that exercises are used, which quickly lead to a success, so that in turn the patient is motivated to go on. After the simple movements are implemented successfully, they are combined to complex movements of everyday life e.g. lifting a glass (cf. figure 4).

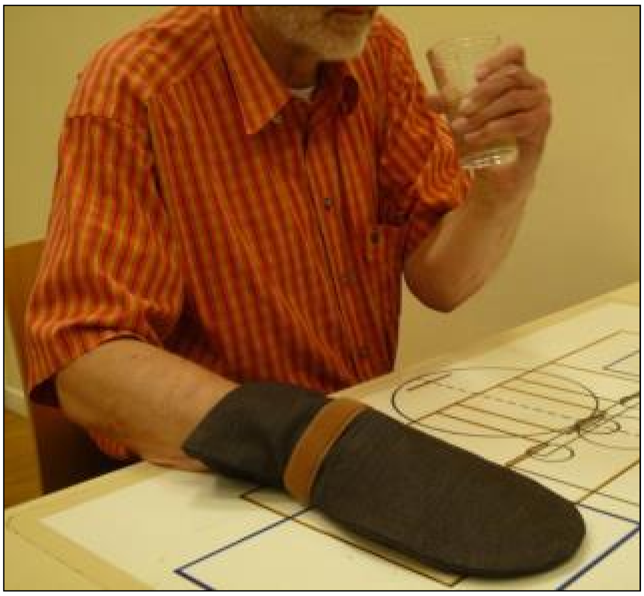

Figure 4: Example for the implementation of the constraint induced movement therapy (Picture source: research team stroke study HOMECIMT)

It is essential that the patient is constantly motivated by the therapist during the whole therapy. This includes for example that successfully completed exercises are rewarded verbally or that in contrast failures are ignored or explained that this might also depend on the daily condition. Moreover, the patient is constantly rewarded for the efforts to improve the exercises and movements. In addition, it is part of the shaping principles that the exercises are always adjusted to the patients individual performance limit, but remain still feasible. It is important that the patient always can complete her or his exercises. If this is not possible, a more simple exercise should be chosen.

Exercises are always quantified and feedback on the quality of the movement or activity is given and documented (Morris et al. 2006, Taub 2012, Bauder et al. 2001, p. 45-48).

2. The restriction of the healthy extremity prevents the patient from using it for activities of daily life. It can be realized for example by a cast, glove or loop, which the person wears on the affected upper extremity (cf. figure 4). The restriction is not indicated during personal care and when wearing a cast represents a danger (Bauder et al. 2001, p. 24-25). The restriction is implemented during the exercises, but also in the time outside of the actual therapeutic setting, so that the patient is forced to use the affected extremity in her or his everyday life.

3. Besides the above described core elements of CIMT an amount of different behavioral strategies and techniques, summarized as “transfer package”, are applied to guarantee that the patient actively participates in the therapy and more important is able to transfer learned activities from the therapy with the affected extremity into the daily life. Morris et al. (2006) as well as Taub (2012) described different strategies to fulfill these aims. Table 1 gives an overview about the behavioral strategies and a short description of each.

Behavioral strategies/techniques	**Short description**
Behavioral contract with the patient and caregiver	The contract with the patient defines the treatment conditions. Additionally a contract with the caregiver can be done to secure the support of the patient in the home environment.
Daily administration of the motor activity log (MAL)	The MAL includes a list of 30 activities of daily life. It is applied on a daily basis by the patient. It asks how often and how well activities were executed (Taub et al. 2011).
Home diary	Documentation of daily activities. Patients should note when they have used their affected extremity and when not why.
Problem solving to overcome apparent barriers to use the affected extremity in the everyday life	On the basis of the MAL and the home diary, problems in using the affected extremity for activities of daily life can be discussed and solved.
Home skill assignment or home practice	Patients are asked to perform additionally to the daily practice with the therapist specific exercises or activities of daily life with the affected upper extremity in their home environment.
Daily schedule	Therapists document for each day the amount of the exercises, the wearing time of the restriction and the applied shaping techniques.

Table 1: Behavioral strategies (“transfer package”) to promote an enhanced usage of the impaired arm in everyday life (Morris et al. 2006, Taub 2012)

Bauder et al. (2001) also described most of the above mentioned techniques, but did not call them “transfer package”. Additionally, she mentioned two further elements of CIMT, which should increase the motivation and self-responsibility of the patient. These are the information of the patient about the theoretical ideas of CIMT as well as the mutual agreement on precise therapeutic goals (Bauder et al. 2001, p. 40-43).

2.6.3 Application of CIMT

CIMT is mainly implemented by physical and occupational therapists, but also by psychologists. The original CIMT comprises 14 days with an extensive exercise program for 10 days (weekdays) for six hours daily in a hospital, therapeutic facility or practice. The less affected extremity is constrained by a splint during 90% of the waking hours (Taub et al. 2006, Morris et al. 2006, Freivogel 2011)[3].

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[3] In a former treatment protocol published 1994 CIMT is applied on 12 days, where on eight days an extensive training of six hours took place (Taub et al. 1994, Bauder et al. 2001).

Besides the original CIMT, which includes in total 60 hours of training, there are applied several modified forms of constraint-induced movement therapy (mCIMT). The modifications refer for example to the total of exercise time, the duration of the whole therapy or the duration of the restriction of the healthy extremity (cf. Peurala et al. 2012, Taub et al. 2006, Freivogel 2011).

Reasons for the development of modifications might be on the one hand that the original CIMT is time and cost expensive and on the other hand that the implementation of the intensive treatment protocol of CIMT is sometimes difficult for stroke patients (Viana & Teasell 2012, Taub 2012, Page et al. 2002).

2.6.4 Evidence of therapeutic results

The German Society of Neurorehabilitation (DGNR) integrated in their guideline about rehabilitative approaches for paresis of the upper limb after a stroke among other rehabilitative approaches also the original form of CIMT and modified forms of CIMT. Based on their literature review of 2009, CIMT and modified CIMT are recommended in their guideline for chronic stroke patients with a partly obtained hand function and a neglect of the affected upper extremity. A moderate to high evidence indicates that CIMT and mCIMT improves arm function and a better usage of the affected extremity in everyday life (Platz al. 2009, p. 91-92). Langhorne et al. (2009) also showed in their systematic review that CIMT and mCIMT are therapeutic interventions for which good therapeutic effects for the improvement of the upper limb are available.

Furthermore, the results of the systematic reviews and meta-analyses about CIMT and mCIMT of Peurala et al. (2012), Shi et al. (2011) and Sirtori et al. (2009) indicate that CIMT and mCIMT have positive benefits on the affected upper extremity after stroke.

2.7 “Cimt at home”

The modified form of CIMT which is applied in the HOMECIMT study is called “Cimt at home”. It is adapted to the home environment of stroke patients with the idea to offer an alternative to the original CIMT, which is very time, personnel and cost intensive. It was aimed to develop a therapy based on the principles of CIMT, which could be provided for more stroke patients with an impairment of the upper extremity. Moreover, it was considered to develop a concept, which would give more personal responsibility to the patients in terms of their rehabilitation after stroke (Barzel et al. 2009, 2013). Before the application of “Cimt at home” in the HOMECIMT study, the new therapeutic concept was developed and its feasibility examined (cf. Barzel et al. 2009, Haevernick et al. 2007, Tetzlaff 2010).

In contrast to the original CIMT, “Cimt at home” is performed by the stroke patient and a NPC under the supervision of a physical or occupational therapist. The NPC may be a family member of the patient, but also other persons such as friends or neighbors of the stroke patient could act as a NPC. The therapy is applied in the patients’ home for a four-week exercise period. Two weeks longer than the original CIMT.

The physical or occupational therapist does not do the practice together with the patient. At the beginning of “Cimt at home”, it is the responsibility of the therapist to inform the patient and NPC about the theoretical ideas of “Cimt at home” with the aim to create an understanding for the therapy and in turn to increase the patients’ motivation for the implementation of the therapeutic elements (e.g. restriction, enhanced usage of the impaired extremity, repetitive training). Furthermore, it is the task of the therapist, besides the preparation of the treatment contract and the agreement on therapeutic goals, to choose together with the stroke patient exercises, which should refer to a practical meaningful task in the everyday life, to introduce the exercises to the patient as well as to instruct the NPC. Moreover, the therapist has the responsibility over the four weeks to check whether the therapy (e.g. implementation of the exercises, documentation) is executed correct or whether any further help is needed during the four-week practice between the patient and NPC.

All the tasks are done in five home visits of 45-60 minutes during the four-week intervention period (Barzel et al. 2013, unpublished trainings material “Cimt at home”).

In the four-week intervention period the patients practice is accompanied and supervised by her or his NPC two hours a day, five days a week, which means that there is a total amount of 40 hours of exercise time. It is the task of the NPC to count and document the number of repetitions of each exercise, to measure the time consumed for each exercise and it also includes the motivation of the patient in the four-week therapy.

The intensive, daily practice consists of repetitive, task-oriented exercises for the affected paretic upper extremity. Moreover, shaping principles are considered and applied in the practice. Besides the two hours of practice, the patient wears a glove for a period of four till six hours on the not affected upper extremity to be motivated to use the affected upper extremity increasingly for activities of daily life.

Furthermore, the following behavioral strategies to maintain and increase the patients' motivation were applied in "Cimt at home" (Barzel et al. 2013):

- Information about the theoretical ideas of "Cimt at home"
- Mutual written agreement on therapeutic goals
- Treatment contract between the therapist, the patient and the NPC (The contract includes the wearing time of the glove as well as activities, which should be performed with the affected extremity.)
- Documentation of daily exercises - trainings diary (The documentation includes the amount of repetitions, the amount of time needed for each exercise as well as the wearing time of the glove.)
- Daily application of the MAL (This contains the documentation of the arm usage for activities of daily life as well as the evaluation of the quality of these activities.)

3 Method

To answer the research question a qualitative study design was applied in this project. Chapter three comprises the rationale for a qualitative research design, the characteristics of qualitative research as well as the detailed description of the study design. The latter one includes information about the qualitative approach used in this project, information about participants, data collection, analysis, ethical considerations as well as information about the application of quality criteria. Finally, information about the researchers' background and its potential influence on the research is provided.

3.1 Rationale for qualitative inquiry

Referring to the aim of this thesis, which is the exploration of the experiences of stroke patients and NPCs with a new therapeutic concept, a qualitative study design was seen to be appropriate. The focus of qualitative research is to discover new aspects or theories in contrast to the focus of the quantitative research, which is mainly the examination of hypotheses. A qualitative research design allows openness to the complexity of the experiences of stroke patients and NPCs as well as the exploration and understanding of the contexts in which they experienced the new therapeutic concept (Flick 2011, p. 27, Finlay 2006, p. 3-8, Creswell 2007, p. 39-41).

3.2 Characteristics of qualitative research

Even though qualitative research embraces a variety of different qualitative approaches (Flick et al. 2007, p.18) there are some characteristics and ideas that are distinct for qualitative research in general. Creswell (2007, p. 16-19) distinguishes five characteristics of qualitative research and its implication for practice based on the philosophical assumptions of ontology, epistemology, axiology, rhetoric and methodology. Table 2 gives an overview about the questions behind these five assumptions and shows the associate characteristics of qualitative research.

Philosophical assumption of…	**Question**	**Characteristics**	**Practical examples**
Ontology	What is the nature of reality?	Reality is subjective and multiple	e.g. use of quotations
Epistemology	What is the relationship between the researcher and that being researched?	Proximity between researcher and researched	e.g. fieldwork
Axiology	What is the role of values?	Acknowledgement of values and biases	e.g. discussion of the research's background
Rhetoric	What is the language of the researcher?	Usage of a more informal and literary language	e.g. usage of qualitative terms
Methodology	What is the process of research?	Usage of a bottom-up approach, emerging study design	e.g. modification of the research design or question in the course of the study

Table 2: Characteristics of qualitative research based on the five philosophical assumptions of ontology, epistemology, axiology, rhetoric and methodology (Creswell 2007, p. 16-19, Ponterotto 2005, p. 130)

Similar ideas are described by Flick (2011). He differentiates three characteristics of qualitative research (Flick 2011, p. 26-30):

1. The object under investigation determines the methods[4]
2. Consideration of different perspectives and its complexities
3. Reflexivity about the influence of the researcher on the research process

The characteristics of qualitative research and its implication for practice were considered and applied in this thesis. Despite their common characteristics, each qualitative approach has its own particular focus and procedures (Creswell 2007, p. 35, Ponterotto 2005 p. 132). For this project a phenomenological approach, in more detail the hermeneutic phenomenological approach guided by Max van Manen, was chosen (van Manen 1990).

3.3 Phenomenology

A phenomenological study is the study of lived experiences or the study of human experiences as they are lived (van Manen 1990, p. 9, Laverty 2003, p. 7). Characteristic for this approach is that common experiences and meanings of a phenomenon for several individuals are described.
Moreover, phenomenology has the aim to find a “universal essence”, which combines the experiences of several individuals (Creswell 2007, p. 57-58). Referring to van Manen “phenomenology is the systematic attempt to uncover and describe the structures, the internal meaning structures of lived experiences” (van Manen 1990, p. 10). He furthermore describes the aim of phenomenology as an attempt to gain “a deeper understanding of the nature of meaning of our everyday experiences” (van Manen 1990, p. 9). Phenomenology as a research methodology has deep philosophical roots derived from the ideas of the German philosophers Edmund Husserl, Martin Heidegger and Hans-Georg Gadamer (for more information see for example Laverty 2003 or Dowling 2007). The experiences of stroke patients and NPCs with “Cimt at home” were considered as the phenomenon of interest.

A phenomenological approach was considered appropriate for the aims of this thesis because the experiences of stroke patients and NPCs with a new therapeutic concept should be described profoundly. Furthermore, it was aimed at giving recommendations for practice based on the patients and NPCs experiences. A phenomenological study design offers the methodological procedures and philosophical frameworks to fulfill these aims (Creswell 2007, p.57-64).

Referring to Creswell (2007) the following two phenomenological research methods can be differentiated: hermeneutic phenomenology and transcendental phenomenology (Creswell 2007, p. 59-60). Both methods differ in the aspect of how strong they integrate or allow interpretations of the researcher.

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[4] German: „Gegenstandsangemessenheit“ (Flick 2011, p. 27)

Whereas hermeneutic phenomenology understands interpretation as an important and natural component, transcendental phenomenology focuses on the pure description of the experience and tries by "bracketing" to set aside the experiences of the researcher with the research topic (Creswell 2007, p. 59-58, van Manen 1990, p. 24-27).

The hermeneutic phenomenological approach by the Canadian Max van Manen was chosen in this study. Due to her professional background as a physiotherapist, the author of this thesis takes the view that the neglect of her own experiences with the research topic would not be suitable for transcendental phenomenology. Therefore an approach, which combines description and interpretation, was considered suitable. Van Manen differentiates six elemental research activities in hermeneutic phenomenological research. Acknowledging that these activities are not clearly separated from each other, he described research as a "dynamic interplay" between six activities (van Manen 1990, p. 30-34):

- Turning to a phenomenon which seriously interests us and commits us to the world.
- Investigating experience as we live it rather than as we conceptualize it.
- Reflecting on the essential themes which characterize the phenomenon.
- Describing the phenomenon through the art of writing and rewriting.
- Maintaining a strong and oriented relation to the phenomenon.
- Balancing the research context by considering parts and whole.

All the research activities described above were considered in the implementation of the qualitative research design.

3.4 Participants

With respect to the research question qualitative interviews were conducted with stroke patients and NPCs. The following section presents the inclusion criteria for stroke patients and NPCs, the sampling strategy, the recruitment process as well as information about the sample size.

3.4.1 Inclusion criteria

The stroke patients needed to fulfill the following inclusion criteria to be eligible for a qualitative in-depth interview:

- Participant of the cluster randomized controlled trial HOMECIMT
- Experiences with the new therapeutic concept "Cimt at home" (intervention group)

Furthermore, it was an important inclusion criterion that the interviewee should have the ability to speak freely and fluently without great speech disorders (e.g. aphasia). Moreover, the interviewee needed to have the cognitive abilities to speak about her or his experiences with the new therapeutic concept.

An exception in terms of the inclusion criteria “ability to speak freely and fluently” was made if the interview with the stroke patient was conducted together with a relative, who acted also as a NPC and was therefore, also able to talk about the experiences of the patient with “Cimt at home”.

For the NPCs only one inclusion criteria needed to be fulfilled so that they could be asked to take part in an interview. They needed to have experiences with “Cimt at home” as a NPC. This meant that these people have signed a treatment contract to support a stroke patient with the daily practice of “Cimt at home”.

3.4.2 Recruitment process

The participants for the interviews were recruited via the HOMECIMT project in cooperation with the HOMECIMT research team because they provided the overview of participants fulfilling the inclusion criteria. After the identification of possible interviewees, the interviewer tried to get in contact with patients and NPCs via telephone. This strategy seemed to be appropriate because a connection between the patients and the NPCs and the HOMECIMT project had been established through the participation of the patients and the NPCs in the HOMECIMT trial. In the telephone conversation the possible interviewees were asked if they would be interested in participating in an interview, which would be particular about their experiences with the new therapeutic concept. In case of interest they received full information about the interview conditions and data protection. This information included the recording and the estimated duration of the interview. After they agreed verbally in the interview an appointment for the interview was made.

3.4.3 Sampling

For the decision, which stroke patients or NPCs should be selected for an interview, two aspects in terms of the sampling strategy had to be considered. First of all, the interviewees were selected due to practical reasons. This meant that the interviewees needed to be accessible for the interviewer. The interviewees’ home needed to be reachable by bus or train and the travel time needed to be proportional to the time frame and financial resources of the study (Flick 2011, p. 167).

Secondly, individuals were selected in the research process based on specific content criteria. Flick (2011) described this sampling strategy, called theoretical sampling, as the most appropriate strategy in qualitative research. In contrast to other sampling strategies, theoretical sampling is characterized by the idea that it does not need to be defined clearly at the beginning, which characteristics an interviewee needs to fulfill to be integrated in the study. Instead individuals are selected based on the expected level of new aspects, which they might bring into the qualitative analysis (Flick 2011, p. 158-165, Merkens 2007, p. 291-292).

In this study the following content criteria were considered in the stepwise selection of the interviewees:

- Sex
- Age
- Employment
- Affected body side (applies only to the patient selection)
- Language ability (applies only to the patient selection)

After the conduction and primary analysis of the first five patient interviews in which the content criteria “sex” and “employment” were already considered, it appeared that so far only right handed stroke patients were interviewed, who were affected by the stroke on their left body side. Some of these patients questioned the meaningfulness of the enhanced usage of the impaired left arm in everyday life because they were right-handed. Therefore, the question arose whether patients, who are affected on their right body side by a hemiparesis and are right handed,[5] would have a different motivation for the enhanced arm usage than those, who are right-handed and affected on their left body side[6]. A reason why until that stage only stroke patients with a hemiparesis on the left body side were interviewed might be that patients, who suffer from a left side hemiparesis, often also have problems with their ability to speak and to comprehend (Sitzer & Steinmetz 2011, p. 49-50, NIDCP 2008). One interview with a patient needed to be excluded from the analysis due to the severity of a speech and language disorder of the patient in the very beginning of the interview phase. As a result patients, who were affected on the right hemisphere and had no restriction in their ability to speak, were favored. Aside from this aspect, it was acknowledged that the first five interviewees were characterized through their relatively young mean age of 50, 8 years. According to the RKI, 85% of all strokes occur in the age above 60 years (RKI 2006).

Therefore, these two content criteria (“age” and “affected body side”) were considered in the further selection of the interviewees. Special attention was paid to stroke patients, who were affected on their left hemisphere, and only had a mild speech disorder so that they were able to participate in an interview. In addition, interviews were planned with patients, who had a severe speech disorder. Additionally, it was tried to select patients above 60 years to have representatives of a typical age group in which strokes occur more often (RKI 2006).

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[5] Respectively are affected on the left body side and are left handed.

[6] Respectively are affected on the right body side and are left handed.

In terms of the composition of the NPCs one further content criterion was of interest, but could not be realized in the sampling. After the conduction of the first interviews with NPCs it became visible that only coaches, who were correctly involved in the practice with the stroke affected relative, were interviewed. Of special interest was furthermore the group of NPCs, who agreed to practice together with the patient, but eventually limited their practice or stopped practicing altogether. Attempts were made to get in contact with two of those NPCs after the associated patient was interviewed. It was impossible to combine an interview with them. Reasons were that the partners of these NPCs, who were firstly on the telephone, disagreed because of family problems with the coach or it was considered senseless because the NPC was not involved in the daily practice. The interviewer did not ask further because she wanted to respect the answers of the former interviewees.

3.4.4 Sample size

There was no previous definition about the number of interviews that were to be conducted with stroke patients and NPCs in this hermeneutic phenomenological study. The reason for this decision was that the selection of the interviewees was guided among other things by the idea of theoretical sampling. In this selection strategy a precise definition of the sample size is not possible before data collection (Flick 2011, p. 161). The number of interviews rather depends on the degree of the saturation of the data. The data is saturated when the conduction of more interviews does not reveal new essential information (Bryman 2012, p.18). In general there is no clear answer in qualitative research to the question of how many interviews can be recommended and are needed for a “good” qualitative study (Baker & Edwards 2012). The answer depends on the saturation of the data (Bryman 2012, p. 18), the set of methods used (e.g. interviews, observation), but also very pragmatically on time and financial resources (Flick 2012, p. 27).

In this project, in total, 20 interviews were conducted with stroke patients and NPCs. Twelve interviews were conducted with patients and six interviews with NPCs. Two further interviews were conducted with a couple consisting of an aphasic stroke patient and a NPC. In one patient interview the NPC of the stroke patient participated actively for a longer period of time in the interview. Therefore, this NPC is treated retrospectively as an individual interview partner (cf. chapter 3.5.4). As already mentioned one patient interview needed to be excluded from the analysis because of the severity of the speech and language disorder of the patient.

For a clear distinction of the experiences of the patients and the experiences of the NPCs it was decided that the three interviews, where two persons were actively involved in the interview, were analyzed from the perspective of the stroke patient and from the perspective of the NPC.

Altogether this means that the experiences of thirteen stroke patients and nine NPCs were included in the hermeneutic phenomenological analysis.

3.5 Data collection

For data collection open qualitative interviews were conducted with stroke patients and NPCs. All interviews were conducted by the author of this thesis.

3.5.1 Interview guideline

The interview guidelines for the stroke patients and NPCs were developed as open semi-structured interview guidelines. That means that the interview should have a certain structure using main or central questions, but allows the interviewer to vary the questions when interesting aspects show up. Further it should allow to vary the structure of the interview guideline in the interview situation (Hopf 2007, p. 351).

The guideline for the patient interview consists of five general themes and in turn five open key questions. In the development of the questionnaire it was made sure that the questions were open and did not already implicate an assumption or idea of the researcher (Flick 2011, p. 221-223). After the first interview, the interview guideline was modified only marginally so that also the first interview could be transcribed and analyzed. The five thematic sections of the guideline are:

1. Life and daily routine after stroke
2. Physiotherapy or occupational therapy after stroke (before participating in the study)
3. **Experiences with the new therapeutic concept**
4. Therapy after the implementation of the new therapeutic concept
5. Final question/Completion of the interview

Theme three is the core element of the interview guideline. This theme consists of one general and open question about the patients’ experiences with the new therapeutic concept. Besides this main question, advanced questions were developed to ask the interviewee for aspects related to the new therapeutic concept. Theme one and two, which include questions about life and therapy after the onset of stroke were designed to start in the interview and to create a trustful atmosphere to the interviewee and her or his particular life situation. Moreover, the answers to these questions allow to embed the experiences with “Cimt at home” in the life context of the interviewees. Theme four includes questions about therapy after the implementation of “Cimt at home”. Theme five offers the interviewee the possibility to add information or new aspects that are important for her or him and have not been mentioned in the former interview.

The interview guideline for the NPCs was designed similar to the guideline for the patients. The five thematic sections were kept to ensure comparability between the interviews with the patients and the interviews with the NPCs. Theme three “Experiences with the new therapeutic concept” is also the core element in the guideline for the NPCs.

Beside the main question of theme three *“Your relative participated in the stroke study XX months/weeks ago. You have supported her or him as a non-professional coach, right? How was that for you? Please tell me”*, advanced questions were prepared. The full interview guidelines for patients and NPCs are presented in the annex on page 95 and 96.

3.5.2 Short questionnaire and postscript

Besides the development of the interview guideline a short questionnaire was developed to evaluate socio-demographic parameters e.g. age, date of stroke, profession, start of the intervention period as well as current therapeutic applications. Moreover, there was also space for notes about special events, impressions and feelings of the interviewer as well as information about the atmosphere in the particular interview situation. Furthermore, interesting aspects that came up by the interviewee after switching off the recording device were noted. This additional information is of interest because it can offer the possibility to interpret and understand the results of the interviews in a more realistic and more comprehensive way (Lamnek 2010, p. 356-358, Flick 2011, p. 29). The short questionnaire for the patients and the NPCs was accomplished in the beginning of the interview and is added to the annex on page 99 and 100.

3.5.3 Course of the interview

The conduction of the interviews with stroke patients and NPCs took place in two periods. The first interviews were conducted in the period of December 2012 until January 2013. In this time predominantly interviews with stroke patients were conducted. In the second period from April 2013 until June 2013 further interviews were conducted with stroke patients and NPCs. Apart from one interview, all interviews took place at the interviewees’ home. The possibility to conduct the interviews at a neutral place was given, but all interviewees were content to conduct the interview at their home. Only one NPC wished to conduct the interview in a quiet restaurant close to her home because she argued that she could be more relaxed in a neutral place.

The course of the interviews was always similar. After address of welcome and thanks for the provided time and willingness to talk about the experiences, the interviewer explained the aim and reason of the interview one more time. Thereafter, the interviewee had to agree by signing the conditions of the interview. Before the start of the interview the short questionnaire was filled out by the interviewer in conversation with the interviewee. The questionnaire was filled out before the interview with the intention to become familiar with each other. Thereafter, the proper interview started. The interviews were recorded with an Olympus Digital Voice Recorder, DS-2400. The duration of the 20 interviews varied between a minimum of 13 minutes and a maximum of 123 minutes. The mean time was 36, 5 minutes (n=20).

The interview guideline was used by the interviewer to give the interview a certain structure and to guaranty that all aspects of interest were addressed. In the interview situation, questions and advanced questions were posed acknowledging immanent and exmanent questions. Immanent questions are connected to things that already have been said by the interviewee. With this kind of questions a certain aspect can be deepened or advanced. They are asked before exmanent questions are used. Exmanent questions do not connect aspects that already have been mentioned, but new aspects that are of particular interest for the researcher. To be able to pose immanent questions in the interview, the interviewer took short notes during the interview when needed (Przyborski & Wohlrab-Sahr 2009, p. 83-85 Lamnek 2010, p. 363).

The follow-up of the interview included the completion of the postscript. This was done shortly after the interview to remember and note all relevant additional information about the interview situation and the atmosphere in the interview.

3.5.4 Interview situation

The behavior of the interviewees towards the interviewer as well as the atmosphere in the interviews was always experienced as friendly, open and cooperative. In some interviews the interviewee seemed to be a little nervous in the beginning of the interview, but this state of mind changed usually in the process of the interview.

Only two interviews were planned to be conducted with a couple consisting of an aphasic stroke patient and a NPC (interview 12 and 14). The other interviews should actually be conducted with only one person. But in four further interview situations it was found that a patient or a NPC joined the interview or was in the same room as a kind of “passive listener”. In two patient interviews the spouse of the patient joined the verbal conversation. Both spouses acted as NPC within the new therapeutic concept. In interview 7 the wife of the patient was asked by the interviewee to join the conversation for some time because he did not want to talk about his wife in her absence. The wife of the patient joined the interview actively and also brought in her experiences with the new therapeutic concept. Therefore, she is treated as an independent interview partner. In interview 8 the husband of the interviewed stroke patient joined already from the beginning the interview, but did not bring in a lot of contents to the interview. He seemed to be more like a silent observer.

In two interviews with a NPC (interview 16 and 18) the stroke patient was present, even though the interviewer explained in advance that it is sometimes easier to speak alone about the own experiences. Similar to the husband of interview 8, these stroke patients did not bring in a lot of contents to the interview and therefore are not treated as an individual interview partner.

The interviewer tolerated these four situations because she did not want to displease the interviewees and her or his relatives. Nevertheless, these interview situations as well as the interview situations of the interviews that were planned to be conducted with a couple were sometimes experienced as sensitive.

Information about atmospheres and special situations experienced by the interviewer might give useful information for interpretation (Lamnek 2010, p. 356-358); therefore, they are described in the following section.

3.5.5 Documentation of the interviewers memories on atmosphere and special situations

Two interviews were conducted with an aphasic stroke patient and his NPC because these two stroke patients were not able to express their experiences (interview 12 and 14). Both patients were affected strongly in their ability to speak and to understand language. They were only able to speak individual words or phrases. It was experienced difficult by the interviewer to conduct an interview with two people, where one person, who was to a certain degree the main character, was almost not able to speak. The interviewer always tried to integrate the patient by posing direct questions to him and giving him time to answer. These attempts were mostly not successful because the patient was not able to articulate. Therefore, the conversation was most of the time between the interviewer and the relative, which felt strange because it was actually the claim also to include the patient in the conversation through eye contact or speech.

There were further situations in these two interviews that were experienced as difficult. Sometimes the relatives spoke about actions or attitudes of the patients that were not experienced as positive (e.g. a reduced motivation for practice). Because of the speech and language disorder, the stroke patients were not able to response to these accusations. Additionally, it was not always clear if the patient understood them at all. Similar experiences were made in two other interviews, where a patient and NPC were present (interview 7 and 16). There also was the situation that the patient was criticized by the relative in terms of rehabilitation efforts and motivation. Contrary to the couples where the stroke patient had a strong speech and language disorder, these patients were able to reply towards the accusations.

3.5.6 Data preparation

After the conduction of the interviews the verbal conversations were transcribed into a written text by using the software f4 (Audiotranskription.de 2012). The transcription was done by following the transcription rules of Kuckartz et al. (2008) modified by Dresing & Pehl (Dresing & Pehl 2012, p. 18-29). The verbal conversations were transcribed word for word without doing corrections in grammar or syntax to gain a precise overview about the interview. Pauses or filler expressions like “mmm”, “äh”, “ähm” or “pfff” were also transcribed as well as double words.

Non-verbal expressions as for example laughing, crying or other things that happened in the interview were noted in brackets. In the case of the nomination of personal names or places, which could jeopardize the anonymity of the respondents, the contents description of the particular person was put in brackets e.g. “first name of the son” or “name of the therapist”.

3.6 Hermeneutic phenomenological data analysis

For the identification and description of the experiences of the thirteen stroke patients and nine NPCs with “Cimt at home” the hermeneutic phenomenological analysis by van Manen was applied. Van Manen does not prescribe a detailed technique for his analysis; instead he gives recommendations and ideas on how to implement phenomenological research (van Manen 1990, p. 27-30, Creswell 2007, p. 59). Van Manen describes the purpose of phenomenological analysis as the attempt to “grasp the essential meaning of something” (van Manen 1990, p. 77). He furthermore recommended approaching the phenomenon “in terms of meaning units, structures of meanings, or themes” (van Manen 1990, p. 78). Van Manen gives to themes and the finding of themes a special significance. He states that the identification of them allows the researcher to describe and analyze the phenomenon (van Manen 1990, p. 78-80). He offers three possibilities to discover themes (van Manen 1990, p. 92-96):

1. **The holistic or sententious approach**

Question: “What sententious phrase may capture the fundamental meaning or main significance of the text as a whole?”

2. **The selective or highlighting approach**

Question: “What statements, or phrases seem particular essential or revealing about the phenomenon or experience being described?”

3. **The line by line reading approach**

Question: “What does this sentence or sentence cluster reveal about the phenomenon or experience being described?

In this study the second approach of identifying important themes was applied. The hermeneutic phenomenological data analysis was done with MAXQDA 11 (MAXQDA 2013).

3.6.1 Procedure of the analysis

The focal point of the hermeneutic phenomenological analysis was on the experiences of the stroke patients and NPCs with the new therapeutic concept “Cimt at home”. Therefore, the analysis regarding the experiences with “Cimt at home” was done very detailed and extensively.

Additionally, it was aimed to embed the description of the experiences of patients and NPCs with the new therapeutic concept, in a short description about the interviewees' experiences with their life after the onset of stroke. Because this information only builds a framework, the hermeneutic phenomenological analysis regarding these theme were done more roughly with the aim to gain a general overview. Despite that the same procedure were acknowledged. Figure 5 gives an overview about the proceeding of the hermeneutic phenomenological analysis:

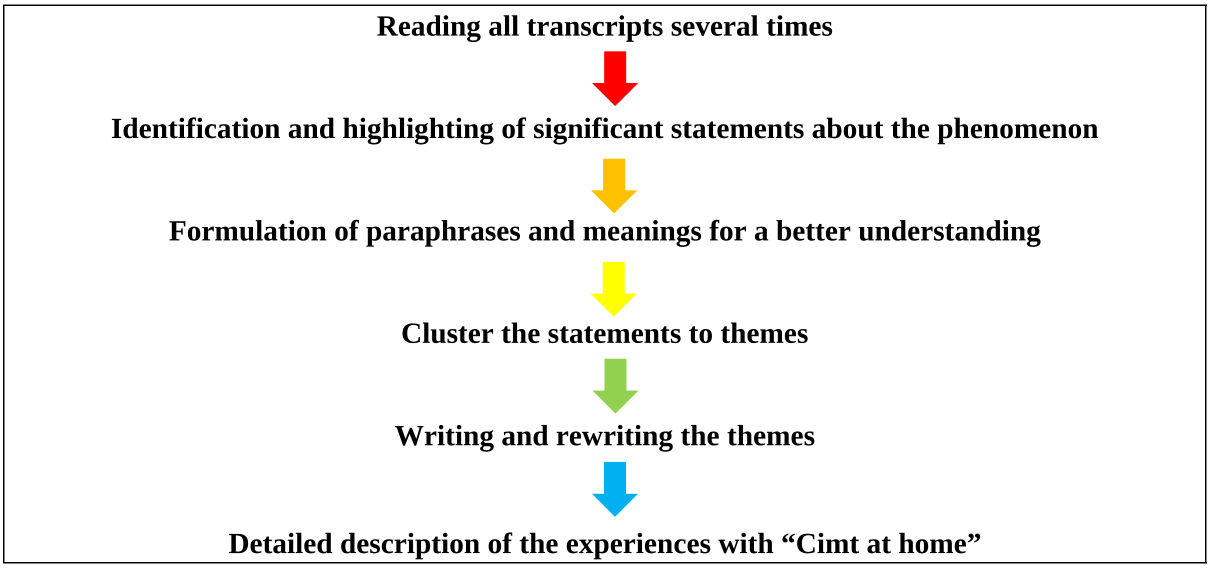

Figure 5: Proceeding of the hermeneutic phenomenological analysis (van Manen 1990)

After reading each transcript several times to get a broad and general impression of each interview, significant statements about the experiences of patients and NPCs with “Cimt at home” and their life after stroke were identified and highlighted in the transcripts. Moreover, meanings and paraphrases of the significant statement were formulated to get a better understanding of the meaning of it. During this phase ideas or interesting aspects that came up to the authors mind were noted in a research diary or in “Memos” of the data analysis software MAXQDA.

Similar or different experiences between the stroke patients respectively NPCs were compared. Thereafter, the important statements were clustered to themes and subthemes. After the identification of themes, the experiences of the stroke patients and the experiences of the NPCs were described in thematic sections by writing and rewriting their experiences (van Manen 1990, p. 131, Creswell 2007). Van Manen understands the process of writing as a process, which does not mean only to write down the results of the hermeneutic phenomenological analysis. Instead he understands the writing and rewriting process as an important element in the research process, which brings the researcher closer to the things of interest (van Manen 1990, p. 111-133, van Manen 2006).

3.7 Ethical considerations

All interviewees were informed verbally and in writing about the interview conditions to acquire informed consent. They were informed that their participation in the interview is free and that there will be no disadvantages for them if they do not participate. Furthermore, they were informed that all interviews will be recorded with a recording device and transcribed for the proceeding qualitative analysis. Moreover, it was advised that there will be no conclusion about the interviewed person. Personal names, places (e.g. cities, work places) or other notes were eliminated in the data preparation. An example of an informed consent for a patient interview can be seen in the annex on page 97.

3.8 Quality criteria

Whereas quality criteria are clearly defined for quantitative research, there is in qualitative research no clear opinion about how quality in qualitative research is measured or how quality criteria should look like (Flick 2011, pp. 485-539, Steinke 2007, pp. 319-331, Creswell 2007, pp. 201-211). Despite that, there seems to be no doubt that the consideration of quality criteria is an important part in qualitative research (Creswell & Miller 2000, Steinke 2007, p. 321-322). Creswell and Miller (2000) described eight common validation strategies for qualitative research based on the definition of “validity” formulated by Schwandt. Schwandt formulated that validity in qualitative research is understood “whether an account accurately represents the social phenomena to which it refers” (Schwandt 1997). The suggested eight validation strategies are (Creswell 2007, p. 207-209, Creswell & Miller 2000):

- **Triangulation**
- **Prolonged engagement in the field**
- **Thick and rich description**
- **Clarification of the researchers background**
- Member checking
- External audits
- Negative case analysis
- Peer review or briefing

Referring to Creswell (2007), at least two of the eight quality criteria should be applied in a qualitative research project to obtain accuracy and credibility of the research findings (Creswell 2007, p. 206). This should be done independently of the qualitative approach chosen. In the present study four validation strategies were applied. Triangulation is the attempt to illuminate a phenomenon from different perspectives e.g. use of different methods or study groups, whereas the second aspect was applied in this project.

Not only stroke patients were asked about their experiences, but also NPCs. (Creswell 2007, p. 208, Flick 2008, p. 519-520). Moreover it was tried to achieve accuracy and credibility by application of three more factors:

- Clarification and description of the researchers’ background
- Rich and thick description of the phenomenon
- Enough time in the field and with the topic

The quality criteria reliability was considered in this work by trying to achieve good and precise quality of data. This was attempted by a clear documentation of procedures, a precise transcription of the verbal conversations as well as the use of field notes (Creswell 2007, p. 209, Silverman 2010, p. 286-290).

3.9 Experiences of the researcher with the research topic

Van Manen recommends the process of reflecting on the own personal experiences in terms of the research topic to avoid that “pre-suppositions persistently creep back into our reflections” (van Manen 1990, p. 47). The author has a professional background as physiotherapist in the early neurological rehabilitation and therefore, also experiences with the physiotherapeutic treatment of severe and moderate stroke patients in a clinical setting. In the early phase of neurological rehabilitation the therapy density is high, which means that the therapist has a close contact to the patients, but also sometimes to the patient’s relatives. It needs to be noticed that the author has limited experiences about the ambulant care of stroke patients. Despite that, there is an understanding and knowledge of possible problems and needs of stroke patients and their families in the home environment. The author has no experiences as physiotherapist with “Cimt at home” or CIMT, but worked for almost two years in the HOMECIMT project as a student assistant. Therefore, there is an understanding of the new therapeutic concept.

In terms of the question, which influence the professional background and previous knowledge of the researcher have had on the research process, following aspects were considered by the author of this thesis. In most of the interviews it came up in the course of the interview that the interviewer had a professional career as a physiotherapist and had worked in the neurological rehabilitation. Therefore, the interviewees knew that the interviewer has a comprehensive knowledge about rehabilitation and stroke. Sometimes there was the impression that common knowledge was assumed by the interviewees. Moreover, there was the impression that some NPCs commented on the low willingness of the stroke patient in terms of rehabilitation efforts because they believed that the interviewer as a physiotherapist would support them. The professional background of the researcher might also have influenced the kind of questioning in the interview, the hermeneutic phenomenological analysis and the interpretation of the results (Creswell 2007, p. 39).

4 Results

This chapter contains the results of the hermeneutic phenomenological analysis of the experiences of stroke patients and NPCs with the new therapeutic concept “Cimt at home”. The experiences of the thirteen stroke patients and nine NPCs are presented each in thematic sections as it is recommended by Max van Manen (van Manen 1990, p. 168).

The description of the experiences with “Cimt at home” is framed by a short description of the patients and NPCs experiences with their life after the onset of the stroke. Prior the presentation of the results of the hermeneutic phenomenological analysis, the first two sections are introducing the interviewees on whom the analysis is based.

In conclusion, the structure of this chapter is as follows:

- Interviewees (chapter 4.1)
- Life after the onset of stroke (chapter 4.2)
- Experiences with “Cimt at home” (chapter 4.3)

It needs to be noticed that the single interviewees are abbreviated with “I” and the identification number of the interview (e.g. I6, I3). In the three interviews were two persons were involved actively in the interview (interview 7, 12 and 14), a differentiation between stroke patient and NPC is made as follows:

- I7a, I12a, I14a = stroke patient
- I7b, I12b, I14b = non-professional coach

In the description of the experiences of patients and NPCs quotations of the interviewees are embedded. The ID of the interviewee (e.g. I1, I3, I4) and the paragraph number of the MAXQDA document refer to the passage in the single transcripts (e.g. I1, 20). The square brackets “[…]” mark remarks in the quotes. Moreover, references to the interviewees and the paragraph number of MAXQDA are also made without quotations with the aim to guarantee traceability.

4.1 The interviewees

Firstly, background information is provided for the thirteen stroke patients; secondly, the nine NPCs are introduced.

4.1.1 The stroke patients

Thirteen stroke patients were interviewed in terms of their experiences with the new therapeutic concept “Cimt at home”. Table 3 on page 34 gives an overview about age, sex, living and employment situation of the thirteen stroke patients. Furthermore, the date of the stroke, the affected body side, handedness and the date of the intervention with “Cimt at home” as well as information about the NPC and the trainings frequency are noted.

Seven out of thirteen stroke patients are female and six of them are male. The age of the stroke patients varies from 37 to 73 years with a mean age of 57, 3 years. The time after the stroke varies between 2 to 21 years. The mean time passed after stroke is 6, 5 years. Eleven of the thirteen stroke patients experienced “Cimt at home” in the period of May till October 2012, which means that the period of time between interview and intervention with “Cimt at home” was no longer than approximately ten months. Only two patients had their intervention with “Cimt at home” already in autumn 2011 (I1, I17). For them the time between intervention and interview were approximately 12 and 19 months. Table 3 also shows that seven out of thirteen stroke patients were affected by a hemiparesis on their left body side and consequently six patients on their right body side. Five patients were affected by the stroke on the side, where there is also their handedness.

In terms of the family status of the stroke patients, three out of thirteen interviewees were at the point of the interview single, eight of them were married and two of them were divorced. Referring to the living situation of the stroke patients, the majority of the patients lived at the point of the intervention period with “Cimt at home” and the interview together with a spouse or a firm partner. Only one interviewee lived alone (I3) and one interviewee (I5) lived together with her teenage son and additionally at the weekends with her partner (long-term relationship). Interviewee 1 lived in the intervention period together with her husband, but they were at that time in the process of separation.

Eight out of thirteen patients were not working any more due to the severity of their stroke. Two patients were already retired before their stroke (I12a, I17) and three patients were able to work full-time (I3) respectively part-time after their stroke (I1, I7a).

All of the stroke patients had chosen a close relative (spouse, partner, brother or son) as their NPC for the practice with “Cimt at home”.

ID interviewee	Age	Sex	Year of stroke	Affected body side	Handedness	Family status	Living situation	(Former) Profession	Current occupation	Start of the intervention	Non-professional coach and trainings frequency
I1	51	Female	1992	Left	Right	Married, since a short time separated	Living alone, no partner, self-supplied	Employee	Employed 15h/week	Oct 2011	Husband, but due to severe family problems almost no practice with the NPC took place
I3	37	Male	2005	Left	Right	Single	Living alone, no partner, self-supplied	Employee	Employed 35h/week	Oct 2012	Brother, but there was no daily practice, also practice with the therapists and alone
I4	62	Female	2008	Right	Left	Single	Living together with her partner	Self-employed	Unable to work already before stroke	Oct 2012	Partner, but I4 practiced most of the time with a therapist and alone
I5	47	Female	2008	Left	Right	Divorced, one underage child, two adult children	Living together with her son, long distance relationship, self-supplied	Employee	Unable to work after the stroke	Jul 12	Partner and son, but due to motivational problems she also practiced alone
I6	62	Female	2009	Left	Right	Married, adult children	Living together with her husband	Self-employed, family business	Unable to work after the stroke	Sept 2012	Husband and sometimes her son, regular practice took place
I7a	57	Male	2008	Left	Right	Married, adult children	Living together with his wife and his daughters families	Self-employed, family business	Self-employed, works part-time in his family business	May 2012	Wife, regular practice took place
I8	64	Female	2007	Right	Right	Married, adult children	Living together with her husband	Employee	Unable to work after the stroke	Oct 2012	Husband, regular practice took place
I9	61	Male	2011	Right	Right	Single	Living together with his partner	Employee + self-employed	Unable to work after the stroke	Jun 2012	Partner, but no practice with the NPC took place
I10	61	Male	2011	Right	Right	Divorced	Living together with his partner	Employee + self-employed	Unable to work after the stroke	Oct 2012	Partner, but there was the impression that a practice with the NPC did not often take place
I11	52	Female	2000	Left	Ambidexterity	Married, two underage children	Living together with her husband and her children	Employee	Unable to work after the stroke	Oct 2012	Husband, but practiced also alone
I12a	73	Male	2007	Right	Right	Married	Living together with his wife	Employee	Pensioner, already before stroke	Oct 2012	Wife, regular practice took place
I14a	56	Male	2008	Right	Right	Married, two underage children	Living together with his wife and his children	Employee	Unable to work after the stroke	Oct 2012	Wife, regular practice took place
I17	62	Female	2011	Left	Right	Married	Living together with her husband	Employee	Unable to work already before stroke	Oct 2011	Husband, regular practice took place

Table 3: Socio-demographic information of the stroke patients

4.1.2 The non-professional coaches

Overall nine NPCs brought in their experiences with “Cimt at home”. Table 4 on page 36 gives an overview about socio-demographic details of the NPCs and information about the date of the intervention with “Cimt at home”.

The age of the NPCs varies from 43 to 70 years (mean age 58, 3 years). Six women and three men were interviewed; all of them were close relatives of a stroke patient. In terms of the occupation, four out of nine NPCs were not working (I12b, I18, I19, I20). Three of those reported that there were retired and one of the four (I19), a 43 year old women, cared for her two young children and the household. Two out of nine coaches worked part-time (I14b, I16). Interviewee 14b additionally cared for her children (I14b). Three interviewees (I7b, I13, I15) worked full-time.

The stroke of their relatives occurred before 2 to 6 years ago (mean 3, 34 years). The period of time between the start of the intervention with “Cimt at home” and the interview varies approximately from 2 to 19 months.

Table 4 also shows that five NPCs were the wife of a stroke patient (I7b, I12b, I14b, I16, I19) and three were the husband (I13, I18, I20). All of these eight interviewees were living together with the patient respectively their spouse. One out of the nine NPCs was the daughter of a stroke patient (I15). She was living together with one of her four children. Her mother lives alone, but very close to her house so that she could care for her after the stroke.

Only the husband of interviewee 7b was able to work part-time after his stroke in the family business. All other relatives of the NPCs were not working any more due to the stroke and other severe diseases (I13, I14b, I16, I18, I19) or because of age (I12b, I20). The age of the stroke affected relatives vary from 49 to 77 years with a mean age of 62, 7 years at the time of the interview (cf. table 4).

Additional note on the relations among the interviewees

It needs to be noticed that besides interviewee 7a/b, 12a/b and 14a/b, also interviewee 6 and 13 and interviewee 17 and 18 were married with each other. Even though the experiences of the patients and NPCs were analyzed and described separately, sometimes it is evident in the description of the experiences that an experience of a patient respectively NPC has a common reference.

ID interviewee	Age	Sex	Profession	Current Occupation (NPC)	Family status	Living situation	Connection to the stroke patient	Year of stroke	Age of the stroke patient	Current occupation of the stroke patient	Intervention period
I7b	57	Female	Self-employed, family business	Full-time	Married	Living together with her husband and the daughters families	Wife	2008	57	Works part-time in the family business	May 2012
I12b	70	Female	Employee	Pensioner	Married	Living together with her husband	Wife	2007	73	Pensioner	Oct 2012
I13	63	Male	Self-employed, family business	Full-time	Married	Living together with his wife	Husband	2009	62	Unable to work after the stroke	Sept 2012
I14b	54	Female	Employee	Part-time	Married	Living together with her husband and her two underage children	Wife	2008	56	Unable to work after the stroke	Oct 2012
I15	50	Female	Employee	Full-time	Divorced, four children, one children lives with her	Does not live together with her mother, but is living very close to her mother's house	Daughter	2011	77	Pensioner	Feb 12
I16	57	Female	Employee	Part-time	Married	Living together with her husband	Wife	2011	66	Unable to work after the stroke	March 2013
I18	62	Male	Employee	Validity pensioner	Married, one adult child	Living together with his wife	Husband	2011	62	Unable to work already before stroke	Oct 2011
I19	43	Female	Employee	House wife	Married, two children	Living together with her husband and her two underage children	Wife	2010	49	Unable to work after the stroke	Oct 2011
I20	67	Male	Employee	Pensioner	Married	Living together with his wife	Husband	2010	63	Pensioner	Oct 2012

Table 4: Socio-demographic information of the non-professional coaches

4.2 Life after the onset of stroke

For a better understanding of the life situations of the interviewed stroke patients and NPCs respectively relatives of the stroke patients a short overview is given about important experiences in the life after the onset of stroke. This includes also, due to the focus of this thesis, general experiences of patients and NPCs with physical and occupational therapy after the stroke. The following description includes no quotations of the interviewees, only references are made. In total, 206 significant statements in terms of the experiences of the patients about their life after stroke were extracted and clustered to themes. In terms of the experiences of the NPCs 165 statements were identified.

4.2.1 The experiences of the stroke patients

Almost all patients described their stroke as a very incisive, dreadful and life changing experience. The stroke happened all of a sudden and meant the loss of normal body and cognitive functions (I1, 12; I3, 10; I5, 6; I6, 18; I7a, 2; I9, 6; I11, 4; I14a, 2; I17, 8). They described paresis as well as the loss of speech, which in turn made it impossible for them to move independently or express their feelings particular in the first time after the stroke (I1, 12; I3, 4; I4, 10-12; I5, 11-12; I6, 6; I8, 2; I9, 40; I10, 7; I14a, 7). Some patients described additionally feelings of great fear, despair and tiredness (I6, 14; I7a, 173; I10, 5-6; I11, 2, 4), but also inadequate euphoria because the whole situation was not realized (I1, 12).

The experience of being helpless and dependent from others because of the loss of functions was described as a very bad experience for many patients in their life after the stroke. Some experienced the dependence from the nursing personal in the acute hospital very badly (I7a, 4-8; I9, 24; I10, 14). And patients, who were not able to express themselves because of speech and language disorders, described it as awful that they were not able to communicate their needs and feelings (I8, 2; I11, 2; I14a, 21; I12a, 9). Interviewee 6 experienced the first time at home terrible because she felt sometimes incapacitated by her family, which always wanted to protect and help her (I6, 15-18). But also at the time of the interview, in the chronic phase of stroke, some patients described that they are still dependent from others in terms of basic needs and/or their mobility. This made them feel sad and restricted in their daily life (I7a, 16; I10, 30-32, 84; I17, 16).

All patients were after their stroke in a rehabilitation clinic. Thereafter, the rehabilitation with ambulant physical and occupational therapy was continued on a weekly basis. They described the therapy in the beginning as very exhausting because basic activities (e.g. sitting or walking) needed to be learned again (I3, 10; I5, 18; I9, 16; I11, 22; I17, 19-22). Despites, therapeutic measurements were often described positively and as a possibility and chance to regain functions and in turn more independence (I5, 52; I7a, 16; I8, 42-43; I9, 58; I10, 10; I11, 22-26; I14a, 21). An important improvement, which was mentioned by interviewee 6, 8, 10 and 11 was the regaining of the ability to walk, which often occurred already in the rehabilitation clinic (I6, 4; I8, 2; I10, 26-28; I14a, 21). Later improvements were of importance when they resulted in participation of meaningful activities in the field of work, household or leisure time (I4, 48; I6, 106; I7a, 68, 90; I8, 44-47; I11, 18; I17, 16). Most of the patients described a friendly relation to their therapist in the rehabilitation clinic and in the ambulant therapy practice. Furthermore, the therapy seemed to be often a part of their life (I1, 22; I4, 40-46; I5, 41-44; I8, 123-124; I9, 105-107; I10, 48; I12a, 30; I14a, 9). Some patients described their therapist as someone, who really understood their situation (I1, 52, 85-88; I6, 4, 23-28; I11, 7-8).

The process of rehabilitation was in general described by some patients as very long lasting and continuous. Particular in the chronic phase of the stroke it was experienced that advancements are little (I6, 92-96; I7a, 14-16; I9, 58; I11, 103) and that sometimes also the motivation for therapy is low (I10, 14; I11, 51). Besides, some patients still have the hope to get back to “normal” or closer to it and were therefore motivated to exercise (I6, 6; I7a, 20; I10, 83; I17, 70-74).

The support of the partner was experienced by many patients, who had a relationship, as very important (I1, 6; I4, 12; I6, 98; I7a, 4; I8, 2; I9, 14; I10, 8; I11, 2). Particular in the acute phase, but also later, the partner was experienced as a psychological support and motivation, but also as somebody, who managed things for oneself. Some also described that their partner needed to take over many tasks of them because they were not anymore able to do them after their stroke. Some experienced because of this a guilty conscience (I4, 56; I9, 85-93; I10, 83; I11, 99; 117, 18). An aspect that came up by four patients with respect to their partner, were the experience that they believe or know that the partner wants them to do more in terms of their rehabilitation (I6, 28-32; I7a, 133-136; I8, 49-53; I10, 95).

The integration in the family or an assisted living and not left alone (I3, 6; I7a, 68-71; I8, 34-35; I10, 97), the acceptance of the own changed situation after stroke (I8, 39; I10, 8; I11, 24, 26; I12a, 11-14), experiences of other stroke patients (I6, 20; I17, 14) as well as the possibility to really try things alone (I1, 16-18; I6, 18; I7, 85-89) were among other things further supportive factors in the rehabilitation process. Not supportive were the experiences of patients when other people did not really understand their situation (I5, 10, 36; I6, 14, 18-20; I10, 8; I11, 14-16), were disrespecting their goals (I7a, 10) or also excessive demands in the rehabilitation clinic (I6, 14).

At the time of the interview some patients could do part-time or even full-time their former work (cf. table 3, p. 34). Other patients were able to do parts of the household, but there were also interviewees, who were not able to manage household activities. Some patients described that their participation in life is still reduced (I5, 52; I8, 4, 6; I10, 29, 97; I11, 16-18; I17, 16) and interviewee 5 and 11 perceived that their life is in general more exhausting because of an increased tiredness and a reduced capacity since the stroke (I5, 9-10; I11, 26).

4.2.2 The experiences of the non-professional coaches

The NPCs perceived the stroke of their relatives similar to the patients as a sudden and shocking experience for which they were not prepared (I12b, 4-6; I13, 2; I14b, 4; I18, 22; I19, 11; I20, 9). Almost all described their intensive, often daily support of the relative in the hospital and rehabilitation clinic as their main task in that time (I7b, 73; I12b, 10; I13, 13; I14b, 20; I15, 7; I16, 11-13; I20, 13). The first time after the stroke was experienced as hard and difficult (I13, 12; I14b, 12; I15, 7; I16, 3; I19, 6-9; I20, 10-11) and feelings of anxiety, overburdening, stress, despair as well as hope that everything might be fine again were experienced (I13, 2; I14b, 12; I15, 50; I16, 2-5, 7; I19, 9). Additional stress was perceived by two interviewees, who were also responsible for their young children at that time (I14b, 9-12; I19, 9).

After the discharge from the rehabilitation clinic, all affected relatives of the NPCs came back in their homes. An exception is interviewee 15; her mother returned in her own house. Interviewee 16 described that she only realized at home how strong her husband was really affected by the stroke (I16, 21) and interviewee 19 made the experience that after the first joy that her husband was back, difficulties arose because of changes in the mood of her husband (I19, 12-13). Interviewee 14b was happy that after her husband was back at home, the daily journey to the rehabilitation clinic ended (I14b, 24).

For most of the NPCs the stroke of their relative meant that they had to take over tasks and responsibilities of the affected partner, which was in the beginning experienced as sometimes hard (I7, 63; I13, 2, 7-8; I14b, 12; I16, 29; I18, 3-6, 18-22). Moreover, it was described by some NPCs that it was a long and difficult process to adapt and accept the new situation after the stroke (I12b, 115-117; I13, 7, 73; I14b, 12; I15, 124; I19, 9-13, 15). Through the stroke of their relative their life is now different than before and not anymore *“normal”* (I13, 2, 6, 15; I14b, 126; I16, 29; I19, 9). Interviewee 12, 13, 16 and 18 said for example that since the stroke, free time activities with their partner are reduced, are no longer spontaneous possible or even if holidays are possible, oneself has more responsibilities than before (I12b, 15; I13, 3-6, 75; I16, 26-29; I18, 31-32). Further, some NPCs perceived that through the care of the relative they have less time for themselves (I15, 18; I20, 64). Interviewee 18 rose up the theme that he also felt exhaust through the care of his strongly affected wife (I18, 46-47).

Also the aspect that some relatives changed, besides their physical disabilities, mentally and in terms of their state of mind was mentioned by some NPCs as a very difficult experience for them (I12b, 19-25; I15, 18, 20; I16, 21; I18, 23-30; I19, 13; I20, 23).

Despite the difficulties with the new situation, interviewee 13 never questioned to stay with his wife after her stroke (I13, 27). Or interviewee 15 explained her engagement in the care of her mother as naturally because her mother also always was there when she needed it (I15, 20).

In terms of the rehabilitation of the affected relative, some NPCs described that they often took part, particular in the first time after the stroke, in physical and occupational therapy sessions to learn how they can support the relative or only to be present (I13, 20-23; I15, 158; I16, 30-31; I19, 18-19; I20, 13).

At the time of the interviews some NPCs were still involved actively in the rehabilitation of the affected relative to support her or him. They described that they are providing possibilities to practice with them or are giving their relatives ideas and advices (e.g. open the door with the impaired hand) (I7b, 59; I12b, 99; I14b, 107-111; I15, 169; I16, 33, 37; I19, 49; I20, 45-52). Interviewee 7b, 12b, 14b, 15, 16, 19 and 20 sometimes experienced that their efforts to support the relative with the rehabilitation were not always seen with pleasure by the affected relative. Furthermore, it was perceived that there is a difference if the therapist gives an advice or them as a relative. Some wondered about this or were sad that the relative gave not so much attention to their efforts (I7b, 54-59; 12b, 57; I14b, 53, 68-69, 81-85; I15, 24-26; I16, 31, 109; I19, 49-51; I20, 15, 21). Particular interviewee 15 and 20 experienced rejections in terms of their efforts because of the depressiv mood of their affected relatives. It was described by them as very difficult to motivate the relative for therapeutic measures (I15, 169; I20, 45-52). Furthermore, interviewee 15 experienced it as very hard to accept that her mother gave up herself and speaks about dying (I15, 124). Both interviewees took professional help to be able to better handle the difficult situation (I15, 124; I20, 17).

Furthermore, it came up in the interviews that some NPCs hoped that their relative would do more in terms of the rehabilitation or would show more ambition to improve (I7b, 52-53; I12b, 33-36; I15, 165; I16, 113-128). And interviewee 19 described the weekly therapy sessions of her husband as positive because they are giving a structure to his days and it is the only time, where he is not present (I19, 19-21).

Despite the difficulties and the changed living situation, some NPCs also mentioned positive experiences. Interviewee 7b described for example the first mutual holiday after the stroke as a very positive experience because she and her husband had a good time together and they were able to manage everything alone (I7b, 79). Also interviewee 16 was happy about situations in her everyday life, which she and her husband managed together (e.g. climbing stairs, able to walk a small distance together) (I16, 23, 24, 33). Interviewee 15 described it as a very positive aspect that now, since the stroke, she and her mother have a closer relationship (I15, 134). Or interviewee 13 described positively that through the stroke of his wife he spends less time in his business and perceived that despite that everything is done correctly (I13, 65).

4.3 The experiences of the stroke patients and non-professional coaches with “Cimt at home” - Overview

By the hermeneutic phenomenological analysis of the thirteen patients’ transcripts overall 275 significant statements about the experiences of the stroke patients with “Cimt at home” have been extracted. In the nine transcripts of the NPCs overall 194 significant statements were identified, which could reveal something about the experiences with “Cimt at home”.

In terms of the experiences of the stroke patients seven main themes arose in the hermeneutic phenomenological analysis:

1. Motivation to participate in the HOMECIMT study
2. Implementation of “Cimt at home” in everyday life
3. The exercises of “Cimt at home”
4. The practice with the non-professional coach
5. Restriction of the healthy arm and enhanced usage of the impaired arm
6. Improvements though “Cimt at home”
7. The role of the therapists in “Cimt at home”

The hermeneutic phenomenological analysis of the NPCs’ transcripts revealed five main themes about their experiences with the new therapeutic concept:

1. Motivation to support a stroke affected relative with “Cimt at home”
2. Implementation of daily practice in everyday life
3. The practice with the stroke affected relative
4. Difficulties with the implementation of the restriction
5. Improvements of the relative made through “Cimt at home”

4.4 The experiences of the stroke patients with “Cimt at home”

The following chapters contain the descriptions of the experiences of the stroke patients with the new therapeutic concept “Cimt at home”.

4.4.1 Motivation to participate in the HOMECIMT study

The patients described different motivations and reasons why they decided to take part in the HOMECIMT study. The list below gives an overview about the different motivations and reasons. Often more than one was mentioned by a patient:

- Hope for improvements
- Interest and curiosity in a new therapy and in a scientific study
- Chance to make a contribution to research
- Wish of the partner
- Already good experience with CIMT

The most important reason why the patients decided to take part in the HOMECIMT study was their hope for improvements. For interviewee 5, 7a and 10 the study participation was a chance for improvements and a chance to get a little bit closer to “normality”, meaning the state before the onset of stroke (I5, 24; I7a, 163, 173; I10, 83). Interviewee 10 said about his motivation: *„Ja, meine Beweglichkeit (.) ich möchte eigentlich, (.) eigentlich möchte ich wieder so sein wie ich am 26. November 2011 war. Das ist meine Motivation“* (I10, 83). Or interviewee 7a described his motvation as follows: *„ich sehe das immer als Chance […] um doch wieder ein bisschen weiter zu kommen“* (I7a, 163). Interviewee 17 participated in the study and always would participate again because she still hopes for improvements of her affected arm: *„Ich würde auf jeden Fall […], wenn mir irgendwas angeboten wird, alles immer wieder mitmachen […] eben halt in der Hoffnung, dass doch irgendwann noch was passiert“* (I17, 66). The prospect of improvements of the impaired arm was also for interviewee 3 and 6 a reason to participate (I3, 16; I6, 76). Interviewee 8 described that she believes that all kind of therapies might be helpful for her, even though improvements are sometimes not directly visible. She explained her motivation: *„dann macht man das und es kann nur gut gehen […], [es] kann nur besser werden“* (I8, 114). Similar to interviewee 8, interviewee 7a and 10 seem to have the idea that all kinds of therapies are helpful, even though the stroke has been already some years ago (I7a, 173; I10, 76-77).

Another reason for the study participation was interest and curiosity in a new therapy (I1, 36-38; I8, 11-113; I9, 135-136; I14a, 9) and in a scientific study (I17, 35-36). Interviewee 9 said for example: *„es war einfach die Neugier, ob es wirklich noch etwas Besseres gibt“* (I9, 136).

Furthermore, the chance to make a contribution to research came up by some patients as a reason for participation (I1, 38; I9, 136; I10, 99). Interviewee 10 believed for example that it is important for the „*Allgemeinheit, dass sich Leute bereiterklären, das mit zu machen*“ (I10, 99). Or interviewee 9 wanted to make a contribution by doing „*Pionierarbeit*“ (I9, 136).

Other reasons for participation were the wish of the partner (I12a, 40-51), but also the aspect that oneself was asked by the therapist for participation seemed to be a reason. Interviewee 1 stated: „*und dann sagt […] mein Therapeut,[…] dass er auch schon jemand empfehlen kann, nämlich mich, da sage ich, das ist doch gut also [lacht] ist doch klar sage ich, dann mache ich damit, warum nicht*“ (I1, 38). Already good experiences with the application of CIMT in the lower extremity were another motivation for interviewee 6 to participate (I6, 4).

4.4.2 Implementation of “Cimt at home” in everyday life

This theme describes the patients’ experiences with the implementation of “Cimt at home” in their everyday and working life and how they perceived their daily life in the time of the intervention with “Cimt at home”. As visible in table 5 this theme is three folded. There were patients, who experienced the coordination of their everyday life and the simultaneous implementation of “Cimt at home” sometimes as difficult and stressful. But there were also other stroke patients, who experienced their daily life not much different than usual. One patient experienced her daily life more conscious through “Cimt at home”.

Main theme	**Subthemes**
Implementation of “Cimt at home” in everyday life	Difficulties with the coordination of everyday life and “Cimt at home”
	Everyday life not much different than usual
	Everyday life more conscious through “Cimt at home”

Table 5: Implementation of “Cimt at home” in everyday life

Difficulties with the coordination of everyday life and “Cimt at home”

An experience common for approximately half of the patients was that the implementation of “Cimt at home” in every day and working life was not always easy to realize (I1, I3, I5, I7a, I9, I11). Therefore, carrying out the therapy and/or their everyday life were sometimes perceived as stressful, exhausting or annoying. The list below gives an overview about reasons why the implementation was sometimes experienced as difficult and stressful:

- a lack of time
- a lack of motivation
- a reduced endurance
- a decreased muscle strength in the afternoons and evenings

Stresses by a lack of time were experienced by patients, who had a current employment, but also patients, who were not working any more, had problems with the implementation of “Cimt at home” due to a lack of time.

Interviewee 1, 3 and 7a described that the coordination of “Cimt at home”, their normal responsibilities and their labor obligations were sometimes hardly to realize (I1, 38, 92; I3, 84; I7a, 36). Interviewee 1 said for example: *„es war alles sehr anstrengend, weil in meinem Alltag da schaffe ich die ganzen Sachen so gar nicht, ich war hinterher immer völlig geschafft, weil du musstest immer die ganzen Wiederholungs-Sachen machen. Das war alles sehr nervend und anstrengend“* (I1, 38). Despite the temporal difficulties, she realized the therapy over the four-week intervention period because she felt committed to the study (I1, 91-92). Also interviewee 7a felt stressed because the exercises as well as the comprehensive documentation of “Cimt at home” were sometimes difficult for him to carry out (I7, 36). Additional stress was perceived by him because of a guilty conscience if it was not possible to realize the exercises due to a high amount of work. He explained how he felt in these situations: *„ah, jetzt hab ich heute keine Therapie gemacht, meine Güte noch mal, Mist was mache ich dann, dann muss ich morgen mehr machen. Und so kommt man dann langsam in Zugzwang. Das war schon so ein bisschen nervig, so ein bisschen Druck“* (I7a, 159). Interviewee 3 described that it was difficult for him to motivate himself after a working day. He said: *„wenn man […] irgendwie schon sieben Stunden oder acht Stunden gearbeitet hat […] und dann sagen wir mal nachmittags oder abends noch was machen soll, ist das halt nicht immer ganz einfach“* (I3, 25-27). Additionally, he experienced his muscles of the impaired arm in the evenings not as powerful as in the morning. Therefore, the exercises in the evenings were more exhausting for him (I3, 21). Interviewee 7a and 3 were both of the opinion that “Cimt at home” would have been better to carry out without their working obligations (I3, 84; I7a, 36).

Interviewee 11, who was not working anymore due to her stroke, experienced the implementation of the enhanced arm usage in her everyday life as very time consuming and exhausting. She sometimes felt a lot of stress because already her normal daily responsibilities (e.g. daily shopping, preparing dinner, caring for her dog) (I11, 46-49) are tough enough for her (I11, 79). She was sometimes so set up that she also thought about quitting the therapy (I11, 67). She said: *„meine Kinder sagten, oh, hoffentlich hat das ein Ende. Ich war so gereizt, aber mit dem Handschuh, das war Quälerei […] ich war nur kaputt, und dann habe ich auch einen Hund […] Spaziergang, ne (.) und ja, das war alles Zeit […] ich war immer kaputt, ich hätte nur schreien können“* (I11, 28). She stuck to the therapy because of her own perfectionism and furthermore, she explained that she also was proud because of all the efforts she did (I11, 35-37, 73-75).

It was hard for interviewee 5 to hold on to the daily practice schema because the four weeks were perceived as very long (I5, 38).

She furthermore described that since her stroke her daily capacity is reduced. In contrast to the time before the stroke, her “battery” is now only charged till noon. She answered to the question how her everyday life was during the four weeks: *„anstrengender natürlich. Weil ich eben halt sehr viel mit links machen musste, ist es halt so, dass der Akku auch mittags alle war […] und dann musste ich nachmittags […] eben halt den Handschuh tragen und dann mit links weiter arbeiten“*. Nevertheless, she completed the therapy. She said: *„ich hatte das Gefühl es bringt eine Menge […] und ich muss dabei bleiben“* (I5, 25-26). Also interviewee 9, who was not working anymore because of his stroke, had difficulties to stick to the therapy because he experienced the daily exercises particular towards the end of “Cimt at home” as disturbing in his everyday life. In contrast to interviewee 5 and 11, he did not name concrete reasons why it was difficult. He said: *„es war sehr störend abends zwischen neun und zehn dann nochmal Erbsen zu zählen, […] fand ich also ein bisschen nervig manchmal, obwohl ich sage mal so, wenn man so was macht, dann muss man es auch durchziehen“* (I9, 109).

Everyday life not much different than usual

Interviewee 10, 12a, 14a and 17 did not perceive their everyday life much different than usually by the implementation of “Cimt at home” (I10, 67-68; I12a, 4, field note I12a; I14a, 133, field note I14a; I17, 38). This experience was made by patients, who did not work anymore due to their stroke or were already retired. Interviewee 17, who was already in an early retirement before stroke, said about her everyday life in the intervention period: *„ganz normal, wie immer, wie vorher oder wie jetzt auch wieder“* (I17, 38). Interviewee 10 also experienced his everyday life in combination with the implementation of “Cimt at home” as normal. He said about his everyday life in the four-week intervention period: *„eigentlich ist der so normal weitergelaufen“* (I10, 86). He only described difficulties with finding time for the practice with his partner. As a reason he mentioned that they were often visited by neighbors, thus it was difficult for them to find time to practice (I10, 61-66).

Everyday life more conscious through “Cimt at home”

Interviewee 8, who was not working anymore because of her speech disorder, experienced her everyday life in the four weeks with “Cimt at home” more conscious and intensive. She tried with purpose to create her daily life in the four weeks less stressful with the aim to be able to use her impaired arm consciously and more often in her everyday life. She said: *„Ich habe den [Alltag] eigentlich sehr viel intensiver gestaltet in dem ich, das alles sehr bewusster gemacht habe, nicht so […] das ich mich selbst unter Druck gesetzt habe, das mache ich nämlich gerne, […] und dann bewusster aber alles gemacht habe […]. Ja und das ich eben durch die ganzen Empfehlungen auch eben mit dem Handschuh aber eben auch mit den Sachen alles, dass ich das eben, so ganz ruhig für mich gemacht habe und dann hinterher ja wie gesagt so weiter versucht habe, auch ohne Handschuh“* (I8, 75).

Interviewee 4 and 6, who were both not working anymore, did not mention in the interview how they perceived their everyday life in the four-week intervention period. They only described that they were able to carry out “Cimt at home” over the four weeks regularly (I4, 75-76; I6, 6, 41-42).

4.4.3 The exercises of “Cimt at home”

Patients’ experiences with the repetitive, task-oriented exercises of “Cimt at home”, which they did on a daily basis, are described in this theme. This theme includes positive and negative experiences with the exercises as well as movement experiences, which some patients made by the repetitive, task oriented exercises (cf. table 6).

Main theme	**Subtheme**
The exercises of “Cimt at home”	Positive and negative experiences with the exercises
	Movement experiences

Table 6: The exercises of “Cimt at home”

Positive and negative experiences with the exercises

Exercises were described and remembered positive by some patients when they experienced an improved exercise performance (I5, 22; I14a, 54) or could made a reference to an improved and meaningful activity of daily life (I4, 62; I7a, 149; I9, 68, 93). Interviewee 4 for example described an exercise as follows: *„ganz einfach [nimmt den Telefonhörer in die Hand], das kann ich jetzt schon, aber das sind solche Sachen, [die] ich jetzt besser kann als vorher und das fand ich natürlich nun wieder sehr gut“* (I4, 62). Or interviewee 5 said: *„Es gab eine Übung, da sollte ich so den Türrahmen, so über meinen Kopf hinweg und dann wieder nach unten gehen. Wie viel ich schaffe in 30 Sekunden und beim ersten Mal […], habe ich [es] einmal geschafft und am Ende der Studie hab ich es 15 Mal in 30 Sekunden geschafft. Das war das Highlight der Studie“* (I5, 22). Exercises also were experienced as positive if they were difficult, but realizable. Interviewee 1 described a good exercise: *„die beste Übung […] war Büroklammern aufnehmen nach Zeit, […] wie viele man schafft und zwar war das so gewesen: Tisch war ein bisschen höher und dann musste man sich irgendwie gerade hinsetzen und dann war so ein Schuhkarton daneben gestellt, da ein Teller darauf und dann musste man die Büroklammern nehmen und in die andere Schale reintun und wieder zurücklegen [...]. Das war ganz schön anstrengend“* (I1, 44).

In contrast, exercises were disliked if there were too difficult or no reference could be made to an activity of daily life. Interviewee 6 could not see a connection between an exercise and her everyday life. She described it as meaningless. She stated that her improvements happen in her everyday life and not by lifting *„100-mal diesen Arm, nie wieder“* (I6, 106). Interviewee 1 did an exercise, which she did not like at all because it was very difficult for her. *„Schrank aufmachen zehnmal nacheinander und da ich links auch nicht so hoch greifen kann und dann musste ich immer am Schrank auf machen und zu machen einem nach dem anderen […] das war so nervig“* (I1, 40).

Also interviewee 17 described that she was sometimes sad because the exercises were too difficult for her to complete successfully (I17, 45-52).

Interviewee 3 experienced the repetitive exercises as strange because he had the impression that the focus of the exercises was more on the quantity instead of the quality of the movements (I3, 90).

Movement experiences

The experience was made by some patients that the more often they did an exercise, the better the exercise performance or the function of the impaired arm (I1, 72; I5, 58; I14a, 54). The wife of interviewee 14b described for example for her language limited husband: *„es normalisierte sich dadurch, dass es dann immer wieder dieselben Bewegungen waren“* (I14a, 54). Or interviewee 1 said: *„dann habe ich das ganz oft gemacht, nachher wurde es besser mit der Übung“* (I1, 72).

Interviewee 6 has been suffering since her stroke from strong pain in her left upper affected extremity and body side. Through the repetitive exercises the pain in her shoulder increased. This had a negative impact on the whole therapy. She said: *„ich war nachher so gefrustet, ich habe nur noch gedacht morgens ran und weg […]. Als ich wusste das ist jetzt vorbei, […] habe ich am Wochenende zwei Tage geheult, weil es hat mich so fertig gemacht diese Schmerzen, die durch diese bescheuerten Übungen gekommen sind“*. Even though her supervising therapist recommended to reduce the exercises or to quit the therapy, she continued (I6, 6, 66). She answered to the question why she carried on with the new therapeutic concept: *„Die Hoffnung, ich wollte mir ja auch nicht nachsagen lassen, hättest du das mal zu Ende gemacht, dann wäre es auch besser geworden“* (I6, 9-10).

4.4.4 The practice with the non-professional coach

The different experiences of the stroke patients, which they have made in the four-week daily practice with their NPC, are described in this theme. All patients had chosen a close family member as NPC. This theme is divided into three subthemes as visible in table 7.

Main theme	Subtheme
The practice with the non-professional coach	Positive experiences
	Difficult experiences
	Modifications of the practice

Table 7: The practice with the non-professional coach

At first positive and difficult experiences, which were made in the practice with the NPC, are described. It needs to be noticed that positive and difficult experiences were sometimes made by the same patient. In the third place this theme contains a description of the modifications when a regular practice with a NPC was not possible or difficult.

Positive experiences

Different positive experiences were made by the patients through the practice with their NPC. A positive experience described by interviewee 12a and 14a was that through the practice more time was spend with the partner (I12a, 41-42; I14a, 130-131). Furthermore, the practice with the NPC was sometimes experienced as funny. The spouse of interviewee 12a spoke for her language limited husband: *„wir haben unseren Spaß gehabt, wir haben uns auch gefreut, wenn es besser wurde. Du hast auch versucht zu mogeln, manchmal noch eine Kugel mehr rein zu schmeißen, die habe ich dann wieder abgezogen [I12a lacht] und er hat, pfiffig ist er ja, dann hat er, ich weiß nicht man musste ja so Klötzchen aufstellen […], dann hat er die letzten die da noch standen, einfach so mit einer Wischbewegung, dann weggemacht [lacht]“* (I12a, 61-66). Even though interviewee 5 experienced the practice with her NPCs as difficult because of a reduced motivation of her coaches to practice with her, it was a positive experience for her that she and her coaches stuck to “Cimt at home” until the end and did not give up before time (I5, 29-30). Interviewee 6, who practiced daily with her husband or son, was happy that she could rely on the support of her family in her rehabilitation process. She said: *„mein Mann hat nach meinem Schlaganfall gesagt, du bist jetzt die Wichtigste und egal was kommt, ich lass dafür alles stehen und liegen und dann ist das erst mal dran“* (I6, 98-100).

Besides the highlighted positive aspects of the joint training, some patients experienced the practice with their NPC as unproblematic and obvious. The practice was described as *„ganz normal“*, *„gut“*, *„gar kein Thema“*, *„ganz normal weg“* (I3, 30-37; I6, 40; I8, 99-100; I11, 40-45; I17, 39-44). Interviewee 11 said shortly: *„Nett, wir sind jetzt ein eingespieltes Team“* (I11, 40-45).

Difficult experiences

Because of different reasons the practice with the NPC respectively single aspects of it, were sometimes experienced as difficult by some patients. The list below gives an impression about aspects, which were mentioned by the patients:

- Advices and proposals of the NPCs were perceived as sometimes stressful
- Listlessness of the NPCs
- Difficult family situation
- Practice with the NPC was no fun

Advices and proposals in terms of the exercise performance, the request of the NPC to do more or the control of the trainings time by the NPC were experienced as sometimes stressful and annoying by some patients (I7a, 51-58; I12a, 56; I14a, 82-88).

The wife of interviewee 12a spoke for her language limited husband: *„wir haben dann gesagt, also komm, du kannst doch, nun mach mal den Knopf vom Fahrstuhl, […] oder mach doch mal spaßeshalber Licht, […] also wenn man sagt, mach es, dann macht er es, aber man muss dann auch vorsichtig sein, manchmal war er dann auch störrisch wie ein Kind, […] aber jetzt sage mir nicht noch so ein blöden Quatsch, ja, du weißt doch das es nur so und so geht und das ich es sowieso nicht mache, so war eigentlich der Tenor“* (I12a, 56). Or the wife of interviewee 14a spoke for her husband: *„Manchmal hast du auch mit mir geschimpft und hast gesagt, nein, das mache ich jetzt nicht“* (I14a, 82-88). Additionally, the aspect that his wife was the one, who controlled the time for the practice was difficult for interviewee 14a so that in turn he sometimes refused the training and wanted to decide himself the time for practice (I14a, 69-76). Interviewee 7a stated that his wife was maybe not a good therapist. According to him a good therapist is “more empathic” whereas his wife was “harder” in the therapeutic setting (I7a, 31-34, 51-58). He explained why he thinks that the expectations about the appropriate therapy workload differ: *„es ist […] für den Ehepartner ohnehin eine Belastung, die Situation, die entstanden ist durch den […] Schlaganfall, so und jetzt möchte natürlich der Ehepartner auch dass es voran geht und dass man mehr macht, dass man sich mehr anstrengt […] so wenn man das denn macht, […] dann meint der Ehepartner man könnte ja mehr, […] bisschen genauer oder schneller oder nochmal eine viertel Stunde und nochmal eine halbe Stunde und da ist es dann, dass man dann als Betroffener sagt, Mensch, jetzt habe ich schon eine Stunde gemacht, jetzt muss es doch mal gut sein“* (I7, 31-34). In this context interviewee 7a recommended that it would maybe be better if a not so close person like a spouse would act as a NPC (I7a, 42-51).

It was experienced by interviewee 1, 4 and 5 that their NPCs only had a reduced willingness to practice with them. Interviewee 5, who practiced weekdays with her teenage son and on the weekends with her partner stated: *„er war schon genervt. Am Wochenende hat das ja mein Freund gemacht und ich hab dann auch gemerkt, das meinem Freund, dass auch zu viel wurde“* (I5, 29-32). She was demotivated and disappointed by the low level of support by her family. She said: *„daran sieht man, dass die anderen Menschen das einfach nicht so sehen, wie wichtig so was ist“* (I5, 31-34). In this situation her occupational therapist as well as the improvements she made motivated her nevertheless to continue with “Cimt at home” (I5, 22). Also interviewee 4, who already practiced on only one day with her partner said: *„das sind natürlich zusätzliche Sachen, die er so gerne nun nicht haben müsste“*. Afterwards, she was excusing her partner because he does in general a lot for her (I4, 99).

During the intervention period interviewee 1 was in a very difficult family situation with her husband. This had the consequence that she finally practiced on her own. She and her husband were in the process of separation; anyhow, her husband had signed the therapy contract, but was demotivated to support her (I1, 50).

She said: *„mein Mann hat eh schon gesagt, dass bringt ja überhaupt nichts, was du jetzt hier machst. […] ich sag gut dann mache das alleine mit dem Stoppen“* (I1, 40). She assumed that “Cimt at home” would have been different as a couple: *„mit mehr Rückgrat halt“* (I1, 54).

Even though interviewee 6 was content that she could rely on her family in terms of her rehabilitation process, she described the practice with her husband as very serious, practically and not funny. But similar to interviewee 4, she mentioned right after, that without her husband she would be even more impaired (I6, 33-40).

Modifications of the practice

The difficult family situation of interviewee 1 and a reduced willingness of the NPCs to train described by interviewee 5 led to modifications of the practice. To realize “Cimt at home” these interviewees practiced completely (I1, 40) or partly alone (I5, 22). Interviewee 5 additionally split the daily two-hour practice in smaller parts distributed over the day so that the practice was easier to handle for her NPCs. Moreover, two people acted as NPCs (I5, 30).

Also other patients described that they did not practice completely with their NPCs (I3, I4, I10, I11). Among three patients (I3, I4, I11) it was obvious from the beginning of “Cimt at home” that their NPCs could not cover the complete practice because of work commitments. In these cases therapists were able to take over parts of the practice (I3, 55-56; I4, 76, field note I4) and/or the patients practiced partly alone to realize the two-hour daily training. To carry out the exercises alone was no problem for them (I3, 26, field note I3; I4, 76; I11, 28, 38-39).

Interviewee 10 practiced also often on his own because it was difficult for him and his partner to find common time to practice (I10, 64). He experienced that it was not so easy for him to stick to the therapy because it was difficult for him to get motivated on his own. He described that sometimes other things in his everyday life were more important. He said: *„dann war es für mich vielleicht wichtiger, mal zu lesen was der HSV macht [lacht]“* (I10, 58). He mentioned that the support through a professional therapist would have been helpful for him (I10, 58). He explained: *„ich bin eigentlich mehr ein Typ, der also jemanden dabei haben will, dann arbeite ich, wenn er sagt, hier mach 25 Kniebeugen und ich kann ihn nebenbei noch totsabbeln, ist gut, […], dann mache ich auch 50 Kniebeugen ohne dass ich das merke, das ist das eigentlich, darum, brauche ich eigentlich mehr so eine Anleitung. Wenn da jemand ist, […] das andere läuft dann so nebenbei und geht leichter, ja, wenn ich alleine bin dann quält man sich doch“* (I10, 58).

Interviewee 9 completely practiced without NPC. He said in terms of the intended practice with his partner: *„nein, also es ging einfach nicht, ich musste sie [seine Partnerin] irgendwann auch mal entlasten, also die hat auch so viel zu tun gehabt“* (I9, 84-85). Moreover, he said that his partner was happy that he finally could do things for himself (I9, 84-85, 88-93).

He also had no problems with the performance of the exercises (I9, 95), but said like interviewee 10 that it would have been better for him to do “Cimt at home” under supervision and not alone because his motivation to stick to the four-week therapy decreased strongly towards the end (I9, 142, 156). He said that he was not disappointed that his partner did not help him, but he answered to the question whether his partner motivated him when his motivation was very low: *„Nö, die hat mich einfach hängen lassen. Das ist auch gut so […] dann musst du es schon selber machen, ja, irgendwie musste ich ja mal“* (I9, 144-146).

Those patients, who practiced sometimes or always alone described that the performance of the exercises, which also included for example the time measurement and documentation, was in general no problem for them. In contrast, interviewee 12a and 14a, who had both a speech disorder and also difficulties with the speech comprehension, were dependent on the support of their NPCs; otherwise the repetitive training was not realizable for them alone (I12a, 58-59; I14a, 108).

4.4.5 Restriction of the healthy arm and enhanced usage of the impaired arm

This theme is divided into two subthemes. It contains the experiences of the patients with the restriction of the healthy arm and their experiences using the impaired arm more often in their daily life (cf. table 8).

Main theme	**Subthemes**
Restriction of the healthy arm and enhanced usage of the impaired arm	Experiences with the restriction of the healthy arm
	Experiences with the enhanced usage of the impaired arm

Table 8: Restriction of the healthy arm and enhanced usage of the impaired arm

Experiences with the restriction of the healthy arm

Different experiences were made with the restriction of the healthy arm. Interviewee 5, 7a, 9 and 10 experienced the wearing of the glove on their healthy arm sometimes as “difficult”, “unaccustomed” and/or “hindering” (I5, 49-50; I7a, 25-28; I9, 62; I10, 78-79). Interviewee 9 said about the glove: *„ich sag mal so, anfangs war es ein bisschen schwierig mit dieser Flosse da rum zu laufen“* (I9, 62). Or interviewee 5 stated: *„der war nie mein Freund. Ich brauche meine rechte Hand, ich brauche sie wirklich viel“* (I5, 49-50). Interviewee 7a sometimes perceived the restriction as a hindrance because all activities could only be carried out slowly (I7a, 25). Despite, he as well as interviewee 10 understood the sense and the advantages of the glove (I7a, 25-28; I10, 78-79). Interviewee 10 said: *„der hat mich natürlich daran gehindert, was ich sonst gemacht hätte, automatisch mit der linken Hand zuzugreifen, klar […], insofern war das ungewohnt, aber auch eben das Positive daran“* (I10, 78-79). Interviewee 11 perceived the wearing of the glove as *„Quälerei“* because movements with the impaired arm were very exhausting for her (I11, 28). Despite, she tried to realize the enhanced usage of her impaired arm in everyday life (I11, 49).

Some patients experienced the restriction of the healthy arm as dangerous because they felt helpless and insecure without the full capacity of their healthy arm (I8, I12a, I14a). Interviewee 12a refused completely to wear the glove in his daily life. His wife spoke for him because of his speech and language disorder and explained why: *„dann nehmen wir ihm auch den Halt, ja dann kann er ja nicht mehr laufen und dann kann er gar nichts machen“* (12a, 43). Also interviewee 14a disliked the wearing of the glove. He perceived it as a threat because he would be helpless in the case of an imbalance (I14a, 95-103). Similar considerations were mentioned by interviewee 8. She stopped wearing the glove because of her risk of falling (I8, 56-60), but she emphasized in the interview that she consciously tried to use her impaired arm more often in everyday life also without the glove. The enhanced arm usage in everyday life was for her the most important component of “Cimt at home” (I8, 49, 56-60, 75). Interviewee 1 said that she never used the glove because it was too difficult for her to put on the glove (field note I1).

Experiences with the enhanced usage of the impaired arm

An experience that was common for many patients was that they experienced the movements and activities, which they performed with the impaired arm, often as “slowly”, “clumsy”, “uncoordinated” or more general as “unattractive”. Furthermore, the enhanced arm usage was sometimes perceived as “exhausting”, “difficult” or as not feasible (I1, 44; I3, 21; I5, 50; I6, 42; I7a, 156-157; I10, 86, 74; I11, 28, 30). Interviewee 7a described for example his experiences with setting the table: *„Tisch aufdecken zum Beispiel das geht dann alles nicht so gut, da muss man dann wieder […] probieren und die Motorik wieder mehr einsetzen und da sagt man doch dann glatt, ach nun, […] ich nehme den Handschuh weg und dann mit der anderen Hand und dann geht das ja viel schöner, viel besser“* (I7a, 23-24). Or interviewee 11 described her experiences with wiping the table: *„wenn ich gewischt habe, das ist auch für mich Quälerei […] manchmal fünf Minuten, Menschen machen das, zack und sind fertig, aber ich fast eine Stunde […] Wahnsinn“* (I11, 30). Interviewee 10 also experienced the enhanced arm usage as very difficult and sometimes not feasible for him. He said: *„das [ist] natürlich ganz schwer gewesen zu Anfang irgendetwas zu machen. Ich habe das zwar immer versucht, aber so greifen und so […] das ging ganz schlecht“* (I10, 54, 68).

Interviewee 8 and 11 made the experience that particular through the enhanced and intensive use of the impaired arm the muscle tension in their neck and/or impaired leg increased. Interviewee 11 said: *„mein Arm perfekt, aber das Gehen schrecklich, ich war richtig ätzend drauf […]“* and *„es war so schrecklich. Mein Arm zog am Nacken und mein Arm war nur so [zeigt die Position ihres Armes]“* (I11, 69, 53-65). Interview 8 also described an increased muscle tension in her neck as well as muscle soreness in her impaired arm. But compared to interviewee 11, she was not demotivated by these side effects because she experienced that by regulating treatments of her therapist the tensions in her neck and arm got better. Moreover, she was very motivated through the improvements she made (I8, 6, 100).

The enhanced usage of the affected arm for activities of daily life was considered to be questionable by three patients (I1, 40; I5, 50; I6, 41-42). All of them were right handed and affected by the stroke on the left body side. They considered it as senseless to use their left hand for a lot of activities because they argued that they normally also would not have used their left hand due to the fact that they are right handed. Interviewee 1 stated for example: *„ich bin da so ein bisschen im Zwiespalt, weil ich immer denke ich muss alles mit links gemacht haben, aber jetzt brauche ich das eigentlich gar nicht mit links. Aber die Studie war eben halt so, dass man immer alles mit links machen sollte“* (I1, 40). Furthermore, they experienced the enhanced usage of the impaired left arm as a *“double burden”* (I1, 44; I6, 41-42). Interview 6 said: *„ich hab mich ja geweigert und das tue ich auch heute noch. […] Ich bin ja betroffen mit der linken Hand, bin aber Rechtshänder und wenn mir jetzt einer erzählen will, ich soll alles mit links machen […] ich hab immer gesagt ich lass mich nicht umpolen. Das ist ja eine doppelte Belastung“* (I6, 41-42).

Other interviewees (I3, I7a, I17), who also were right handed and affected on the left body side, did not mention this topic. Just like interviewee 4, who has a hemiparesis on the right body side and was left-handed, did not question the meaningfulness of the enhanced arm usage. Moreover, interviewees, who were right handed and were affected on their right body, did not mention in the interview a special motivation to use their impaired right arm (I8, I9, I10, I12a, I14a).

4.4.6 Improvements through “Cimt at home”

Almost all patients described improvements, which they made through “Cimt at home”. Anyhow, there were differences in the evaluation and perception of the improvements made. Some stroke patients were happy about the advances, but some patients also were disappointed because they had expected more from the new therapeutic concept. This theme describes firstly the improvements of the patients and secondly the significance of these improvements for the patients (cf. table 9).

Main theme	**Subthemes**
Improvements through “Cimt at home”	Improvements
	Significance of the improvements

Table 9: Improvements through “Cimt at home”

Improvements

The perceived improvements described by the patients can be differentiated in the below listed categories:

- Conscious enhanced usage of the impaired arm in everyday life
- Improved activities of daily life
- Improved functions
- Improved exercise performance

It was experienced by half of the patients that through “Cimt at home” their awareness for the enhanced usage of the impaired arm in everyday life increased (I1, 92; I3, 48; I5, 26; I7a, 155; I8, 49-54; I10, 71-72; I11, 85-89). Interviewee 3 stated for example about an acticity at his work place: *„ich mach das Drehen zwar nicht mit der linken Hand, aber ich kann zum Beispiel den Schraubendreher halten mit der linken Hand, das hab ich vorher eigentlich so, wenn ich mich recht erinnere nicht gemacht, also mir wurde das irgendwie bewusster“* (I3, 48). Interviewee 7a described that by “Cimt at home” his confidence in his impaired arm grew. He said: *„und das man [jetzt] auch die Hand mehr einsetzt, weil man ja weiß oder weil man Übungen gemacht hat und es wird einem bewusst, dass der Arm doch was kann, auch wenn diese Studie jetzt abgeschlossen ist“* (I7a, 155). And interviewee 8 said: *„das Wichtigste [was] ich daraus gelernt habe, eben bewusst nicht so instinktiv alles mit links zu machen, sondern bewusst auch an die rechte Hand zu denken, dass sie auch noch da ist“* (I8, 49-54). Interviewee 5 and 8 made furthermore the positive experience that through the continuation of the enhanced arm usage also after the four-week intervention period, more activities of daily life improved (I5, 26-28; I8, 71). Interviewee 5 said: *„das ist ja nun schon fast wieder ein Jahr her und […] ich sortiere immer noch mit der linken Hand die Spülmaschinensachen aus, da brauche ich die rechte Hand kaum noch, ich mache viel mehr mit links als vorher“* (I5, 26-28).

In terms of their motivation to realize the enhanced arm usage after the four-week intervention period, some patients also described that the enhanced arm usage is sometimes dependent from good mood and enough time (I5, 54; I6, 77-82; I10, 74; I11, 85-89). Interviewee 11 said for example: *„wenn es schnell gehen [soll], natürlich eben schnell mit rechts [gesunder Arm]“* and *„manchmal ist man dann nicht gut drauf und dann öhh“* (I11, 85-89). Also interviewee 5 experienced that it is difficult for her to motivate for the enhanced arm usage when she is not feeling well (I5, 54). And interviewee 10 explained that when an activity lasts too long he ends up using his healthy hand: *„dann habe ich manchmal Probleme an die Kaffeemaschine ranzukommen […], dann nehme ich das natürlich in die linke Hand […], ich will den Kaffee ja irgendwann auch trinken, nicht nur rumspielen“* (I10, 74).

Improved activities of daily life were experienced also by approximately half of the patients (I1, 76; I4, 83-95; I5, 26-28; I7a, 149; I8, 68, 116-118; I9, 70, 123-126; I11, 51). Interviewee 1 for example stated: *„und da hat sie das gemerkt [ein Kollege] und ich selbst ja auch, beim Umschlagen [der Zeitung], auch diese Fingerfertigkeit […] nicht so wie früher, aber doch so dass es dann besser geworden war […]. Und das Umschlagen ging […] ganz locker, Mensch toll“*(I1, 76). But she also mentioned that without constant training the advances she made decreased again (I1, 72-74). Or interviewee 9 experienced positively that after the implementation of “Cimt at home” it was easier for him to put dishes into the cupboard (I9, 123-126).

And interviewee 8 said in terms of pegging out the washing: *„Wäsche aufhängen mit links [gesunder Arm], ich habe mich fast umgebracht, um das denn auch über die Leine zu bekommen und jetzt kann wenigstens auch die rechte Hand unterstützen“* (I8, 68).

Improved functions that were perceived by some of the patients were a better mobility of the impaired arm (I10, 69-70; I12a, 54), a better grasping function because the hand is more relaxed or calm (I6, 43-48; I14a, 57-68) and more shoulder stability (I7a, 151). Some patients experienced also an improved exercise performance (I1, 72; I3, 40-44; I5, 24; I14a, 54). Interviewee 3 described for example: *„also ich hab da von meiner Physiotherapeutin so eine Art […] Steckspiel mit Holzkugeln und das ging eigentlich relativ gut von der Hand so nach einer Woche ungefähr“* (I3, 40-44).

Significance of the improvements

Many patients experienced the improvements they made as “positive”, “joy”, “motivation”, “unexpected success” or as a source of hope because improvements were still possible (I1, 76; I4, 62; I5, 22, 23-34; I7a, 137, 155; I8, 134-140; I10, 72; 12a, 66; I14a, 94; I17, 51-52). Interviewee 5 for example was very happy about the improvements she made because she did not expect that she would be able to carry out “Cimt at home” at all. She said: *„das Schöne daran ist, dass man wirklich am Anfang dachte, man kann das nicht schaffen“* (I5, 19-22). Or interviewee 10 stated: *„Das hat uns ein ganz schönes Stück weitergebracht“* (I10, 72). Although interviewee 17 was disappointed because she perceived no improvements by “Cimt at home” (I17, 67-69), she remembered positively that she sometimes was happy because an exercise was completed successfully (I17, 51-52).

Even if improvements could be described, some patients had expected more and long-lasting improvements through “Cimt at home” (I3, 14-16; I6, 69-74; I9, 101-103; I10, 54; I11, 91-93). Interviewee 11 said: *„Ich bin ein bisschen traurig, ich habe da mehr erwartet sage ich mal, gut, Erfolgserlebnis wegen meiner Autotür*[7] *[…], also ich hätte mir noch mehr gewünscht irgendwie so mit meinem Arm“*. Additionally, she was disappointed that her improvements were quickly gone (I11, 91-93). But she also assumed that her advances were gone quickly because she was in the holiday directly after “Cimt at home” (I11, 51). Interviewee 9 also said that he expected more from this intensive and long therapy. He particular was disappointed that his improvements only lasted shortly. He stated: *„es ist besser geworden, aber nicht dauerhaft. Es wurde dann plötzlich wieder ein bisschen schlechter […] und das fand ich ein bisschen traurig“* (I9, 101-103).

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[7] Spontaneously the impaired arm was used for closing the car door (I11, 51).

He answered to the question what he had expected: *„Ich will nicht sagen, dass ich so eine Art Wunder erwartet hätte aber, irgendwo schon [lacht]. Irgendwo doch, ich habe immer gedacht, Mensch, jetzt machst du diese ganzen Sachen, […] das muss doch irgendwo auch mal was richtig Greifbares bringen“* (I9, 160-164). Also interviewee 3 and 6 did not achieve the aims they had made or wished. Both were in some way disappointed that they did not perform better (I3, 14-16; I6, 69-74). They reflected both that maybe their expectations and goals were too high. Interviewee 6, who had wished that her very affecting pain would improve stated: *„ich habe befürchtet, dass die Ziele zu hoch waren, […] das sollten Sie vielleicht generell sagen, nicht so große Schritte, lieber kleine Schritte, […] das Erfolgserlebnis [ist] […] größer“* (I6, 69-74). She recommended doing less particular with patients, who suffer like her from pain (I6, 74). And interviewee 3 said: *„es kann natürlich auch sein, dass ich zu hohe Erwartungen hab, aber es hat sich einfach nicht sehr viel getan“* (I3, 14-16). He considered that maybe the four-week intervention period was too short for him and in general this therapy too late because his stroke already was seven years ago. Interview 10 also expected more, but he also said that he never is content with his advances (I10, 54). Like interviewee 3, he also thought that “Cimt at home” needed to be longer and that he would have profit more if he would had more functions in his impaired arm before (I10, 74-75, 54).

4.4.7 The role of the therapists in “Cimt at home”

This theme contains the patients’ experiences, which they have made with the support and guidance by their supervising therapist during the implementation of “Cimt at home”.

Most of the patients described that the guidance of their supervising therapist was appropriate for them and that they felt well cared for by the therapists during the four-week intervention period. (I4, 100-103; I5, 22-44; I6, 59-62; I7a, 35-36, 161; I8, 101-106; I9, 105-107, 157-160; I10, 60; I12a, 75-78; I14a, 91-92; I17, 57-60). Interviewee 8 described for example that the support was sufficient for her, but she also stated that her therapist made the experience that some patients were also overwhelmed with “Cimt at home”. She described the visits of her therapist as follows: *„von ihm habe ich die Informationen bekommen und er hat […] geguckt wie ich das mache […] für mich war es ausreichend, ich weiß nicht, wer vielleicht nicht schon so weit war wie ich, ob das dann auch ausreichend war“* (I8, 101-106). Or interviewee 7a said about the tasks of his supervising therapist: *„die [hat die] Aufzeichnungen nachgesehen, was wir gemacht haben, wie wir es gemacht haben, ob da eine Tendenz war, dass man, ich sag mal eine Übung innerhalb der Wochen schneller konnte, oder ob es gleich bleibend war […]. Also das hat die dann überprüft und kontrolliert“* (I7a, 161). Two interviewees experienced the therapy setting in “Cimt at home” not very different than usual (I6, 62; I9, 105-107). Interviewee 9 said: *„Für mich war es eigentlich nicht viel anders gewesen. Ich hatte jede Woche eine neue Aufgabe mitbekommen und die habe ich eben nun gemacht und das wars“* (I9, 105-107).

In contrast, interviewee 1 described that she had wished more support from a therapist in the four-week intervention period. She said about the home visits of her supervising therapist: *„ich fand die Zeit immer so ein bisschen kurz, ich habe eigentlich mehr gedacht, dass die Therapeuten so ein bisschen mehr noch die Übungen mitbegleiten. Es wurde nur gesagt, du machst jetzt die Übungen so und so, du übst sie dann bis zum nächsten Mal, du musst sie aufschreiben so und so. Das war's quasi. Nur ne halbe Stunde, die Übungen selbst wurden gar nicht so mit dem Therapeuten gemeinsam gemacht, es wurde angesprochen und dann musste man es halt für sich selbst üben"* (I1, 70). It needs to be noticed that interviewee 1 practiced most of the time alone because of severe family problems with her former husband (I1, 40).

Also interviewee 9 and 10, who were in general content with the guidance of their supervising therapist, wished more support from a therapist with the execution of the exercises (I9, 105-107; I10, 60). Both interviewees described difficulties to stick to the daily exercises alone[8]. Therefore, they considered that it would be in general better to do the exercises of "Cimt at home" with a therapist. Interviewee 10 said: *„ich bin eher so ein Mensch, der das besser macht, wenn da jemand ist, der Ahnung hat, der weiß was er macht und sagt was ich machen soll, dann mache ich das. Manchmal fehlt mir so, nicht der Antrieb, aber ach, wenn das so ist, lass es mal sein. Ist ja nicht richtig eigentlich, […] aber der Mensch ist halt so"* (I10, 55-58). And interviewee 9 said: *„wenn der Mensch erst einmal alleine […] auf sich selbst gestellt wird, etwas zu machen, dann wird er es nicht tun. Nun kann man natürlich sagen, er muss es, Eigenverantwortung was weiß ich denn, er wird es trotzdem nicht tun"* (I9, 156-157).

Interviewee 11, who experienced particularly the enhanced arm usage as very exhausting (I11, 28-30, cf. chapter 4.4.2), felt sometimes alone with her stresses in the four-week intervention period. Therefore, she would have wished more support through a therapist. She answered to the question if she felt appropriate cared for: *„Ich sage nein, […] ich war gestresst und alleine, verzweifelt sage ich mal. Ich habe Tage gezählt hoffentlich ist es fast vorbei"* (I11, 66-67).

For interviewee 3 and 5 it was important and helpful that their supervising therapists motivated them to stick to the new therapeutic concept. Interviewee 5 was at some points in the four-week intervention period disappointed because their NPCs did not support her in the way she had wished; furthermore, it was difficult for her to motivate herself to the exercises and the enhanced arm usage at the end of the four weeks.

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[8] Interviewee 10 only has practiced sometimes with his NPC and interviewee 9 has practiced completely without NPC (I9, 84-85; I10, 58, 60-66, 91).

In these situations her occupational therapist motivated her nevertheless to continue (I5, 22, 38, 56). She said: *„ohne sie, hätte ich das nicht geschafft, […] die ist […] wirklich immer positiv, die ist immer gut gelaunt und hat immer noch [einen] Punkt wie sie einen anheizen kann, sie schaffen das, wir schaffen das, ich stehe ihnen doch bei"* (I5, 56). Also interviewee 3, who had problems to motivate himself after a working day, said about his therapist: *„die war fleißig dabei mich zu motivieren [lacht]"* (I3, 24).

4.5 The experiences of the non-professional coaches with “Cimt at home”

In the following chapters the experiences of the nine NPCs with “Cimt at home” are described in five thematic sections:

1. Motivation to support a stroke affected relative with “Cimt at home”
2. Implementation of daily practice in everyday life
3. The practice with the stroke affected relative
4. Difficulties with the implementation of the restriction
5. Improvements of the relative made through “Cimt at home”

4.5.1 Motivation to support a stroke affected relative with “Cimt at home”

Four different motivations were mentioned by the NPCs why they decided to take part in the HOMECIMT study and to support a stroke affected relative with “Cimt at home”. Often more than one reason came up in an interview:

- Chance for improvements
- Possibility to support the stroke affected relative in the rehabilitation process
- Opportunity to make a contribution to research in the field of stroke rehabilitation
- Obligation

The main motivation to support a stroke affected relative with “Cimt at home” was the prospect that through the participation in the HOMECIMT study the relative would make improvements in terms of her or his affected upper extremity (I12b, 33-40; I13, 37, 75; I14b, 8; I15, 177-181; I16, 49; I18, 125; I20, 21, 31). Interviewee 12b, who was the driving force for the study participation of her husband, believed that there was still potential in the impaired arm of her husband and therefore, the HOMECIMT study a chance to see what might be possible. She said: *„wir meinen eigentlich alle, er könnte vielleicht noch ein bisschen mehr mit der Hand, aber weil er so gut behütet wird, hat er sich in seiner Nische eingerichtet“* (I12b, 33). Her language limited husband needed to be persuaded to participate in the HOMECIMT study. She said that he is satisfied with his situation and therefore, his motivation for the new therapeutic concept was low (I12b, 42, 71). Also interviewee 15 was the driving force behind the study participation of her 77-year old mother. She strongly hoped that the impaired arm of her mother would improve through “Cimt at home” (I15, 177-181). She furthermore was content that she could support her mother in her rehabilitation process (115, 75). Also interviewee 16 participated in the HOMECIMT study because of the prospect that her husband could profit from the new therapeutic concept (I16, 49). She believed in general that improvements, which her husband will achieve, would also be good and helpful for her (I16, 49). She also stated that she is always happy when she can support her husband.

She said *„also für mich ist immer das Positive, dass ich meinen Mann unterstützen kann, das steht für mich an erster Stelle und dann verzichte ich auch auf meine Zeit“* (I16, 95). Interviewee 14b said that in terms of the rehabilitation process of her husband everything should be done, which might be helpful for him (I14b, 8). Because of that, it seemed to be obvious to participate in the HOMECIMT study and to implement the new therapeutic concept.

The possibility to support research activities in the field of stroke rehabilitation was for some NPCs a further motivation to participate with their affected relative in the HOMECIMT study (I12b, 107; I14b, 126; I15, 80; I16, 95; I18, 125). I14b said for example: *„ich finde das gut […] das alles gemacht wird, dass das für die betroffenen Leute leichter gemacht wird, […] und wenn es nur probiert wird, aber Hauptsache es versucht irgendjemand diese Situation zu ändern, dass es vielleicht verbessert wird, […] dass man halt nicht da steht und sagt ja mmm schade, das ist jetzt so“* (I14b, 126). Or interviewee 12b said about “Cimt at home”: *„Ich finde die Idee unheimlich gut“*. Moreover, she hoped through the participation in the HOMECIMT study to strengthen the role of the occupational therapy (I12b, 107).

Interviewee 13 understood the support of his affected wife in terms of her rehabilitation as an obligation. He said: *„ich habe mich generell so darauf eingerichtet […], wenn es jetzt heißen würde heute Nachmittag um vier, obwohl ich da irgendeinen Termin habe, ist hier angesagt eine Übung mit meiner Frau zu machen, die Ärzte haben das empfohlen, ich hätte dann Zeit, das wäre finde ich normal […] das ist einfach Pflicht, das ist Christenpflicht […] das sind halt die guten Zeiten und die schlechten Zeiten, die man miteinander verbringt“* (I13, 27). He also hoped that his wife could make improvements or simply could keep the current state (I13, 37).

4.5.2 Implementation of daily practice in everyday life

Different experiences were made by the NPCs with the daily support of the relative with the exercises of “Cimt at home”. There were NPCs, who experienced the coordination of everyday life and practice with the relative as sometimes stressful and not so easy to realize. But there were also NPCs, who perceived the coordination of everyday life and practice with the relative as possible. Therefore, this theme is divided in two subthemes as it is visible in table 10.

Main theme	**Subthemes**
Implementation of daily practice in everyday life	Difficulties with the coordination of everyday life and daily practice
	Coordination of everyday life and daily practice was compatible

Table 10: Implementation of daily practice in everyday life

Difficulties with the coordination of everyday life and daily practice

Because of temporal difficulties, five of the nine NPCs experienced their daily life in combination with the daily support of the relative with the exercises of “Cimt at home” as sometimes or often stressful (I7b, 43-49; I12b, 42; I14b, 132; I15, 75, 77; I19, 25, 29). Nevertheless, all NPCs could realize the daily exercises with their stroke affected relative over the four-week intervention period.

Interviewee 14b, who was working part-time and was mainly responsible for the household and their children, retrospectively said about the two-hour daily practice: *„ich habe halt einen großen Garten und ich habe ein Haus und ich habe meine Kinder, die noch keine Führerscheine haben und ich arbeite denn noch nebenbei und irgendwo muss das alles fließen und deswegen sind halt keine zwei Stunden jeden Tag drin, das wir das machen können, das ist wirklich nur, wenn ich denn mal Zeit habe“* (I14b, 132). She considered therefore, that it would be better if in the future of this therapeutic concept from which she was strongly convinced therapist could take over the daily two-hour practice (I14b, 132). In spite of the temporal difficulties, she realized the practice with her husband even if it meant that they sometimes practiced in the late evenings. She stuck to the therapy because of her hope for improvements and because she wanted to support the therapist of her husband and the HOMECIMT study (I14b, 77). Interviewee 7b, who worked full-time in the family business, also experienced the coordination of her working responsibilities and the obligations of “Cimt at home” sometimes as stressful because the practice with her husband was not easily implemented in her everyday life (I7b, 43-49). Interviewee 15, who worked full-time, described that she often only could realize the practice with her mother by shifting the working time and by hurrying after work (I15, 75, 77).

Interviewee12b, a 70 year old, retired woman also described temporal difficulties with the implementation of the daily training. She said: *„Ich habe zugestimmt, weil ich nicht wusste wie viel Arbeit für mich dabei rauskommt. […] wenn ich das gewusst hätte, hätte ich es vielleicht in dem Moment gelassen“* (I12b, 42). She stuck to the therapy because she was interested in what kind of improvements might be still possible and because she wanted to support the occupational therapist of her husband (I12b, 70-71). It was helpful for her when the supervising therapist sometimes took over the practice with her husband. Furthermore, she described that this was a chance for her to prove that she did everything right in the guidance of the exercises (I12b, 75).

Interviewee 19 experienced the daily training with her husband due to the fact that it was very time consuming and took a long period of time as *„hart“* and *„zermürbend“* (I19, 25, 29). She was responsible for the household and her two young children. The daily two hours of practice were missing in her everyday life.

She said: *„Also ich habe ja mit meinem Mann zwei Stunden täglich mit Stoppuhr und Notizen [geübt], […] hätten wir gewusst was uns da erwartet, hätten wir wahrscheinlich nicht mitgemacht. Haben es aber durchgezogen, weil es auch unser Wesen halt einfach ist, was wir anfangen, ziehen wir auch durch, aber auch die Kinder, manchmal mussten die mich dann ersetzen mit Stoppuhr, weil ich irgendeinen Termin hatte. […] Es hat schon arg in den Alltag eingegriffen und ich war froh als es vorbei war, also wir alle“* (I19, 25). Besides the temporal difficulties, she additionally experienced the daily repetitive exercises with increasing time as boring (I19, 29, 37). She furthermore said that she understood everybody, who quits this therapy (I19, 55).

Coordination of everyday life and daily practice was compatible

Interviewee 13, 16 and 18 experienced in contrast to the other NPCs the coordination of their everyday life and/or their working obligations and the realization of the two-hour daily practice with their affected relative as compatible and temporally unproblematic.

Interviewee 13 described that it was always realizable for him to do the daily exercises with his wife. He explained why: *„ich bin selbstständig und bin in dem Alter, wo man entweder sich so halbwegs freigeschwommen hat oder halt nicht und ich meine wir haben uns so halbwegs freigeschwommen und ich kann mir die Zeit doch schon einfach nehmen. […] Das ist […] relativ leicht, wenn man so einen Job hat wie ich“* (I13, 26-27). Interviewee 13 considered himself in a very happy situation because people with other professions probably do not have the same flexibility (I13, 63). Also interviewee 16 did not perceive the coordination of her daily routine, her working obligations (she worked part-time) and the practice with her husband as stressful. She said about her everyday life in the four-week intervention period: *„eigentlich ist der normal geblieben, […] wir haben das dann immer so zwischendurch gemacht, aber das jetzt dadurch der Alltag irgendwie, sicher für mich ist das, weil ich musste mir die Zeiten, […] ja auch nehmen, aber so was da habe ich auch kein Problem mit, also die nehme ich mir dann auch, also das ist dann für mich auch wichtig, dass mein Mann eben üben kann“* (I16, 49). It was not experienced difficult by her that she had less time for herself because she was very willing to support her husband with his rehabilitation (I16, 48-49).

Interviewee 18, who does not work anymore, said in terms of his everyday life during the implementation of “Cimt at home”: *„ja genau wie immer. Was soll ich da sagen [lacht]. […] Da muss ich auch immer alles machen und da haben wir denn die Übungen gemacht, ich meine so machen wir auch ab und zu mal Übungen“* (I18, 73). For him it was no temporal difficulty to integrate the practice with his wife in his daily routine.

4.5.3 The practice with the stroke affected relative

The different experiences of the NPCs, which they have made in the practice with the stroke affected relative, are described in this theme. It is divided into six subthemes, which are listed below in table 11.

Main theme	Subthemes
The practice with the stroke affected relative	Advices and suggestions were sometimes understood as “too much” by the relative
	It does not feel good to see the efforts of the relative
	Difficulties with the implementation of the exercises because of the low motivation of the relative
	Responsibility for the implementation of the exercises
	Difficulties with the framework conditions of the exercises
	Positive experiences through the practice with the relative

Table 11: The practice with the stroke affected relative

Except interviewee 15, who supported her mother, all NPCs supported a spouse or partner with the exercises of “Cimt at home”. The daily training was implemented by all NPCs as far as it is assessable according to the protocol of “Cimt at home”. It needs to be noticed that some NPCs described positive as well as difficult experiences with the practice.

Advices and suggestions were sometimes understood as “too much” by the relative

It was an experience for some NPCs that advices and suggestions, which they gave in terms of the exercises, were sometimes understood as too much and annoying by the affected relative (I7b, 54-58; I14b, 81-85; I16, 65).

Interviewee 14b described for example that her husband sometimes responded annoyed to her therapeutic advices because she was too strict (I14b, 81-85). She experienced it negatively that he sometimes did not carry out the exercises in the way she thought to be correct: *„er wollte dann nur auf Geschwindigkeit, also das habe ich dann so ein bisschen als negativ empfunden, dass ich sagte, jetzt mach das mal vernünftig, denn sonst bringt das auch nichts“* (I14b, 53). It was furthermore experienced difficult for interviewee 14b to convince her husband to do the exercises at a time when it was appropriate for her. Due to her children, working and household responsibilities she only had a narrow time window for the practice with her husband. She had the impression that it was particular difficult for her to become accepted because she was his wife. (I14b, 74-75, 69-73). Also interviewee 7b experienced that her advices and requests in terms of the exercises of “Cimt at home” were sometimes too much for her husband. She was conscious about that and explained that in contrary to his therapists, she knew better about the full potential of her husband and therefore, could asked for more (I7b, 51-53).

Interviewee 16 already had made the experience that her husband did often not accept her therapeutic advices in the same way as he accepts advices and ideas of his physical and occupational therapists (I16, 31). In contrast to these past experiences, she was happy about the willingness of her husband to practice with her in “Cimt at home” (I16, 43). Anyhow, she described that sometimes she was too strict for him: *„manchmal wurde ihm das auch zu viel, weil ich dann auch manchmal ein bisschen strenger war“* (I16, 65).

Interviewee 12a did not make the experience that her husband reacted annoyed to advices in the two-hour practice, but she reported that he reacted negatively when she reminded him to use his impaired arm more often in everyday life (I12b, 57).

It does not feel good to see the efforts of the relative

To see the efforts of the affected partner with the exercises of “Cimt at home” were experienced by interviewee 13, 18 and 19 as sometimes not a good feeling (I13, 25, 33-35; I18, 89; I19, 37).

Interviewee 18 and 19 experienced that for their affected relative the exercises were often very exhausting and difficult. Interviewee 18 said: *„zu zusehen wie sie sich angestrengt hat, ist natürlich ein bisschen blöde“* (I18, 89). And interviewee 13 experienced that through the exercises of “Cimt at home” the shoulder pain from which his wife has been suffering since her stroke increased. He said *„gleich zu Anfang habe ich gedacht, das ist doch viel zu anstrengend, ich habe ihre Schmerzen dabei gesehen und habe ihre Überforderung dabei gesehen und war ein bisschen schockiert, dass man da so rangeht […] und habe aber gedacht, vielleicht gibt sich das. Vielleicht macht das einen Sinn die Übung jetzt so oft zu wiederholen“* (I13, 25). Moreover, he said about his role as NPC and whether he liked the practice with his wife: *„Mein Ding ist es nicht, ich sage mal andere zu quälen. […] Das würde mehr Spaß machen, wenn es ihr auch Spaß gemacht hätte“* (I13, 33-35). Even though interviewee 13 was unsure whether the exercises were good for his wife, they carried out the therapy over the four-week intervention period (I13, 25, 39-41).

Difficulties with the implementation of the exercises because of the low motivation of the relative

Two NPCs (I15, I20) experienced the support of the affected relative with the implementation of “Cimt at home” as very stressful and difficult because of the low motivation of their relatives to carry out the daily exercises of “Cimt at home” (I15, 32-33; I20, 64). Both NPCs associated the low willingness to practice with depressed mood from which their relatives suffered.

Interviewee 20, a 67 old retired man, said about the practice with his wife and the four-week intervention period: *„in der Zeit war meine Frau noch wechselhafter in den Stimmungen. Manches Mal ist es mir sehr schwer gefallen sie überhaupt dazu zu bewegen die eine, die zweite, die dritte Übung [zu machen], nachher haben wir dann von unserem Therapeuten, eine vierte und ich glaube sogar eine fünfte Übung dazubekommen, […], aber sie war immer schwer, schwer, schwer ranzukriegen“* (I20, 27). He explained her low motivation with the depressive mood from which she has been suffering since her stroke. Because of the depression, it was very difficult for her to see her rehabilitative progress. She was listlessness to do the daily exercises because the advances she made were always too small for her. Interviewee 20 tried to motivate her by making the improvements visible: *„Ich habe auch versucht meiner Frau [die Erfolge] deutlich zu machen, aber das ist bildlich nicht angekommen. Auch wenn man gesagt hat, […] da hast du 20 Sekunden für gebraucht und jetzt schaffst du das in 15 oder 10 Sekunden aber das hat sie nicht als Erfolg gesehen“* (I20, 41). Another reason why the practice with his affected wife was difficult for interviewee 20, was the aspect that his wife is in general much more motivated when she is doing therapy with a therapist or a not so close person (I20, I15). He attributed this behavior also towards her depression. He considered that maybe “Cimt at home” would be more effective if a therapist would be responsible for the implementation of “Cimt at home” (I20, 35). Despite the difficulties, he always tried to practice with his wife. For that he adapted the practice time to the mood of his wife and always tried to motivate and convince her by praise, but also with pressure (I20, 28-29, 32-33).

In contrast to interviewee 20, interviewee 15 realized in the four-week intervention period of “Cimt at home” that the listlessness of her mother in terms of the implementation of the new therapeutic concept may results from a depression (I15, 35). She believed in the beginning that her mother was also motivated to do the therapy, but it became increasingly clear for interviewee 15 that her mother did not see any sense in the exercises and in her live anymore because of her impairments after the stroke. Interviewee 15 described: *„wir sollten uns ja immer Übungen aussuchen. Meine Mutter sagt, such du dir mal was aus! Ich sag, du pass mal auf, ich soll mir schon aussuchen wegen Essen, da sagst du nichts mehr […] ich sage du sollst fit werden, du möchtest wieder Deine Hand bewegen, du möchtest Deinen Fuß wieder bewegen können. Ich habe keine Lust mehr, sagt sie zu mir […] wofür ist der ganze Scheiß, wofür bin ich denn zu gebrauchen“* (I15, 32).

Because of her great motivation to support her mother with “Cimt at home”, interviewee 15 engaged herself also in the development and improvement of her mother’s exercises. It was therefore a very bad experience for her that her mother responded to an idea very angry and hurting. She has tried to create an easier exercise by providing her mother a doll carriage instead of her walking frame. Because of the idea with the *„Puppenwagen“*, her mother felt not taken serious.

Interviewee 15 considered that this experience influenced the motivation of her mother to implement the daily exercises badly (I15, 28-30) and even may have triggered her depressive mood. Because of these considerations, she still feels guilty and responsible (I15, 54, 56). Particular in the difficult situations with her mother, she sometimes felt alone and thought that more professional support by a therapist would have been good for her (I15, 144-145).

Interviewee 15 tried till the end to realize the daily training with her mother. With increasing frustration she also used a lot of pressure to force her to stick to the therapy. She said for example*: „weiß du was, wenn du nicht bereit bist zu üben, was für dich zu machen, bin ich nicht bereit meine Zeit für dich zu opfern"* (I15, 33). Interviewee 15 was very disappointed because she had believed that her mother also had a strong ambition to improve (I15, 20, 86). Further, she was sad that her mother only realized sometimes her strong willingness to help (I15, 78, 35). Through the implementation of "Cimt at home" it became clear for interviewee 15 that her mother has no courage to live anymore. This made her very sad because her mother is a very important person in her life (I15, 41, 80). Also interviewee 20 described feelings of anger and frustration because his good intentions were not seen and understood by his wife, even though he could explain her behavior because of the depressive disorder (I20, 31).

Responsibility for the implementation of the exercises

Just like the previous subtheme, this theme includes only the experiences of interviewee 15 and 20. Both made the experience that because of the low motivation of their affected relative it was particular in their responsibility that the daily exercises of "Cimt at home" were carried out. This responsibility was experienced sometimes as a burden and they were thus relieved to follow their normal procedures and to give up the responsibility after the four-week intervention period.

Interviewee 20 said: *„insgesamt […] ist man nachher zum Ende der Therapie schon [so] gewesen, dass man sagen konnte […] Gott sei Dank ist vorbei, denn man hat sich dann wieder auf einen anderen Ablauf einstellen können. So war dann auch immer für mich der Druck da, wir müssen heute noch wieder und den Druck dann auch weiter zu geben, gerade wenn es dann ein Tag war, wo es nicht so ging"* (I20, 44). Interviewee 15 described the practice with her mother at the end of the four-week intervention period as a burden only. She only stuck to it because she felt responsible for the HOMECIMT study. She said: *„sie hat ja nachher gar nichts mehr gemacht, wo ich sie gezwungen habe was zu machen. […] Es wurde für mich nachher einfach nur eine Last, weil […] wir haben versprochen diese Studie durchzuführen und wenn ich etwas verspreche, dann halte ich das ein"* (I15, 75).

Difficulties with the framework conditions of the exercises

Interviewee 14b and 15 experienced the handling and use of the stop watch in the exercises as problematic. They described in this context that they did not like the focus on the swiftness of the exercise performance (I14b, 53; I15, 76-77). Interviewee 14b argued that thereby the movements were not done correctly. Interviewee 15 perceived that the stop watch put additional stress on her mother, but also on herself. Because of this, she stopped using the stop watch and only counted the repetitions (I15, 77). Interviewee 14b also had problems with the handling of the stop watch and experienced therefore the use of it as an additional effort (I14b, 80-81).

The preparation of good therapy conditions in the home environment was experienced by interviewee 20 sometimes as difficult. Due to limited possibilities in the home environment, in contrast to a therapeutic practice, he had the impression that exercises could not always be optimally conducted (e.g. table was too low). Anyhow, he tried his best to create good "therapeutic" conditions for his wife in their home environment (I20, 60-62).

Positive experiences through the practice with the relative

Different positive experiences were made and described by the NPCs through the practice with their stroke affected relative.

For some NPCs it was a positive experience that the joint training with their relative was sometimes funny and joyful (I12b, 62-67; I15, 72; I16, 64-65). Interviewee 12b, 14b and 15 furthermore mentioned that they liked that through the daily training more time was spend together (I12b, 42; I14b, 129-132; I15, 102-104).

Interviewee 16 made the positive experience that her husband was willing to practice with her and to accept most of her advices and corrections in terms of the exercises. She said: *„mein Mann hat auch gut mitgemacht, […] also er hat auch nicht mit mir […] geschimpft [lacht], dass er gesagt hat, das mache ich nicht oder ich bin zu streng“* (I16, 43). Even though interviewee 15 experienced the practice with her mother as very exhausting, she also made positive experiences. She said for example: *„wo ich mit ihr die Übungen gemacht habe, ob das jetzt negativ oder auch positiv war […]. Es ist doch irgendwie eine andere Verbindung zwischen mir und meiner Mutter, eine engere Verbindung gewesen, die ich auf eine Art genossen habe und sie aber auch“* (I15, 128). Furthermore, it was a good and satisfying feeling for her when her mother sometimes acknowledged the constant support she gave to her (I15, 130-133). For interviewee 19 the practice with her husband was stressful because of temporal constraints, but the practice itself was no problem: *„das war kein Problem, weil wir sonst auch viel, schon früher immer, […], möglichst viel zusammen gemacht haben […], also es hat keine Spannungen gegeben“* (I19, 30-31). Also interviewee 18 described the practice with his wife as positive: *„wenn es was gebracht hätte, hätte es mir ganz gut gefallen“* (I18, 78).

4.5.4 Difficulties with the implementation of the restriction

This theme contains the experiences of four NPCs with the implementation of the restriction by the affected relative. It was experienced by these NPCs that the implementation of the restriction was difficult because the acceptance of their affected relative to wear the glove was low. These NPCs tried to persuade and to convince their relative to wear the glove, but it was often not successful. Reasons, which the NPCs mentioned, were the feeling of being helpless with the glove (I12b, 44; I14b, 121-123; I15, 65; I20, 37) and the conscious perception of the own limitations through the "forced" usage of the impaired arm (I15, 84).

Interviewee 14b described for example the wearing of the glove as *„Zwangsmaßnahme"* (I14b, 121-123). She said: *„den hat mein Mann ganz besonders gerne getragen [lacht], da hat ihn meistens meine Tochter überlistet. [Sie hat] sich mit ihm unterhalten und der Handschuh und ja dann rüber und dann hat sie ihm das so richtig schön fest gezurrt, […] teilweise [lacht] war der Arm denn schon halb abgestorben, […] wenn man das nicht so richtig fest gemacht hat, war er auf einmal runter, dann hat mein Mann nämlich so lange geschüttelt bis er runter war"*(I14b, 95). Interviewee 20 said about his wife and the restriction: *„den Handschuh konnte sie dann auch nicht den ganzen Tag [tragen], weil sie dann in Anführungsstrichen hilflos war, denn der rechte Arm war nicht so weit, dass er wirklich richtig unterstützend in der Wohnung etwas machen konnte, das war schon schwierig, dann flog auch der Handschuh mal"* (I20, 37).

Interviewee 15 was frustrated that her mother sometimes put on the glove only while she was lying in the bed (I15, 84). She believed that maybe the realization of the restriction and in turn the enhanced usage of the impaired arm in everyday life would have been more successful when she or another person could have spent the whole day with her mother to motivate and to control the realization of the restriction and the enhanced arm usage (I15, 91, 96-97). She considered additionally that besides the above mentioned reasons; also the low motivation of her mother was a reason for the limited implementation of the restriction. She said: *„es ist ganz, ganz schwierig, wenn diese Person alleine ist, diese Eigendisziplin und wenn man denn noch in ein Loch fällt, dann passiert gar nichts mehr"* (I15, 91).

Other NPCs did not mention experiences with the restriction of the healthy arm by their affected relatives in the interviews.

4.5.5 Improvements of the relative made through "Cimt at home"

Most of the NPCs perceived improvements of their relative through the implementation of "Cimt at home". They described improved activities of daily life (I7b, 149; I16, 50-51), functional improvements (I12b, 55, 94; I14b, 67; I15, 124; I20, 37) or improved exercises performances through the new therapeutic concept (I14b, 67; I19, 40-43).

The improvements were perceived as positive, as a surprise or also as a source of hope that improvements are still possible (I7b, 137; I12b, 55; I14b, 53, 92-93; I16, 43; I19, 38-41; I20, 37). Interviewee 7b said for example: *„wir haben eigentlich bis dato gedacht die Hand wäre […] nicht mehr zu gebrauchen und wir waren sehr, sehr, sehr erstaunt was doch innerhalb dieser vier Wochen in den wir geübt haben möglich ist"* (I7b, 137). Interviewee 14b was enthusiastic that improvements of her husband were seen immediately after a two-hour exercise session (I14b, 53). Similar it was described by interviewee 16: *„ich muss sagen, man hat auch gemerkt, es wurde tatsächlich von Tag zu Tag mehr"* (I16, 43). Moreover, she said if it were up to her, she would have continued the therapy over a longer period of time because she thought that it would be even more effective (I16, 43, 113).

Interviewee 20 described that the exercise protocol was helpful and motivating for him because improvements of his wife were immediately visible for him (I20, 38-41). In contrast, he had difficulties to perceive improvements of his wife in everyday life. He said: *„vieles im Alltag merkt man selbst auch am wenigsten, dass merken auch wieder Außenstehende mehr als wie man das selbst merkt, weil jeden Tag oder jede Woche so ein kleiner Zipfel dazukommt"* (I20, 38-41). Interviewee 13 was unsure whether his wife made improvements, but he considered the fact that maybe she could hold her functional abilities was positive. He said: *„ich weiß nicht was da überhaupt hängengeblieben ist […], es kann sein […] und wenn […] es das ist, dass sich die ganze Chose nicht verschlechtert hat. […], dass befürchtet man ja immer in dieser Situation […]. Positiv ist vielleicht das nichts schlechter ist, sondern vielleicht besser"* (I13, 37).

Even though interviewee 19 experienced the improved exercise performances of her husband as positive, she was at the same time a little bit disappointed that the improvements were not applicable in his everyday life. Only in the exercises improvements were visible. She described: *„Das einzige was eben leider nicht war […] dass die Hand außerhalb dieser Übungen mehr […] im Kopf war, […] bei den Übungen war sie präsent, […] aber sofort nach den Übungen nicht mehr, dass hat also nicht Klick gemacht"* (I19, 41). Interviewee 15 was very disappointed that her mother was only able to make little improvements in terms of her impaired arm because of her depressive mood (I15, 124). She had wished very much that her mother would make good improvements through the implementation of "Cimt at home" (I15, 86).

Besides, interviewee 15 described that she is still motivated to practice with her and even to implement “Cimt at home” a second time because she cannot accept that her mother gave up herself (I15, 179-181).

Interviewee 12b, who was the driving force of the study participation of her husband, was happy about the functional improvements her husband made through “Cimt at home”. But she considered that “Cimt at home” would have been probably more successful if her husband really would have been motivated to do the new therapeutic concept. She said that maybe younger people, who still have more own goals, would profit more from “Cimt at home” (I12b, 57, 71-73).

As the only NPC, interviewee 18 described that his wife made no improvements in the four-week intervention period. He was generally frustrated that despite all the therapeutic efforts his wife did, the impaired arm did not improve (I18, 69-72).

Three NPCs moreover commented on the preconditions of the achieved improvements of their affected relative (I7b, I14b, I19). They experienced that the improvements their relative made with “Cimt at home” were only realizable with a lot of will (I7b, 143), power of endurance (I19, 39) and regular practice (I7b, 143; I14b, 93; I19, 39). All of them had experienced that these preconditions were not so easily to achieve (I7b, 43-49; I14b, 132; I19, 25, 29, 37, 55).

5 Discussion

This master thesis investigated the experiences of chronic stroke patients and NPCs with the new therapeutic concept “Cimt at home”. Its special elements are the implementation at the home environment of the stroke patients and the integration of NPCs in the guidance and conduction of the patients’ exercises. Through the inclusion of the perspectives of stroke patients and NPCs in the research of this new therapeutic concept, important information about the practical implementation of “Cimt at home” has been extracted. In the following sections the main findings as well as the methods used in this thesis are discussed.

5.1 The experiences of stroke patients and non-professional coaches

As the description of the patients’ and NPCs’ experiences shows, many similar experiences were made with “Cimt at home”. The main themes of the stroke patients are also found in the main themes of the NPCs and vice versa. Two exceptions are the themes “Experiences with the exercises of Cimt at home” and “The role of the therapists in Cimt at home”. These themes only emerged in the analysis of the patients’ transcripts. Despite many similarities, the results also show differences in the experiences within the individual themes. Experiences with the enhanced arm usage or the experience that oneself had expected more from the new therapeutic concept were predominantly described by stroke patients. In contrast, some NPCs experienced that “Cimt at home” was connected with the full responsibility for the realization of the exercises or that it was not a good feeling to see the efforts of the affected relative.

By theme building a structured presentation of the patients’ and NPCs’ experiences with “Cimt at home” was possible. In reality such a clear classification does not exist and therefore, the single themes also needed to be seen as a whole with complementary and overlapping experiences (van Manen, 1990, p.168).

5.1.1 Motivation for study participation

Stroke patients as well as NPCs mentioned the hope for improvements as the main motivation for the participation in the HOMECIMT study. In addition, the possibility to make a contribution to the research in the field of stroke rehabilitation and interest in a new therapy were mentioned more frequently. These findings are confirmed by McCann et al. (2010) and Lawton et al. (2003), who investigated patients’ motivations to participate in intervention studies. The patients’ hope that progress could be achieved also reflects the belief of many stroke patients that physical and occupational therapy are in general a chance to regain lost functions and independence (cf. chapter 4.2.1). Also Maclean et al. (2000) reported that stroke patients often believe that rehabilitation measures have an important part in their recovery after the stroke.

Similar results were identified by Pound et al. (1994) with respect to the meaning of physiotherapeutic interventions.

Seven out of nine NPCs described that they are still involved actively in the rehabilitation process of their stroke affected relative (cf. chapter 4.2.2). This might be an additional explanation why these NPCs were willing and motivated to support their relative with the daily exercises of "Cimt at home".

5.1.2 Improvements and patients' expectations and hopes

Almost all stroke patients and NPCs described improvements through the new therapeutic concept. Feelings of joy and hope were associated with the improvements made (cf. chapter 4.4.6, 4.5.5). Improvements were also a motivation to carry on with the therapy. The improvements described by the interviewees e.g. enhanced arm usage, improved activities of daily life or improved functions are also found in the reviews and studies of Shi et al. (2011), Peurala et al. (2012) and Wolf et al. (2006).

Although almost all patients perceived improvements, some were disappointed that they did not make more and longer lasting improvements through "Cimt at home". The patients' hope for greater improvements is surprising particularly with respect to the fact that realistic therapeutic goals were agreed with the patient and NPC in advance. Dowswell et al. (2002) found that even though stroke patients seemed to know that a particular physiotherapeutic intervention would focus on functional outcomes, they still hope for "more general changes". They assumed that this gap might be an expression of the difficulty to accept the often immense changes and impairments that arose after a stroke. The result of Dowswell et al. (2002) might be also an explanation for the great hope of some patients in the present study. Additionally, the aspect that "Cimt at home" is a new therapy might also have led to increased expectations (cf. Bauder et al. 2001, p. 33). These findings indicate that it seems to be important to be aware of the possible hopes and expectations of patients, even though an agreement was made on therapeutic goals. To avoid disappointments, Bauder et al. (2001, p. 33) recommended to inform the patient that CIMT may lead to good improvements, but that this therapy is not a "magic bullet". The additional constant discussion and clarification of the patients' hopes and expectations over the four-week intervention period of "Cimt at home" might be supportive for patients to have more realistic expectations.

Besides these considerations, the results indicate that the agreed therapeutic goals might have been too high for some patients. Realizing that the agreement on therapeutic goals was difficult for some therapists, the HOMECIMT project currently investigates in what way physical and occupational therapists have implemented agreement procedures in setting therapeutic goals in "Cimt at home". The results of this investigation might give answers to this consideration.

5.1.3 The implementation of “Cimt at home” in everyday life

The present results show a contrasting picture of how patients and NPCs experienced the implementation of “Cimt at home” in their everyday life. Whereas some interviewees experienced the implementation of “Cimt at home” in their everyday and working life as manageable, there were other interviewees, who experienced difficulties and stresses with the coordination of “Cimt at home” and their everyday responsibilities (cf. chapter 4.4.2, 4.5.2).

Perceived difficulties and stresses with the coordination of “Cimt at home” and everyday life could depend on the occupational status of the patient. It seems that without working obligations “Cimt at home” might be good to combine with everyday life. Furthermore, the results indicate that a reduced capacity after stroke might be another factor why the coordination of everyday life and “Cimt at home” might be experienced also without working obligations as exhausting. Two patients described that already their normal everyday life is challenging because of a reduced capacity and an increased tiredness since the onset of stroke. This experience was also described by Röding et al. (2003). They found that an increased tiredness after a stroke had a strong influence on the patients’ capacity to manage everyday life. Through the implementation of “Cimt at home” additional stress was perceived by the above mentioned patients.

In the opinion of the author, the NPCs’ experiences do not allow to identify clearly distinct factors which might have an influence on the experience whether the coordination of everyday life and “Cimt at home” was difficult or not. It seems that working obligations and household responsibilities of the NPC might be reasons for perceived stress and difficulties. This aspect is supported by the patients’ experiences that the daily two-hour practice with a NPC needed to be modified because of the NPCs’ work commitments (cf. p. 50). Nevertheless, there were NPCs, who had no problems to combine work, household and “Cimt at home”. Another factor, which seems to have an influence on the experience whether the coordination of everyday life and “Cimt at home” was sometimes difficult, was the responsibility for children.

One patient experience suggests that it might be helpful for patients and NPCs to create consciously the everyday life in the four-week intervention period of “Cimt at home” calmer and less stressful. The supervising therapists could consider in advance jointly with the patient and NPC possibilities, which might be supportive in the four weeks. Ideas could be an additional support by a relative or friend to manage everyday life or fewer appointments during this time. Furthermore, an appropriate period for the implementation of “Cimt at home” (e.g. holidays, weeks of less labor) should be selected together.

Because a two-hour daily training with a NPC was not possible, some stroke patients modified the two-hour practice to realize “Cimt at home”. Those patients described that they e.g. practiced during the day alone and in the evenings or on certain firmly agreed days together with their coach (cf. chapter 4.4.4). The reduction of the two-hour practice with a NPC could be in general an idea to create the practice of “Cimt at home” more flexible and easier to integrate in the daily routines of NPCs. Also employed patients might profit from a split into joint and self-practice. Particularly when the NPC also works full-time the implementation of the exercises would concentrate on the evenings, which might be stressful. A partial self-practice might be in turn easier to be integrated during the own daily schedule. Moreover, the results indicate that the selection of more than one NPC might be supportive for the relief of the NPC and for the realization of the daily practice with a NPC. Galvin et al. (2011) found supportive factors for the adherence to an eight-week long family-mediated exercise (seven days a week/ 35 minutes) in which a relative practices with a stroke patient. They also identified that it was helpful when more than one person was integrated in the practice with the patient. Another patient’s experience of the present study suggests that it might be also supportive for the realization of the practice with the NPC to split the practice into smaller parts distributed over the day.

In this context it should be mentioned that the conduction of the daily exercises without or with little support by a NPC was for many patients possible (cf. p. 51), but in the opinion of the author it seems not to be advisable. The results indicate that patients, who practiced predominately alone, wished more therapeutic support because they felt alone with the exercises or because it was difficult for them to motivate themselves for the daily training (cf. chapter 4.4.7).

5.1.4 The exercise principles of “Cimt at home”

It is an important element of “Cimt at home” and CIMT in general that exercises are task-oriented and designed by considering shaping principles (cf. chapter 2.6.2). The results of this thesis confirm the importance of these principles for the patients’ motivation to keep on to the daily exercises (cf. chapter 4.4.3). Exercises were preferred by the patients when improvements were visible or a reference could be made to an improved activity of daily life. Patients were not motivated to implement the exercises when they were too difficult or no reference to a meaningful activity could be made. The aspect that “Cimt at home” was new for the participating therapists might have led to the development of exercises that were sometimes not sufficiently task-oriented or not sufficiently oriented towards the shaping principles. In the advanced training of “Cimt at home” the communication of the exercises principles forms an important part. With respect to the present results it could be supportive for the patients’ motivation to focus even more on these principles in the advanced training of “Cimt at home”.

5.1.5 The practice between patient and non-professional coach

More time spent together, a more intensive relationship, fun and happiness about the patients' improvements and willingness to practice as well as pride that despite difficulties the exercises of "Cimt at home" were realized, were all positive experiences made by the interviewees in the daily training of "Cimt at home". Furthermore, there were interviewees, who only spoke little about the practice with their relative in the interview, but it seemed to be clear that the mutual conduction of the daily exercises was not a great deal for them (cf. chapter 4.4.4, 4.5.3).

The results indicate that there also might be potential for conflicts when patient and NPC are practicing together. Advices of the NPCs in terms of the correct exercise performance or the total amount of practice time were perceived by some stroke patients as stressful. Some NPCs noted that it seems to be a difference if they or the therapist gave an advice. The descriptions of patients and NPCs suggest that such experiences were not only made in "Cimt at home" (cf. chapter 4.2). There sometimes seemed to be a general conflict between patients and relatives about the right amount of rehabilitation efforts. Even though these discrepancies did not lead to a termination of the practice between patient and NPC, it seemed to be a "topic" for some interviewees. Therefore, it would be an idea that the supervising therapist tries to identify potential conflicts jointly with the patient and NPC in advance and during the four-week intervention period in order to find out mutual agreements on how to manage these conflicts. By doing this, the role of the patient and NPC in the practice might be clarified. For example, the patient tries to accept that the NPC is allowed to give advices in the implementation of the exercises "like a therapist" and the NPC tries not to overdo it and tries to give advices only in the time of the two-hour practice and not during the whole day.

It was an experience for three NPCs that it was not always a good feeling to see the efforts of the affected relative with the exercises of "Cimt at home" (cf. p. 64). Particular one NPC was terrified by seeing the effort and pain of his wife. In terms of this experience it needs to be noticed that the supervising therapist recommended to do less or to quit the therapy because of the increasing shoulder pain of his wife. Despite increasing pain his wife continued because she did not want to give up (cf. p. 47). It is questionable how this experience could have been avoided although the supervising therapist gave respective recommendations already. It only can be assumed that it would have been helpful if the therapist would have given more information about the execution of the exercises to the NPC. The NPC described that he was unsure how much "pain" and "effort" was tolerable. More information might have been helpful for him to decide whether the exercises are on the performance limit (as it is intended in "Cimt at home") or above. Altogether, it could be helpful for NPCs to know how challenging an exercise should be. As a result it may be easier to bear the efforts of the partner.

Seven out of thirteen patients described that the practice with the NPC was not always and in two cases almost never realizable (cf. chapter 4.4.4). Reasons were, besides working obligations, a reduced willingness of the NPCs to train and in one interview severe family problems. Some patients' experiences suggest that the reduced willingness of the NPCs was connected to aspects, which might belong to the consequences of the stroke. One patient described that her partner was not pleased to practice with her because of all the other tasks he already does since her stroke. Another patient said that he practiced alone because his partner needed to be relieved. It seems that for some NPCs, the additional tasks that arose after the relatives' stroke have had an influence on their willingness to support the patient with the exercises. Also these NPCs were informed in advance about their tasks in "Cimt at home" and had agreed to support the patient. Based on the results it only can be assumed that there might be barriers for relatives to openly say that there is no willingness for a daily, four-week practice. Supervising therapists should be aware about this aspect when "Cimt at home" will be applied.

5.1.6 Self-motivation of the patient as a precondition for "Cimt at home"

The patients' motivation is, referring to Freivogel (2011) and Bauder et al. (2001, p. 57), very important for the realization of CIMT. Cross-thematic results of this thesis underline this importance (cf. chapter 4.5.3, 4.5.4, 4.5.5). The daily practice with the stroke affected relative, the relatives' motivation as well as the implementation of the restriction was particular for two NPCs difficult and burdening because of a low motivation and depressive mood of their relative. The low motivation of the affected relative meant that the responsibility for the realization of the exercises was completely taken over by these NPCs. Cameron et al. (2011) and Anderson et al. (1995) showed that a depressive mood, mental and behavioral changes of a stroke patient can lead to an increased burden of the caring relative. Therefore, it should be considered if "Cimt at home" is appropriate for patients with a low motivation and/or depressive mood or if the implementation puts an additional stress to the caring relative. With respect to the selection of stroke patients, which would profit from "Cimt at home", it should be tried to identify whether the patient is really motivated to implement "Cimt at home" and maybe not only the relative of the patient.

5.1.7 Enhanced usage of the impaired arm

The enhanced arm usage was for many patients connected with sometimes great efforts. Activities, which were performed with the impaired arm in everyday life, were often experienced as not effective, unattractive, difficult and also sometimes as very exhausting (cf. chapter 4.4.5).

Already in the beginning of this project the question arose whether patients, who are affected on their dominant body side, have a different motivation to increasingly use their impaired arm than patients, who are affected by the stroke on their less dominant body side. (cf. chapter 3.4.3).

Patients, who were affected on their dominant body side, did not mention in the interviews a special motivation for the enhanced arm usage. Vice versa, there were patients, who were affected on their less dominant body side and questioned for that reason the enhanced arm usage in everyday life (cf. chapter 4.4.5). Based on the present results a clear answer to the above mentioned question seems to be not possible, but the results indicate that the handedness of a patient might have an influence on the patients' motivation for the enhanced arm usage. Miltner et al. (1999) and Rijntnes et al. (2005) investigated in terms of CIMT whether the handedness of a stroke patient had an influence on the primary outcomes. Their results indicate that the handedness had no influence on the patients' outcomes. Referring to that, one could assume that there also was no different motivation for the enhanced arm usage. It needs to be noticed that both studies only had a relatively small sample size (n = 15 and 26). It will be of interest, when the results of the HOMECIMT study are available, to know whether the patients' handedness had an influence on the primary outcomes or not.

Referring to the result that there are patients, who might question the enhanced arm usage of their less dominant arm, it should be considered how the motivation of these patients for the enhanced arm usage could be increased. It already belongs to the protocol of "Cimt at home" that patients and NPCs are informed in advance about the theoretical ideas of "Cimt at home" with the aim to raise their understanding and motivation for the therapeutic components (cf. chapter 2.6.2, 2.7). This also includes information about the meaning of the enhanced arm usage. "Cimt at home" is applied over a relatively long period of time; therefore, it could be supportive for the patients' motivation when the supervising therapist additionally informs the patient continuously over the four week intervention period about the meaning of the enhanced arm usage.

5.1.8 Restriction

The wearing of the glove was described by some patients as sometimes unaccustomed and hindering in their everyday life because they could not act in a way they usually do (cf. chapter 4.4.5). These experiences are consistent with the descriptions of Bauder et al. (2001, p. 44). However, some patients also saw the positive aspects of the glove because they knew about the aims of the restriction. By wearing the glove they were motivated to use the impaired arm for activities of daily life.

The feeling of helplessness and insecurity by wearing the glove were another experience described by some patients and NPCs. These patients avoided the restriction or rejected the glove. It would have been possible to stabilize in case of an imbalance with the glove used in the HOMECIMT study. Furthermore, patients were informed in advance about the partly restriction of the healthy arm. Anyhow, the results show that some patients did not accept the glove because they felt insecure.

In the opinion of the author, it should be considered how in the future practice of “Cimt at home” this experience could be handled. It would be a possibility to exclude patients with balance problems from “Cimt at home”. But referring to one positive patient experience, it seems to be possible to improve activities of daily life, even if the restriction was stopped in the early beginning of “Cimt at home”. This patient concentrated consciously on the realization of the enhanced arm usage during the four-week intervention period of “Cimt at home” (I8, cf. chapter 4.4.5, 4.4.6). This experience goes conform with a study of Uswatte et al. (2006). They compared four different treatment protocols of CIMT, which included also a treatment protocol without restriction. They found that there was no difference in the outcomes between the four treatment protocols after the intervention. Also Morris et al. (2006) assumed that CIMT can be effective without the restriction. But they also emphasized in this context the importance of their behavioral techniques to induce the enhanced arm usage (cf. chapter 2.6.2). Otherwise, they considered that CIMT would not be successful without restriction. Because of the different and individual experiences of the patients, it is recommended by the author that it should be discussed individually with the patient and NPC if a restriction should be implemented or not. A general exclusion of these patients does not seem to be meaningful.

5.2 Methodological considerations and limitations of this thesis

To answer the research questions a qualitative study design connected with the conduction of in-depth interviews was applied in this project. Among the different qualitative approaches, the hermeneutic phenomenological approach by Max van Manen was chosen to describe the experiences of stroke patients and NPCs with the new therapeutic concept (van Manen 1990). With respect to the question whether the present data is saturated, meaning whether more interviews would have gained additional important new findings (Bryman 2012, p.18), the author of this thesis received the impression that a high degree of saturation has been achieved. Nevertheless, there are some methodological aspects that need to be considered in the interpretation of the present results.

5.2.1 Influence of the study participation

It basically needs to be noticed in the interpretation of the interviewees’ experiences with “Cimt at home” that this new therapeutic concept was tested in a RCT. The interviewees not only implemented “Cimt at home”, but also took part in a comprehensive clinical trial. Even though single experiences of the interviewees suggest that the study participation and its perceived obligations sometimes had an impact on the experiences with “Cimt at home”, it seems not to be possible to separate these experiences (cf. chapter 4.4.2, 4.5.2). In the present study design it was not possible to exclude the influence of the study participation, otherwise there would have been no other possibility to gather information about the experiences of stroke patients and NPCs.

5.2.2 Sampling non-professional coaches

An important aspect, which needs to be discussed critically, is the sampling of the NPCs. All NPCs trained with their stroke affected relative as it was intended by “Cimt at home”, even though it was sometimes difficult for them. In contrast, the patients’ experiences indicate that the practice with the NPC was not always possible to be implemented. Thus, it seems that the sample of the NPCs represents only those coaches, who were able and motivated to implement “Cimt at home” with a stroke affected relative. This unbalanced composition was already recognized during the recruitment of the interviewees (cf. chapter 3.4.3). It would have been of interest also to speak with NPCs, where only a limited or no practice with the patient was possible. Therefore, it was tried to get in contact with NPCs, where previous interviewed stroke patients already had described that the practice with the NPC was not carried out regularly. These recruitment attempts were not successful. This problem might have been avoided if interviews were arranged immediately with a stroke patient and the associated NPC so that straightaway patient and NPC were asked for an interview. Since in this project firstly mainly patients were interviewed and thereafter, mainly NPCs this recruitment strategy was not anymore possible to apply. This aspect should be considered in further, similar investigations. The sampling of the NPCs can be seen as the main limitation of this thesis. It is important to bear in mind that limitation when interpreting the experiences of the NPCs.

5.2.3 Sampling stroke patients

In the selection of the stroke patients it was tried to ask increasingly patients above 60 years for an interview because most of the strokes occur in the age group above 60 years (RKI 2006). Despite that only seven out of thirteen stroke patients slightly over 60 years could be interviewed (mean age 57, 3 years, range 37-73). This means that the sample of the thirteen stroke patients still consists of relatively young stroke patients. This aspect should be taken into account if the results of this thesis are transferred to older stroke patients. It would be of interest when the results of the HOMECIMT study are available to know the mean age of all stroke patients, which were included in the RCT. Maybe the result will indicate that in general rather “young” stroke patients participated in the study and implemented the new therapeutic concept.

5.2.4 The experiences of stroke patients with a severe speech and language disorder

The inclusion of the experiences of stroke patients with aphasia was an aim of this work. To gather information about the aphasic stroke patients’ experiences, interviews were conducted with the patient and their spouses, who could give these patients a “voice” and were able to talk about the patients’ experiences with “Cimt at home”. In the analysis the difficulty arose that it was sometimes difficult to differentiate between the unique experiences of the aphasic stroke patients and the experiences of their spouses. The impression was that the experiences of the aphasic stroke patients sometimes may have been colored by the spouses’ experiences.

Although only two interviews with aphasic stroke patients were conducted, this aspect should be noticed. For future research with aphasic stroke patients it is recommendable to consider also other methods of data collection such as observation.

5.2.5 Application of quality criteria

The consideration of quality criteria is an important part in qualitative research designs (Creswell & Miller 2000, Steinke 2007, p. 321-322). The quality criteria “validity” was achieved by considering four validation strategies recommended by Creswell & Miller: triangulation, prolonged engagement with the research topic, comprehensive description of the experiences of patients and NPCs as well as the disclosure of the researchers’ background.

It would have been enriching also to discuss the results of this thesis with the interviewees to know whether the results really represent their experiences with “Cimt at home”. Because of the limited time frame of this thesis, this additional step was not realizable. Nevertheless, in four cases consultation was held with the interviewees to guarantee that the author understood their experiences with “Cimt at home”. The quality criteria “reliability” was tried to be guaranteed by achieving a good quality of data. Reliability is also often obtained by a procedure called intercoder agreement, which means that multiple coders analyze the transcript data (Creswell 2007, p. 210-211). Even though this strategy would have probably enhanced reliability, it could not be applied because only one person performed this research.

6 Recommendations and outlook

In the last chapter of this thesis recommendations for a future practice of “Cimt at home” and an outlook on further investigations with respect to “Cimt at home” are provided.

6.1 Recommendations for a future practice of “Cimt at home”

Based on the experiences of the stroke patients and NPCs and the considerations made in the discussion recommendations for a future practice and further development of “Cimt at home” in the ambulant care of stroke patients with physical and occupational therapy were formulated and are presented below. The author of this thesis is conscious that some of the recommendations refer to elements that already belong to “Cimt at home”. These came up to be important in the interviewees’ experiences and are therefore mentioned in the recommendations again to underline their significance.

1. The motivation of the stroke patient as well as the availability of personal goals for improvements is very important for the implementation of “Cimt at home”.

2. For the motivation of the stroke patient, it is important that the NPC is also motivated and willing to support the stroke patient regularly and reliable in the four-week practice.

3. The coordination of everyday life and “Cimt at home” might be especially stressful for employed patients and NPCs as well as for patients, who suffer from a reduced capacity to manage everyday life. Therapists should consider jointly with the patient and NPC possibilities to create the everyday life less stressful and calmer in the four-week intervention period. Furthermore, they should select an appropriate time for the implementation of “Cimt at home”.

4. To relief the NPC and to make the daily practice more flexible it could be supportive to split the practice into self-practice of the patient and joint practice of patient and NPC and to choose more than one NPC to be responsible for the support of the patient. Furthermore, the splitting of the two-hour practice into smaller parts might be also supportive for NPCs, but also for patients for a better integration of the daily exercises in everyday life.

5. The therapist should be aware that despite the agreement on therapeutic goals, patients might have still ambitious expectations and hopes on “Cimt at home”. It seems to be important to clarify patients’ expectations in advance and continuously during the four-week intervention period as well as to provide information about which improvements can be achieved through “Cimt at home”. Furthermore, it must be transparent for the patient that improvements only can be maintained if the enhanced usage of the impaired arm is continued after the four weeks.

6. The restriction of the healthy arm might not always be accepted by patients due to associated feelings of helplessness and insecurity. Because it may be possible to make improvements also without restriction, it is proposed that the therapist discusses individually with the patient and the NPC whether a restriction should be implemented or not.

7. The enhanced usage of the impaired arm might be for some patients, who are not affected on their dominant body side, questionable. To maintain and enhance the patients' motivation for the enhanced arm usage, information about the theoretical ideas of "Cimt at home" not only at the beginning of the therapy, but also during the four weeks might be supportive.

8. It is important for the patient to conduct meaningful and realizable exercises in "Cimt at home". The meaningfulness and feasibility of the exercises supports the patients' motivation to carry out the exercises over the four-week intervention period.

9. There might be potential for conflicts when patient and NPC are practicing together. To minimize disagreement it could be a possibility to identify potential conflicts jointly with the patient and NPC in advance and continuously and to find mutual agreements on how to overcome these conflicts. By doing this the role of the patient and NPC in the training could be clarified.

10. Information about how challenging an exercise may be could be supportive for NPCs to bear the efforts of the patient with the exercises and to realize whether an exercise is too difficult.

11. To stop the time is one of the principles of "Cimt at home". Therapists should practice the safe handling of the stop watch with the NPC so that the NPC feels comfortable with it in the practice with the stroke patient.

12. "Cimt at home" might be sometimes challenging and stressful during the four-week intervention period. Therefore, it seems to be important that the therapist repeatedly asks for possible difficulties and stresses during the four weeks and tries to work out solutions jointly with the patient and NPC. Aspects that could be ask by the supervising therapist are e.g.:

    - Is it possible for you to coordinate everyday life and "Cimt at home"?

    - How does the daily training work? Is it fun? Which difficulties did you experience?

    - How is your motivation to carry on "Cimt at home"? Are the exercises meaningful to you? Is there a need for improvements? In what situation of your daily life did you notice practical benefits caused by the therapy?

    - How does it work to use your impaired arm in everyday life? How does it feel to put on and off the glove? How does it feel to wear the glove?

    - How does the documentation of "Cimt at home" work? Do you feel comfortable with the handling of the stop watch?

6.2 Outlook

The detailed description of the patients' and NPCs' experiences as well as the resulting recommendations serve a future practice and further development of "Cimt at home" in the ambulant care of stroke patients. The author of this thesis is conscious about that only the application of the recommendations will finally show how realizable they are and if they will improve the implementation of the new therapeutic concept from the perspective of the stroke patients and NPCs. In the discussion also possible modifications of "Cimt at home" were outlined. Proposed alternatives are the splitting of the practice into self-practice of the patient and joint practice with the NPC as well as the possibility to implement the enhanced arm usage also without restriction. Just like the efficacy of "Cimt at home" with its components is tested, these proposed alternatives needed to be investigated in terms of the question whether they show evidence of good therapeutic results.

Through the exploration of the patients' and NPCs' experiences it is now possible to give together with the results of the HOMECIMT study comprehensive information about the new therapeutic concept "Cimt at home". Furthermore, it will be interesting when the results of the HOMECIMT study are available to investigate whether there are possible relationships between the findings of this thesis and the results of the RCT. For example, from the present results the hypothesis could be established that for employed stroke patients "Cimt at home" is more difficult to realize and therefore, the regular practice and the enhanced arm usage less frequently possible. It would be of interest if consequently these patients show fewer improvements in the primary outcomes in contrast to retired patients. Moreover, one could compare the results of the primary outcomes with common experiences of the interviewed patients to identify supportive and non-supportive factors. For example, the question could be pursued whether there is a difference in terms of improvements between patients, who regularly practiced with their NPCs or not or whether there is a difference in terms of improvements between patients, who were disappointed despite improvements or not.

Within the framework of the HOMECIMT project also focus group discussions with participating physical and occupational therapists about their experiences with "Cimt at home" were conducted. It would be enriching to compare the qualitative results of this thesis with the findings of the focus group discussions and to investigate whether similar experiences were made with "Cimt at home" or if the therapists differentiate in their experiences on the new therapeutic concept.

These above mentioned issues will allow the further evaluation and possible adaption of this new therapeutic concept for chronic stroke patients in the ambulant care with physical and occupational therapy. Referring to the diverse and severe consequences of a stroke, it is necessary that continues research in terms of new and innovative interventions for stroke patients is done.

7 Literature

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8 Declaration of independent work

“I hereby declare that I wrote this thesis without any assistance and used only the aids listed. Any materials taken from other works, either as a quote or idea, have been indicated under ‘Literature’.”

Place, date

Signature Anne Stark

9 Annex

The annex contains the following documents:

- Open interview guideline - Stroke patients
- Open interview guideline - Non-professional coaches
- Informed consent letter
- Short questionnaire - Stroke patients
- Short questionnaire - Non-professional coaches

9.1 Open interview guideline – Stroke patients

Leben und Alltag nach dem Schlaganfall

Leitfrage: ***Sie hatten vor XX Jahren/Monaten einen Schlaganfall. Wie war das denn überhaupt nach dem Schlaganfall? Erzählen Sie doch mal…***

Wie war das so als Sie wieder Zuhause waren? Wie ist es Ihnen da ergangen? Erzählen Sie doch mal…

Physio- oder Ergotherapie nach dem Schlaganfall (vor der Studienteilnahme)

Leitfrage: ***Als Sie dann wieder Zuhause waren, haben Sie wahrscheinlich auch weiter Therapie (z.B. Ergo- und/oder Physiotherapie) erhalten? Wie war das mit der Therapie für Sie?***

Erfahrungen mit dem neuem therapeutischem Konzept

Leitfrage: ***Sie haben ja nun vor XX Wochen/Monaten an der Schlaganfallstudie teilgenommen und das neue therapeutische Konzept angewandt. Wie war das für Sie? Erzählen Sie doch mal…***

Wie haben Sie Ihre **Ergo bzw. Physiotherapie** in der Zeit der Studie erlebt?

Wie war es mit Ihrem/Ihrer **Therapeuten/Therapeutin**, der/die Sie in der Studie begleitet hat?

Wie haben Sie Ihren **Alltag** in dieser Zeit erlebt? Wie war Ihr **Tagesablauf** in dieser Zeit?

Wie war das in dieser Zeit mit Ihrem/Ihrer **Angehörigen/ in**, die/der Sie beim Üben begleitet hat?

Versuchen Sie sich nochmal zu erinnern, gab es vielleicht Situationen in diesen vier Wochen, die für Sie besonders **positiv oder negativ** waren? Können Sie mir darüber etwas berichten?

Hat sich vielleicht etwas durch die **Therapie verändert**? Erzählen Sie doch mal…Wie haben Sie das so erlebt?

Physio- oder Ergotherapie nach der Anwendung des neuen therapeutischen Konzeptes

Leitfrage: ***Nun sind ja schon XX Monate/ Tage nach Ihrer Studienteilnahme bzw. nach der Anwendung des neuen therapeutischen Konzeptes vergangen. Ich gehe davon aus, dass Sie weiterhin Ergotherapie oder Physiotherapie erhalten. Stimmt das? Wie sieht Ihre Therapie denn jetzt aus? Erzählen Sie doch mal?***

Wie ist das denn jetzt mit **Ihrem/Ihrer Therapeuten/Therapeutin**?

Ende/Abschluss

Leitfrage: ***Wir sind nun von meiner Seite zum Ende unseres Gespräches gekommen. Möchten Sie vielleicht noch etwas ergänzen oder erzählen worüber wir noch nicht gesprochen haben?***

9.2 Open interview guideline – Non-professional coaches

Leben und Alltag nach dem Schlaganfall des Angehörigen

Leitfrage: ***Ihr/e Angehörige/r hatte vor XX Jahren/Monaten einen Schlaganfall. Wie ist es Ihnen nach dem Schlaganfall Ihres/Ihrer Angehörigen ergangen? Erzählen Sie doch mal…***

Als Ihr/Ihre Angehörige/r wieder Zuhause war, wie ist es Ihnen da ergangen? Wie war diese Zeit? Wie haben Sie das so erlebt?

Physio- oder Ergotherapie nach dem Schlaganfall (vor der Studienteilnahme des Angehörigen)

Leitfrage: ***Als Ihr/e Angehörige/r dann wieder Zuhause war, hat er/sie wahrscheinlich auch weiter Therapie (z.B. Ergo- und/oder Physiotherapie) erhalten? Wie haben Sie das so mit der Therapie wahrgenommen? Erzählen Sie doch einfach mal…***

Erfahrungen mit dem neuen therapeutischen Konzept als nicht-professioneller Übungsbegleiter

Leitfrage: ***Ihr/e Angehörige/r hat ja nun vor XX Wochen/Monaten an der Schlaganfallstudie teilgenommen und das neue therapeutische Konzept angewandt. Sie haben ihn/sie dabei ja als Übungsbegleiter/in unterstützt, oder? Wie war das für Sie? Erzählen Sie doch einfach mal…***

Wie haben Sie Ihren **Alltag** in dieser Zeit erlebt? Wie war Ihr **Tagesablauf** in dieser Zeit?

Wie war das in dieser Zeit mit Ihrem/Ihrer **Angehörigen,** den/die Sie beim Üben begleitet haben? Wie ist es Ihnen damit ergangen?

Erzählen Sie doch mal, was waren denn so **Ihre Aufgaben beim gemeinsamen Üben**?

Versuchen Sie sich nochmal zu erinnern, gab es vielleicht Situationen in diesen vier Wochen, die für Sie besonders **positiv oder negativ** waren? Können Sie mir darüber etwas berichten? Erzählen Sie doch mal…

Haben Sie das Gefühl, dass sich etwas durch die Therapie verändert hat? Erzählen Sie doch mal…

Physio- oder Ergotherapie des/der Angehörige/n nach der Durchführung des neuen therapeutischen Konzeptes

Leitfrage: ***Nun sind ja schon XX Monate/Tage nach der Studienteilnahme bzw. nach der Anwendung des neuen therapeutischen Konzeptes vergangen. Ich gehe davon aus, dass Ihr/e Angehörige/r auch weiterhin Ergotherapie oder Physiotherapie erhält. Stimmt das? Wie sieht die Therapie Ihres/Ihrer Angehörigen denn jetzt aus? Erzählen Sie doch mal…***

Üben Sie manchmal immer noch **gemeinsam**? Erzählen Sie doch mal…

Wenn ja, welche **Rolle oder Aufgaben** haben Sie denn innerhalb der Therapie?

Ende/Abschluss

Leitfrage: ***Wir sind nun von meiner Seite zum Ende unseres Gespräches gekommen. Möchten Sie vielleicht noch etwas ergänzen oder erzählen worüber wir noch nicht gesprochen haben?***

9.3 Informed consent letter

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6. Mai 2013

Schlaganfall-Studie

Sehr geehrte(r) Frau/Herr

vielen Dank für Ihre Teilnahme an der Schlaganfall-Studie. Sie haben viele Fragen beantwortet und sind selber nur wenig zu Wort gekommen. Heute möchten wir Sie einladen, uns mehr über Ihre persönlichen Erfahrungen zu erzählen.

Wir werden diese Gespräche mit mehreren Studienteilnehmern und Angehörigen führen und in die Auswertung der Studie miteinfließen lassen. Wir haben für Sie nachfolgend zusammmengestellt, was die Teilnahme am Gespräch für Sie bedeutet:

- Das Gespräch wird Frau Anne Stark, eine Mitarbeiterin unseres Studienteams, bei Ihnen zu Hause führen.
- Ihre Teilnahme ist freiwillig. Wenn Sie nicht teilnehmen, entstehen Ihnen keinerlei Nachteile.
- Das Gespräch wird auf Datenträgern aufgezeichnet und im Anschluss transkribiert, d.h. in eine schriftliche Form übersetzt.
- Die Auswertungen des Gesprächs und des Kurzfragebogens erfolgt pseudonymisiert (verschlüsselt). Auch mögliche Veröffentlichungen der Studienergebnisse erfolgen ohne Rückschlüsse auf Ihre Person.

- Sie können Ihre Einwilligung zur Teilnahme jederzeit ohne Angaben von Gründen widerrufen. Wenn Sie Ihre Teilnahme zurückziehen, werden die bis dahin erhobenen Daten vernichtet und nicht für die wissenschaftliche Auswertung verwendet.
- Die Aufzeichnung bzw. Speicherung der Daten erfolgt über die Dauer von 10 Jahren.

Wenn Sie sich ausreichend informiert fühlen, mit der Teilnahme am Gespräch und der Aufzeichnung einverstanden sind und keine weiteren Fragen haben, bitten wir Sie, dies mit Ihrer Unterschrift zu bestätigen.

____	____
Vor- und Nachname Studienteilnehmer/in	Ort, Datum, Unterschrift Studienteilnehmer/in
	____
	Ort, Datum, Unterschrift Studienmitarbeiterin

Am Ende der Studie, wenn bei allen Studien-Teilnehmern die drei Hausbesuche stattgefunden haben, werden wir Ihnen über die Ergebnisse berichten. Das wird noch etwas dauern, voraussichtlich bis Herbst 2013.

Mit freundlichen Grüßen

9.4 Short questionnaire – Stroke patients

Interview Kurzfragebogen – Patient/Patientin

Teilnehmer (Angabe verschlüsselt):

Alter:

Geschlecht:

Familienstand:

Beruf:

Aktuelle Berufstätigkeit:

Datum des Schlaganfalls:

Wie häufig erhalten Sie zur Zeit Ergo-und/oder Physiotherapie in der Woche?

Wo findet die Therapie statt? (Zuhause oder in der Praxis)

Zeitraum der Studienteilnahme:

Nicht-professioneller Übungsbegleiter:

Teilnehmende Berufsgruppe an der Studie (ET/PT):

Datum des Interviews:

Uhrzeit des Interviews:

Dauer des Interviews:

Ort an dem das Interview durchgeführt wurde:

Anmerkungen zum Interview: z.B. Atmosphäre, Stimmung, besondere Vorkommnisse, Interaktion, schwierige Passagen

9.5 Short questionnaire – Non-professional coaches

Interview Kurzfragebogen – Nicht-professionelle/r Übungsbegleiter/in

Teilnehmer (Angabe verschlüsselt):

Welche Verbindung besteht zum/zur Studienteilnehmer/in? (z.B. Angehöriger, Freund, Nachbar)

Alter:

Geschlecht:

Familienstand:

Beruf:

Aktuelle Berufstätigkeit:

Zeitraum der Studienteilnahme:

Datum des Schlaganfalls des Angehörigen/Freundes/Partners etc.:

Datum des Interviews:

Uhrzeit des Interviews:

Dauer des Interviews:

Ort an dem das Interview durchgeführt wurde:

Anmerkungen zum Interview: z.B. Atmosphäre, Stimmung, besondere Vorkommnisse, Interaktion, schwierige Passagen