

## Stroke patients' and non-professional coaches' experiences with home-based constraint-induced movement therapy: a qualitative study

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### Abstract

**Objective:** To investigate the experiences of chronic stroke patients and non-professional coaches with home-based constraint-induced movement therapy (homeCIMT).

**Design:** Qualitative study embedded within a cluster randomized controlled trial investigating the efficacy of homeCIMT to improve the use of the affected arm in daily activities.

**Setting:** Patients' home environment.

**Participants:** 13 stroke patients and 9 non-professional coaches' alias family members who had completed the four-week homeCIMT programme in the context of the HOMECIMT trial.

**Interventions:** Semi-structured interviews; qualitative data were analysed using the methodology of the hermeneutic phenomenological data analysis.

**Results:** We identified six themes in the qualitative analysis describing the experiences of patients and non-professional coaches with homeCIMT: (1) homeCIMT can be integrated into everyday life with varying degrees of success; (2) training together may produce positive experiences as well as strain; (3) self-perceived improvements during and following homeCIMT; (4) using the affected arm in everyday life is challenging; (5) subjective evaluation of and experiences with homeCIMT-specific exercises; and (6) impact of professional therapists' guidance and motivation during homeCIMT. Statements regarding theme five and six were only provided by patients, whereas the other themes contain both, the experiences of stroke patients and non-professional coaches.

**Conclusion:** Patients' and non-professional coaches' narratives offer a detailed insight into the manifold experiences with the practical implementation of homeCIMT that may help improve implementing the homeCIMT programme and similar approaches involving increased training duration and intensity and/or involvement of family members.

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homeCIMT programme and similar approaches involving increased training duration and intensity and/or involvement of family members.

## Keywords

Stroke, home rehabilitation, constraint-induced movement therapy, family involvement, qualitative study

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## Introduction

In stroke rehabilitation, repetitive, task-specific training is one of the key principles.<sup>1,2</sup> For stroke patients with upper limb dysfunction, constraint-induced movement therapy and its modifications are one of the most promising techniques taking this principle into account.<sup>1-4</sup> To induce the use of the affected arm in everyday life,<sup>5</sup> constraint-induced movement therapy comprises an intensive motor training, the use of adherence-enhancing behavioural methods and the immobilization of the non-affected hand.<sup>5,6</sup> A four-week home-based training in conjunction with the support of a non-professional coach (e.g. family member) and reduced professional assistance to meet ambulatory care conditions (home-based constraint-induced movement therapy (homeCIMT)) is one way to deliver constraint-induced movement therapy to patients in long-term care.<sup>7</sup> The HOMECIMT trial showed homeCIMT to be superior to conventional therapies with regard to the self-perceived use of the stroke-affected arm in daily activities.<sup>8</sup>

HomeCIMT and other forms of constraint-induced movement therapy have been shown to be particularly effective in improving upper limb function post stroke.<sup>1,3</sup> However, these interventions will only work if patients adhere to them. Constraint-induced movement therapy requires numerous hours of repetitive exercises, which are likely to present a challenge for patients.<sup>9,10</sup> Regarding homeCIMT, the involvement of a non-professional coach might be an additional challenging aspect for both, patients and non-professional coaches. Thus, it is vital to better understand the users' experiences with different forms of constraint-induced movement therapies in order to adapt the way how we deliver these interventions and maximize adherence to them. However,

there are only few investigations with the users' perspectives on constraint-induced movement therapies. We are only aware of three minor qualitative studies investigating the experiences of two or three patients with modified constraint-induced movement therapies.<sup>11-13</sup> A qualitative research approach, in particular, provides information about the users' experiences with the practical application of a therapy.<sup>14,15</sup>

In addition to the cluster randomized controlled HOMECIMT trial, we conducted a comprehensive qualitative study to explore the users' perspectives on homeCIMT following the driving question: What are the experiences of chronic stroke patients and non-professional coaches with homeCIMT?

## Method

This qualitative interview study about the experiences of stroke patients and non-professional coaches with homeCIMT was embedded within the cluster randomized controlled HOMECIMT trial, which had been designed to compare homeCIMT with conventional physical or occupational therapy in ambulatory care for patients with upper limb dysfunction following stroke. Details of the HOMECIMT trial have been published elsewhere.<sup>8,16</sup> The study protocol has been approved by the Ethics Committee of the Medical Association of Hamburg (approval no. PV 3737) and is registered at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) (NCT01343602). The qualitative study was carried out from October 2012 to October 2013.

As qualitative research approach we have chosen the hermeneutic phenomenological research methods of Max van Manen.<sup>17</sup> Phenomenological research is characterized by the description and

understanding of several individuals' common experiences with a specific phenomenon.<sup>18</sup> This study regards homeCIMT as the specific phenomenon of interest where stroke patients and non-professional coaches share their experiences.

### **Setting**

The therapeutic concept homeCIMT takes place in the patients' home. Stroke patients train their affected arm each weekday for 2 hours over a four-week period without professional assistance, but with the support of a non-professional coach. This can be a family member, life partner or friend of the patient willing to support the daily training sessions. Physical or occupational therapists use contact hours (five home visits each lasting 50–60 minutes) to instruct and supervise patients and non-professional coaches together in homeCIMT and to adapt the training to the patients' abilities. The instructions include goal setting, responsibilities of the non-professional coach and exercise performance, among others. To induce the use of the affected arm, patients are encouraged to wear a glove that immobilizes the non-affected hand during training and for additional 2–4 hours daily.<sup>8,16</sup>

### **Sample and recruitment**

Participants for an interview were recruited from the HOME CIMT trial population.<sup>8</sup> All stroke patients who had completed the homeCIMT intervention and all associated non-professional coaches were eligible to participate in an interview about their experiences with homeCIMT.

Patients were 18 years of age or older and had suffered a stroke at least six months prior to enrolment in the HOME CIMT trial with subsequent mild-to-moderate impairment of arm function and a minimal residual hand function, no or mild-to-moderate impaired verbal communication and had been participating in the intervention group of the trial.<sup>8</sup> Non-professional coaches were family members and life partners, rarely friends, who had agreed to support a patient with homeCIMT in the context of the HOME CIMT trial.

Patients with impaired verbal communication were not excluded from taking part in an interview if their non-professional coach agreed to participate in the interview to support the patient in expressing her or his experiences. Apart from patients with speech disorders, we aimed at conducting individual interviews with patients and non-professional coaches without special focus on including particular dyads. However, if both, the patient and the associated non-professional coach, were interested in an interview, we allocated two individual interviews.

The purposeful selection of interviewees considered gender, age and employment status of patients and non-professional coaches as well as patients' handedness to create a diverse sample. Data needed for the selection of patients were extracted from data already collected in the HOME CIMT trial.<sup>8</sup> As no personal data had been collected from non-professional coaches in the HOME CIMT trial,<sup>8</sup> we used the HOME CIMT trial staff's personal knowledge to select non-professional coaches according to the aforementioned criteria. In this study, sample size was determined by theoretical data saturation.<sup>14,19</sup>

Potential interviewees were approached via telephone and invited for an interview regarding their experiences with homeCIMT. Interested patients and non-professional coaches were informed verbally and in writing about the aim of the qualitative study and interview conditions to obtain their informed consent.

All in all, we conducted 19 interviews which comprised 10 interviews with patients; 6 interviews with non-professional coaches; and 3 interviews with a dyad, that is, a stroke patient with a moderate speech disorder and a non-professional coach (two interviews) and one interview where the patient spontaneously asked his wife (alias non-professional coach) to participate.

### **Data collection**

Regarding qualitative data collection, semi-structured interviews were conducted using almost the same interview questions for patients and non-professional coaches to facilitate comparability.

During the interviews, participants were asked to talk about their experiences with homeCIMT. To get more detailed information, advanced questions including questions regarding the everyday life with homeCIMT, training with a non-professional coach and positive or negative experiences were posed if necessary. In addition, patients were asked about their therapist in homeCIMT.

As the interviewees and the interviewer (A.S.) had not previously known each other personally, A.S. (a female physical therapist (BSc) and health scientist with experience in the field of neurological rehabilitation) introduced herself and her professional background before the interview. Background information on patients and non-professional coaches to be interviewed (e.g. gender, age, family status, employment status and date of stroke) had been recorded prior to each interview.

All interviews were carried out over the period of December 2012 to June 2013 and were conducted in the interviewees' own homes or in an alternative private venue according to their preference. The interval between interview and completion of homeCIMT was on average 248 (SD: 160; min: 45, max: 565) days. The duration of the interviews varied between 13 and 123 (mean: 37, SD: 24) minutes. The interviews were tape-recorded and transcribed verbatim.<sup>20,21</sup>

### Data analysis

To identify the users' experiences with homeCIMT, the methodology of the hermeneutic phenomenological data analysis was applied.<sup>18</sup> The procedure of the phenomenological data analysis was conducted as follows: at first, each transcript was read several times to get a general impression of the interviews. Subsequently, 'significant statements' about the patients' and non-professional coaches' experiences with homeCIMT were identified and highlighted. Thereafter, 'significant statements' were combined to create themes. Finally, the experiences of patients and non-professional coaches were described in thematic sections by writing and rewriting their experiences.<sup>17,18</sup>

MAXQDA 11 software was used for analysing the qualitative data. Data saturation was achieved

after the 13th patient interview and the 9th non-professional coach interview because the analyses of these interviews did not reveal new themes regarding homeCIMT experiences.

In the first step, the qualitative analyses were done separately for stroke patients and non-professional coaches. The three dyad interviews were analysed from the patients' and from the non-professional coaches' perspectives. In the second step, both analyses were considered together.

The qualitative data analysis was performed predominantly by A.S., but to ensure intersubjective comprehensibility,<sup>22</sup> regular discussions about the interviewees' statements and themes took place with A.B. (a female medical doctor, board certified in general medicine and researcher with extensive expertise in stroke rehabilitation), C.F. (a female full professor of empirical social research methods with extensive experience in qualitative research), B.T. (a female trained in occupational therapy (MSc) and researcher with comprehensive expertise in stroke rehabilitation and qualitative research) and M.S. (a male full professor of medicine, board certified in general medicine with extensive experience in quantitative and qualitative research).

## Results

The patient sample (Table 1) consisted of seven women and six men with a mean age of 57.3 (SD: 9.0) years and a mean time frame after the last stroke of 6.5 (SD: 5.3) years. All patients had chosen a close relative (e.g. spouse or children) or life partner as non-professional coach for the daily training.

Regarding the non-professional coaches' sample (Table 2), there were six women and three men with a mean age of 58.3 (SD: 9.0) years. All non-professional coaches assisted a close relative during the daily training according to homeCIMT (eight spouses, one daughter).

### Experiences with homeCIMT

Six themes were built describing the essential experiences of patients and non-professional coaches with homeCIMT (Figure 1).

**Table 1.** Characteristics of stroke patients.

ID	Age (years)	Gender	Time frame since last stroke (years)	Affected side	Employment status before/after stroke
Pat_1	50–60	Female	21	Left	Employed/employed
Pat_2	<50	Male	8	Left	Employed/employed
Pat_3	>60	Female	5	Right	Retired/retired
Pat_4	<50	Female	5	Left	Employed/retired
Pat_5	>60	Female	4	Left	Employed/retired
Pat_6	50–60	Male	5	Left	Employed/employed
Pat_7	>60	Female	6	Right	Employed/retired
Pat_8	>60	Male	2	Right	Employed/retired
Pat_9	>60	Male	2	Right	Employed/retired
Pat_10	50–60	Female	13	Left	Employed/retired
Pat_11	>60	Male	6	Right	Retired/retired
Pat_12	50–60	Male	5	Right	Employed/retired
Pat_13	>60	Female	2	Left	Retired/retired

Pat: stroke patient.

**Table 2.** Characteristics of non-professional coaches.

ID	Age (years)	Gender	Employment status	Time frame since last stroke (years) <sup>a</sup>
NPC_1	50–60	Female	Employed	5
NPC_2	>60	Female	Retired	6
NPC_3	>60	Male	Employed	4
NPC_4	50–60	Female	Employed	5
NPC_5	50–60	Female	Employed	2
NPC_6	50–60	Female	Employed	2
NPC_7	>60	Male	Retired	2
NPC_8	<50	Female	House wife	3
NPC_9	>60	Male	Retired	3

NPC: non-professional coach.

<sup>a</sup>Information refers to the patient supported by the interviewed non-professional coach.

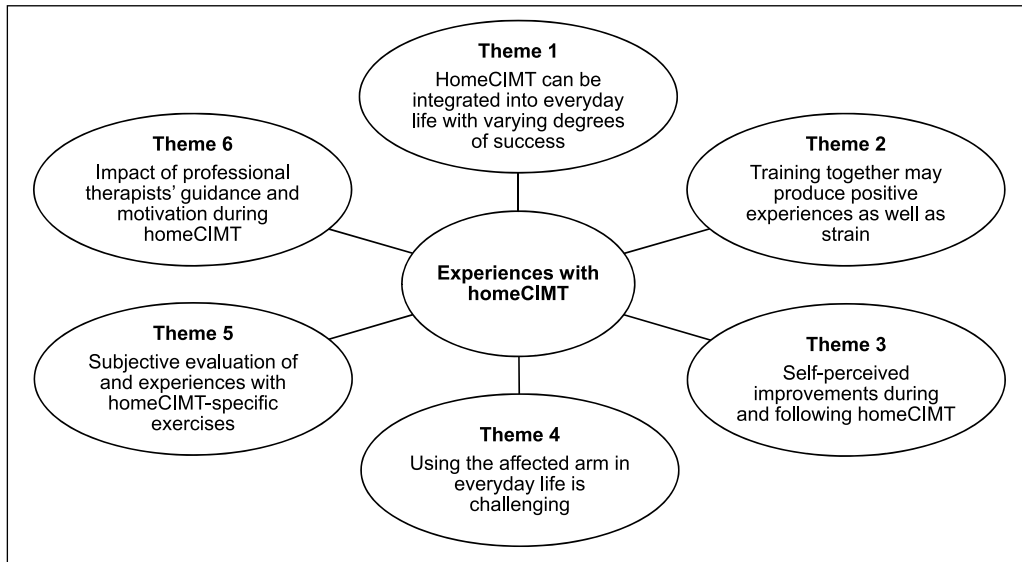
Statements regarding the themes ‘Subjective evaluation of and experiences with homeCIMT-specific exercises’ and ‘Impact of professional therapists’ guidance and motivation during homeCIMT’ were provided by patients, whereas the other four themes contained both, the experiences of stroke patients and non-professional coaches with homeCIMT.

*HomeCIMT can be integrated into everyday life with varying degrees of success.* Patients and non-professional coaches had different experiences regarding

the management of everyday life and simultaneously practicing homeCIMT.

For employed patients as well as non-professional coaches regardless of employment status, the lack of time was considered a stress factor. A non-professional coach, who practised homeCIMT with her husband, said:

I have a big garden, a house and my kids that don’t have driver’s licences yet, as well as working part-time and somehow I have to manage everything; which is why we don’t have two hours every day for



**Figure 1.** Themes regarding the experiences of patients and non-professional coaches with homeCIMT.

the exercises, it's something we can only do when I actually have time. (NPC\_4)

An employed patient reported that he experienced performing homeCIMT in the evening after a full working day as demanding and his muscles of the affected arm did not feel as strong as in the morning, which made the exercises more difficult for him. Both aspects made it more difficult for him to motivate himself for homeCIMT. He said:

I had worked (...) and then always having to work two additional hours in the evening [for the homeCIMT-specific exercises] and then having to wear the glove (...) well, that was (...) pretty tough over the twenty days.

What exactly was the tough part?

Well, you see, it's hard to motivate yourself after work (...) to do anything (.) and I noticed the longer I needed to use my hand at work to do something the harder it got to do anything with my hand at all. (Pat\_2)

A reduced capacity and the feeling that managing everyday life was challenging enough after having suffered a stroke were perceived as

additional reasons why homeCIMT was not always easily carried out in everyday life. For example, patient 4 experienced the increased use of the affected arm for activities of daily life in the afternoons, induced by homeCIMT, as particularly exhausting. She explained that ever since her stroke, her 'battery' only lasted until noon.

Patients, who were unemployed or retired, experienced their daily lives during homeCIMT as not much different than usual and considered the implementation of homeCIMT as manageable. However, there were also non-professional coaches, both unemployed and employed, who described the daily training with their relative as manageable in everyday life:

Actually, things stayed the same [...] we did the exercises in between but it didn't mess up our daily routine. Sure, I had to take [...] the time but didn't have a problem with it [...], it's important for me too that my husband practices. (NPC\_6)

A retired patient reported that she lived a more conscious life through homeCIMT. She purposely tried to make her daily life less stressful and calmer during the course, aiming to use her affected arm consciously and more often. She said:

I actually organised my [everyday life] a lot more consciously by being more aware of [everyday activities] and not under such pressure, that I put myself under pressure which I tend to do a lot, now, I have to do this and that and, afterwards, I did everything more consciously during the research project [HOMECIMT trial]. [...] I did it bit by bit for myself. (Pat\_7)

*Training together may produce positive experiences as well as strain.* In addition to talking about their experiences of integrating the homeCIMT components in everyday life, the interviewees reported on their experiences of practicing with each other. Both patients and non-professional coaches described practicing together during homeCIMT as a positive experience in the sense of spending more time with each other:

We had our fun and we were happy when things got better. (NPC\_2)

Patients also reported that they were happy about the support of their family in homeCIMT because they noticed that they could rely on the support of their families during their own rehabilitation process. Happiness about the spouse's willingness to train with oneself, the relative's one's appreciation for the support as non-professional coach and a closer relationship were positive aspects of training together and only reported by non-professional coaches.

Patients and non-professional coaches also reported difficulties while training together. At times, patients perceived the non-professional coaches' comments on training performance and intensity or the use of the affected arm as stressful or annoying. A patient explained why he thought expectations towards the appropriate therapy workload differed:

The situation resulting from the stroke is stressful for the spouse as it is, and now the spouse obviously wants progress to be made, wants one to do more for it and wants one to put more effort into it. Especially as the spouse believes that one is capable of doing more [...], being a bit more precise or faster, or adding another quarter or half hour. That's when one as a stroke patient says: Man, I've been at this for an hour now, that's enough. (Pat\_6)

Non-professional coaches, who perceived their stroke-affected relative as difficult to motivate for the training and to use the affected arm more often in everyday life, to some extent experienced their task as non-professional coaches as stressful and difficult. For example, a non-professional coach, who continuously tried to motivate his wife to do the exercises, experienced his wife as being discouraged because she regarded the progress she had made as too little. He explained her behaviour to be caused by a depression as a sequela of her stroke. He described himself being sometimes frustrated during homeCIMT because his good intentions were not recognized. Moreover, he felt burdened as being in a way responsible for the implementation of homeCIMT.

Vice versa, there were also patients who reported that their non-professional coaches had not given them the support they had hoped for. For example, patient 4 was somewhat disappointed as her family seemed not to understand the importance of the therapy and did not support her the way she had hoped for. However, to facilitate her regular daily training, she chose more than one non-professional coach and split the 2-hour training between her non-professional coaches. From her point of view, the perceived listlessness of her coaches arose from them being too strained from supporting her with homeCIMT.

Another patient chose to train on her own as she experienced her husband to be unmotivated towards her daily training, which, in her opinion, might have been caused by the ongoing divorce proceedings. Work or household commitments of the non-professional coaches were other reasons patients reported in the interviews for practicing alone and not always together with their non-professional coach as determined at the beginning of the four-week course of homeCIMT. However, patients also explained that they were capable of managing the training including time measurement and documentation by themselves.

*Self-perceived improvements during and following homeCIMT.* Patients and non-professional coaches reported improvements they had perceived during and following the course of homeCIMT, such as enhanced use and/or increased awareness of the affected arm in

everyday life, improved function (e.g. hand mobility) or improved performance of CIMT-specific exercises (e.g. faster exercise performance):

I don't turn the screwdriver with my left hand, but I can hold it with my left hand which, if I remember correctly, I hadn't been able to do before. I became more conscious of it. (Pat\_2)

Self-perceived improvements through home-CIMT were assessed differently: There were patients and non-professional coaches who said that they were very pleased with the progress, describing it as '*joyful*', '*motivating*', '*unexpected successes*' or as a source of hope. Nonetheless, non-professional coaches also mentioned that the success of homeCIMT would have been even greater if the stroke-affected relative would have shown more motivation to participate in the therapy. Furthermore, they said improvements were only feasible with a lot of willpower, endurance and regular training.

Other patients and non-professional coaches mentioned they had expected more or long-lasting improvements. They were also somewhat disappointed because they themselves or their relatives had not performed better:

I'm not saying that I have been expecting a miracle, but I guess I sort of had [laughs]. I always thought: Man, now you're doing all these exercises, [...] there must be some concrete results eventually. (Pat\_8)

Patients, who, from their point of view, considered the therapy as not being successful, stated the following reasons: the four-week period was considered too short to make reasonable improvements, the stroke had occurred too long ago or the affected upper limb had too few functions. Patient 5 assumed that she probably had set her goals too high and recommended taking smaller steps and not to have exaggerated expectations.

With regard to the time following the completion of the homeCIMT course, patients reported that a continued enhanced arm use further improved everyday activities. However, there were also patients who noticed that gained improvements decreased without constant training:

The therapy has been over for almost a year and [...] I still empty the dishwasher with my left hand. I barely need the right one, and, in general, I do much more with my left hand than before. (Pat\_4)

*Using the affected arm in everyday life is challenging.* As described in the previous theme, interviewees perceived the advanced and increased use of the affected arm through homeCIMT in everyday life as an improvement. However, using the affected arm in everyday life with simultaneous immobilization of the healthy arm was also a challenge. A patient described his experience with using his stroke-affected arm for setting a table during homeCIMT:

Setting a table doesn't work as well, you have to [...] try and increase the motor skills and you are often tempted to say: I'll take the glove off and use my other hand, everything is much nicer and better. (Pat\_6)

Other patients described the performance of their stroke-affected arm during daily life activities as '*slow*', '*clumsy*', '*unattractive*', '*exhausting*' or simply '*difficult*'. Right-handed patients with a left-side-affecting stroke regarded it partially senseless to use their stroke-affected left hand for activities they normally performed with their right hand and perceived the required enhanced use of their left hand as a '*double burden*'. Increased muscle tone in the neck or the impaired leg or muscle soreness during the enhanced use of their affected arm was also described as an experience with homeCIMT but did not lead to the cessation of the therapy.

The immobilization of the non-affected hand by wearing a glove was occasionally experienced as '*difficult*', '*unaccustomed*', '*hindering*' or unusual with regard to activities customarily performed with the other arm. However, patients appreciated the new experience of using the stroke-affected arm in their daily life activities:

The glove naturally hindered me in doing what I would normally have done, automatically grabbing something with my left hand [...] and, of course, it was an unusual feeling but it was also the good part. (Pat\_9)

There were also patients who reported that they refused or minimized wearing the glove as they felt insecure without relying on the full capacity of their non-affected hand. This experience was in line with the report of non-professional coaches. A patient, who had stopped wearing the glove because she was afraid of falling, emphasized instead the importance of the use of the enhanced arm in everyday life for her improvements. A non-professional coach referred to a patient's reduced motivation leading to a less frequent use of the glove.

*Subjective evaluation of and experiences with homeCIMT-specific exercises.* Patients also talked about their experiences with their individually adjusted homeCIMT-specific exercises that they performed during their daily 2-hour training. They perceived exercises as positive and meaningful if they led to an improved performance or if the exercises were linked to a meaningful activity of daily life. Exercises were also seen positive if they were achievable although difficult. Vice versa, if these conditions were missing, patients disliked their exercises:

There was one exercise where I was supposed to run my hands along the doorframe, up over my head and then back down. The goal was to see how often I could do it in 30 seconds. The first time [...] I managed [it] once, towards the end of the study I managed [it] 15 times in 30 seconds. It was the highlight of the study. (Pat\_4)

Patients had a positive experience with the fact that the more often they repeated an exercise, the better the exercise performance and the better the function of the impaired arm.

Patient 5 experienced shoulder pain through the repetitive exercises causing a negative impact on the entire therapy. Even though her therapist recommended to reduce the exercises or to quit homeCIMT, she continued because she hoped that the exercises would improve her impaired arm despite the pain.

*Impact of professional therapists' guidance and motivation during homeCIMT.* During homeCIMT, patients felt well cared for by their professional therapists

and reported that their guidance and support were satisfactory to carry out the daily training of homeCIMT.

Patients experienced the therapists' motivation as particularly meaningful and felt motivated to stick to the therapy over the four-week course. However, there were also patients who said that more support from their therapists would have increased their motivation. This was particularly experienced by patients who felt temporarily overburdened or predominately trained without non-professional coaches. A patient who sometimes trained without a non-professional coach said:

I'm the type of person who does things better when someone else is there and knows what he/she is doing and tells me what to do. Then I'll do it. Sometimes I don't have the, I wouldn't say motivation, but, well, then I think: Just let it be. It's not good, [...] but that's the way humans are. (Pat\_9)

## Discussion

Both patients and non-professional coaches reported on self-perceived improvements of the stroke-affected arm through homeCIMT; however, patients had occasionally hoped for major improvements. The interviewees perceived the implementation of homeCIMT in everyday life with varying degrees of success with the reconciliation of therapy and work and household commitments playing an essential role. Regarding the training sessions of patients and non-professional coaches, the interviewees reported positive experiences when doing the training together as well as on the stress and strain due to different opinions and motivations regarding the therapy's implementation. The immobilization and the increased use of the stroke-affected arm was a challenge and could not be implemented with the same success for each patient.

In contrast to many other therapeutic approaches for stroke patients, constraint-induced movement therapy requires a significantly higher intensity and frequency of training which, in the case of homeCIMT, is implemented with the support of a non-professional coach. Our study found that, to a certain extent, completing the increased duration of

training in addition to work and household commitments was deemed challenging which, in turn, might have affected the patients' and non-professional coaches' motivation and capacity to regularly implement the therapeutic components. For example, patients stated the non-professional coaches' obligations as reasons why they also had to train on their own. Even though patients were able to carry out homeCIMT by themselves, some of them would have liked more professional support to boost their motivation. Other studies on constraint-induced movement therapy<sup>9</sup> or other forms of therapy involving increased training duration/intensity and integration of family members<sup>23,24</sup> also identified temporal constraints to be potential barriers to their implementation. Regarding the integration of homeCIMT in everyday life, we also found that a reduced capacity to manage everyday life after stroke as described by Rödning et al.<sup>25</sup> was an additional challenging factor.

The involvement of a non-professional coach is crucial to homeCIMT.<sup>8</sup> However, there are other therapies integrating family members into the rehabilitation process following stroke.<sup>26</sup> We learned that practicing together resulted in positive experiences, such as having fun or spending more time with each other. However, practicing together was perceived as burdensome if the patient or non-professional coach showed a lack of motivation to train or to carry out the therapy as intended. In line with our results, Vloothuis et al.<sup>23</sup> found that an eight-week caregiver-mediated exercise programme could become burdensome if only the patient or caregiver was primarily responsible for the success of the therapy. However, the analysis of two studies<sup>27,28</sup> within a systematic review on outcomes of caregiver-mediated exercises after stroke showed no significant effects on caregiver strain.<sup>26</sup> A different qualitative study on users' experiences with a family-mediated exercise programme did not report on this issue.<sup>24</sup>

In contrast to our study, the qualitative studies of Vloothuis et al. and Galvin et al. did not show that patients occasionally felt stressed because of the non-professional coaches' advices on their training performances (e.g. to use the affected arm

more often in everyday life). A possible explanation could be that both studies focused on users' experiences with caregiver-mediated exercises starting already in inpatient rehabilitation.<sup>23,24</sup> Possibly, patients in our study were stressed by their relatives' advices, as they had been patients in the chronic phase of stroke and might very well have received this type of advice ever so often since having suffered their stroke.

Patients and non-professional coaches appreciated self-perceived improvements during and following homeCIMT (e.g. enhanced use of the affected arm and improved activities of daily living). However, in accordance with the results of Gillot et al.,<sup>11</sup> we also found that patients occasionally had hoped to perform even better and were therefore disappointed. Interesting was the fact that, even though professional therapists had been trained to set realistic and achievable goals in homeCIMT together with the patients and non-professional coaches, some patients hoped assiduously for more improvement. Dowswell et al. described that even though stroke patients actually knew that a therapeutic intervention would focus on functional outcomes, they diligently hoped for 'more general changes'. They assumed that this gap might express the difficulty to accept the immense changes following stroke.<sup>29</sup> In addition, homeCIMT itself, being a time-consuming and intensive therapeutic approach, might have triggered increased expectations.

The immobilization of the non-affected hand is a key element of constraint-induced movement therapy. During the interviews, we learned that there were patients who had adjusted well to the glove, even though they felt that using it was unusual and challenging, whereas other patients refused the glove due to feeling insecure. Borch et al.<sup>12</sup> confirmed our findings that immobilization might be a challenge but did not report on insecurities or refusals of the glove. However, they only interviewed three patients and the modified constraint-induced movement therapy took place in a clinical setting with enhanced therapeutic supervision 28 days after stroke. In a laboratory setting, Uswatte et al.<sup>30</sup> compared four different protocols of constraint-induced movement therapies where

immobilization did not make a difference regarding the outcomes. Consequently, future studies on the need for immobilization of the non-affected arm should consider the setting such as the patients' home environment and particularly the caregivers' involvement over the course of the constraint-induced movement therapy.

In addition, our results also underline the importance of well-designed repetitive, task-specific exercises. Morris et al.<sup>5</sup> and Taub<sup>6</sup> also describe that exercises in constraint-induced movement therapy need to be challenging yet always feasible, and Walker and Moore<sup>13</sup> conclude that adhering to meaningful occupations during constraint-induced movement therapy may positively influence motivation and adherence to a challenging treatment protocol. Furthermore, there is also evidence on the importance of task-specific exercises on brain reorganization linked to functional outcomes.<sup>31</sup>

Some limitations of this study need to be acknowledged. First, we only interviewed non-professional coaches who trained with a stroke-affected relative and patients who trained or wished to train with their non-professional coach. However, during the interviews, we heard about non-professional coaches who did not regularly support the daily training and we heard about patients and non-professional coaches who showed a low motivation to train according to the interviewed non-professional coach or patient. Second, our interviewed patients (mean age: 57.3 years, SD: 9.0 years) were of younger age considering that the majority of strokes in Germany occur above the age of 60 years.<sup>32</sup> Both the above-mentioned aspects may influence the generalizability of our findings to other chronic stroke patients and non-professional coaches. Third, our interviews generally took place 248 days after the completion of homeCIMT. Therefore, one should keep in mind that patients' and non-professional coaches' recollections of homeCIMT might have changed over time. Fourth, homeCIMT is a form of constraint-induced movement therapy developed for chronic stroke patients in ambulatory care. The users' perspectives on constraint-induced movement therapies in more acute stages following stroke may be

different and therefore need to be examined in other comprehensive qualitative studies.

Our findings may be helpful for the practical implementation of homeCIMT, particularly regarding adherence. However, we believe that our findings are also valuable for other forms of constraint-induced movement therapies and approaches requiring increased duration and intensity of training and involvement of family members. One finding of our research is that therapists together with the patient and non-professional coach have to decide in advance the best possible time to carry out the therapy and how to provide potential extra support over the intervention period. Regarding the underlying interactive concept of homeCIMT, therapists are advised to actively look for potential strain and burdens resulting from the joint training of the patient and non-professional coach in order to lend additional support, if necessary.

Further recommendations for therapists are the constant clarification of both the patients' and non-professional coaches' expectations and hopes to avoid disappointment over the course of the therapy and the selection of motivating task-specific, challenging and feasible exercises. Regarding immobilization, we recommend therapists to actively ask for the patient's experience with wearing the glove and to allow for adaptations in case of difficulties. In addition, with regard to eligible patients, therapists should consider the patients' and non-professional coaches' motivation as well as mental and physical endurance for undergoing the training process given the intensive, time-consuming and eventually challenging four-week course of home-based training.

Further research should focus on possibilities of how to support patients and family members implementing the therapy in their home environment. Concerning homeCIMT, we seek to provide motivational support with the daily training by providing a specific application software enabling patients to conduct homeCIMT on their own thus allowing them, at least to some extent, to train alone in the absence of a non-professional coach.

### Clinical messages

- Stroke patients and non-professional coaches appreciate self-perceived improvements of the stroke-affected arm, having fun and spending time together during homeCIMT.
- An intensive daily training over a four-week course is feasible but the compatibility with everyday life and strain-causing different views on training performances can be challenging.

### Authors' note

During this study, A.S. was affiliated with the Department of Health Sciences, Faculty of Life Sciences, Hamburg University of Applied Sciences. The idea and implementation of this qualitative study was part of a master thesis. However, the results presented in this article have not yet been published.

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### Author contributions

A.B. initiated the qualitative study. A.S. and A.B. developed the research question. A.S. designed the study, conducted the interviews and predominately performed the qualitative analysis. As part of the analysis, A.B., B.T., C.F. and M.S. regularly discussed the results of the coding process with A.S. to ensure a high-quality analysis. A.S. wrote and revised the first draft of the manuscript, and A.B. contributed significantly to subsequent manuscript revisions. All authors read the final draft of the manuscript and revised it for important intellectual contents.

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