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RESEARCH PAPER

Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine

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Abstract

Purpose: To increase understanding of stroke survivor's needs to successfully re-establish attachment to meaningful places at home and in the community. **Methods:** Qualitative research methodology including in-depth interviews with stroke survivors in the clinical, post-discharge and reintegration phases of the rehabilitation process. **Results:** Participants longed for recovery and domestic places in the clinical phase, for pre-stroke activities and roles in the post-discharge phase, and for recognition and a sense of belonging in the reintegration phase. The participants' selves had changed, while the spatial and social contexts of their homes had remained the same. Their spatial scope became smaller in both a social and a geographical sense. It was difficult to achieve a feeling of being at home in their bodies and own living environments again. The complexities that needed to be dealt with to engage with the outside world, turned participants unintentionally inwards. In particular, family members of participants with cognitive problems, longed for support and recognition in dealing with the changed personality of their spouses. **Conclusions:** Rehabilitation should put greater effort into supporting stroke survivors and their families in home-making and community reintegration processes, and help them to re-own and renegotiate their disabled bodies and changed identities in real life.

Keywords

Continuity of patient care, environment, identity, place attachment, stroke

History

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► Implications for Rehabilitation

- The experienced self-body split, identity confusion and related mourning process should be foregrounded in the post-discharge phase rather than functional recovery, in order to help stroke survivors understand and come to terms with their changed bodies and selves.
- In the post-discharge and reintegration phases stroke survivors should be coached in rebuilding meaningful relations to their bodies, home and communities again.
- This home-making process should start at real-life sites where stroke survivors wish to (inter)act.

Introduction

Most stroke survivors and their families perceive the transition from the rehabilitation clinic to home as an exciting yet difficult period [1]. While “going home” is seen as an important milestone in the rehabilitation process, “being home” is

accompanied by the development of greater self-awareness of deficits. Stroke survivors increasingly come to realize that their pre-discharge expectations of life do not match real-life experiences. Many of them experience a downward spiral of physical decline, social isolation and depression after discharge from the rehabilitation clinic [2–4].

Living with disabilities after a stroke, at home and in the community, needs to be regarded as a lifelong effort [5,6]. To ease this effort, rehabilitation medicine should gain more knowledge about the transition from the able to the disabled self, the role of environments in societal participation, the importance of meaning and choice when thinking about life situations, and the change in abilities across the life course of stroke survivors [7]. Within this context, rehabilitation medicine can learn from the bonds between

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people and places/environments as set out in cultural geography [8,9] and environmental psychology [10].

Addressing the problematic integration of stroke survivors into their own living environments is especially urgent when taking account of demographic changes and related cost-saving incentives in European countries. To relieve pressure on healthcare systems, there is a trend towards transferring multidisciplinary treatment delivered in stroke rehabilitation units to home and community alternatives at an earlier stage [11,12], and encouraging self-management [13]. Several scholars doubt whether primary health care and rehabilitation medicine are sufficiently equipped to adequately support stroke survivors and their families in their own living environments [7,14,15]. Although rehabilitation emphasizes the importance of involvement in real-life situations, its primary focus is on motor learning and functional independence of the disabled body rather than on social learning and societal participation of the disabled self [7,16].

In order to gain insight into stroke survivors' needs at home, we focused on the bonding between stroke survivors and their meaningful places during stroke rehabilitation. Thereby, we used the concepts place attachment and place identity that are described in cultural geography and environmental psychology [17–26]. Place attachment involves the interplay of affect and emotions, knowledge and beliefs, and behaviors and actions in reference to a place [26]. It is the product of both feeling attached to a place and the dynamic process of the appropriation of places involving both the physical and social aspects of them [22,23]. Place identity can be defined as the process by which people portray themselves, through interaction with specific places, in terms of belonging to that particular place [20]. Meaningful places thus become part of who we are and the way we understand ourselves [24].

People develop attachment to places on various spatial scales that are all interrelated, such as body, home and community [22]. The body space has been described by Rich [25] as “the geography the closest in”. It is argued that bodily identities associated with disability or illness are continuously contested or renegotiated by their bearers [18,19]. The home space is conceptualized as a material and affective space shaped by people's everyday practices, lived experiences, social relationships, memories and emotions [17]. At home, people interact daily with its physical aspects, thus creating homely routines which strengthen their attachment to the home place [22]. People are also emotionally tied to the broader community they live in, which typically consists of the immediate neighborhood [22]. Within the community, people interact with place by visiting or avoiding places, both voluntarily and involuntarily [21].

The aim of our transdisciplinary encounter is to increase understanding in the support that stroke survivors and their families need to successfully renegotiate their attachment to meaningful places, first in the rehabilitation clinic and subsequently in their own living environments. By drawing contrasts between the clinical, post-discharge and reintegration phase, with an attentiveness to people–place relationships, we want to gain insight into the role of environments in taking up post-stroke life including patients' and family caregivers' needs and concerns.

Methods

Design

Qualitative research methodology was employed including in-depth interviews. Inspired by empirical philosophical work we used the contrast between different realities – in this study, rehabilitation phases – as a tool to articulate silent layers and issues that deserve concern and care [27–30].

Participants

Stroke survivors with multifaceted problems, who were receiving or had received multidisciplinary treatment in a rehabilitation stroke unit, participated in this study. The characteristics of the participants are summarized in Table 1. All interviewees participated voluntarily in the study and signed a consent form. The Medical Ethical Review Committee of the University Medical Center Groningen exempted this study from being reviewed.

Setting

The stroke unit is located in a Dutch rehabilitation center that accommodates different diagnosis groups in specialized rehabilitation units. Participants were admitted for multidisciplinary treatment to the rehabilitation stroke unit after discharge from acute stroke units in hospitals in the region. All participants received multidisciplinary rehabilitation from the same team, consisting of physiatrists, physical, occupational and speech therapists, nutritionists, psychologists, social workers and nursing staff, all specialized in stroke rehabilitation. Both inpatient and outpatient rehabilitation is offered. At least once during inpatient rehabilitation, stroke survivors are being visited at home by an occupational and/or physical therapist to assess whether returning home will be possible, and what kind of adaptations are needed. Patients are prepared to go home by means of weekend leaves.

Data collection

Data were collected through semi-structured in-depth interviews with 33 stroke survivors. Participants' needs, concerns and relationships with meaningful places were discussed by focusing on three phases in the rehabilitation process: (1) clinical phase, (2) post-discharge phase and (3) reintegration phase. All interviews were conducted at a location that was convenient for the participants, and in the presence of a significant other.

Twenty-four participants, who were in the post-discharge or reintegration phase and had been discharged home between 2005 and 2010, were interviewed once in 2010 or 2011. They were asked to reflect on their experiences in the rehabilitation clinic, discharge home and their current lives at home and in the community. To be able to go deeper into the complicated topic of looking forward and backward to experiences, needs and concerns, it was decided to extend the recruitment with nine participants who were in respectively the clinical and post-discharge phase at time of the interview. The nine participants were interviewed twice in the course of 2011 or 2012, once during inpatient rehabilitation in the clinic and once after being discharged home. In the first interview, they were questioned about their experiences in the clinic and their expectations about going home. In the second interview, they were asked to recount their actual discharge experiences at home and in the community. Overall, the three interview guides covered the same questions. Learning experiences in the first set of interviews in 2010/2011 were used to refine the questions in the second and third set of interviews in 2011/2012. Therefore, inductive interferences were made to open new paths of inquiry.

Data analysis

Interviews were digitally recorded, files were transcribed verbatim and coded using Atlas-ti, a software package for qualitative data analysis. A combination of inductive and deductive coding was applied [31]. Inductive coding involved reading and rereading the material to identify issues raised by the participants themselves. An overarching theme emerged from the initial coding process. Subthemes were subsequently articulated by

Table 1. Participant characteristics.

Pseudonym	Age (years)	Stroke	Effects of stroke	Marital status/ children (living at home)	Moved	Work status	Interview during clinical stay (months)	Interview after discharge (months)
John	57	Ischemic stroke left	Motor and cognitive problems	Single/2 (1)	Yes (a)	Incapacitated	–	3
Paul	50	Ischemic stroke left	Motor problems	Single/2	No	Working	–	15
Jim	66	Ischemic stroke left	Motor and behavioural problems	Married/2	No	Pensioner	–	14
Simon	58	Ischemic stroke left	Motor, behavioural, mood and swallowing problems	Single/2	Yes (a)	Incapacitated	–	48
Mary	41	Ischemic stroke right	Motor, cognitive and mood problems	Single/–	Yes (b)	Working	–	19
Tom	60	Ischemic stroke right	Motor, cognitive and speech problems	Married/2	No	Incapacitated	–	41
Caren	60	Ischemic stroke right	Motor and cognitive problems	Single/–	No	Partly incapacitated	–	20
Sam	40	Hemorrhagic stroke right	Cognitive, mood, speech and sight problems and epilepsy	Cohabiting/1 (1)	No	Partly incapacitated, partly sickness benefit	–	20
Nina	47	Hemorrhagic stroke left	Motor, cognitive, and sight problems	Married/2 (1)	No	Incapacitated	–	15
Violet	42	Hemorrhagic stroke left	Motor and cognitive problems	Cohabiting/2 (2)	No	Incapacitated	–	11
James	58	Ischemic stroke right	Cognitive and behavioural problems	Married/2 (2)	No	Sickness	–	3.5
Victor	71	Ischemic stroke left	Motor and speech problems	Married/2	No	Pensioner	–	16
Rose	53	Hemorrhagic stroke right	Motor and cognitive problems	Married/2 (2)	No	Incapacitated	–	29
Laura	49	Hemorrhagic stroke left	Motor and cognitive problems	Married/–	No	Sickness benefit	–	18
Steven	49	Ischemic stroke right	Motor and cognitive problems	Married/1 (1)	No	Sickness benefit	–	29
Ben	31	Ischemic stroke left	Motor and cognitive problems	Cohabiting/–	Yes (a)	Unemployed	–	32
Marc	68	Ischemic stroke right	Motor and speech problems	Married/2	No	Pensioner	–	67
Daniel	81	Ischemic stroke left	Motor problems	Single/2	Yes (a)	Pensioner	–	37
Joan	64	Hemorrhagic stroke left	Motor and cognitive problems	Single/–	No (c)	Incapacitated	–	67
Sarah	67	Hemorrhagic stroke right	Motor, cognitive, behav- ioural and speech problems	Married/2	Yes (a)	Pensioner	–	46
Bob	63	Hemorrhagic stroke right	Cognitive and behavioural problems	Married/1	No	Sickness benefit	–	31
Isa	48	Ischemic stroke right	Motor and cognitive problems	Single/–	Yes (a)	Incapacitated	–	72
Linda	72	Ischemic stroke right	Motor and behavioural problems	Single/2 (1)	No	Unemployed	–	57
Mike	69	Ischemic stroke right	Motor and behavioural problems	Married/6	No	Pensioner	–	8
Kate	61	Ischemic stroke right	Motor problems	Married/5 (1)	No	Unemployed	1.5	6
Regina	55	Ischemic stroke right	Motor and cognitive problems	Widow/2	Yes (a)	Unemployed	3	5
Henry	69	Ischemic stroke right	Motor problems	Married/1	No	Pensioner	1	3
Ron	63	Ischemic stroke right	Motor and cognitive problems	Married/–	No	Pensioner	1	1
Molly	46	Ischemic stroke left	Motor and cognitive problems	Married/1 (1)	No	Sickness benefit	1	1
Howard	51	Ischemic stroke left	Motor, cognitive, speech and sight problems	LAT relationship/1	No	Unemployed	2	3.5

(continued)

Table 1. Continued

Pseudonym	Age (years)	Stroke	Effects of stroke	Marital status/ children (living at home)	Moved	Work status	Interview during clinical stay (months)	Interview after discharge (months)
Roy	66	Ischemic stroke left	Cognitive problems	Single/–	No	Pensioner	1	4
Peter	46	Ischemic stroke left	Motor and behavioural problems	Married/2 (2)	Yes (d)	Sickness benefit	1	3
Raymond	68	Ischemic stroke right	Motor problems	Married/2	No	Pensioner	1	4

Moved: (a) ground floor apartment, (b) house in a quiet district of a city, (c) assisted living home, (d) terraced house in a city

drawing contrasts between the empirical material collected in respectively the reintegration, post-discharge and clinical phases of the rehabilitation process. In other words, data analysis progressed by pinpointing differences and similarities in inductively coded needs and concerns of participants in the distinguished phases. The subthemes that emerged from the coded material in each phase were subsequently refined by deductive coding derived from literature: i.e. by focusing on the three spatial scales – body, home and community – on which meaningful relationships with places were developed. Coding and analysis were carried out by the first and second author and reflected on by the last author.

Results

The overarching theme “longing for” emerged from the empirical material, and three different sub-themes were identified by contrasting the three phases that participants went through: (1) clinical phase: longing for bodily recovery and domestic places; (2) post-discharge phase: longing for pre-stroke activities and roles; (3) reintegration phase: longing for recognition and a new sense of belonging. The three sub-themes were further articulated on the spatial scales of the body, home and community (Table 2).

Clinical phase: longing for bodily recovery and domestic places

Attachment to the home place is abruptly disrupted in the acute stage, when stroke patients are transferred to a hospital for medical care, and after that to a rehabilitation clinic for multidisciplinary treatment.

Body

Having survived the stroke, most participants experienced a sudden loss of control over parts of their body. Kate, for example, initially perceived the paralyzed left side of her body as useless and unpredictable. Through practice, she could gradually move her left side again, which gave her confidence that her body would recover:

Kate: If you can't do anything, what use is your body? . . . You can't lift your hand, you can't move your fingers. . . . I could see a hand moving, I thought good grief, that's my hand. That was scary. Your brain sends a signal to your fingers and you still can't move them. . . . Very gradually the movement came back, and you really begin to practice . . . and suddenly you think, it'll be OK again.

Henry, who was also left hemiplegic, experienced his body as dependent on others, but expected that training would give him back his independence.

Henry: You have the feeling that you can't do anything anymore . . . There were three other people who were allowed to walk with a rollator or go to the toilet by themselves. I always had to ring the bell . . . I used to think, I wish I'd come far enough to manage by myself again . . . They expect things to get better, with support and training here. You know you're not there yet. . . . You're away for a couple of months, but you soon catch up again once you're home.

Most participants spoke about their disabled body as if the disability was temporary. It would take some time, but if they trained hard enough, they would go home and resume the life they lived before the stroke. They saw the training in the clinic as a necessary step towards regaining control over their bodies, and therefore appreciated the safe environment that the clinic provided:

Howard: It's like a paradise. . . . They're always ready to help if you have problems, they'll do anything for you . . . You get help from all sides.

Some participants perceived the professional supervision as overprotective. They felt they had not only lost control over their body but also the power to make their own decisions. They expressed their relationship with the professionals in terms of guardianship rather than partnership:

Raymond: They want me to use a wheelchair because there isn't supervision everywhere in the building. If I fall, they want to be nearby. They don't want to take any risks. The nurses walk around at night, there's always someone keeping an eye on you – for example, to make sure you're not lying on your affected arm.

During inpatient rehabilitation, our participants thus perceived their bodies as useless, scary, unpredictable or dependent and longed for bodily recovery. This focus on recovery allowed them to put their longing for home on the back burner.

Home

Participants described the transition from home to the hospital and rehabilitation clinic as a process of being torn away from their familiar everyday environment:

Kate: You're perfectly alright one day, and the next you're in hospital. Two weeks after that you're in a rehabilitation center. You're just snatched away from home, with a handicap. That's just how it feels.

Leaving home for the clinic so abruptly was nevertheless perceived as vital; they had no choice, since the necessary

medical care and multidisciplinary treatment could not be provided at home. Family members visited participants, bringing personal belongings and the closeness of family life with them to the clinic, which created a feeling of being at home in the clinic:

Regina: I've brought photos from home so that I'm surrounded by the people who are important to me... And I've brought my pillow from home so that I can sleep comfortably.

Nevertheless, our participants had difficulties in adjusting to the institutional setting. Compared to life at home, they had to adhere to a relatively strict timetable in the clinic, in order to enable the professionals to work efficiently. The examples reported were getting up early, dressing and eating at a certain time, having fixed appointments for therapy and receiving visitors during predetermined time periods:

Molly: I could always do as I pleased, but not anymore. You really have to keep to the rules here.

Some participants, however, liked the structure of the daily routines offered by the rehabilitation team, as it stimulated them to work on recovery:

Peter: What I mean by that is doing set things at set times. The whole day is planned out for you... Given my limitations and tiredness at the moment, if that wasn't the case I'd just be sitting at home.

Participants also attempted to create private places in the public space of the rehabilitation clinic, to retreat to a place where other people would not disturb them.

Regina: At night I have my tent. I close the curtains completely so that it's really private... my own space... I look forward to escaping, then I can just be myself again and do as I please.

Although our participants longed for domestic and private life at home, most of them were able to find a balance between their longing for home and working on bodily recovery by creating home-like places within the rehabilitation clinic.

Community

To create a sense of community, participants sought ways to interact with other people in the clinic. Participants met up with fellow patients in the dining room, corridors or waiting rooms, and chatted with each other, as neighbors might on the street or in the supermarket. Howard had chosen the couch near the coffee machine as his favorite spot.

Howard: We meet up there in the evening, have a chat. Make a few jokes, that's the best thing. And the room, of course. Quietly watching TV on the bed in the evening. Then one person asks something, then someone else.

In a certain way the rehabilitation clinic resembled a neighborhood in a village or town, as wards join onto corridors which lead to central halls, which in turn link departments and different therapy spaces, just like houses join onto streets leading to squares that link different areas and public spaces. Yet the clinical environment was adapted to the patients' disabilities, and the multidisciplinary team determined, in consultation with the patients, when it was safe for them to move in (or to) a particular part of the clinic, with what kind of aid. Some participants

objected to the spatial restrictions, which they experienced as being imposed on them by the staff:

Regina: When I leave the ward, I actually wander all over the building... Wherever I need to be, I go everywhere... "We've been looking for you". I say to them, Well, I'm in the building aren't I?... I don't go outside much. I don't like going out in the wheelchair at the moment, it feels too unsteady.

Most participants told us that there was no reason to wander around or go outdoors because everything they needed was provided and available inside the clinic. They accepted and appreciated the safe and temporarily restricted environment of the clinic, for they believed it would soon be replaced by something better and permanent: independent and able body acting willingly in familiar home and community settings. That is indeed what they longed for.

Post-discharge phase: longing for pre-stroke activities and roles

After being discharged home, most of the participants still attended the clinic for outpatient multidisciplinary treatment 2–3 times a week for a couple of months. The ties with the clinic are gradually undone in the post-discharge phase.

Body

When at home after being discharged, most of our participants felt ill-prepared for the transition from the clinic to home. Although they were happy to be home again, their body was not as fully recovered as they had hoped. Taking up their pre-stroke roles and activities was experienced as confronting.

Kate: Then I want to do this, and do that... And I want to get it done the same day and I don't manage it. That really drives me mad.

Our participants explained how they needed all their energy to perform daily activities that they used to do pre-stroke without even thinking.

Peter: Before the stroke I didn't have to think about what I was doing, I just did it. Your routine, day-to-day things, getting up, drinking coffee, having breakfast, shaving, cleaning your teeth, having a shower. Now I really have to think about those things while I'm doing them. I need to be very aware of how I use that right arm.

Some participants spoke about their hemiplegic body as something foreign. Kate, for example, tended to objectify her sore hemiplegic arm by speaking about it as a thing alien to her.

Kate: It's not the fact that I can't do anything with it, but the fact that it's sore... Sometimes I wake up in the middle of the night because it's so sore... It's just so irritating that the wretched thing won't work.

Other participants felt frustrated because their bodily impairments were not always visible to significant others. Take Henry, who found it difficult to explain to other people how his problem of dizziness restricted his abilities.

Henry: When people break an arm or leg, you can see that something's wrong. But you can't tell by looking at me that there's anything wrong. It's in your head, isn't it. They think you've recovered from it, but that isn't the case.

These experiences with bodies that remained out of control, unresponsive and sore had a negative effect on the participants' state of mind and some became depressed.

Regina: That aimless life, I couldn't cope with the idea of having to carry on with half my body paralysed. . . . I really thought, if that's how I've got to live, then I don't want to carry on.

Only a few participants reported that getting on with life again in the post-discharge phase was as they had expected. Most participants however began to realize in this phase that the brain damage caused by the stroke had not only affected their bodies physically but had also affected them mentally, which took a great deal of their energy and drained their vitality.

Home

In spite of their disappointing bodies, most patients enjoyed being in their own living environment again, and felt that being there would enable further bodily recovery.

Henry: You're in your own space here, your own bed, your own things and people who live here. Then you feel at home again. And then you start to think, things are getting better, I'll soon be able to do this or that again . . .

However, being at home also reminded them of their former healthy selves and the activities they used to do, which made them long for recovery even more strongly.

Roy: Last summer I was repainting the house. That all had to be left. And the allotment; they've just put some potatoes in there. This year wasn't the same as normal. I'll pick up where I left off once the therapy's finished.

Although some participants continued to believe that everything would go "back to normal" in due course, others began to realize in the post-discharge phase that their life would never be the same again, and this hit them hard.

Regina: Now you're dependent on any form of help you can get. Before the stroke, I used to do everything myself. Then I could still use both hands. There was the housework, I had my own flat. I did the shopping myself, I did everything myself. . . . The children would call in: 'Mum, my trousers need mending, can you do it for me?' If the children needed looking after, Mum did it. But that's all finished now, I can't manage it anymore.

People who were surrounded by their family experienced fewer difficulties with life back home than single people. Nevertheless, most of our participants did not manage to feel at home in the way they had before the stroke, and experienced difficulties with taking up pre-stroke roles. Kate, for example, tried to take up her previous role of "mother-in-charge" without a second thought.

Kate: You think, I'll just start doing that again. But you can't. You're mothered on all sides. . . . You think, yes but I'm only paralysed. . . . They thought there was something wrong 'upstairs' as well, but that's still all OK. How you react yourself, but also how others react. They were so terribly careful and considerate, it was nauseating. That really took some getting used to, because before the stroke, I was the boss and that was that.

In the clinic, stroke patients had put their fate in the hands of the professionals, thereby working on recovery in a place which was unfamiliar but adapted for their disabled body. In contrast, in the post-discharge period, they had to take up responsibility for their own life and their not yet fully recovered body, in a space that looked familiar but needed to be adapted to their disabled body, as well as engage in renegotiation with their proxies. Reshaping life at home was experienced as very difficult by most participants, and taking up a meaningful community life proved to be even harder still.

Community

During the post-discharge phase most participants spent their days at home rather than in the wider community, because home was exhausting enough. As a result of the physical limitations, arranging activities in the outside world was indeed time-consuming, and emotional barriers or lack of energy prevented participants from taking part in community life.

Peter: Actually only one thing has changed, and that's the fact that I'm not back at work yet. The children still have to go to school, so we go out, have coffee somewhere. But shaving, showering, you name it, the everyday things. That's all so tiring that I don't feel like doing anything else for the rest of the day.

Also, limited transport or not being allowed to drive a car restricted them to indoor activities. In some cases, these mobility barriers could be lifted, as with Howard, who was able to extend his activities outdoors once he had his mobility scooter.

Howard: I have my freedom back again now. I take part in fishing competitions and in the afternoon I go and visit my mates on the scooter. I feel like doing things again.

Other participants had to get used to a new community as they were forced to move house. Most of them experienced difficulty with creating a sense of attachment to their new community. Take Regina, who, although she had several lessons on driving her mobility scooter, felt out of place in her new environment and did not dare to actually use it there.

Regina: It's just that, I don't know this area at all. And I've never been in a shop with a mobility scooter. So you can go and sit on your mobility scooter with your crazy head, and then what?

In the post-discharge phase, it seems that for most participants it is too premature to expect community integration and societal participation. Rather, they need all their energy to come to terms with bodily changes and to recreate a sense of belonging in their own homes. These tasks are demanding enough, and in many cases there is no "room" left for the community. The tiring bodily experiences at home appeared to be an early indicator of the difficulties people would have engaging with the wider community around them. Although our participants longed to take up pre-stroke activities and roles, they began to realize their lives would never be the same again. That troubled them.

Reintegration phase: longing for recognition and a new sense of belonging

The ties with the clinic were severed in the chronic stage. Some participants succeeded in reintegrating into the community to a certain extent, but most experienced huge problems when they became aware that no further recovery could be expected.

Body

When discussing their bodily experiences in the reintegration phase, some participants reported that their bodily recovery had not just stopped but had even declined.

Mary: Your body's already giving you trouble. That's already a hindrance, because of the cramps. But if that goes on for too long and you don't move around enough, you stiffen up even more. After a while I couldn't even reach my own feet.

Participants sometimes did not want to venture outdoors as they felt embarrassed about the visible changes in their appearance:

Rose: I don't like other people seeing me, so I tend not to go out. I always think I look terrible, although other people say that's not the case.

The most distressing bodily experiences, however, were articulated in terms of bodily estrangement due to the more invisible cognitive and behavioral impairments, which made participants feel that they were no longer in charge of either their physical body or mental body. These participants had to deal with a changed self:

Steven: I no longer feel at home in my own body. I was a bricklayer, always out working and hardly ever at home. And now it's the other way around... My concentration isn't as good, and I'm not physically well either... I have changed. Especially, with talking. And everything makes me laugh.

Most participants had expected that their physically impaired bodies would be back to normal in the post-discharge phase, but discovered in the reintegration phase that this was not feasible. Some had accepted this and were able to re-define and re-own their changed body and related self over time. Others continued to struggle, or retreated to a few "safe" places. They all longed for recognition of the physical, cognitive or behavioral problems they had to face.

Home

When living at home again, many participants described the clinic in retrospect as "safe, surrounded by professionals and fellow sufferers", "conveniently arranged", "cosy", "a second home" and described their actual home place as "demanding", "worrying", "silent" and even "a black hole". Several participants preferred to restrict their living space to a few areas inside the home, like Caren, who recreated a safer and more homely place on the smaller spatial scale of her bed.

Caren: I go to bed as early as six in the evening, because it's safe there. That's where I feel most comfortable, I can move around in bed. Normally I just stumble around a bit the whole day.

Participants who were dependent on professionals to help them into and out of a wheelchair found themselves restricted in privacy and domestic life, as their daily routines were determined by formal care schedules.

Joan: I always need someone to help me get up in the morning, and to go to bed at night. If there's a film on, and someone comes in after ten o'clock, I have to go to bed. Then I miss most of the film... I used to go to bed around eleven thirty. Now I sometimes have to go upstairs as early as nine o'clock.

With regard to their social place identities, several participants explained that they found it difficult to interact with

significant others. Mary, for example, spoke of a "short circuit" in her head.

Mary: I can't see the bigger picture. Everything gets too much for me. I can't keep my attention on things at all: snappy, you know, when people come up to you and you say "not now!"... That you can't tell by looking that there's something wrong, that you have to live a very structured life now, that people can't just call in... that it's all too much and you're so tired all the time. You come up against that constantly. It's so frustrating.

Many other participants discussed their changed bodies and selves in the context of altered relationships with family members and friends, and had difficulties re-establishing their place identity. Steven, for example, seemed to have accepted that his post-stroke life was in no way comparable to his pre-stroke life, but his wife doubted this:

Steven: It's OK, enough hobbies, such as cleaning. It's hard work though, vacuuming upstairs and downstairs. I do get tired doing that.

Steven's wife: It actually feels very odd that this is enough for someone who was used to working 50 or 60 hours a week.

Many partners of stroke survivors with cognitive and behavioral problems felt alone and also experienced huge difficulties in getting on with life again. Tom's wife, for example, had to manage with a husband who had entirely changed:

Tom's wife: He doesn't know when things need doing, and he can't think what he has to do next... He always needs to be directed, even the simplest things... He can manage fine, as long as I'm nearby. But there's no way he could manage on his own... You've lost each other. The person who comes home to you is someone completely different. Your whole life has been turned upside-down, that's the best way to describe it.

In the reintegration phase, most participants struggled to give meaning to their place identities in relation to their home. Feeling at home, with other household members as well as visitors, was often described as difficult to achieve. The participants' selves had changed, while the spatial and social contexts of their homes had remained the same, which often resulted in an inconsistency between the two, and turned our participants unintentionally inwards. In particular, the family members of participants with cognitive, communication or behavioral problems longed for support and recognition in dealing with the changed personality of their spouses, and in re-defining their life and relationship.

Community

Many participants found it difficult to engage in meaningful interaction in the community. They longed to create a sense of continuity between their pre- and post-stroke lives by engaging in similar activities, but this was not always possible. Some missed their pre-stroke community life deeply. Mary, for example, had dramatically rescheduled her socially active and entertaining pre-stroke life:

Mary: I had a job and I was someone who wanted to build a career. When I got home I'd do the shopping, have a meal. Give the house a quick once-over, then go to the gym. And at the weekend I often went away with friends. I had a very busy social life. There's nothing left of that at all now. The world has become very small. Actually, I'm more or less confined to the house now.

And, Tom, who was always on the move pre-stroke, was now dependent on his wife to go out:

Tom: Before, I had a lot of freedom. For my work I'd run an errand here, an errand there, arrange this, arrange that. I was always there, but that's not possible now. I forget everything and I can't remember where the house is.

Others explained how they were able to develop new community activities, often with the help of significant others. Family members or friends played a major role in involving participants in the community, and made it possible to visit meaningful places:

Steven's partner: We've still got the caravan on Ameland. We really enjoy it. He never used to like going there, but now he thinks it's fantastic. It's ideal now, because he manages really well in the caravan and I have some time to myself, simply to finish a book or something. I really enjoy that. He can go for a walk, we have plenty of help there so everything works out well, that's really good.

Similarly, travelling through Europe with a motor-home made the lives of Charles and his wife pleasantly challenging again. They created a new sense of liberty and belonging in the world, despite Charles' communication problems and physical limitations:

Charles' wife: In the summer we go away with the motor-home. If it goes well we don't come back until September. We tour around Europe. Often we don't have breakfast until 11 o'clock. If the weather's too hot or too cold, we move on somewhere else. If the weather's good enough we explore the local area, go shopping. He connects up the electricity supply for the motor-home, makes sure we have enough water and that the toilet is emptied. He does all that... We put the mobility scooter on the back of the motor-home and I do the driving.

The empathy, understanding and creativity of significant others enabled some of our participants to re-own their post-stroke bodies and changed selves within various home and community places, where they experienced a new sense of belonging. For many others, however, their body, home and living spaces became smaller in both a social and geographical sense. Often this was caused by misunderstanding or lack of recognition of their changed selves by significant others, such as family members, friends, colleagues and professionals, and in some cases by the participants themselves. These experiences prevented them from

renewing their sense of attachment to various spatial places, and kept them longing for the unachievable.

Discussion

In this transdisciplinary encounter, the focus on place attachment in stroke rehabilitation assisted us in gaining a better understanding of people–place relationships between the different rehabilitation phases our participants went through. To some extent the attentiveness to people–place relationships may have predisposed the nature of the data arising from the interviews. Though by inductive coding (noting unique issues raised by participants) and drawing contrasts between the different phases in the rehabilitation process, subthemes relevant for the different phases emerged rather open-minded from the empirical material. Ideally, a study has a mix of inductive and deductive codes [31]. This was the case in our study, as we subsequently organized the empirical material by deductive codes that came from place attachment literature; namely, the three spatial scales body, home and community [22].

Our study revealed that most participants longed for *physical recovery and domestic places* in the clinical phase, for *pre-stroke activities and roles* in the post-discharge phase and for *recognition and a sense of belonging* in the reintegration phase. Although their sense of longing was strong in each phase, they often discovered that what they longed for was difficult if not impossible to achieve. During inpatient rehabilitation, they were supported by the multidisciplinary team in optimizing bodily recovery and independent living in safe and appropriately adapted places in the clinic. This created a sense of temporarily belonging in the clinic on the one hand, and a rather carefree and unrealistic longing to return to unchanged domestic places post-discharge, on the other. To various degrees, both the stroke survivors and the multidisciplinary team appeared to be inattentive to the complexities that need to be dealt with within the outside world after inpatient rehabilitation.

Although, we acknowledge that this lack of attentiveness to the outside world is necessary in order to focus on the best possible functional recovery and independence in the clinical phase, we argue that the complexities of life post-discharge need serious attention and definitely another focus in the reintegration phase. Our study confirmed the importance of meaning and choice in the post-discharge and reintegration phase [7]. Attempting to independently undertake as many activities as possible in the post-discharge and reintegration phases may overburden stroke survivors, and even eventually exhaust them such that they lose their independence altogether. Indeed, it should be acknowledged

Table 2. Overview of experiences and needs of stroke survivors during the rehabilitation process.

Theme	Clinical phase	Post-discharge phase	Reintegration phase
<i>Longing for</i>	<i>Bodily recovery and domestic places</i>	<i>Pre-stroke activities and roles</i>	<i>Recognition and new sense of belonging</i>
Body	An impaired and dependent body	A disappointing physical and mental body	A redefined body and related changed self
Home	Temporary belonging to an unfamiliar place (clinic) adapted to an impaired and dependent body	Permanent being at a place that looked familiar but needed to be renegotiated and adapted to a not fully recovered body	Sense of belonging at familiar but often limited home spaces with a re-owned body
	Daily routines are scheduled	Daily routines are time- and energy-consuming	Daily routines are demanding
	Family members: role of visitors	Family members: role of informal carers	Family members: altered relationships
	Balance between longing for home and working on recovery	Discrepancy between actual being at home and remembered feeling at home	Inconsistency between changed identities and social contexts of the home
Community	Indoors, rather safe and untroublesome	Outdoors, rather unsafe and troublesome	Outdoors, rather pondering, and in few cases challenging
	Surrounded by skilled professionals and aware fellow patients	Exposed to unskilled and unaware people	Build up and facilitated by significant others

that they can choose to be dependent or independent in daily life in various ways [15]. On one day, they may choose to dress and wash themselves, while on another day, it may be better to ask for assistance with such self-care to be able to work or visit friends. Professionals should therefore help stroke survivors and their family caregivers in seeking to establish and secure a few forms of independence, carefully adjusted to the places they would like to be.

A limitation that needs to be addressed in future studies has to do with the exploratory and cyclic nature of our study. We discovered in the first set of interviews with participants in the reintegration phase that many of them glorified their stay in the rehabilitation centre in retrospect. To gain more in-depth information about this topic, we broadened the recruitment by also interviewing stroke survivors in the clinical and post-discharge phase. To tackle this complicated topic of looking backward and forward to needs, concerns and experiences as well as looking at the present situation, it would have been better to interview the same participants in all three rehabilitation phases.

Despite these limitations, our case study illustrates the interwoven nature of the concepts of place attachment and identity, showing how a sudden change in identity, due to the abrupt onset of a stroke, can disturb a person's attachment to place, both as an outcome and a process [26]. After their stroke, our participants could not identify with their own bodies, homes or communities as they had before. The physical and cognitive changes they had undergone disturbed their attachment to place, as an outcome of the stroke. At the same time, the process of re-establishing meaningful relationships with places proved to be difficult for our participants in all three phases of the rehabilitation process. They continually struggled with challenges, such as unrealistic expectations held by themselves and significant others, unexpected complexities in daily life, and different feelings of longing. These difficulties might be due to the nature of the target group that was our object of study: severely affected stroke patients with multifaceted problems, who had received multidisciplinary treatment in a rehabilitation stroke unit. However, other studies have described similar problems in a sample of stroke survivors aged between 20 and 61, who probably had less severe disabilities [32].

On the smallest distinguished scale – the body – our participants struggled to (re)create a sense of familiarity with their disabled bodies, especially in the context of the unrealistic longings they kept alive. They experienced the transition from being able to disabled [7] as no longer feeling at home in their own bodies. This alienation has been expressed as living with an altered identity or perception of self [33–35], or a self-body split [36]. It is this self-body split, identity confusion and the related mourning process that should be foregrounded in the post-discharge phase by the rehabilitation team, in order to help stroke survivors and their families understand and come to terms with their changed bodies and selves. This is important because many problems are not only invisible to significant others, but are also difficult for stroke survivors themselves to understand. A “coming out” process needs to be facilitated to re-experience a sense of belonging to meaningful places at home and in the community.

On the spatial scale of the home, our participants longed to return to the privacy of homely routines and close relatives while they were still in the clinic. However, *being* at home in the discharge phase did not spontaneously result in actually *feeling* at home again. As their bodies had been transformed, their former home often no longer evoked the expected feelings of comfort, privacy, intimacy, security, autonomy and safety [37]. Our participants discovered a discrepancy between the actual and remembered home. Private places had to be redefined and pre-

stroke roles and domestic activities had to be contested and renegotiated, which was experienced as extremely fatiguing by both stroke survivors and their families. Participants experienced difficulty with redefining relationships in meaningful ways, which for some participants turned their previously comfortable and secure home into a place of loneliness, decline and despair. In a phenomenological study, similar experiences were described in terms of “struggling to re-enter the family” and “screaming for acceptance” [32]. Rehabilitation should therefore put much more effort into supporting stroke survivors in the home-making process and help them contest and renegotiate their disabled or ill identities in the bodily geographies of everyday life [38]. This could be achieved by enacting the home-making process at real-life places where stroke survivors wish to act and interact, and by assisting in adapting the physical environment as well as in taking up former roles and engaging in former or new activities. Moreover, the home-making process at real-life sites could be continued by coaching over distance with screen-to-screen applications.

Functioning on the scale of the neighborhood or the wider community was the most challenging aspect for our participants [39]. In the clinic, community life was mostly indoors, scheduled, and therefore manageable. Upon returning home, our participants focused on feeling at home in their own bodies and homes again. Our study indicates that stroke survivors first have to learn to assess their abilities and limitations in, and re-establish their belonging to, a rather complex indoor home world and only then can they take up the challenge of dealing with the elusive complexities of the outside world and re-establish a sense of belonging to the community. In a few successful cases, family members or friends facilitated active involvement in community life, by engaging stroke survivors in new activities and helping them to escape from the drudgery of daily life and isolation at home, for example in new travel destinations and or new places of recreation [40,41]. However, stroke survivors and their families could be supported and coached in this in a more structured and professional way. It is a challenge for rehabilitation centers to learn how to assist stroke survivors post-discharge in rebuilding meaningful relationships with their bodies, homes and communities.

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Declaration of interest

The authors report no conflicts of interest.

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