

Experiences of stroke patients

A qualitative study about the expectations and experiences of stroke patients in The Netherlands

Jelle Straatsma

s1778587

straatsmajelle@hotmail.com

Supervisor: Louise Meijering

Master Population Studies

Population Research Centre Groningen

25-09-2012, Groningen

I. Acknowledgements

First of all, I would like to thank my supervisor Louise Meijering and my gatekeeper Christa Nanninga because this thesis could not have been made without their help. Louise Meijering was always ready to help and even though I was not always on time with my deadlines she was very optimistic. Because of Christa Nanninga I was able to go to the rehabilitation clinic and find the participants for this study, without her this would not have been possible.

I would also like to thank the staff in the rehabilitation clinic, they always wanted to help if I could not find something or someone. And of course I would like to thank the participants who allowed me to interview them. They were very open and even let me into their home to interview them a second time. Even though they went through a very difficult time they helped me and shared their feelings and experiences.

I would also like to thank my mother, she went through a similar process as the participants in this study and because of her I got interested in the topic.

II. Abstract

Objective. The objective of this thesis is to explore what stroke patients in a rehabilitation clinic expect from being home after leaving the rehabilitation clinic and what they experience when they are at home afterwards.

Place attachment. The concept of place attachment is used in this thesis to understand how participants felt connected to the rehabilitation clinic and their homes.

Research design. It is an exploratory research. Ten stroke patients were interviewed at a rehabilitation clinic about their experiences and expectations. When these participants were dismissed from the rehabilitation clinic and were home, nine of the ten participants were interviewed a second time about their experiences at home.

Results. The relationships with other patients in the rehabilitation clinic was important for the participants, they felt supported by each other.

Most participants had positive expectations about going home, but when they were home they noticed they still had troubles with fatigue and mobility.

Relationships changed for some participants because of the stroke. Some participants felt left alone and this had a big impact on their lives.

Some participants felt a strong attachment to the rehabilitation clinic, even when they had already left.

Conclusion. Expectations differed from the experiences that the participants had at home. Some participants expected almost full recovery while others were not that optimistic. But the participants experienced more problems than they expected when they were at home.

Keywords. Stroke patients, place attachment, experiences, expectations, comparison

III. Table of contents

- 1. Background, objective and research questions 6
 - 1.1 Background..... 6
 - 1.2 Objective and research questions 6
- 2. Theoretical framework..... 7
 - 2.1 Place attachment..... 7
 - 2.2 Literature review 8
 - 2.3 Conceptual Model 10
- 3. Research Design 11
 - 3.1 Type of research 11
 - 3.2 Methods of data collection 11
 - 3.3 Operationalization..... 12
 - 3.3 Participant recruitment 13
 - 3.4 Ethical considerations 15
 - 3.5 Positionality 15
 - 3.6 Data analyses and quality..... 16
- 4. Results 17
 - 4.1 Experiences in the rehabilitation clinic 17
 - 4.1.1 Schedule 17
 - 4.1.2 Therapies 18
 - 4.1.3 Places..... 19
 - 4.1.4 Relationships 21
 - 4.1.5 Information..... 22
 - 4.2 Expectations 24
 - 4.2.1 Daily schedule..... 24
 - 4.2.2 Mobility 25
 - 4.2.3 Relationships 26
 - 4.3 Experiences at home 28
 - 4.3.1 Mobility and fatigue 28
 - 4.3.2 Moving..... 29
 - 4.3.3 Transition from the rehabilitation clinic to day therapy 31

4.3.4 Relationships	32
4.4 Comparison	34
4.4.1 Daily schedule and rehabilitation process	34
4.4.2 Moving.....	36
4.4.3 Relationships	36
5. Discussion	38
6. Conclusion	40
7. References.....	43
8. Appendices	46
8.1 First interview guide.....	46
8.2 Second interview guide	52
8.3 Code tree.....	56

1. Background, objective and research questions

1.1 Background

The Netherlands are aging. In 2011 approximately 2,6 million people were aged 65 years and older. It is estimated that this figure will increase to approximately 4,5 million in 2050 (Statistics Netherlands, 2011). Elderly have a higher chance to get strokes than younger people. A stroke is more often disabling than fatal and rehabilitating from a stroke is very time consuming and therefore very expensive (Mazza et al., 2001). In an older population more people will get strokes and more people will become patients at rehabilitation clinics.

A major step in the aftermath of a stroke for the patient is returning home from the rehabilitation clinic. Therefore it is important to research how stroke patients experience being home after rehabilitating in a rehabilitation clinic and what the problems associated with returning home and being home are. It is also interesting to know what expectations patients have about going home, and the difference with the experiences when they are home. These expectations could influence their experience and by comparing the expectations and experiences differences between them can be found.

1.2 Objective and research questions

The objective of this research is to explore what stroke patients in a rehabilitation clinic expect from being home after leaving the rehabilitation clinic and what they experience when they are at home afterwards.

Main research question:

How do the expectations stroke patients have about home after leaving the rehabilitation clinic compare to the experiences when these stroke patients are home?

Sub-questions:

What are the experiences of stroke patients when they are in a rehabilitation clinic?

What do stroke patients expect being home will be like?

In what way are the expectations of stroke patients affected by the information they have received?

In what way are the expectations of stroke patients affected by the rehabilitation process?

What are the experiences stroke patients have when they are at home after leaving the rehabilitation clinic?

What is the difference between the expectations that stroke patients have about home and the experiences they have when they are at home?

2. Theoretical framework

This chapter contains the theoretical framework for this thesis. First, the concept of place attachment is discussed. Then the relevant literature is examined. Finally the conceptual model is explained.

2.1 Place attachment

Almost all people have places that they are attached to. A person has a special bond or connection with this place, and this makes it more important for him or her than for other people, who do not have this special bond. Places like this could be where someone is born, where someone is living now or where someone had an event or experience that is important for this person, such as the place where a person met his or her partner for the first time. People can get attached to places like this (Relph, 1976).

The process of emotionally bonding with a place is the most important concept of place attachment. These bonds can be formed because of the people who are there living in this place, for example relatives and neighbours. A place a person can be attached to could be a house, but also to an entire neighbourhood. People can also feel attached to places on a smaller scale, for example a certain room or a certain chair. Not only the social aspect of a place is important in place attachment. Also the physical quality of a place is important (Fried, 2000; Chow and Healey, 2008). Because of the connection a person has the desire to maintain close to the place. (Higaldo and Hernández, 2001)

A difficulty with the concept of place attachment is that scientists are not clear about this concept. According to Pretty (2003) and Higaldo and Hernández (2001) different concepts such as place identity, place attachment and sense of community all overlap. However, recently Scannell and Gifford (2010) have organized the different definitions of place attachment and created a three-dimensional framework. The three dimensions related to place attachment are the person, the place and the process. Scannell and Gifford correctly state that attachment can occur for both an individual or a group. However, in this thesis the place attachment of a group is less important and therefore left out.

The first dimension is about the person, this is the individual that is attached. This dimension is about why the person is attached to a certain place. This can be because of certain personally important experiences that this person had in this place. It is important to understand that the place might not be special for another person, but because of the experience that a person had in this place it becomes special for this person (Scannell and Gifford, 2010).

The second dimension in the framework is the way the individual is connected to a place. The psychological aspects of place attachment are emotion, cognition and behaviour. People can feel a certain connection or emotional bond to a place. As mentioned earlier, people can feel attached to a place because they have certain positive memories about that place. Behaviour that people show in relation to place attachment is that they have the desire to be close to this place (Scannell and Gifford, 2010).

The third and final dimension is about the place itself. As previously mentioned, people do not only feel attached to a place because of the place itself. This can happen, people can become attached to

a place because of for example the architecture, but often people feel attached to places because of social interactions. They feel attached to a certain place because of the people who live in or go to this place (Scannell and Gifford, 2010).

Attachment to a place can change. This could either happen because the place changes or because the person changes. When someone gets a stroke there is a good chance their mobility is not as good as before the stroke (National Stroke Association, 2012). The person might not be able to move through their home as good as they used to do. They could have been very attached to their home before the stroke but this might change after the stroke. As an example, imagine a stroke patient who returns from the rehabilitation clinic to his or her home without the ability to walk properly. The patient might not be able to access the home and this could change the way the patient is thinking about the home, he or she might not feel the same attachment to the place. The place itself can also change. For example, the people in the place could act differently after the patient had a stroke or changes could be made to the home, such as extra banisters.

2.2 Literature review

Most qualitative literature about stroke patients discuss the experiences and feelings patients had when they were either in the rehabilitation clinic or when they had already left. Additionally, there are also studies about both the experiences in the rehabilitation clinic and afterwards at home.

For stroke patients, the initial moments of a stroke were unpredictable, they did not know what was going to happen and there was a lot of uncertainty (Eilertsen et al., 2009; Burton, 2000). At first, stroke patients did not seem to realized that there was a high chance that some of the effects of the stroke would be permanent (Eilertsen et al., 2009; Lewinter and Mikkelsen, 1995). Some patients would have liked more information about what was going to happen at this stage (Olofsson et al., 2005). According to Rodgers et al. (2001) not only patients but also families of the patients would have liked more information. However, the study suggests that the information that is often provided, such as leaflets or flyers, are not very helpful. More personalized information would be better.

In most studies the patients had positive opinions about the rehabilitation clinic they were in. (Olofsson et al., 2005; O'Connell et al., 2001) Patients perceived a high quality of care. However, this was not the case in every study. Lewinter and Mikkelsen (1995) interviewed a group of 19 patients about their experience in a rehabilitation clinic. Patients felt that more training would have been better, none of the patients felt the training was enough. After coming home the patients all felt that they had to do more training.

Patients who were rehabilitating in a rehabilitation clinic generally had positive expectations about the future (Olofsson et al., 2005; Burton, 2000). Patients had the expectation that if they got home they would get better. Hafsteinsdóttir and Grypdonck (1997) show in their study that stroke patients often had clear goals for themselves in relation to functional abilities, but that the staff in the rehabilitation clinic did not always think these goals were realistic. Also, patients saw the rehabilitation as a way to return to the life they had before the stroke, while the staff focused more on the return of movement. However, a study by Burton (2000) shows that the early goals were usually set by professionals, and that only later in the process the patients themselves formulated goals.

When patients left the rehabilitation clinic and went home their lives were still affected by the stroke, for some patients more than for others. It is unlikely that patients recover fully from a stroke, some patients began to realize this when they got home. They were happy to be at home but were confronted with daily chores and noticed these chores were difficult to complete (Eilertsen et al., 2009). A quantitative study by Carod-Artal et al. (2000) shows that 38% of the patients they researched were depressed after they had left the rehabilitation clinic, mostly because they were not able to work due to their disability and because their social activity declined.

According to Hart (1988) stroke patients that had left the rehabilitation clinic often had trouble to receive additional help. They felt there was a lack of continuity of service provision, like day therapy. The participants thought of this as setbacks in their rehabilitation process and felt left alone after leaving the rehabilitation clinic, because they did not receive any care or therapy anymore.

Some patients complained that the clinical environment where they learned abilities was different from their own environment when they returned home. In the rehabilitation clinic everything was adjusted to the needs of stroke patients, but this was not the case in their own homes. This indicates that the patients had not realized this difference in environments, they had not expected this (Olofsson et al., 2005; Burton, 2000).

No studies were found about the concept of place attachment in relation to stroke patients. However, relocation in relation to place attachment has been researched. The moves to and from the rehabilitation clinic are relocations. According to Scannell and Gifford (2010) some people that move locations try to make the new place similar to the old place, to recreate some of the place attachment. Stroke patients could also do this by bringing objects that are special to them to the rehabilitation clinic.

A stroke can have a wide variety of different outcomes. Most patients have trouble with the functioning of their arms and legs, most of the times with either the right or the left arm and leg. Other possible effects are problems with sight, reading, calculating, memory, speech, swallowing, balance, writing and coordination. Also changes in character and emotions can occur. This all depends in what place of the brain the stroke occurred (National Stroke Association, 2012).

How much the stroke patients will recover is dependent on the severity of the stroke and the quality of the healthcare. However, even the best rehabilitation clinic cannot promise that their patients will recover. Good care increases the chances of recovery but it is no guarantee. (National Stroke Association, 2012)

What this study adds to the existing knowledge is what stroke patients experience when they come home and what the difference is between their expectations and experiences. There are few studies about the expectations that stroke patients have about going home. No studies could be found that compared the expectations and experiences of stroke patients, so this will be new information.

It is not only important for the healthcare staff to know what the patients experience but it is also important for policy makers if they want to make better decisions about rehabilitation healthcare, such as the information they provide to the stroke patients.

2.3 Conceptual Model

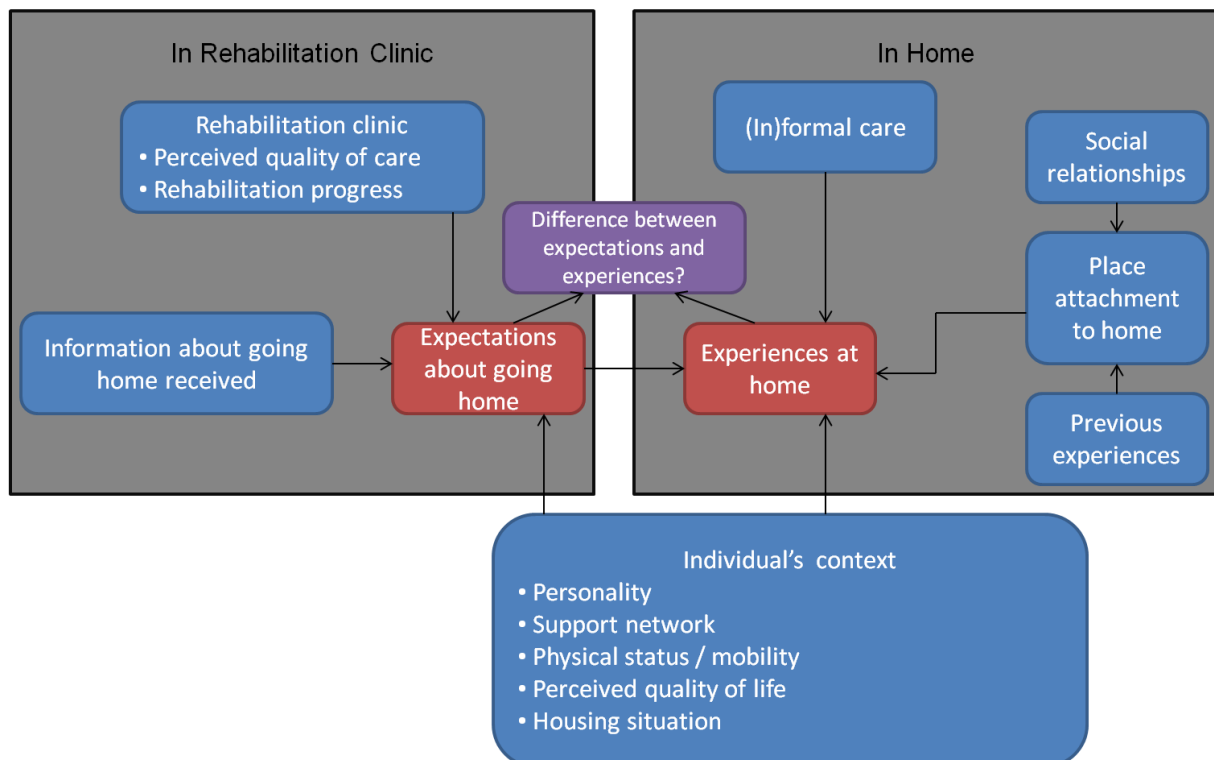
The conceptual model is shown in figure 1. The left side of the conceptual model is when the stroke patient is in the rehabilitation clinic, the right side is when the patient has returned home. The patients' expectations about going home can be influenced by a number of factors. The rehabilitation clinic plays an important role in the expectations. The perceived quality of the care received and the progress made by the patient could influence the patients' expectations. If the information about the stroke and rehabilitation process is not given, not understood by the patient or if it is of bad quality, it could result in reduced health and emotional problems. If this happens the expectations of the patients will be affected (Rodgers et al., 2001).

Both the expectations when the patient is in the rehabilitation clinic and the experiences when the patient is back at home are influenced by the individual patient. For example, if a patient has a home that is on the third floor with no elevator, that patient might not have positive expectations about going home, because this patient might not be able to walk the stairs properly. When this person is home, this will influence the experience of being home. The experiences in the home are also influenced by formal and informal care.

The experiences at home are also influenced by how much the stroke patient is attached to his or her home. This place attachment to home is created through social relationships in the home and neighbourhood and through previous experiences in the home (Scannell and Gifford, 2010).

Then the question is whether there are differences between the expectations and experiences and if so, why there are differences. This is the outcome of the model and the outcome of the research.

Figure 1: Conceptual Model



3. Research Design

This chapter looks at how the research was designed. First, the type of the research is discussed. Then there is an explanation about which methods were used for this research and how the data was collected. This is followed by the operationalization of the concepts that were described in the theoretical framework. After this there is a section about participant recruitment. Then the ethical considerations regarding the study are discussed. After that there is a section about the positionality of the researcher. Finally the data analysis and quality of the data are addressed.

3.1 Type of research

The research is exploratory, because it is a relatively new subject. Even though there are already a lot of studies about the medical outcomes that a stroke can cause (e.g. Deliargyris et al., 2005; Song et al., 2005; Hohmann et al., 2009) and there are also researches about experiences stroke patients have in rehabilitation clinics (e.g. Lewinter & Mikkelsen, 1995; Murray & Harrison, 2004), there is not much about expectations and the move from a rehabilitation clinic to home. There are studies about the experiences that patients have when they leave the rehabilitation clinic but there are not a lot of studies about the expectations that stroke patients have and because of that there are no studies that compare the expectations and experiences. This is what makes this research exploratory and how it adds to the body of scientific knowledge.

This is a longitudinal qualitative study. Longitudinal studies are used to study changes over time. This study is longitudinal because the patients are interviewed twice with time in between, when they are in the rehabilitation clinic and when they are at home. Even though there is not a lot of time in between the observations and there are only two points in time, the situation the participants are in is changed so much that the participants have different experiences. The difference between the two points in time is the key to this research and that makes it a longitudinal study (Babbie, 2010). It is a qualitative study because this is the best way to find out what people think and feel, which is the purpose of this research (Hennink et al., 2010).

3.2 Methods of data collection

To collect the data in-depth interviews were used. This method is the best way to get to know more about the personal experiences the patients have (Hennink et al., 2010). The research questions are about what the patients expect and experience and in-depth interviews are the best way to receive this information. The interviews were done in a rehabilitation clinic in the north of the Netherlands and at the participants' homes.

For conducting these interviews, two interview guides were made. One interview guide for the first interviews, and another interview guide for when the participants were at home. The second interview guide was made after the first interviews were finished. There was a general layout for the second interview guide, but for every participant the interview guide was slightly different. After reading the transcript of the first interview with the participant relevant questions were added and irrelevant questions were removed from the second interview guide. These interview guides can be found in the first two appendixes. They are in Dutch, as the interviews were also in Dutch. All the quotes in this paper are translated from Dutch to English, as close to the original meaning as possible.

In the quotes (...) is used to show that a part of the transcript is removed from the quote. This is used at times when a participant said something relevant, after that something that was not relevant for the particular quote was removed and replaced with (...). This is then followed by again a relevant part of the quote. Also the brackets [and] are used in some of the quotes. These brackets are used to show that part of a quote is replaced with something that the participant did not say. This can be done for anonymity purposes, for example if the participant used a name of a place and this is replaced with a description of that place. The brackets are also used to clarify some parts of a quote, for example if a participant said 'it was good', the word 'it' could be replaced by [the therapy] to clarify the quote.

The participants were found through a gatekeeper. A former employee in the rehabilitation clinic got in contact with two therapists who were working in the rehabilitation clinic. They briefly explained the study and asked the stroke patients if they would like to participate and do two interviews. It had to be two interviews, because this way there could be made a comparison between the expectations that the participants had in the rehabilitation clinic and then the experiences when they were at home.

The first interview was done in the rehabilitation clinic, there were rooms available that were private and quiet. One participant preferred to stay in her room so the interview was done there. This was not a problem, because there were no other people during the interview. The second interview was done at the participants' homes. When setting the date for the second interview, participants who had a partner were asked if their partner would also like to participate in the interview. Having the partner present during the interview could produce additional information, because they were able to tell their side of the story.

There had to be enough time between the first and second interview, so that the participants were back at home during the second interview. The time between the two interviews varied from one to six months. This resulted in more variation between the interviews, some participants were still adjusting to being back at home while others had already started to continue with their lives. All participants were at home for long enough to feel what it was like to be home and how the stroke affected them so this did not create any problems.

3.3 Operationalization

The concepts mentioned in the theoretical framework were operationalized with different questions in the interview guides. The following questions are examples to show how the concepts were operationalized.

To establish what the participants experienced in the rehabilitation clinic they were asked to describe a normal day for them there. To understand the whole story the participants were also asked to what happened to them leading up to the institutionalisation in the rehabilitation clinic. The participants were also asked about what they were feeling when they were in the rehabilitation clinic.

The place attachment concept was operationalized with questions about different places in and outside the rehabilitation clinic. Where did the participants go and what was their opinion about these places? There was also a question about their favourite place in the rehabilitation clinic and why they liked it. These questions were asked to find out why and how they felt connected to these places.

To find out what their expectations were about going home in the future there were also a number of questions. The participants were asked what they thought a normal day would look like when they were at home. Another example of a question was about their relatives, how did they think the stroke would influence their relationships when they would be back at home?

The second interview guide was as mentioned different for every participant, but the general subjects were the same. There were again questions about what the participants experienced, but now about what they experienced in their homes. How did they feel about being home? How was a normal day organized? There were also questions about comparisons between this daily schedule and their daily schedule in the rehabilitation clinic and before they had the stroke.

The concept of place attachment is again operationalized with questions about places and how the participants felt when they were there, but this time the questions were about places in the home and outside.

There were also questions about the relationships with relatives, and if they had changed after the stroke. Finally the participants opinion about the rehabilitation clinic was asked.

3.3 Participant recruitment

The population is stroke patients in the Netherlands. Data saturation was reached after eight or nine interviews, but ten interviews were done. This is because there was a chance that not all participants could be reached for the second interview. Reasons for this were that they could refuse to do the second interview, could not be reached for a second interview or that they were still rehabilitating in the rehabilitation clinic. One participant was still in the rehabilitation clinic at the time of conducting the second interviews and therefore could not be included in the second round of interviews. However, the first interview is still usable. A comparison between the expectations and experiences at home cannot be made for this participant, but the first interview does contain information about the experiences in the rehabilitation clinic and the expectations about home that the participant had. The other nine participants were all interviewed a second time at their home.

The requirements for patients to participate in the study were that they:

- Had a stroke.
- Were rehabilitating in the rehabilitation clinic.
- Had been at least once at home during the weekend.
- Could communicate well enough to participate in an interview.
- Were capable to endure an interview that could take one and a half hours.

Whether a patient was suitable for participation according to these requirements was decided by the therapists.

Table 1 shows the effects of the stroke that the participants themselves have addressed when they arrived in the rehabilitation clinic and the effects they addressed during the second interview, when they were at home. The table also shows additional data about the participants.

Table 1: The participants

Pseudonym	Age range	Effects of stroke	Employment status	Moved?	Number of weeks in Beatrixoord at first interview	Number of weeks home at second interview
Mr. Henson	70-75	Problems with speech and memory	Pensioned	No	4	16
Mr. Woodward	60-65	Problems with balance, swallowing, fine motor skills	Pensioned	No	5	13
Mr. Hankins	50-55	Paralyzed on the left side, problems with sight, speech	Unemployed	No	7	14
Mr. Mullin	45-50	Paralyzed on the right side, increased emotions	Employed	Yes	5	12
Mr. Torgerson	60-65	Paralyzed on the left side	Pensioned	No	5	4
Mr. Swafford	65-70	Paralyzed on the left side	Pensioned	No	3	16
Ms. Adams	60-65	Paralyzed on the left side	Unemployed	Yes	11	19
Ms. Brouwer	55-60	Paralyzed on the right side	Unemployed	No	3	n/a
Ms. Rollin	60-65	Paralyzed on the left side	Unemployed	No	6	23
Ms. Blaker	45-50	Paralyzed on the right side, problems with speech	Employed	No	4	3

3.4 Ethical considerations

Participation in the interview was voluntary and the participant could stop at any time with the interview or skip questions. None of the participants wanted to stop or take a break during any of the interviews. In the first interview contact details were asked to contact the participant for the second interview, but this information was only used for this purpose.

The aim was to cause minimum harm to the participants. For some participants the subjects were emotional, for example when a participant was talking about . If a participant got too emotional the interviewer changed to a lighter topic or asked if the participant needed to take a break from the interview. For example, one participant was very emotional when telling about what happened at the moment of the stroke. Because of this the topic was changed to places that the participant went to in the rehabilitation clinic. Later she agreed to talk about the stroke again. She mentioned afterwards that it felt good to talk about, but that it was difficult.

At the start of an interview the participant was asked if the conversation could be recorded. A transcript has been made of these recordings. The recordings and transcripts are only used for the research. In publications the participants' personal information will always be kept confidential, no names or personal information will be disclosed. Some quotes have been taken from the transcripts but it was made sure that nobody can identify who said it originally.

Additional ethical consideration is needed because during some of the second interviews the partner was present. After some consideration the participants who had a partner were asked to also invite their partner to join the second interview. This was obviously without obligation, if either the participant or the partner did not want this the interview would have been done without the partner, but all the participants with a partner agreed. The amount of additional information gathered this way seemed to overshadow the loss of information because of the fact that it was not a private interview. However, it is important to keep in mind that questions about the partner while the partner is present might not have been answered with total honesty, even though no sign of this was noticed during the interviews.

3.5 Positionality

Qualitative research is influenced by the person that does the researching. Therefore it is important to reflect on my own positionality (Hennink et al., 2011).

During the interviews I tried to establish rapport to make them comfortable, I talked about the participants day or the weather before we started the interview. I also tried not to be superior in relation to the participant. An example of this is how I dressed, I tried to dress decently but casual. Wearing something official looking, for example a suit, could give participants the feeling I was superior and that would make it more difficult to create rapport.

I am relatively young so I also tried to make sure the participants did not feel superior over me. For example, if the participant asked what the research was about I made sure I knew what I was going to say, so that the participant knew it was a genuine research.

I did not mention that my mother had a stroke a year prior to the interviews. I did not want the participants to think I was already knowledgeable about the emotions and experiences that they went through because of the stroke. I wanted them to tell their experiences without them thinking I would compare or judge those experiences.

3.6 Data analyses and quality

All the interviews were transcribed in Dutch. These transcriptions were imported in the program Atlas.ti 6.2. This program was used for the analysis and all the transcribed text was coded. A code is a topic, issue, idea, opinion, etc., that came up during one or more of the interviews (Hennink et al., 2011). Some parts were given multiple codes while other parts were just about one topic and got one code.

The code tree, with code families included, can be found in the appendix. After everything was coded the analysis was done. With the use of the program relations between codes can be found and analyzed. An example of this is that participants without a partner seemed to be more likely to have negative experiences than participants with a partner.

In general, the interviews went quite well. The initial interviews were a bit uneasy, because it took some time to get familiar with the interview guides and the target group, but this did not influence the interviews very much, all the interviews were useful. Sometimes more probing questions could have been asked, possibly more information could have been gathered that way. This was the case with participants who were not very open and eager to tell their story. Others almost could not stop talking and guiding this was sometimes difficult but because these participants were so open a lot of information could be gathered. Not all this information was always relevant but this did no harm to the research, because there was also a lot of information that was relevant and interesting.

There were some cases where the recording was unclear, but this was never more than one or two words and did not happen often. No important information was lost this way. Due to the translation some meanings could be lost, but effort has been made to avoid this problem as much as possible. The quotes were not just translated literally, but were first read in the context they were said in. Then the meaning of the quote was reproduced in English as close to the original meaning as possible.

4. Results

The results are divided into four parts, in chronological order. The first section is about the experiences the participants had in the rehabilitation clinic. After that the expectations participants had about going home and how these expectations were influenced are discussed. Then there is a section about the experiences the participants had when they left the rehabilitation clinic and went home. Finally, a comparison is made between their expectations and experiences.

4.1 Experiences in the rehabilitation clinic

When a person has a stroke, they do not go to a specialized rehabilitation clinic immediately, they are first send to a hospital. After being in the hospital the participants went to the rehabilitation clinic. For the participants this took between three days to two weeks. This section describes the experiences the participants had in the rehabilitation clinic.

4.1.1 Schedule

In the rehabilitation clinic every participant had their own daily schedule. However, apart from having different therapies the rest of the schedule was quite similar. Patients woke up between 7:30 and 8:00 am, depending on how much time they needed to wash and get dressed. Then between 8:00 and 9:00 am they had breakfast together in the common room. If a patient was not able or did not want to eat together they could eat in their room but was is encouraged to eat in the living room, because therapists could watch them there. The nutrition therapists liked to observe what the patients were eating and other therapists liked to watch how the patients were eating. For example, whether a patient used both hands and was able to cut something. The participants preferred eating together, because they like the company, but because of the therapists who are watching it was uneasy at first.

"You have to get used to it, that you are being watched. For me, my left hand does not function that well. (...) When they observe this and think something should be done about it they tell you when you go to the therapy." Mr. Torgerson

So this participant had to get used to the fact that he was being watched when he was eating. But when the therapists noticed something about his eating they do not interrupt him while he was eating but told him when he went to therapy. He did not seem to mind it that much and understood why he was being watched. Other participants did not mention that they were being observed while they were eating, so it was not something they seemed to mind.

After breakfast there were therapies until 12:00 am. Then there was a warm meal and a rest period. Patients often watched television or slept for an hour and around 1:30 pm the therapies started again. These would continue until 4:00 pm and at 5:00 pm there was another meal. In the evening the patients had their own free time, most participants filled this time by watching television and receiving visitors. Visitors were able to come in the evening and during the day at times when the participant did not have therapy.

This was the general schedule, but note that it was not the same for everyone. The therapies varied for every patient and some patients had more therapies than others. This is because every patient is

seen as an individual case and the therapies are adjusted to their personal needs. The best therapy for one patient might not be the best for another.

During the weekends patients who were able to function well enough were allowed to go home. This was determined by the rehabilitation physician together with the rest of the staff. Whether a patient was allowed to go home depended on their abilities and housing situation. For example, a participant who lived in a house with multiple floors had to be able to climb the stairs. The first weekend at home was often short, one or two days. Later in the rehabilitation process the participants could stay the entire weekend at home, from Friday evening to Sunday evening.

How the participants experienced going home during the weekend influenced their expectations about being home permanently. Generally patients experienced the weekends at home as pleasant, they were back in their own environment and they had time to relax.

“When I went home [during the weekend], that is obviously nice. Because it are all your own things, your own stuff, your own home. Yes, that is your own home again.” Ms. Brouwer

This participant explained why she liked going home during the weekend. She felt connected to her home was happy to be there. But especially the first time is difficult for some, some participants had to face what it was like being home and how the effects of the stroke influenced this.

“I can move pretty good. But you do notice a difference, at home there are doorsteps and you do not have those here. But they are not that high, so if you are aware of it, it is not a problem.” Mr. Hankins

If this participant would not have gone home during the weekends he would not have known what to expect, now he knew the doorsteps were not a big problem for him, there was a difference between his home and the rehabilitation clinic, but he knew what to expect. This is why participants went home during the weekends, to get used to being home, to find out what it would be like.

4.1.2 Therapies

Most of the participants' time in the rehabilitation clinic was filled with therapies. When the participants were new in the rehabilitation clinic they were tested to find out what the difficulties were and what could be done about them. They were physically and psychologically tested to find out which therapies were best for them. For example, when a patient did not have a speech related problem there was no need for speech-language pathology for that patient.

After this first period the participants were assigned to the appropriate therapies. The most common therapies for the participants were physiotherapy, occupational therapy and speech-language pathology. Additionally most patients had agenda training in the beginning of the day.

According to the Chartered Society of Physiotherapy (2012), “Physiotherapy helps restore movement and function to as near normal as possible when someone is affected by injury, illness or by developmental or other disability”, such as a stroke. An example of physiotherapy is walking on a treadmill, or trying to climb the stairs. According to the World Federation of Occupational Therapists (2011) “Occupational Therapy is a client-centred health profession concerned with promoting health and [wellbeing] through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life.” In occupational therapy in the rehabilitation clinic patients learn to do everyday activities such as baking an egg or vacuuming. They can also request

additional abilities they would like to learn, for example, one participant wanted to be able to play golf again, and the physiotherapists practised this with him. According to the American Speech-Language-Hearing Association (2012) “speech-language pathologists treat speech, language, cognitive-communication and swallowing disorders.” Agenda training started after breakfast and the patients had to write down what they were going to do that day, what therapies they had at what time. Agenda training was used to improve writing skills and memory.

Participating in the therapies took a lot of effort. Especially the physiotherapy was physically tiring for the participants. However, the participants did not see this as a bad thing. The therapies were adjusted for them so that it was difficult but doable.

“If you think you are going to [the rehabilitation clinic] to rest and relax, you shouldn’t go at all because that’s not going to happen. You find out soon enough that you are here to do something.”
Mr. Woodward

“I think it’s busy, but that is a good thing.” Ms. Blaker

So even though the therapies were not always easy, the participants wanted to go there because they realized it was good for them.

With the therapies the parts of the brain that were affected by the stroke were being stimulated, so that other parts of the brain could take over the function of the affected part. Whether a therapy was successful or not was dependent on the quality of the therapy, the therapy should be well adjusted to the patient so that the exact problems could be tackled. This is why every patient had different therapies. In the rehabilitation clinic the participants liked the therapies, they felt the therapies were adjusted to their needs. But even though the therapy could be perfect it did not guarantee improvement. Good therapies only increased the chance of recovery.

4.1.3 Places

Patients who had a stroke have rooms in the same corridor in the rehabilitation clinic. There were eight rooms with four beds in each room, however there were mostly two or three patients per room. If the participants were not in their room they were often in the living room, at the bench near the corridor, in the cafe or at the places where the therapies were.

The living room was in the same corridor as the patients' rooms. In the living room patients ate together and there was also an area where they could sit and watch television together. The agenda training also took place here. At the start of the corridor was a half round bench. For some participants this was a meeting place to talk to other patients and visitors. There was a coffee machine and a nice outside view where a botanical garden could be seen.

“My favourite place is here in the front, where the coffee machine and the bench are. That’s my favourite place. We get together in the evening and talk there. Just to have some fun, that is what I like about it.” Mr. Hankins

This participant liked the bench, but it is not about the bench itself. It is about the feelings attached to that place. Even though the bench could have been very comfortable, that is not why he liked it. The people who came there made it his favourite place. There were also participants who did not have a favourite place and did not feel the same connection.

Downstairs in the rehabilitation clinic was a cafe, called the 'tuincafé' (garden cafe). This was a place where people could sit and buy something to drink or to eat. Some participants went there to sit with their visitors. If the weather was nice they could sit on the terrace outside.

"In the evening I often go to the tuincafé and buy a sandwich or a cup of coffee. And if the weather is nice I will sit outside on the terrace, enjoying the fresh air." Mr. Hankins

The cafe was a place where the participants could go to and without having to worry about rehabilitation. They could just do something normal like buying something to eat or drink. Not all the participants felt this way, some did not go to the cafe often.

The place patients went for their physiotherapies was the gym, where various exercise machines could be used, such as treadmills and home trainers. When participants were talking about the gym they said it was a place where they had to do a lot, it took a lot of effort. But when they were done they often felt good about themselves, because they knew it was good for them. There was also a special swimming pool where the depth could be adjusted.

"I really like [to swim]. (...) It is very calming, it is relaxing. (...) It is just, being yourself. And trying to walk on your own legs again." Ms. Adams

This participant really liked to go to the swimming pool to swim. She noticed a calming effect and in the water it was easier to walk. Because of this she felt that she could be herself, not confined to a wheelchair but just as she was before. When she would go home she expected to keep swimming because she enjoyed it that much.

For occupational therapy there was a room where patients could use a stove or other everyday appliances. Outside the rehabilitation clinic were a number of walking routes that could be used by therapists to walk together with the patients. If patients were not able to go to the therapies on their own a nurse would help them or the therapist would go to the patients' room to do the therapy there.

The entire rehabilitation clinic as a place was also important for some participants. An example of this is when a participant went back to the rehabilitation clinic for a check-up after he was already discharged from the rehabilitation clinic and lived at home.

"I was pretty early so I had a look around on the unit and there was one man, he hugged me, immediately crying. That was very emotional. Everybody else was new, but it was just amazing to see it all again. And I went to the room again, but they were all to physiotherapy or something, so I did not know who they were. But it was occupied, my bed, so. But I talked to the nurse and rehabilitation physician. I liked that, to be back on my former place." Mr. Hankins

When this participant went to the rehabilitation clinic he felt a strong connection with the place. He still called the bed he was in 'his bed' and the rehabilitation clinic 'his place'. He felt this attached to the rehabilitation clinic because of the connection with other people and because of what he experienced there. Other participants also felt connected to the rehabilitation clinic, some called it their temporary home or called their bed 'their place'. But there were also participants who did not feel this attachment. They also did not have a favourite place or strong relationships with other patients. It seems that participants who had gone through a lot in the rehabilitation clinic were more

attached to it than participants who were in the rehabilitation clinic for a shorter amount of time and had a smoother rehabilitation process.

4.1.4 Relationships

The relationships with other patients and the staff was very important to feel at home, safe and at ease in the rehabilitation clinic. Having a good relationship with roommates and other patients resulted in a better overall experience in the rehabilitation clinic.

"We talk with each other, someone has this, the other has that. And you talk about these things with each other. We also laugh with each other. And if you can't work something out others try to help you. We are in here together, so it is good that we can talk about it." Mr. Henson

This participant explained that because he had good relationships with other patients they helped each other with problems they faced. They were in it together so they were able to support each other. But the relationships that were made in the rehabilitation clinic were not very sustainable.

"It strikes me that if someone that was here and he goes home, he is forgotten pretty soon. It are temporary contacts, you know?" Mr. Woodward

He noticed that even though he had some good contacts with other patients, if they went back home he did not think about them anymore. This was also the case for other participants, they did not exchange addresses or phone numbers, they had no contact with patients who left the rehabilitation clinic. But there were also participants who were thinking about keeping in contact with other patients. This shows that some participants developed more relationships than others. It seems that participants who were longer in the rehabilitation clinic and who had less contacts outside the rehabilitation clinic felt they had stronger relationships with other patients. If a participant is visited every day by friends and family he or she has less of a desire to create strong relationships with other patients.

Relationships between patients in the rehabilitation clinic were not always good, and this sometimes caused problems.

"[My roommates] had a good connection with each other, but not with me. (...) I am lying next to the window and they just blocked me, if I wanted to leave I constantly had to ask if I could get out. And in the morning they didn't know how fast they had to go to the shower and I didn't even get a chance. (...) I really wanted to die then." Ms. Adams

This is an extreme example. The participant had such difficulty with her roommates that she did not want to live anymore. She was not the only participant who had trouble with other patients at some point in the rehabilitation clinic, but these problems were less severe. Having a difficult relationship with other patients affected the rehabilitation process.

"[The rehabilitation] was suddenly not going well. Because it really affects you. It destroys you." Ms. Adams

Because of the bad relationships this participant had with her roommates it was not going well with the rehabilitation. This shows the effect that relationships can have on the rehabilitation process.

When the relationship is good it can have a positive effect, but a bad relationship can have a negative effect on the rehabilitation progress.

The participants were very positive about the staff. During therapies they were positively encouraged and if a participant did something wrong they got constructive criticism from the therapists.

“The best [thing about the rehabilitation clinic] is that [the staff], and especially the physiotherapists, that they are so positive. That they are really active with you. That’s what I think. And they are also very encouraging about everything you do.” Ms. Rollin

None of the participants had complaints about the staff in the rehabilitation clinic. The positivity of the staff seems to be very important. When the staff was positive, the patients were also more likely to be positive. This made them want to their best during the therapies which helped the rehabilitation process.

Not every participant was entirely satisfied with everything in the rehabilitation clinic. For example, some of the participants thought the rules were very strict. One participant was not allowed to walk by herself even though she felt she could do it, but she did understand that it was not safe enough yet. The complaints that some participants had were minor. Overall the participants thought the rehabilitation clinic was very beneficial for them and the relationships with the staff were very good.

4.1.5 Information

Some participants knew at what date they were going home. These participants were almost done rehabilitating in the rehabilitation clinic and did not have to stay long anymore. For other participants it was less clear when they were going to leave.

“Yesterday I had a conversation with the doctor, four weeks here and then I will do day therapy. So that is... but if it goes well maybe earlier or it might take longer.” Mr. Swafford

This participant did get an approximate date, but it was still uncertain. If the rehabilitation went well he could go home quicker, if it did not go well it could take longer. This shows the uncertainty that participants had. Participants who had more certainty about the date of going home seemed to have more concrete expectations. This is probably because they were longer in the rehabilitation process and had a better understanding of the effects of the stroke that they would have when they would go home. It was a lot less certain for a patient who was just one week in the rehabilitation clinic than a patient who had almost finished rehabilitating.

Another explanation is that at the initial stages of rehabilitation the participants did not have time to think about the future a lot. Their lives had suddenly changed and they were busy with all the changes and not thinking about what it would be like when they would go home.

Some participants did not seem to have gotten much information about what would happen if they left the rehabilitation clinic and went home.

“I think the information should be better. It can be better. Especially in the beginning I have had little information. Yes, a leaflet, I think it was called ‘after a stroke’, but it is very brief and you have to figure out the rest for yourself. (...) [I would have preferred to have more information about] what could happen, how you feel. Uncertainty, things like that.” Mr. Mullin

This participant would have liked more information, so he could have prepared himself better at the beginning of the rehabilitation process. If he would have gotten this information he felt his expectation could have changed. However, not all the participants agreed with this.

"We are informed about everything. (...) Now that I am about to leave, they show the progress that I have made. (...) And also the first weekend, I was not allowed to go home that weekend. I was disappointed, but they did not trust it yet and later I was happy about it, because they were right."

Mr. Hankins

This participant was very happy with the way information was provided. He was not allowed to go home during the first weekend and afterwards he understood why he was not allowed. So some participants felt the information could be better while others thought the information was good. An explanation for this could be that some participants understood information better or were easier pleased with the information they received.

4.2 Expectations

Some participants had not thought about what would happen if they went home while others had thought about it a lot and already had ideas about what they were going to do in the future.

4.2.1 Daily schedule

When participants were talking about the future they were generally pretty optimistic. Some had already thought about what they would do when they would go home.

"I have search for charity work here on the computer, I want to do something like that in my neighbourhood, because I don't just want to sit and do nothing. I want to work again, even if it is just charity work. (...) And I want to go to the gym, I want to get to 100% again, well, you'll never get 100% but I just don't want to sit and do nothing. I already have a planning on how my day will look like, fishing and if I can drive again I can also go to my caravan. I want to enjoy life." Mr. Hankins

This participant already had detailed ideas about his future. He wanted to be busy. Some participants had a similar view, they wanted to stay active. These participants would like to be able to do the things they were doing before they had the stroke. However, there were also participants who had not thought about their daily schedule at home that detailed.

"I don't think [I will be able to work]. If I could work again it would be better than I expected. (...) But I haven't really thought about [my schedule] yet." Ms. Blaker

She did not think she would work again, but had not thought about other aspects of her life when she would return home. This was the same for some of the other participants, they did not think about it much when they were in the rehabilitation clinic. They were busy with rehabilitating and were not thinking much about the future. There did not seem to be a difference in the experiences that the participants had when they later were at home between participants who had detailed expectations about their daily schedule and those who did not. So for example, participants that had detailed expectations did not seem to have more structured lives when they were at home than participants that had not thought about it in detail. This will be discussed more later.

Apart from work, participants also had expectations about their hobbies and other activities, such as the household. Again some participants expected that they would be able to do these things in the future.

"I am going to do the same things. Except, it might be slower." Mr. Henson

He wants to do the same hobbies as he did before he had the stroke, such as working in the garden and visiting family. However, he also notices that it might not go as easy as before, it might go slower. This is similar to other participants' expectations, they want to be able to do the things as they did before, but they are unsure if it will be possible.

If the rehabilitation was going well and the participants noticed improvements they were also expecting more improvements in the future, which caused them to expect that their daily schedules would be similar to their daily schedule before they had the stroke.

"[I am positive] because I have recovered very quickly, also physically I am like I was before [the stroke]. It also means I can climb the stairs on my own at home. I can even cycle. I have some

problems with my left hand, but other than that I can do everything I could before I had the stroke."
Mr. Torgerson

This participant was very positive about the future, because he recovered quickly and therefore he was also very positive about the future. Other participants who recovered quickly also had positive expectations about the future. When participants noticed that things were not going that smoothly their expectations were sometimes different.

"Sometimes I think, I am leaving [the rehabilitation clinic] this Friday. How do I have to do that? But I have to go on and it is going to work out. (...) But with limitations, you just know you cannot do everything that you did before." Mr. Hankins

This participants expectations are influenced by his rehabilitation progress. He knew he was going home soon but he still had limitations. Other participants who also noticed limitations had similar expectations. Some participants realized these limitations were permanent and these participants had to accept it and learn to live with it. Others expected improvements when they were home, either with or without the use of day therapy.

4.2.2 Mobility

A major impact of the stroke for most participants was reduced mobility. For the participants, the important aspects of mobility were walking, cycling and driving a car. Some of the participants were not able to walk anymore, or could only walk with the help of mobility aids such as a cane or a walker. This is an important aspect, because this leads to different expectations.

"At a certain point it was like, this is it. This is going to be the wheelchair. Yes alright, I am not that strong anymore." Ms. Adams

This participant knew she would not be able to walk for long distances anymore and would be confined to a wheelchair. Because of this she knew she would not be as mobile as before the stroke. For others this is different, they notice improvements in their mobility and expect it to keep getting better.

"It is going very fast. Last week I started walking with a cane.(...) I am not as mobile as before. That should improve later, because I have lost some strength. (...) That has to be rebuilt." Ms. Brouwer

This woman noticed loss in mobility but was positive about the future. First, she was not able to walk, but then she could walk with the help of a cane. She noticed improvements and because of that she expected to rebuild her strength and improve her mobility.

Even though some participants knew that they would probably have difficulties with mobility in the future, they expected to overcome these difficulties. For example, the participant who had to stay in the wheelchair did not expect to be confined to her house. She expected to use a mobility scooter when she wanted to go outside. Other participants that had difficulties with mobility had the same attitude. However, when these participants were at home some of them did notice a reduced mobility and with that reduced freedom. This will be discussed more elaborate later.

Being able to cycle and drive is also an important aspect of mobility. After a stroke patients were not allowed to drive a car for either three or six months, depending on the type and severity of the stroke. Cycling was allowed, but if patients had trouble with their arm or leg it was difficult.

"I don't think I will recover for 100%, that will be very difficult, but I hope I will get far enough so that I can walk and cycle again. Walking is going pretty good now but I can't cycle yet, at least not on a normal bike, I did cycle on a tricycle. And I hope to get my driving license and to be able to function quite well again. (...) I hope I can drive my car again. But that's, well, I kind of count on that actually. If I can see properly and the control [over my hand] is normal again." Mr. Torgerson

This is again an example of a participant who noticed improvements, he was able to walk again. Because of these improvements the expectations about driving and cycling were positive. Even though the participant had problems with his hand and seeing he was confident he would be able to drive in the future. This shows that even though some participants had severe mobility problems they expected to recover almost completely if their rehabilitation progress went well. However, this did not turn out this way for every participant when they were at home.

The effects of the stroke could be so severe that it was necessary for a participant to move.

"I cannot get into my home anymore, because the doorsteps are too high. It is a wheelchair unfriendly house. So, then it is clear, I have to move. So the social worker called and called and eventually they could find a home for me. (...) So I saw it and I had to say if I agreed with it. I don't have a choice. Because I can say, 'I don't want this because it is way too small', and it is really small, but it doesn't matter. At least I have something for myself. (...) But it is a temporary solution, because they are going to try and find something bigger for me." Ms. Adams

This participant could not go to her home when the rehabilitation would be over. She knew she had to move because she was confined to a wheelchair and her home was not wheelchair accessible. But this was the only participant who talked about moving, others did not mention having to move because of their stroke. For other participants moving did not seem to be on their minds, they did not seem to expect this. However, another participant did move after he left the rehabilitation clinic. This shows again that not all the participants' expectations were realistic.

4.2.3 Relationships

Most of the participants did not expect any changes in the relationships they had. They expected that everyone would treat them like they have been treated before they had the stroke.

"[The relationships] will just continue. I am certain about that. However, if I go home [during the weekends] than [my husband] sits next to me. And I say, 'no, you should just do what you want, I get nervous when you always sit there.' And I know that he wants to do something. (...) But it is also difficult for him, he has to get used to it." Ms. Rollin

At first, this participant was very confident that her relationships would be the same as before the stroke. But when she thought about it she realized that during the first weekends at home her husband was very protective and always kept an eye on her. But she expected him to get used to it and that when she would go home permanently this would be over. Other participants expected the same, their relationships with their friends and family would not change.

There were also participants that did not have certain relationships. Some participants did not have someone to rely on, like a partner.

“Almost everyone has people who support them, I do not have that. And then they say, ‘but you cannot count on that’, but then I say, ‘you do it too’. I said, ‘you all have a partner’. I said, ‘and they protect you’. I said, ‘but I do not have that’. ‘Well, you cannot see it that way’. But I say, ‘it is that way’. “ Ms. Adams

This participant explained why she expected it was going to be more difficult for her to go home in comparison with other patients. She was talking about a discussion she had with another patient. She realized that she could not count on the same support as the other patients, because she did not have a partner. But there were people who visited her when she was in the rehabilitation clinic.

“People who came to me [before the stroke] are still coming, that is nice. (...) ‘And do not go too far away, we still want to visit you’. I said, ‘no I will not’. [laughs]” Ms. Adams

So she realized she was going to have more difficulties because she did not have a partner, but she did expect others to visit her often at home.

4.3 Experiences at home

In this section I will discuss the experiences patients had when they leave the rehabilitation clinic and went home permanently.

4.3.1 Mobility and fatigue

When the participants were at home, mobility was still an important subject for them.

"I didn't have my mobility scooter and I was at home alone. A friend came once a week and I had my book, but [in the rehabilitation clinic] were the therapies. And I had more friends there. But now [that I have my mobility scooter] I am not bored anymore. (...) [When I did not have my mobility scooter] I could not go anywhere. My brother went with me to the shop with the car sometimes or to watch football, but I was dependent on someone else. (...) Now I have more freedom." Mr. Hankins

This participant did not have a mobility scooter the first weeks after he went home. This shows the impact that a reduced mobility can have. Because he did not have a mobility scooter, he could not go outside the house on his own. He was bored because of that and when he got his mobility scooter this feeling went away. This quote also shows that a reduced mobility can have a big impact on the feeling of freedom. When he got his mobility scooter he regained this freedom and could go to other places by himself. Other participants who had trouble with mobility noticed reduced freedom, they could not get out of their home easily and were dependent on others. But for Mr. Hankins, the problem was solved by getting a mobility scooter. For other participants the problem was not solved.

"I have never been to a shop with a mobility scooter. And you can sit on the mobility scooter like a fool, but then? Then you are just in the way. (...) Imagine I collide with something. No, that is scary." Ms. Adams

This participant had a mobility scooter but was too afraid to use it, even though she had learned to use one in the rehabilitation clinic. This shows that mobility can not only be physically affected, but also emotionally. Because of this the participant felt confined to her house, she was not able to go out on her own.

It is important to notice that a reduced mobility is not always the cause of not being able to walk, cycle or drive anymore. Fatigue also had a big effect on the participants.

"[Before the stroke] we could get on the bike and just cycle. I cannot do that anymore. Yes, only to the shop is possible, that is about five kilometres away, but then it is over." Ms. Rollin

This participant was able to cycle again, but due to being tired quickly she could not reach many places. Even though five kilometres is quite far, she was used to cycling longer distances. More patients noticed that fatigue was a problem for them.

"I would like to go [to the store] with the walker, but I cannot keep it up and go through the entire store. I would like to join [my mother] but then I would just be in the way and I do not want that, you know?" Mr. Hankins

This participant was able to walk with a walker, but because it was too tiring to walk through the entire store he did not go. He was also afraid that he would be in the way. This is another example where fatigue results in reduced mobility. However, the participant could have used his mobility

scooter in the store, so fatigue did not seem to be this participants only obstacle for not going to the store. He possibly also did not like to go into a store with his mobility scooter, because he was afraid or embarrassed. This is again an example that shows how mobility can also be emotionally affected.

Fatigue did not only influence mobility, but also other aspects of the participants' lives.

"I would like to tell you that after I had not been home approximately six months, all together, if you get home you want to do everything like you did it before the stroke. And I cannot cope with it that well, I had difficulty with it. I tried to do things but I was too tired. I had trouble with that the first few weeks. Now it is better." Mr. Torgerson

This participant had problems with fatigue when he was home. He tried to do the things that he was used to do before the stroke but noticed it did not go as well as before. It was too tiring for him at first. He was confronted by this when he left the rehabilitation clinic but when he was more used to it and had accepted the situation, he felt it was better. This was both a combination of coming to terms with his situation and an actual improvement, he did not get tired as quickly as before and he knew his limits. More participants had similar issues, due to fatigue they were not able to have the same daily schedule as before and had to adjust to a new schedule.

And it is not only physical fatigue, some participants also got tired when they were with a lot of people.

"If there are a lot of people. And if I talk to them. If I keep quiet it is fine, but when I begin to talk to them they can hear (...) that I get tired." Mr. Henson

More participants mentioned this. They noticed they got tired quickly when there were a lot of people around them. However, the participants also noticed that this was getting better over time. The participants had to learn to cope with these changes. At first this was difficult, because took time to adjust to the new situation.

4.3.2 Moving

A recurring topic among some of the participants was moving to another house. Some had already moved because it was not doable to live in their previous home due to the effects of the stroke.

"I am reliant on public transport, which is not available there and there are no shops. We lived in the middle of nowhere, outside the village. (...) These things are better here." Mr. Mullin

This participant explained the reason why he moved. He was not allowed to drive and the shops were not nearby. Therefore he was reliant on public transport, but in the secluded area that he lived were almost no busses so this was difficult. This was better at his new home, but moving also creates new difficulties.

"I went to bed at eleven yesterday evening and you hear everything, the neighbours and the people walking on the street. And I was not used to that. I lived totally free, fourteen years I heard nothing. (...) But there also lives family here and it is also good for me because I can get to places more easily. [But] to feel at home, that takes time. Or maybe never, I cannot tell right now." Mr. Mullin

He did not feel at home yet, he was not attached to this place. He saw that some things were better, but he also noticed problems in this new home. It was more noisy and he did not feel at home. He also did not know if he would ever feel at home.

Another participant who moved was the woman that was confined to a wheelchair. She first moved to a temporary home, which was very small. She moved because she could not go to where she lived before the stroke, the doorsteps were too high for a wheelchair.

"It was not nice. The people were nice, but the house was terrible. I was on the fourteenth floor and had a fear of heights. So I always had my shades closed but if I got to the seventh floor in the lift I was already getting dizzy. That was not a success." Ms. Adams

She moved twice since she was discharged from the rehabilitation clinic. The first home was very small and in a tall building. And because she was not very mobile this caused a lot of problems.

"It got so bad I had a terrible fear of heights and I said, 'I am not going up there anymore'. Then they had to get nerve tablets." Ms. Adams

This shows what can happen if a person is not comfortable with the place they live. But after a couple of months she found another home and this was much better.

"There was not another place for me, no other place. But I tried as long as I had to, to get a new place. (...) And now I have a palace here. Yes I like it here, I live here for three weeks but it feels like three months.(...) I feel at home here." Ms. Adams

She moved to another house that was bigger and not in such a high building. She felt much more at home and was happier in this new place.

There were other participants who were thinking about moving. They had not actually made plans to move, but they were thinking about it. Due to the effects of the stroke the participants could not always help with chores around the house as much as they were used to. Moving to a different house that would be easier to maintain could solve this problem.

"We have to take care of it all. (...) And it is pretty big. We divided it between us, but if it is dependent on one person than it becomes difficult. So then you have to make a choice, or you outsource the tasks, but that is difficult with the finances, or you move. But that would be a big loss, that is difficult. You don't just leave everything behind. So as long as we can cope we won't move." Mr. Torgersons partner

The wife of this participant explained why they were thinking of moving. Due to the stroke the participant could not help with the household as much as they were used to. She felt an increased pressure on her, she had to do it alone. Moving to a smaller place could be a solution to these problems. On the other hand she also felt that it would be a big loss to move, they were very attached to this home and they did not want to leave it. Other participants had the same view, moving would help to reduce the amount of household work, but to move and leave everything behind would also be a big loss. They felt a strong attachment to the place they were living in.

4.3.3 Transition from the rehabilitation clinic to day therapy

For some participants there was a long time between the moment of going home and the beginning of day therapy. This was only the case if the day therapy would not be at the rehabilitation clinic, if it was at the rehabilitation clinic it continued immediately the next week.

"I have to say, if I had known everything I might have made the choice [to continue my day therapy in the rehabilitation clinic]. I haven't been to day therapy yet, so it could be very good. (...) But I have been at home for already one month and I haven't had any physiotherapy or occupational therapy."
Mr. Torgerson

There did not seem to be a lot of communication between the rehabilitation clinic and other facilities that provided day therapy. This participant wanted to continue with his therapy after he got home, but he was waiting for it for one month already. Other participants who had day therapy somewhere else also had similar complaints. Having to wait for additional therapy was not beneficial for the rehabilitation process. It was better to continue with the day therapy the moment the participants left the rehabilitation clinic, because therapy gets less effective as time goes by (National Stroke Association, 2012).

Also, some patients did not go to day therapy at all. Some did not go because was not needed, but for others it actually was.

"It is difficult, I'll tell you I have never had a stroke before and you think you can walk if you are lying in your bed. Because then you feel no pain. But if you get up, then there is still pain. It is also because I laid in my bed for weeks. (...) But it is already going better, I am glad I am as far as I am. I have to rehabilitate, but for ten times for half an hour I have to pay 750 euro's, I won't do that, it is too expensive. And I don't have it either." Mr. Hankins

When the day therapy is delayed or the patient doesn't go at all the rehabilitation process slows down. This participant had pain and difficulty walking, but he did not go to day therapy. Not having the money, or not willing to pay it, had a major impact on his rehabilitation process. He was still noticing improvements, but not nearly as fast as in the rehabilitation clinic and this might be because he had no therapies anymore.

Another difficulty some participants had was that there were no therapies every day anymore. They were told to do exercises and go to day therapy, but this is the responsibility of the patients themselves. Some participants found it hard to continue exercising without the many therapies that were offered in the rehabilitation clinic.

"If you get in the rehabilitation clinic, although it is forced, but you are being occupied with sports exercises especially designed for you, that is very enjoyable, if you have gotten used to it. (...) I have to say, I miss that. I am not that enthusiastic to [do exercises now] but if it would have continued I would have benefited from it." Mr. Torgerson

This participant did not have the willpower to do exercises on his own, even though he liked the exercises that were provided in the rehabilitation clinic. But because he did not have to do it when he was back at home, it was difficult for him to get motivated. Because of this he did not feel as in shape as he did when he was in the rehabilitation clinic. This was not the case for everyone though, some

participants did their exercises every day. The participants that did exercises seemed to improve more quickly at home than the participants that did not do exercises, which indicates that the exercises were important.

4.3.4 Relationships

The support from family was very important. Especially the partner was important and participants who had a partner benefitted from this, they felt supported by their partner.

"I like it that [my wife joins me if we go to day therapy]. If I have to cross the road I like it. Because you have to look to your left and right there. Often I say, you have to look if we can cross. The reassurance, you know? Especially looking to the right, then I really have to stand still and look, is something coming?" Mr. Hummel

This participant felt supported because his wife always joined him when he went to day therapy. He acknowledged he could get there on his own, but he felt reassured when his wife joined him, especially when he had to cross a road. Other participants had similar experiences, their partners aided them and they always had someone that they could ask for help.

Some of the participants noticed changes in relationships when they were home. Some of these changes were more subtle than others.

"Everybody was smothering me, I really didn't like it. (...) And our children also called a lot, and [before the stroke] they always called me, but then they always called dad." Ms. Rollin

This participant noticed that her family members were smothering her and were not treating her the same as they did before she had the stroke. She was not happy about this, she wanted to be treated normally, but it took some time before her husband and children realized this. After these initial weeks the her family began to realize she did not liked to be smothered and their relationship began to change back to how it was before the stroke. Other participants also wanted to be treated like a normal person. This seemed to be important for them, they did not want to be treated as a stroke patient. In order for the participants to feel normal and continue with their lives, their friends and families had to treat them as normal persons.

Another example of changing relationships is of a participant who lost a lot of friends because of the stroke. Less people contacted him after he went home and he felt left behind.

"When I got home they haven't called me once, so I am not going there anymore. (...) There is only one former colleague and he already said it at the start, 'now you will know who are your real friends'. And he is right." Mr. Hankins

This participant felt disappointed by his friends. He felt left alone by his friends, they did not contact him after he got home. Another patient had a similar experience, but other participants did not notice differences in relationships with other people.

The participants who felt let down by their friends did not have a partner and both had the feeling of depression at some point after they left the rehabilitation clinic.

"I did not want to eat, I really wanted to die because I was very depressive, it was very bad. Not wanting it anymore, the purposeless life." Ms. Adams

So it seems that having relationships with other people also gives participants meaning, because if these relationships are not there participants felt that life was meaningless.

Not every participant had a partner. There seemed to be a difference between participants with a partner and those that did not have a partner. The participants who had a partner did not notice much difference in the relationships with their friends and acquaintances, but the participants who did feel left alone by their friends did not have a partner.

An explanation could be that participants without a partner have different personalities than the participants with a partner. Another explanation could be that the partners were responsible for maintaining the relationships.

Not every participant without a partner noticed changes in relationships. Not having a partner did not necessarily mean that their friends would leave them. It should be noted that there seems to be a relationship but that this could be just a coincidence.

It is interesting to see that not only the participants themselves were affected by the stroke but their relationships as well. These changes in relationships had a great impact on the lives of the participants, especially when the participants felt left alone.

4.4 Comparison

This section is about the comparison between the expectations and experiences the participants had. Most participants were happy to be home again. This had been their goal for the duration of the rehabilitation process and they wanted to get back to their own environment.

However, some of the participants did not realise that the rehabilitation was not yet over when they returned home. Their expectations were that everything was going to be all right when they got home, but it takes a long time to do the things they were used to do before the stroke, if they get to that point at all.

4.4.1 Daily schedule and rehabilitation process

Most of the participants had trouble with fatigue, they were not able to do the things as they did them before the stroke, because they got tired a lot quicker. It seemed they had not realized this would be such an obstacle when they were in the rehabilitation clinic. In the rehabilitation clinic the participants noticed that they were often tired, more than before the stroke, but they did not seem to realize this would still be a problem when they went back home. A possible explanation is that this could be because there was a scheduled rest period in the rehabilitation clinic and participants did not do this anymore when they were back at home.

"I do not expect a lot of problems, because I am still improving in my functioning. So if more time goes by, I will be able to function more. And I expect that, seeing how I am now, that there will be no problems." Mr. Mullin

This participant expected a lot of improvement, similar to the expectations of other participants.

"The last few weeks I am not walking and cycling because of the bad weather, but normally I am. And that was so tiring that the day was already over. So it was just resting a lot of the time." Mr. Mullin

But when he was home he experienced a lot of fatigue. Later he explained why he thought he was tired more often than before the stroke.

"Automatisms, that not everything goes as automatically as before, that troubles me the most." Mr. Mullin

Because this participant had to think about everything he did, such as walking, shaving or brushing his teeth and because of this he got tired quickly. This is also what other participants who were tired a lot mentioned, and they did not expect this to be a problem when they were in the rehabilitation clinic. Because of this the participants that experienced fatigue were not able to pick up their lives as easily as they expected. They had to adjust their expectations and learn to cope with living with the fatigue.

It seemed that some of the participants underestimated the challenges that they had to face when they went back home. Especially some of the participants who thought that everything was going to be all right were disappointed, they were not able to do all the things they were used to do. The rehabilitation process takes a long time and it did not stop when they left the rehabilitation clinic. Even the participants who recovered quickly noticed difficulties, such as not being allowed to drive a car or not being able to work in the garden.

“In my mind I think, it is getting better, I will soon be able to do this again, and that again. But what [my wife] already said, I expected it to go faster. (...) I expected not to be as dizzy and nauseated anymore. And I tried some cycling, but it is not going very well.” Mr. Woodward

This participant was very positive when he was in the rehabilitation clinic. He recovered quickly and thought he would be able to do a lot of things again when he would go home. But it did not turn out the way he expected it to be. He was still struggling with his balance and because of that he often felt dizzy and nauseated. More participants who were very positive in the rehabilitation clinic were disappointed about their rehabilitation progress.

Some participants had not realized that the environment at home would be different from the rehabilitation clinic.

“When you are at occupational therapy in [the rehabilitation clinic] there are special tables. They can be adjusted for height, but we do not have them [at home]. I do not have an adjustable table. And if I sit here it is difficult to put my elbow on the table. In [the rehabilitation clinic] they would have adjusted the table.” Mr. Torgerson

In the rehabilitation clinic everything was adjusted so that stroke patients could easily use it, but this was not always the case at home. Some participants who were in the rehabilitation clinic did not realize this until they were home. The situations in the rehabilitation clinic were not always the same as the situations at home and when participants did not realize this their expectations could have become too optimistic.

The expectations were influenced a lot by how well the rehabilitation process went. If the rehabilitation process was going well the expectations for the future were more positive because of that. Participants who were really positive about the future were sometimes disappointed when they were at home, even though they might have rehabilitated fairly well in comparison with other patients. But because the rehabilitation in the rehabilitation clinic went so quickly these patients expected this to continue when they were at home. This is not always the case, the final stages of rehabilitation can take a long time. This can lead to disappointment even though everything went well in comparison with other patients. When the participants compared themselves to other patients they realized that it could have been much worse and this caused them to feel better about themselves. But even though these participants had improved more at the time of the second interview, some of them were disappointed because they were expecting too much. They expected that their lives would be more the same as before the stroke, but in reality they still had problems with mostly fatigue and mobility.

There did not seem to be a clear relationship between participants who thought about the future and participants who had not thought about what would happen when they got home. Participants who thought about what would happen the future did not seem to be better prepared when they got home. This might be because in reality it is very difficult to predict what will happen when patients go home. There are many aspects that are hard to predict, how much will they recover, how will the people around them react, how will they adapt to their environment and how quickly will they accept their possibly permanent limitations caused by the stroke.

It can be debated whether it is a bad thing that patients are sometimes 'too' positive when they are in the rehabilitation clinic if they do have high expectations. Some of their expectations might not be realistic but if a patient expects that if he or she works hard everything is going to be fine, they do give themselves the best chance of recovering. However, they might feel disappointed when it does not turn out the way they expected. Whether or not a patient benefits from being 'too' positive depends on the kind of person, for some it will be helpful and for some it will not.

4.4.2 Moving

The participants who had already moved in between the first and second interview did not have much choice. Ms. Adams was not able to return to her home because the doorsteps were too high for a wheelchair and Mr. Mullin lived in a place where there was almost no public transport. Ms. Adams already knew in the rehabilitation clinic that she had to move, she already expected it. Mr. Mullin did not mention it during the first interview, but in the second interview he said he and his wife had already thought about it before he had the stroke. But because he could not go anywhere due to the lack of public transport they speeded up the process and moved quickly after he was dismissed from the rehabilitation clinic. Mr. Mullin knew a person that was interested in buying the house so after he found a new house it was possible to quickly arrange the move.

Even though Ms. Adams knew she had to move when she was in the rehabilitation clinic, she did not expect it to have such a big effect on her life. She recognized that it was too small, but this home was only temporary and she expected to find something bigger soon. But when she was in her new apartment she faced all sorts of problems, her room was indeed too small but she also had a fear of heights. And she had to wait four months until she could move again, to a bigger apartment that was not so high. She did not expect it to take this long and she also did not expect to have such a bad time in the small apartment. So even though she expected to have some problems because she had to move, she did not expect it to be as severe as it was.

The participants who were thinking about moving but had not moved yet noticed less problematic difficulties. For Mr. Torgerson and Mr. Woodward the houses they were living in were sometimes difficult to maintain, because they could not do as much as before the stroke. When they were in the rehabilitation clinic they did not mention this, it seemed that they did not expect this. Moving could be a possible solution to their problems, but both were not sure yet.

4.4.3 Relationships

Some participants who experienced a change in relationships did not expect it when they were in the rehabilitation clinic. Other participants did not expect changes and also did not experience any.

Ms. Rollin, who noticed that her husband was more protective during the weekends when she went home, also felt smothered when she was at home permanently. She did not expect this, she thought it would be over soon but it took more time than she expected. Another participant also noticed this even though he had not expected it.

With some things I think, I have to do that. But then they say, 'you should not do that just yet, you have to take it easy'. And then I say, 'but I can do it'. But they still think, no. If I have to do some work or something they say, 'you just take it easy'. (...) But they mean it well, I accept it." Mr. Henson

This is a similar difference between expectation and experience. He did not expect any difference in relationships when he was in the rehabilitation clinic, but when he was back at home he noticed that his brothers and sisters did not want him to do much. But the participant knew they meant it well and he was happy he was supported by them.

As already mentioned there were also participants who experienced other difficulties regarding relationships. Some participants felt let down by their friends, they did not visit anymore. When Ms. Adams was in the rehabilitation clinic people visited her, and she expected them to also visit her when she was at home. But after she dismissed from the rehabilitation clinic these people did not come or called anymore. She felt very disappointed by this and this caused her to become depressive. This was a similar experience that Mr. Hankins had, he also expected that his friends would visit him but felt let down by them when he was back home.

Some participants expected to keep in contact with other patients who were in the rehabilitation clinic.

"I will never forget this, the people here, they are great. And the patients also. I will visit a couple of patients, and I will try to get their phone number and address if they want to, to keep in contact. There are a couple of patients who are really dear to me." Mr. Hankins

He explained during the first interview that he would like to stay in contact with other patients. However, when this participant was back at home this did not happen, he did not have contact with any of the patients he knew from the rehabilitation clinic.

"[I miss] my friends there, the patients. I went through a lot with them. I miss that. (...) But I do not know where they live." Mr. Hankins

He would have liked this, but they did not exchange information. More participants felt the same, they would have liked to meet other patients they met in the rehabilitation clinic. Some were curious about how others were doing but they did not have any contact information. Not all the participants wanted this, but it might be a good idea to advise patients who are going to leave the rehabilitation clinic to get some contact information from other patients, because they might like to contact them in the future, even though not everyone realized this when they were in the rehabilitation clinic.

5. Discussion

Similarly to the findings in other studies (Eilertsen et al., 2009; Burton, 2000) the participants initially did not have detailed expectations about the future when they went to the rehabilitation clinic. When the participants were longer in the rehabilitation clinic they started to define goals and expectations.

In this thesis relationships with other patients in the rehabilitation clinic played an important role. Other studies did not mention these relationships (e.g. Eilertsen et al., 2009). Because of the relationships that some participants had with other patients they felt emotionally bonded with the rehabilitation clinic. Participants that had good relationships with other patients seemed to feel more attached to the rehabilitation clinic (Scannell and Gifford, 2010).

Some participant thought the information that was received was not enough, while other participants felt like it was good. Other studies also suggested that more information should have been provided to stroke patients (Olofsson et al., 2005; Rodgers et al., 2001). The way information was presented could also be improved, instead of providing impersonal flyers it would be better to provide personalized information, such as talks with the staff.

The participants in this study had positive expectations about going home, but before they were home they were not fully able to understand how the effects would influence their lives. This was similar to findings in other studies (Olofsson et al., 2005; Burton, 2000). One reason for this was that the participants learned their abilities in a clinical environment. When the participants went home they realized that not everything was adjusted for them and this sometimes caused problems.

Participants that left the rehabilitation clinic and wanted to go to day therapy had trouble doing this. The day therapy did not start immediately after leaving the rehabilitation clinic. Hart (1998) also noticed this problem. Patients felt they had fallen into a gap because the therapy did not continue.

None of the participants were finished rehabilitating at the time of the second interview. Even though some participants expected it would be over when they got home, this was not the case. Participants still noticed that some parts of their lives were affected by the stroke. Burton (2000) also saw that there was no 'common path of recovery', every rehabilitation process was different. He advises that stroke services should take the long-term needs into account. This is something the rehabilitation clinic might be able to do better, especially in relation to the transition from the rehabilitation clinic to day therapy.

In the conceptual framework the concepts of formal and informal care and personality were discussed. However, none of the participants were using formal care and the only informal care they received was from their partner, which was already discussed as the support network. Personality is difficult to grasp, it does influence the expectations and experiences but it is hard to measure.

The concept of place attachment (Scannell and Gifford, 2010) is not only relevant to the participants when they were at home, as was shown in the conceptual model. Some of the participants also felt attached to places in the rehabilitation clinic. A very good example of this is when Mr. Hankins went back to the rehabilitation clinic for a check-up after he had already gone home.

He still called the bed he used when he was there his own bed. He was attached to the place because of the people, he met one patient who he knew and he did not know the other new patients. Because of the contacts that he had he felt attached to the place, but he also recognized that those people were not there anymore. But he still called it 'his place', he still felt a connection because of the experiences that he had when he was there.

This experience can be related to the three-dimensional framework by Scannell and Gifford (2010). The first dimension is about the person, Mr. Hankins was attached to the rehabilitation clinic because of what he had experienced there. The second dimension is about the way the individual is connected to the place, Mr. Hankins felt an emotional bond with the rehabilitation clinic and had memories of what had happened there. The third dimension is about the place itself, Mr. Hankins felt attached to the rehabilitation clinic because of the people that he met there. Even though most of these people were not there anymore he still felt the connection.

Place attachment is also very important when the participants were in the rehabilitation clinic and were thinking about home. Most wanted to go home as soon as possible and be with their friends and families again. But they also realized that they had to stay in the rehabilitation clinic to rehabilitate. Some participants noticed during the weekends when they were home that they could not do much and therefore wanted to go back to the rehabilitation clinic again.

What Ms. Adams experienced after she moved shows the impact moving can have on a person. She did not feel at home and was afraid because of her fear of heights. She did not feel attached to her home and this caused a lot of problems for her. The participants who were thinking about moving realized that some things would be better or easier when they would move. But because they felt attached to their home and neighbourhood this was a very difficult decision, leaving their home would feel like a loss.

Because most people have a strong feeling of place attachment to their home, moving is a big decision. The participants felt connected to their home because of all the things they had experienced there and because of the people that lived there, for example their neighbours. They had a lot of memories about their home and this caused an emotional bond with the place (Scannell and Gifford, 2010).

6. Conclusion

The objective of this research was to explore what stroke patients in a rehabilitation clinic expected about being home after leaving the rehabilitation clinic and what they experienced when they were at home afterwards.

Most of the participants found the experience in the rehabilitation clinic positive. They were very positive about the staff and the facilities and did not have a lot of complaints. The relationships with other patients were very important. Having a good relationship with roommates and other patients helped participants, they felt supported by each other. But a bad relationship also caused severe problems, up to a point where a participant did not want to live anymore.

Most participants were optimistic about the future, they thought it was going to be better when they got home. There were some participants who thought their lives would go back to normal, the way they lived before the stroke. Others expected some difficulties, such as not being able to work anymore, but thought this would be temporary. There were also participants that knew some of the effects of the stroke would likely be permanent.

The speed of the rehabilitation process influenced the expectations the most. If the rehabilitation process was going well and participants noticed improvements they were positive about the future. If there were setbacks in the rehabilitation process participants were less optimistic and did not expect to recover fully.

The information received from either the rehabilitation clinic or other patients did not influence the participants' expectations a lot. Some participants felt the information they received was good while others thought they could have used more information about what to expect.

After rehabilitating in the rehabilitation clinic some participants had the desire to continue with day therapy. Some participants did this in the same rehabilitation clinic and they did not experience any problems, but some participants who wanted to rehabilitate at another facility noticed that there was a long time, up to a month, before the day therapy started. This could have had a bad influence on the rehabilitation process.

The support of family and friends was very important. Participants who had a partner benefitted from this. Some participants noticed changes in relationships. Some felt they were smothered while others felt neglected by their families and friends. The participants who felt neglected and left alone by their friends were severely affected by this and this caused depression.

Another experience that some participants had was that they moved after they left the rehabilitation clinic. Moving has a lot of implications, they did not only have to adjust to their lives because of their disabilities but also because they moved to a new place.

To conclude, a comparison can be made between the expectations that the participants had in the rehabilitation clinic and the experiences at home. It seemed that the participants had not expected the rehabilitation process to take this much time. Some expected it to be almost over when they would go home, but when they were home they still noticed difficulties in especially mobility and

fatigue. Some participants did not expect that the stroke would have such a big effect on their life, only when they came home they realized that some effects of the stroke could be permanent.

There are some limitations in this study. All the participants went to the same rehabilitation clinic, so it is very focused on this clinic and it does not represent all rehabilitation clinics in the Netherlands. Another limitation is that there was only one participant who was mainly cognitively impaired while the rest of the participants were mainly physically impaired because of the stroke. More cognitively impaired participants might have resulted in different outcomes. In this research this was not possible, due to the fact that there were no other suitable patients that were cognitively impaired available.

Further research could be done on this topic. A quantitative research on the correlation between whether a patient has a partner and the quality of life could be done. If it shows that patients without partners are more likely have a lower quality of life or to become depressive after a stroke it could be wise to pay extra attention to stroke patients without a partner after they leave the rehabilitation clinic, because they would then be more vulnerable.

Another interesting study could try to research whether it is a good thing for stroke patients to sometimes feel 'too' optimistic about the future when they are in a rehabilitation clinic. Some of the expectations that participants had were not very realistic, but this positive thinking might have helped them in the rehabilitation process. It would be interesting to know whether this would be the case. A study could be done to find out whether stroke patients that had very optimistic expectations were also more motivated during the rehabilitation process.

It would also be good to study a group of stroke patients over a longer period of time. The participants in this study were not all finished fully with their rehabilitation. They left the rehabilitation clinic but some were still recovering. A longer study would be interesting, because during the second interview some participants also talked about expectations about the future, for example, that they would like to work again but were not yet able now. It can be interesting to see how the stroke affects their lives after a longer period of time.

I can also make some policy recommendations. When a patient knows at what date he will leave the rehabilitation clinic it would be good for him or her to already think about day therapy. This patient can then start this process when he or she is still in the rehabilitation clinic, so there will not be a large amount of time without therapy when he leaves the rehabilitation clinic. The staff in the rehabilitation clinic could advise patients about this. Another solution could be a better communication between the rehabilitation clinic and the facilities that provide day therapy in order to reduce the waiting time.

It could also be a good idea to provide more information to the patients. Some participants felt they had not gotten enough information about what was going to happen and felt unsure about this. The best way to provide this information is by having talks with the patients, instead of an impersonal flyer with information. More information about the importance of exercises when the patients leave the rehabilitation clinic could be beneficial too, because not every participant did these exercises.

Whether it is a good idea to adjust patients' expectations when they seem 'too' optimistic is a difficult topic. Some patients might feel discouraged if they would be told that some of the limitations because of the stroke have a high chance of being permanent. On the other hand, some participants were disappointed when they were at home and had not recovered completely.

7. References

- American Speech-Language-Hearing Association (2012), *Fact Sheet for Speech-Language Pathology*, <http://www.asha.org/careers/professions/slp> last visited on 10-08-2012
- Anderson R. (1992), *The aftermath of stroke: the experience of patients and their families*. New York, Cambridge University Press.
- Babbie, E. (2010), *The Practice of Social Research*. Cengage Learning: Wadsworth
- Benjamin, D. & Stea, D. (1995), *The Home: Words, Interpretations, Meanings and Environments*. Aldershot: Avebury.
- Burton, C. R. (2000), Living with stroke: a phenomenological study. *Journal of Advanced Nursing*, 32(2), 301-309.
- Byrne, D., Goeree, M.S. & Hiedemann, B. (2009). Formal Home Health Care, Informal Care, and Family Decision Making. *International economic review*. 50(4) 1205-1242
- Carod-Artel, J., Egido, J.A., González, J.L. & de Seijas, E.V. (2000). Quality of Life Among Stroke Survivors Evaluated 1 Year After Stroke. *Stroke, Journal of the American Heart Association*. 31, 2995-3000.
- Chartered Society of Physiotherapy (2012), *What is physiotherapy?*, <http://www.csp.org.uk/your-health/what-physiotherapy> last visited on 10-08-2012
- Chow, K. and Healey, M. (2008). Place attachment and place identity: First-year undergraduates making the transition from home to university. *Journal of Environmental Psychology*, 28(4), 362-372.
- Deliargyris, E.N., Upadhya, B., Applegate, R.J., Kontos, J.L., Kutcher, M.A., Riesmeyer, J.S., & Sane, D.C. (2005). Safety of Abciximab Administration During PCI of Patients with Previous Stroke. *Journal of Thrombosis and Thrombolysis*, 19(3), 147-153.
- Eilertsen, G., Kirkevold, M., & Bjørk, I. (2009), Recovering from a stroke: a longitudinal, qualitative study of older Norwegian women. *Journal of Clinical Nursing*, 19, 2004–2013.
- Fried, M. (2000). Continuities and discontinuities of place. *Journal of Environmental Psychology*, 20, 193-205,
- Hafsteinsdóttir, T. & Grypdonck B (1997), Being a stroke patient: a review of the literature. *Journal of Advanced Nursing*, 26, 580-588.
- Hart, A. (1998), "The use of pluralistic evaluation to explore people's experiences of stroke services in the community", *Health and Social Care in the Community*, 7(4), 248–256.
- Hennink M., Hutter I. & Bailey A. (2010), *Qualitative Research Methods*. Sagepublications: London.
- Higaldo, C.M. & Hernández, B.(2001). Place attachment: conceptual and empirical questions. *Journal of Environmental Psychology*, 21(3), 273-281

- Hohmann, C., Klotz, J.M., Radziwill, R., Jacobs, A.H. & Kissel, T. (2009). Pharmaceutical care for patients with ischemic stroke: improving the patients quality of life. *Pharmacy World & Science*. 31(5) 550-558.
- Lewinter M., Mikkelsen S. (1995), Patients' experience of rehabilitation after stroke. *Disability and Rehabilitation*, 17(1), 3-9.
- Mazza, A., Pessina, A.C., Pavei, A., Scarpa, R., Tikhonoff, V., and Casiglia, E.(2001), Predictors of stroke mortality in elderly people from the general population: The cardiovascular study in the elderly. *European Journal of Epidemiology*. 17(12), 1097-1104
- Moore, J. (2000). Placing Home in Context. *Journal of Environmental Psychology*. 20(3), 207-217
- Murray, C.D. & Harrison, B. (2004). The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. *Disability & Rehabilitation*. 26(13), 808-817.
- National Stroke Association (2010), Stroke 101 Fact Sheet. <http://www.stroke.org> last visited on: 23-10-2011.
- National Stroke Association (2012), *Stroke Survivors: Effects of Stroke*, <http://www.stroke.org/site/PageServer?pagename=EFFECT> last visited on 12-08-2012
- O'Connell, B., Hanna, B., Penney, W., Pearce, J., Owen, M., Warelow, P. (2001), "Recovery after stroke: A qualitative perspective", *Journal of Qualitative Clinical Practice*, 21, 120–125.
- Olofsson A., Andersson S. O., Carlberg B. (2005), 'If only I manage to get home I'll get better'- Interviews with stroke patients after emergency. *Clinical Rehabilitation*, 19, 433-440.
- Omachonu, V. K. (1990). Cited in: Arneill, A.B. & Devlin, A.S. (2002). Perceived quality of care: the influence of the waiting room environment. *Journal of Environmental Psychology*. 22(4), 345-360.
- Pretty, G.H., Chipuer, H.M. & Bramston, P. (2003). Sense of place amongst adolescents and adults in two rural Australian towns: The discriminating features of place attachment, sense of community and place dependence in relation to place identity. *Journal of Environmental Psychology*, 23(3), 273-287.
- Relph, E. (1976). *Place and placelessness*. London: Pion.
- Rodgers, H., Bond, S., Curless, R. (2001) Inadequacies in the provision of information to the stroke patients and their families. *Age and Ageing*, 30, 129-133.
- Scannell, L., & Gifford, R. (2010), 'Defining place attachment: A tripartite organizing framework'. *Journal of Environmental Psychology*. 30, 1-10.
- Song, Y., Kwon, S.U., Sung, J., Ebrahim, S., Smith, G.D., Sunwoo, S. & Yun, Y.S. (2005). Different risk factor profiles between subtypes of ischemic stroke. A case-control study in Korean men. *European Journal of Epidemiology*. 20(7), 605-612.
- Statistics Netherlands (2011). *CBS*, <http://www.cbs.nl/> last visited on: 18-09-2011
- WHOQOL, the world health organization quality of life assessment (1995). Position paper from the world health organization. *Social Science & Medicine*, 41, 1403-1409.

World Federation of Occupational Therapists (2011), *What is Occupational Therapy?*,
<http://www.wfot.org/> last visited on 10-08-2012

8. Appendices

8.1 First interview guide

Uitleg onderzoek (voorafgaande aan het interview)

Goedemorgen/middag, mijn naam is Jelle Straatsma en ik ben met een master thesis bezig over de ervaringen en verwachtingen van patiënten die rehabiliteren na een beroerte.

- Het doel van mijn onderzoek is om te kijken op welke manier de revalidatiezorg voor mensen na een beroerte/CVA verbeterd kan worden.
 - Voor mijn onderzoek ben ik geïnteresseerd in hoe mensen met een CVA hun verblijf in het revalidatiecentrum en later thuis ervaren.
 - Ik wil graag interviews afnemen bij mensen die opgenomen zijn in het revalidatiecentrum. We willen kijken of er een verschil is tussen ervaringen op het moment dat mensen nog opgenomen zijn in het revalidatiecentrum en na het ontslag.
 - Heeft u nog vragen of wilt u nog iets meer weten over de interviews of het onderzoek?
-
- Vragen aan de participant waar hij/zij graag wil zitten tijdens het interview.
 - Recorder klaar zetten en water of drinken klaar zetten.

Voordat we beginnen met het interview, zou ik graag wat algemene gegevens van u willen hebben.

Algemene gegevens

- Naam
- Adres
- Woonplaats
- Telefoonnummer
- Type woning
- Geboortedatum
- Burgerlijke staat
- Beroep
- Datum CVA
- Datum opname

Dan beginnen we nu met het interview (recorder aanzetten)

Interview

Introductie

Goedemorgen/middag Dhr/Mevr ... Bedankt dat ik dit interview bij u mag afnemen. U heeft ingestemd met het afnemen van dit interview en dat dit interview opgenomen wordt en dat de gegevens gebruikt zullen worden voor verder onderzoek. Uw naam zal onbekend blijven, waardoor niemand zal kunnen achterhalen dat u dit bent.

Ik zou u een aantal vragen willen stellen over hoe u, na het krijgen van het CVA, het verblijf hier in het revalidatiecentrum ervaart.

Plekken in het revalidatiecentrum

Waar (plek) – Wat (activiteit) – Wie (met wie) – Hoe (gevoel)

Kunt u vertellen wat u in het revalidatiecentrum op een dag doet van opstaan tot slapen gaan?

Tijdstip	Activiteit
< 9.00 uur	Douchen/wassen/aankleden
8.00-9.00 uur	Ontbijten
9.00/10.00-12.00 uur	Therapie
12.00-12.30 uur	Middageten (brood)
12.30-13.00-14.00 uur	Rusten
13.00-17.00 uur	Therapie (en bezoek vanaf 15.00 uur)
17.00-18.00 uur	Avondeten (warm)
18.00-20.00 uur	Bezoek

Reden opname (CVA)

Kunt u mij vertellen wat er gebeurd is, waarom u opgenomen bent in het revalidatiecentrum?

NB. Eventueel ingaan en dieper doorvragen op lichamelijke en niet-lichamelijke gevolgen van een CVA, zie eind interview.

Kamer

Kunt u mij vertellen hoe uw kamer eruit ziet?

Hoe beweegt u zich in de kamer?

Welke spullen heeft u van huis meegenomen?

- Waarom? Wat voor gevoel geeft het u?

Hoeveel tijd brengt u door op uw kamer?

- Is dit ook veranderd in de tijd?

Deelt u uw kamer met anderen?

Zo ja,

- Met hoeveel personen deelt u uw kamer?
- Hoe vindt u het dat u uw kamer deelt met anderen?
- Hoe is het contact met uw kamergenoten?

Zo nee,

- Hoe vindt u het dat u een kamer voor u alleen heeft?
- Heeft u daar zelf om gevraagd? Is daar een reden toe?

Kunt u aangeven wie er gedurende een dag op uw kamer komen?

- Verschilt dat over de dag?
- Wat voelt u daarbij?

Hoe voelt u zich hier op uw kamer?

- Verschilt dat per dagdeel (bv 's nachts anders dan overdag)?

Hoe slaapt u?

Heeft u een favoriete plek op de kamer? Waar? Waarom?

Andere plekken

Kunt u vertellen naar welke plekken u nog meer naar toe gaat?

NB. Voorbeelden: Afdeling (kamer, douche, toilet, dagverblijf), therapieruimtes (inclusie sporthal), tuincafe, buiten.

- Waar is deze plek?
- Kunt u beschrijven hoe de plek eruit ziet?
- Hoe ervaart u deze plek/ruimte?
- Hoe gaat u daar naar toe?
- Gaat u er alleen heen, of met begeleiding? Waarom?
- Wat voor afstanden moet u overbruggen?
- Hoe beweegt u zich in die ruimte? Wordt u hierbij geholpen?
- Welke mensen komt u tegen in deze ruimte?
- Hoe voelt u zich in deze ruimte?
- Naar welke plek gaat u het liefst? En waarom?
- Naar welke plek gaat u het minst graag? En waarom?

Buiten

Gaat u hier weleens naar buiten?

- Kunt u eens vertellen hoe u dat doet?
- Gaat u alleen of met begeleiding? Waarom?
- Waar gaat u dan heen?
- Wat voor afstanden kunt u dan overbruggen?
- Is deze afstand vergelijkbaar met voorheen?
- Gaat u vaak naar buiten?
- Zou u vaker/minder vaak naar buiten willen? Waarom? Waarom kan dit niet?
- Zijn er ook dingen die u belemmeren om naar buiten te gaan? (fysiek, psychosociaal)
- Met wie gaat u? Of alleen?

Naar welke plek gaat u het liefst?

- Waarom is dat uw lievelingsplek?
- Wat voor gevoel geeft het u om daar te zijn?

Zijn er ook plekken die u juist vermijdt?

- Kunt u uitleggen waarom dat is?
- Hoe voelt u zich daarbij?

Dagindeling/routines/ritmes/gewoontes

Kunt u mij vertellen wat u vindt van de dagindeling in het revalidatiecentrum?

Hoe deelde u voorheen uw dag in?

- Wat is daarin het verschil met nu u in het revalidatiecentrum bent?
- Wat voelt u daarbij?

Mensen

NB. Eventueel navragen, als het nog niet aan bod geweest is bij de plekken

Lotgenoten

Welke mensen zoekt u hier in het revalidatiecentrum op?

- Waarom wel (gezelligheid, ervaringen uitwisselen etc.)?
- Waarom niet?

Familie/vrienden/kennissen

Zou u kunnen vertellen wie er bij u op bezoek komen:?

Wanneer komen ze?

Wat doet u samen?

Waar gaat u dan heen?

Hoe voelt het om deze mensen om u heen te hebben?

Zijn uw sociale contacten na uw beroerte/CVA veranderd?

- Kunt u daar meer over vertellen? OF Wat is er veranderd?
- Waarom?

Personeel/behandelaars

Wat vindt u van het personeel/de behandelaars hier in het revalidatiecentrum?

- Heeft u goed contact met ze?
- Is er ook een bepaalde persoon/personen belangrijk voor u?
- Wat maakt dat deze persoon belangrijk voor u is?
- En wat voor gevoel heeft u hierbij?

Steun

Door wie voelt u zich gesteund?

- Waarin ervaart u deze steun?
- Wat doet dit met u?

Thuis

Weekendverlof

Bent u al thuis geweest in het weekend?

- Kunt u beschrijven hoe dat was?
- Hoe voelde het om weer thuis te zijn?
- Hoe vaak bent u thuis geweest?
- Een dag, meerdere dagen of ook nachten?

Indien vaker: Hoe is het thuis zijn nu vergeleken met het begin?

- Wat is er veranderd?
- Voelt het thuis zijn zoals voor het CVA?

Verlangen naar huis

- Denkt u vaak aan thuis?
- Kunt u aangeven waar u dan aan denkt?
- Gebeurt dit vaak op een dag? Of juist op specifieke momenten?
- Hoe gaat u hiermee om?
- Wat helpt u dan? Of wat doet u dan?
- Is dat gevoel ook veranderd sinds het begin van uw opname? (erger of beter)

Hoe kijkt u aan tegen het weer naar huis gaan?

- Heeft u een idee op welke termijn u naar huis zou kunnen gaan?
- Hoe zal het zijn om weer thuis te zijn?
- Heeft u dit ook al met andere mensen besproken (en met wie)?

Plekken thuis

Kunt u vertellen hoe een dag er vroeger uit zag?

- Wat is er veranderd?

Naar welke plekken ging u allemaal?

- Wat deed u daar?
- Hoe voelde u zich op die plekken?
- Wat is het verschil met nu? Hoe komt dit verschil?

Op welke plek bent u thuis het liefst?

- Kunt u beschrijven waarom u het liefst naar deze plek gaat?
- Is dat nu nog steeds uw lievelingsplek? Waarom wel/niet?

Welke plekken bezocht u voordat u het CVA kreeg?

- Hoe ging u daarheen?
- Hoe voelde u zich daar?
- Wat is het verschil met nu?

Sociale contacten

Bent u iemand die er van houdt om mensen om u heen te hebben thuis?

- Kunt u eens vertellen hoe dit eruit zag thuis?
- Hoe was u dat thuis gewend?
- Krijgt u thuis veel bezoek, of gaat u juist op bezoek?
- Wat voor gevoel geeft u dat?

Problemen CVA

NB. Eventueel navragen, als het nog niet aan bod is geweest bij plekken

Lichaam

Wat zijn voor u de grootste lichamelijke veranderingen geweest als gevolg van uw CVA?

Kunt u me vertellen hoe uw lichaam voelt nadat u het CVA heeft gekregen?

- Wat is er veranderd?
- Wat is het verschil met voorheen?
- Voelt uw lichaam nog als uw eigen lichaam? Waarom wel/niet?
- Hoe merkt u dat als u activiteiten onderneemt?

Hoe beweegt u zich nu?

- Is dit anders vergeleken met voorheen?

- Wat is er anders?
- Maakt u ook gebruik van hulpmiddelen? Zo ja, welke?
- Hoe voelt dat?
- Heeft u hulp nodig met transfers (in/uit bed, toilet)
- Wordt u begeleid tijdens het lopen/voortbewegen?

Voelt u zich thuis in uw lichaam?

- En is dit gevoel in de loop van de tijd ook veranderd?

Psychisch/gedragmatig

Zijn er ook niet zichtbare lichamelijke veranderingen?

- Bv veranderingen in onthouden, concentratie, rekenen, meerdere dingen tegelijk doen, rijden in de ruimte, de weg vinden etc.?
- Bent u voor wat betreft uw gedrag/karakter veranderd? (sneller verdrietig, sneller boos?)
- Geeft uw omgeving ook aan dat er dingen veranderd zijn?
- Waar merkt u dit aan?
- Wat doet dit met u?

Is uw zelfbeeld (het beeld dat u van uzelf heeft , hoe u over uzelf denkt) veranderd? (positief, negatief)

- Op welke manier merkt u dit?
- Wat doet dit met u? Wat heeft dit voor gevolgen?

Algemeen

Als u naar het revalidatiecentrum kijkt, hoe zou u het aan iemand beschrijven die hier nog nooit is geweest?

- Is dit gevoel/idee ook veranderd naarmate u hier langer bent?
- Kunt u aangeven of u zich thuis voelt in het revalidatiecentrum?
- Waardoor komt dat, kunt u dat uitleggen?
- Wat voor gevoel heeft u hierbij?

Als u naar huis gaat, wat zal u dan het meeste missen van het revalidatiecentrum? Waarom?

En wat zou u juist niet gaan missen als u weer thuis bent? Waarom?

Afsluiting

Wilt u misschien verder nog iets kwijt wat nog niet aan de orde is geweest?

Wat vond u zelf van het interview?

Dan wil ik u hartelijk bedanken voor dit interview.

- Recorder uitzetten -

8.2 Second interview guide

Uitleg onderzoek (voorafgaande aan het interview)

Goedemorgen/middag, mijn naam is Jelle Straatsma en zoals u zich misschien nog herinnert ben ik bezig met een master thesis over de ervaringen en verwachtingen van patiënten die rehabiliteren na een beroerte.

- Het doel van mijn onderzoek is om te kijken op welke manier de revalidatiezorg voor mensen na een beroerte/CVA verbeterd kan worden.
- Voor mijn onderzoek ben ik geïnteresseerd in hoe mensen met een CVA hun verblijf in het revalidatiecentrum en later thuis ervaren.
- Ik wil graag kijken of er een verschil is tussen ervaringen op het moment dat mensen nog opgenomen zijn in het revalidatiecentrum en na het ontslag.
- Heeft u nog vragen of wilt u nog iets meer weten over de interviews of het onderzoek?
- Vragen aan de participant waar hij/zij graag wil zitten tijdens het interview.
- Recorder klaar zetten.

Interview

Introductie

Bedankt dat ik hier mocht komen en het tweede interview mag afnemen. U heeft al ingestemd met het afnemen van dit interview en dat het opgenomen mag worden, wilt. Uw naam zal net zoals het vorige interview onbekend blijven, afgezien van mijn begeleider zal niemand erachter kunnen komen dat u dit bent. Gaat u hiermee akkoord?

Recorder aanzetten

Introductievraag

(indien mensen niet zijn verhuisd)

Hoe is het om weer thuis te zijn?

Komt dat overeen met de verwachtingen die u had van het weer thuiskomen toen u in het revalidatiecentrum verbleef? Zo nee, waarom niet?

(Indien mensen wel zijn verhuisd)

Hoe is het om hier te wonen?

Komt dat overeen met de verwachtingen die u had toen u in het revalidatiecentrum verbleef? Zo nee, waarom niet?

Dagindeling

Kunt u vertellen wat u op een normale dag doet, van opstaan tot naar bed gaan?

Wat vindt u hiervan?

Kunt u vertellen wat uw weekindeling is? Doet u hetzelfde in het weekend als door de weeks?

Wat vindt u hiervan?

Hoe verschilt dit met het programma in het revalidatiecentrum?

Hoe verschilt dit met hoe het was voordat u de beroerte had gehad?

Is de taakverdeling thuis veranderd in vergelijking met voor de beroerte?

Datum van ontslag

(als de participant al wist wanneer hij/zij naar huis zou gaan)

Bent u ook daadwerkelijk op [datum] naar huis gegaan? Zo niet, waarom niet?

Vind u dat u op het goede moment naar huis bent gegaan? Waarom wel/niet?

Plekken

Thuis

Kunt u wat vertellen over uw huis? Hoe lang woont u er, met wie?

Wat is uw favoriete plek in uw huis? Waarom is dit uw favoriete plek?

Topical probes: Bepaalde stoel, bepaalde kamer

Is dit verandert nadat u weer thuis bent gekomen?

Hoe beweegt u zich in uw huis?

Topical probes: traplopen, hulpmiddelen zoals stok/rollator

Naar welke plekken in huis gaat u?

Naar welke plekken zou u graag toe willen in huis, maar gaat u niet? Waarom niet?

Is dit vergelijkbaar met hoe het was voor de beroerte?

Kunt u zich goed in huis verplaatsen? Zo nee, hoe komt dit?

(indien er aanpassingen aan het huis waren gedaan)

U vertelde in het vorige interview dat [aanpassingen aan het huis] zijn gedaan. Zijn er nog verdere aanpassingen gemaakt?

Heeft u behoefte aan verdere aanpassingen? Welke? Waarom is dit nog niet gedaan?

(indien er geen aanpassingen aan het huis waren gedaan)

U vertelde in het vorige interview dat er geen aanpassingen aan het huis waren gedaan. Zijn er nog aanpassingen gedaan na het interview? Waarom wel/niet?

Heeft u behoefte aan aanpassingen? Welke? Waarom is dit nog niet gedaan?

Topical probes: Steunen in douche/wc, verhoogde wc, verlaagde drempels, vlakke ondergrond, keukengerei, bed op begane grond.

Buiten / andere plekken

Kunt u vertellen naar welke plekken u verder nog meer naar toe gaat buiten uw huis?

Topical probes: Winkel, werk, op visite, wandelen, andere plekken in relatie met dagindeling.

Waar is deze plek?

Hoe vaak gaat u hier naartoe per week?

Kunt u beschrijven hoe de plek eruit ziet?

Hoe gaat u daar naar toe? Is dit vergelijkbaar met voorheen?

Wat voor afstanden overbruggt u?

Hoe beweegt u zich in die ruimte?

Welke mensen komt u tegen in deze ruimte?

Hoe voelt u zich in deze ruimte?

Naar welke plek gaat u het liefst? En waarom?

Naar welke plek gaat u het minst graag? En waarom?

Zijn er plekken waar u naartoe zou willen maar waar u niet naartoe gaat? Waarom?

Zijn er plekken waar u voor de beroerte wel kwam maar nu niet meer? Waarom niet meer?

Mensen

Familie/vrienden/kennissen/collega's

Zou u kunnen vertellen wie er bij u op bezoek komen?

Is dit veranderd ten opzichte van voor de beroerte? Zo ja, waarom?
Wanneer komen ze?
Wat doet u samen?
Waar gaat u dan heen?

Wie komen er verder bij u in huis?

Ziet u nog mensen die u heeft leren kennen in het revalidatiecentrum? Zo niet, waarom niet?

Gaat u zelf ook bij mensen op bezoek?
Is dit veranderd ten opzichte van voor de beroerte? Zo ja, waarom?
Hoe gaat u daar naartoe?
Wat doet u samen?
Waar gaat u dan heen?
Hoe voelt het om deze mensen om u heen te hebben?

Zijn uw sociale contacten na uw beroerte/CVA veranderd?
Kunt u daar meer over vertellen? Of wat is er veranderd?
Waarom?
Is er een verschil tussen de periode voor de beroerte en nu?
Is er een verschil tussen de periode dat u in het revalidatiecentrum was en nu?

Steun

Door wie voelt u zich gesteund?
Waarin ervaart u deze steun?
Wat doet dit met u?
Maakt u ook gebruik van het internet voor sociale steun of om informatie te verkrijgen? Zo niet, zou u daar gebruik van willen maken?

Gevolgen CVA

Kunt u kort vertellen wat de gevolgen van de CVA waren?

Waar heeft u thuis het meeste hinder van als het gaat om de gevolgen van de beroerte? (Lichamelijk gevolgen/minder zichtbare (geestelijke) gevolgen?)

Wat is er veranderd in de gevolgen van de CVA na uw ontslag bij het revalidatiecentrum?

Vervolg behandeling

Wordt u nog behandeld voor de gevolgen van de CVA? (dagbehandeling/fysiotherapie)
Zo ja: Waarom? Hoe/wat? Hoe vaak?
Zo nee: Waarom niet? Heeft u er behoefte aan?

Bent u na het ontslag terug naar het revalidatiecentrum geweest? Waarom (niet)? Had u hier behoefte aan gehad? Waarom (niet)?

U vertelde dat u [hobby's/vaardigheden] weer wilde leren/oefenen nadat u naar huis zou gaan. Hoe is dit gegaan? Heeft u hier hulp bij gehad? Wat voor hulp?

Krijgt u nog andere vormen van hulp? Wat voor hulp is dat? Hoe ervaart u die hulp?

Topical probes:

Informele hulp: hulp van partner, familie, buren, vrienden.

Formele hulp: Dagzorg, tafeltje dekje, schoonmaker.

Heeft u behoefte aan (andere vormen van) hulp?

Afsluitende vragen

Wat vind u van de manier waarop het revalidatiecentrum u heeft voorbereid op het naar huis gaan?

Hoe kijkt u terug naar uw periode in het revalidatiecentrum?

Wat mist u het meest aan het revalidatiecentrum? Wat mist u juist niet?

Wilt u misschien verder nog iets kwijt wat nog niet aan de orde is geweest?

Dan wil ik u hartelijk bedanken voor dit interview.

Recorder uitzetten

8.3 Code tree

Basic codes

First interview

Second interview

ID 1

ID 2

ID 3

ID 4

ID 5

ID 6

ID 7

ID 8

ID 9

ID 10

Single

Widowed

Unemployed

Retired

Male

Female

Employed

Married

Effects of stroke

Problem with functioning limbs/hands

Other effects of the stroke (mental)

Problems with speech

Problems with sight

Problems with mobility

Mobility aids

Other effects of stroke

Money problems

Independence

Increased emotions

Fatigue/resting

Feeling of self

Letting go of control

Cycling

Driving

Expectations about home

Obstacles in home

Talking about going home

Planned therapy when home

Adaptions to home

Thinking about going home

Indication date going home
Hobbies/other activities
Going home during the weekends
Information received
Daily schedule future/expectations future

Experiences in the rehabilitation clinic

Feeling at home
Things brought from home
Privacy
Feeling afraid
Sleep
Relation with other patients
Relation with roommates
Feeling safe

Perceived quality of care

Rehabilitation progress/improvements
Rules
Opinion about staff
Opinion about therapies
Workload in the rehabilitation clinic
Opinion about the rehabilitation clinic
Opinion about schedule
Opinion about date going home

Places in the rehabilitation clinic

Room in the rehabilitation clinic
Least favourite place in the rehabilitation clinic
Favourite place in the rehabilitation clinic
Favourite place in room
Outside
Tuincafé
Bench in corridor
Sports facility
Living room

Daily schedule

Daily schedule before stroke
Daily schedule in the rehabilitation clinic
Daily schedule future/expectations future
Daily schedule at home
Comparison daily schedule

Relationships

Change in relationships
Children

Partner
Family
Friends
Support
Visitors
Asking for help

Therapies

Occupational therapy
Physiotherapy
Speech-language Pathology
Agenda training

Care

Informal care
Formal care

Feelings in home

Feeling satisfied
Feeling disappointed
Assurance
Opinion about being home

Places at home

Favourite place at home
Places in home
Places outside home
Information about home

Moving

Moving
Thinking about moving

Connection to the rehabilitation clinic

Seeing people from the rehabilitation clinic
Going to the rehabilitation clinic

Rehabilitation at home

Day therapy
Exercises