

re | HABIT

„BACK TO THE FAMILIAR“

*Rehabilitation experience design
for stroke patients with hand impairment*

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4. Inquiry questions

In the background research we postulated the need for a focus shift from technology driven concepts to a more human centred approach. Technology plays an important role in making home rehabilitation for stroke survivors more effective, lightweight and portable as well as overall more economical than formerly used static and passive tools. But while it may make home rehabilitation theoretically feasible, it doesn't take into account the social barrier of using this training tools on a daily basis and over a very long time period. Furthermore is our main age group (starting from 50 up to 80 years) very heterogeneous in terms of interests, use of technology, social conduct, personal health and mobility.

4.1. | *The eight main questions*

We formed eight main categories focusing on the overall topics of motivation, tasks, interests and habits. They represent the foundation of later applied methods and separate their results.

4.1.1. | *1. Tasks in focus of therapy*

It's vital to define the driving force in therapy: The task(s) the patient trains for and which he or she is determined to relearn. Without a clearly set goal by the patient, therapy will not show the desired progress. For further concept ideas it could be helpful to focus on the most frequently mentioned areas of tasks (e.g. activities in the kitchen or bath).

4.1.2. | *2. Long term motivation*

For chronic stroke patients relearning a certain flow of movement can take several months or even years. Patients' methods against boredom and the driving force behind their favourite immersive activity or hobby could support and ease this process over a longer time.

4.1.3. | *3. Feedback*

As stated by therapists an accurate feedback is a key to relearn movements. While therapists but also family members try to support and encourage, criticism accompanied by small progress isn't easy to deal with. For future rehabilitation tools it's a challenge to bring together precise correction and supportive feedback.

4.1.4. | *4. Cooperative social actions*

After a stroke the speech centre can be heavily damaged and a lot of social habits and hobbies (e.g. most sports) aren't possible to exercise

any more. Very often a chronic stroke patient can carry on his daily tasks but loses all social contacts connected to mentioned activities. Identifying the patient's most missing social circles as well as recreations could lead to a powerful motivation enhancer which until now rarely has been paid attention to. Furthermore, by including external groups into rehabilitation exercises, the risk for the inevitable loneliness is decreased.

| 5. Adapted objects of support

4.1.5.

For some stroke patients with walking disability a wheel chair can bring back some independence but it is also a stigma of the affliction. Differentiating the supporting from the invidious objects will help to shape a training object with higher patient acceptance. Additionally, objects of daily living can stand for fond memories, personal orientation, independence, time periods but also for impairment and stigma.

| 6. Emotional state

4.1.6.

As the emotional state of the patient is the premise of rehabilitation, general and recurring events during a week or a day could be used to build on.

| 7. Week structure

4.1.7.

The loss of independence and most often of the former employment ask for a newly structured week. Future exercises should be integrated into this. Further it could be very helpful for the patient to be encouraged by the exercise or service to work on his or hers weekly plan.

| 8. Novelties, ideas and crazy contraptions

4.1.8.

As designers we believe in the value of experimental thoughts, crazy ideas and fearless proposals. The ideas and thoughts of patients and therapists in the matter of better training tools should be considered.

Methods

5.

In order to get information related to these mentioned questions we used established methods formerly with ethnological background but by now also often applied in design research. In any case it's important to get into touch with stroke survivors and their therapists.

| Qualitative interviews

5.1.

Qualitative interviews can be held in two ways: focused interviews and narrative interviews (Hopf 2005). We used narrative interviews to

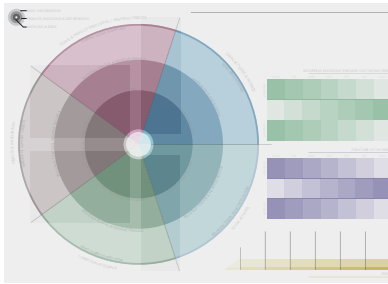


FIG.12 | INTERVIEW SHEET

go deeper into our relevant topics. This method is important to catch subjective sensations in patient's lives. The basic idea is to let the interview-partner speak freely. The interviewer acts as guide and motivator when the interview-partner stagnates in his telling.

Our focus was to get more information about motivation and objects the patients often use at home. To prepare our interviews we developed a graphical overview based on our main questions. We structured our five main questions into three sub categories:

- *basic and general information*
- *patients' feelings and own reflections*
- *own ideas and used methods*

This sheet was used as guide during interviews. When interview partners agreed, we also recorded the interviews. When it was possible we held the interview at patients' homes. Thus we could observe them during their activities like making coffee or washing dishes.

5.2. | *Cultural Probes*

In order to get to know the main habits of our users we thought about the use of Cultural Probes. This method extracts a lot of subjective perception in familiar environment and a lot of unforeseen (Gaver W. et al 2004). This is achieved by different playful tasks and objects sent to the participants in order to express themselves and map their feelings and thoughts.

This could be a good base also in the prototyping work phase. But due to the heterogeneous abilities of stroke survivors it was almost impossible to create general tasks. Additionally, time restrictions and the anticipated too vague results detained us from using this method during context phase and we postponed it.

5.3. | *Participative observation*

To get better insight into daily routines (in our case hidden and unconscious ones) participative observation would have been an ideal method. There researchers become part of life by living very close together with the relevant people over such a period of time that he has no significant influence on people's behaviour anymore and thus can observe the original, pure conduct (Hopf 2005).

Unfortunately, this method could not be applied since it demands a longer period than at hand and because we would have intruded into the patient's privacy. We tried to incorporate at least our observations from the interviews and attended support groups as side notes.

6. Interviews & participative observations

All names of interview partners are changed. The given first name and the slogan (e.g. the engineer) are only used to help remembering and compare the person and their main interests. They should not be discriminative.

| **Stroke Patient interviews**

| **Patient interview “Tony” 57y**

THE ENGINEER - Motivated by force through technology

As a programmer and electrical engineer he is an experienced technician. The stroke in 2004 was a huge impact. Since then he is often tired and very soon exhausted. Therefore he is unable to go back to his old job but still loves technical devices, his iPhone 4 and his computer to work in Excel or solve mathematical puzzles.

In daily life he does almost everything with his healthy hand because for self therapy at home he feels too helpless. He would do these exercises only when receiving a professional feedback, assistance and daily advice. He came up with the idea that the feedback is brought to him through a technical device e.g. as an iPhone App.

He wanted to sign up for forced-use therapy but received no money from health insurance. So he's not doing it although he is sure that this type of therapy would be a more efficient way to rehabilitate. He would like to do more sports with people but mentioned that it is very difficult to find friends with similar disabilities and equal interests.

| **Patient interview “Ernst” 65y**

THE TALKER - Motivated by social contact

He is an educated forestry agent, likes to read newspapers and books and enjoys watching TV. At home he takes care of the household bills and loves to be among people so he visits old friends at the ETH for a coffee and a chat. During his everyday life he uses his healthy arm and caresses his two cats with it because his “cats don't like his paralysed hand”. The cats leave when he touches them with that impaired hand. He has a limited tactile feeling in it what can be potentially hazardous therefore, he must always visually check if everything is ok. Exercises at home bore him because he can't talk to anyone. But there is an exercise that he's been exercising since recently: He places a broomstick between the legs and moves the broom handle back and forth with his paralysed hand. This exercise is to train his shoulder. Ernst would like to return into inpatient care because people there are very guarded and there is always someone to chat with.

| **Patient interview “Mary” 51y**

THE BUSY ONE - Motivated by playing an instrument
(if she had more leisure time)

After her musical education she became a full time mother of four kids and cared for her handicapped daughter. Since the stroke in 2007 she has a hard time to meet all ongoing house hold tasks and feels sometimes misunderstood. Next to therapy and the involved long travel time most of her time is consumed by being at home, cooking for her family and accompanying her handicapped daughter to her therapies. In therapy she is focused on rehabilitating the affected hand so far that she can use it as holding hand. She mentioned to like being at the clinic because of the feeling of acceptance. Since she can open the

6.1.

6.1.1.



FIG.13 | USED TECHNOLOGY

6.1.2.

6.1.3.



FIG.13 | MOBILES CREATE INDEPENDENCE

impaired hand just passively and has not enough time to train it, she does everything with the healthy side. In the kitchen she has an adhesive board, which allows her to prepare and cook with just one hand. She makes her exercises in the morning in front of the mirror or when she is in bed. To improve her walking (during the day she uses a wheelchair) she forces herself to climb the stairs to go to bed. She likes the music during the therapy and would like to have an object, which she could use as substitute to her flute on which she was trained.

6.1.4. | *Patient Interview “Peter” 65y*

THE DOCTOR - Motivated by measurable progress



FIG.14 | MEASURABLE PROGRESS

After having for 25 years his own doctor's practice, the stroke in spring 2008 changed his whole life. The past hobbies (gliding, motor bike riding and skiing) became impossible to be carried on. It helps him to still occasionally meet or accompany some of the friends he had shared these hobbies with in the past. Through intense training driving a car is possible, as well as riding a bike; riding the motor bike is a distant goal. While he has never had problems to accept even childish exercises in the past, it's vital for him to see measurable results in a weekly time frame. Therefore he also exercises up to 5 hours in relation to 1 hour occupational or physical therapy. His new found focus of activities lays - inspired and animated by his children - in the field of design (digital photography and typesetting with hot type). These new found common interests are also a way of staying in contact with them.

He mentioned to not yet have found a structure on weekly basis and fears a bit isolation due to living mostly alone. While he would love to exercise with a flight simulator he's not particularly interested in any other games and rather pleased with the little “homework” from the therapists and his workout on the stationary bike or small stretching exercises.

His ex wife has also been suffering from a stroke and the following impairments since the age of 32, but 30 years later there are almost no limitations left. In a meeting she defines the two similar looking stroke cases as totally different in terms of motivation. In her situation at the time the stroke was separating her from four children, lead to impossibility to perform most daily activities and was thus for her an obstacle to overcome at any cost necessary. For her this pressure to rehabilitate in any aspect of daily life would be impossible to create through self motivation. Her motivation for total rehabilitation has after 30 years not yet vanished and she claimed to have had recent major progress with yoga (e.g. able to completely stretching the impaired hand). She believes the current age to be unimportant for “brain self repair” - so called neuroplasticity (Encyclopædia Britannica). The only thing important is an overall very strong motivation to complete the tasks, even without immediate results.

| Patient Interview “Steve” 39y

THE FAMILY MAN - Motivated by recreation

Fighting with strabismus and a left side hemiplegia the former cabinetmaker had to undergo two surgeries and an occupational re-training. He works now four times a week for two hours in the office of a joiner's workshop. While stating to have almost no impairments today (aside from walking, keeping balance and quicker exhaustion) he regrets to often not being able to meet his two kids' standards (e.g. playing football). To him goals and focused exercising create unsupportive pressure. He tries to train his impaired side by consciously performing several actions with both hands (e.g. changing gears on his special three wheeler recumbent bicycle). His new found hobby is playing chess and due to that he is a member of a chess club. Home exercise and rehabilitation games are not a no go for him, although he doubts the dynamical difficulty (most rehabilitation games are too easy for him) and the adaptability (due to his difficulty with balance the danger of falling has to be addressed). His former interest in working with the computer is also reduced due to eye fatigue and troublesome use of the impaired hand.

6.1.5.



FIG.15 | FOR BICYCLE TOURS

| Patient Interview “Bea” 67y

THE CLEAR-MINDED - Motivated by curiosity for new things

She worked as executive assistant in an IT company and was always up to date with technology. Shortly after retirement she had a stroke and since then has been bound (for 1.5 years) to a wheelchair. She lives in a nursing home in the city and has lots of activities. She often discusses with the staff about current world events or visits an art museum or a park with old friends. She is also very curious and therefore a bit impatient and likes structure in her daily life. The main goal is that she can walk again. For this reason rehabilitation exercises will not so much focus on her arm. The only exercise in that context which she has to do as homework relates to her shoulder. The therapy sessions are very exhausting for her. With every move she must focus explicitly on the affected body part and its motion.

In her spare time she likes to surf the web with her MacBook, read newspapers or watch podcasts. Shortly after the stroke she had hardly been able to concentrate and read only with great difficulty, so this progress brought back a huge amount of life quality.

6.1.6.

| Patient Interview “Fred” 60y

THE CRITIC - Motivated by music

At the age of 56 he had a stroke on the right side of the brain. Due to this impairment it became impossible to keep his shared practice as family doctor and he couldn't play the saxophone in a band anymore. At the first conducted therapy the allegation of him having a hemispatial neglect and a lack of interest in therapy made him feel angry and led to further discussions with therapists. During exercises he felt several times misunderstood and treated like a child.

6.1.7.

While he's trying to reconnect with former band members and practises singing (blues, latino, funk and even beat boxing) he misses the old times.

He visits with interest a support group on weekly base where the focus is set on creating something together (e.g. doing handicrafts, cooking or solving brain training puzzles).

Body exercises (e.g. stretching) are best for him when integrable into daily routine or waiting times. He dislikes training objectives and objects due to their stigmatic nature. He stated to not being focused on specific goals, but to improve his walking skills by doing small hikes. Describing them to be best "with a bench to rest in sight and the anticipation of a smoke". A future exercise object of higher acceptance would be always at hand, small, easy to store and inconspicuous. Not necessarily a game, definitely not a toy but maybe a playful and abstract music interface.

6.2. | *Qualitative interviews with brain injured patients*

We have conducted two interviews with people who suffered from brain injuries after having accidents. While they differ in many ways from stroke survivors (because of other injuries and complications) their motivation for rehabilitation is very relevant and can show the possibilities of rehabilitation and training.

6.2.1. | *Patient Interview "Brad" 49y*

THE RESURRECTION - Motivated by sheer will power

A heavy motorcycle accident changed the life of Brad shortly before his 19th birthday. He had heavy brain injuries and several broken bones. The first ten days he was clinically dead. They were followed by four months in coma. He woke up with 50% of his left brain surgically removed which is why his right side of the body was completely paralysed. He could not walk and talk anymore. This happened 30 years ago.

Brad has a tremendous positive energy. His will to achieve more and to fight for it is impressive and contagious. His recipe for success is setting realistic goals and to pursue them with an iron will which means to work hard, to be consistent, never give up and think positive. Brad has established himself at home a "gym" where he trains 3-5 times a week. He defines the exercises along with his therapists and discusses the progress with them.

Since more than 20 years he's been working in a company from Monday to Friday in the morning. Without this work, he would break down. He appreciates that his colleagues and his boss respect him as he is.

He plays two or three times a week mini golf, takes the train for leisure activities and enjoys going hiking usually with his girlfriend and disabled colleagues.

| **Patient interview “Ron” 40y**

THE DUTYFUL - Motivated by Games during therapy session

Ronny had a heavy motorcycle accident including several broken bones and serious head injury. By his staying power he has reached a lot. Contrary to the predictions of doctors he is able to walk again. He is very proud of that.

Ron was never into computer games but liked the games with the ARMEO (Background Research) very well. He would like to take ARMEO home to be able to practice every day. The greatest motivation is that he sees clearly his progress. During the therapy he is focused on the game and due to that he forgets about his injured arm. Ron would like to work again but it is not feasible because of his insurance.

6.2.2.



FIG.16 | ARMEO TRAINING

| **Qualitative interviews with therapists**

For therapists the main goal in their work is a fast and sustainable rehabilitation of their patients. From case to case they see their clients one to three times per week. The main problem mentioned is that the stroke affected ideally train their impaired limbs every day. Also short exercise (e.g. about ten minutes, three times a day) would be sufficient. To encourage them home work is given. But due to several reasons these get often neglected.

We asked about stroke, therapy, home-rehabilitation and motivation.

6.3.

| **Therapist interview: “Othmar” physiotherapist**

As example for the long-lasting rehabilitation he mentioned children and their learning time for complex movements. Kids motivation increase in play and this process in their age is also accepted by society. For stroke survivors it's hard to get this acceptance and also to get motivation through games. The main issue is that they already were able to do these movements and they find oneself forced to relearn them. Othmar uses individual music during therapy and adjusts the repetitive movements to the rhythm of the sound together with feedback for correct movements and support for wrong ones.

In home rehabilitation patients often are unsure if they do movements right or wrong in lack of feedback and support. But at least, exercises at home don't have to take a long duration. Its good enough to run exercises around five minutes repetitively twice to triply a day.

6.3.1.



FIG.17 | STANDARD TEST

| **Therapist interview: “Farrel” occupational therapist**

He mentioned that hemiplegics often ignore their impaired side. He advises them to lay as example their hand on the table during a meal so that the brain learns to recognize it again as part of the body. In some therapies he stimulates the affected hand with cold or warm packs or different brushes to reestablish brain connection. Further, many people overestimate their own capabilities after stroke. Periodically tests are important on the one hand to capture the progress,

6.3.2.

on the other hand to send the results to the health insurance to attest progress. For hand rehabilitation the shoulder is an important part for fine motor skills. In therapy it should be activated through movement before. Overall he arranges the therapy goal together with the patient. Sometimes he also uses rehabilitation devices such as the Armeo. For patients, it provides an extra motivation because of the progress which is more visible.

He told that often when stroke-survivors went home after hospital stay, their partner reduce the patients basic tasks by helping them to dress up or cooking a meal. In fact the daily activities should be done as autonomous as possible. The patients also often don't do the given homework in lack of motivation or discipline. Thereby it would be adequate when they do their training three times a day for ten minutes. Important for him is, that they are done regularly. As given idea, the training object could additionally measure the exercises so that he can check for progress.

6.3.3. | *Therapist interview: “Amy” physiotherapist*

Amy said that in general the social environment of stroke affected were very important. Support groups are a motivation for many to never give up and to share experiences. The more optimistic the disabled is, the more they exercise, the better the healing. Depressed people have a worse healing process. Amy said it is essential in the therapies to define individual goals together with the patient in which they must be realistic. Under challenging and overburdening demands are discouraging. These tasks should be integrated into everyday life so that they are meaningful. Variety can also be motivating, especially for exercises over years. To monitor and supervise the patient plays a crucial role. Often they don't want to disappoint the therapist.

In her opinion an exercise reminder might be helpful. Also a small portable device that can be taken anywhere and calls the patient to exercise could help.

6.4. | *Participative observation in support groups*

6.4.1. | *Participative observation “Wipkinger-Stamm”*

This support group organised by FRAGILE Suisse included around 20 members between 35 and 75 years old and from different social backgrounds. The majority of them suffered from brain injuries. They sat in a circle around several large tables and consumed snacks and coffee. Once everyone had been introduced, they naturally began to talk and discuss mostly usual things as politics, fashion or hairstyles.

One often mentioned issue was to regain independence by living at home again by one self. Achieving this goal is a great motivation in the first phase of rehabilitation. Thereafter, occupations and hobbies were very important but had to be associated to their interests before the accident and adjusted to a certain extent. Hobbies included learn-

ing languages, swimming, computers, games, puzzles, listening and collecting music and gardening. Many members work part-time in real jobs which is important for recognition and self-esteem. Another point of discussion were difficulties to stay socially connected. Some lost many of their longtime friends after the stroke so the immediate family and few friends became the focus of social contacts. If they are alone in public, they are often misunderstood or even discriminated (e.g. are taken for drunkards).

The head of the group told us that many overestimate their abilities but that it is important that people try and fail again and again. She also said that the daily life for many is too fast, most have a slower perception than healthy people.

| *Participative observation support group “Alte Kaserne”* 6.4.2.

Organised by FRAGILE Suisse this monthly support group included seven participants with an age range from approximately 35 to 70 - but the average age was around 60. The majority suffers from brain injuries and is troubled in walking, remembering things and coordination. The meeting was held by two leaders and was subdivided into social activities (e.g. singing, interchange), brain exercises (e.g. guided talk about a predefined topic with picture cards as guidelines and a word puzzle, part of it similar to scrabble) and ended by a get-together with some soft drinks at the nearby bar.

While focus was set more on training and less on interchange and personal feelings, the overall mood was humorous. Heavy topics as death got addressed with sarcasm and the scarce nagging about the current state was treated with wit or got ignored. The topics of the “brain games” were based on the interests of the participants (e.g. talking about the reappearing birds in the forest during springtime and old professions). Although for some the exercises were difficult they mostly managed to help each other to solve them. Some stated to be disappointed of their results, others meant to finish it at home.

| *Participative observation of therapy sessions* 6.5.

For patients the therapy session is very important. First, they assign to the visit that they are not left alone and feel accepted in their limitations. They also draw some hope for a possible rehabilitation out of the expert’s attendance. This in turn leads to increased motivation. Normally, two therapy sessions of 45 minutes per week will be held. This can be done focusing on a specific goal which was defined as such by the GAS (Goal Attainment Scale) at the beginning of treatment period. These objectives often affect ADL such as for example to cook or to comb the hair. The main goal is always to reach as much independence as possible. A therapy starts often by activating the injured part by the therapist or later on by a machine. Then the patient has to do specific tasks during which the therapist gives responses related to the moves and, if needed, support. In the arm and hand therapy sessions we observed the relationship between patient and therapist as well the objects that are used.



FIG.18 | ACTIVATION PHASE

6.5.1. | *Observation of therapy: “Ernst” 65y*



FIG.19 | “HAND BICYCLE” TRAINING

First, Ernst activated his shoulder and wrist on a so called “hand bicycle” for about 15 minutes meanwhile the therapist observed and asked him whether it was pleasant or not. After that the therapist opened carefully the patient’s hand to loosen muscle tensions. To increase the little tactile sensation left in the paralyzed hand it’s vital to remind the brain that this hand is part of the body, too. To perform this task a special vibrator is used as stimulus.

The main motivation for Ernst to visit the therapy is the social contact with the therapist. They’ve been knowing each other since several years so Ernst appreciates their personal chatting and the relaxed and direct communication.

6.5.2. | *Observation of therapy: “Ron” 40y*



FIG.20 | ARMEO TRAINING

Eight times a week Ron visits the clinic for therapy. Together with the therapist he has chosen a series of eight games that he now plays regularly in the ZAR (center for ambulatory rehabilitation). These eight games are controlled by ARMEO.

Ron says that his motivation to play games is the clearly visible progress, the absent thoughts about the impaired hand, the focusing on the task and the dynamical adjustment of difficulty. But still he needs to help out with his healthy hand in the majority of the games.

6.5.3. | *Observation of therapy: “Tom” 65y*



FIG.21 | AMADEO TRAINING

Tom has problems talking so it was difficult to interview him. While he was sitting in a wheelchair the therapist opened and closed his paralyzed hand. After ten minutes Tom started the training on the AMADEO (a therapy machine for fine motor skills) by depositing his hand on it. This machine helps to make the same exercise as with the therapist except that it can register even smaller movements. Tensing and extending moves are made visible through two indicators on the screen (displayed as smileys), which are happier when more force is measurable. The therapist motivated the patient additionally.

6.5.4. | *Observation of therapy: “Mary” 51y*



FIG.22 | INTEGRATION OF PERSONAL OBJECTS

She visits the classic therapy (without technical machines). The repetition there is increased to three times a week and takes one hour each time. The therapy session is divided into small exercises which are specifically addressed to one area of the impaired upper body.

Interestingly, the therapist integrated various everyday objects into therapy. For example, the patient had to catch a juggling-towel with the healthy hand while holding the limited hand on an empty PET bottle and trying to stabilise it. Another example is a training object (stick) with an integrated personal item of the patient (a bell from her mother). During individual exercises the therapist and the patient made small talk which distracted the patient from her limited hand and the exercises and resulted in a better exercise outcome.

Conclusion

7.

In our quantitative interviews with stroke patients of different ages we compared their point of views (when possible) with the ones of relatives, other brain injured and therapists. Because of the limited time frame of two weeks and the highly individual answers our conclusions will be general and need ongoing review through future conversations, later iterative prototype testing and comparison with literature containing broader interviews with stroke patients about their emotions, tasks and goals like held in “The Aftermath of Stroke: The Experience of Patients and their Families” (Anderson 1992).

| *The main inquiry questions*

7.1.

| *1. Tasks in focus of therapy*

7.1.1.

Most of our interview partners stated not to have an immediate task they want to achieve and train specifically for. Instead they like to improve in more general actions (e.g. walking, grasping objects). So the advised exercises from the therapist are often neglected due to various reasons: time pressure (e.g. cooking), stigma (exercises appearing to be silly and childish), uncertainty or inattention (e.g. walking exercises).

Some patients even mentioned to dislike this goal orientated method - as it is creating frustration because of lack of progress - and to be bored of it in the chronic phase.

While a specific task to relearn and to train at the beginning of rehabilitation in a clinical therapy session can create a very powerful motivation, it doesn't in a longer time frame at home. There the temptation of helping out with the healthy side is too ubiquitous.

In general upper arm and hand rehabilitation is continuously low prioritised since walking and talking are more important for independence. This leads to the impaired side of the upper body being a great deal less used than it would actually be possible.

| *2. Long term motivation*

7.1.2.

The best motivation for rehabilitation is simply not having any other choice than to regain control over ones body as soon as possible (e.g. out of responsibility for others). The family plays an important part in creating a motivation to overcome very bothersome tasks (which are in their nature helpful for rehabilitation). Children push their impaired parents subliminally into using both sides at the same time. We think this could be one of the main reasons for younger stroke survivors to rehabilitate significantly better than older ones. Cause is not their age but their undoubted need for ongoing change and resulting will for rehabilitation. On the other hand stroke patients over 50 have often described their lives to have come to a stop. But neuroplasticity should generally be possible, almost independent of any given age. This got confirmed by several interview partners and finds its explanation in literature (Norman 2007). It shifts the topic of stroke

home rehabilitation from a physical centred and medical neuroscience standpoint to a more psychological view.

Second important is an inner motivation - the sheer will to rehabilitate on a personal basis. While this seems very obvious, it could still be enhanced by integrating applied methods of training and extended measurement of progress.

Third important for long-term motivation can be personal interests, especially if the circumstances, the environment and the personal will do not create urge enough.

Patients try to base their activities on interests already there before the stroke, new found hobbies after the stroke are not the rule because their abilities to learn new activities are very limited and would cost quite an effort.

In our interviews important activities included following topics: Playing music with others, working with the computer (e.g. organising financials, surfing the net), cooking in a household, playing with children, doing excursions (e.g. visiting exhibitions), playing games (mostly card games) or doing sports (mainly skiing and biking). This list should not be seen as complete. But the tendency of complex interactions (also with technology) and body activities but the absence of virtual actions (e.g. playing video games) should be considered. The overall disinterest of video games can be elucidated by the age allocation of our interview partners (the average age was approximately 50). It is very probable that in 30 to 40 years this will drastically change.

Generally, we believe the collective activities to be more motivating except for some sportive ones which can create a new set of problems (e.g. muscle impairment, different difficulty levels and cognitive impairment). This can sometimes be solved by individual additional supporting objects (e.g. special three wheeler recumbent bicycle).

7.1.3. | 3. *Feedback*

During a session the therapist's feedback is important to insure the correct motions and to create best exercise conditions. In our interviews patients said to have mostly liked correction from the therapist. As vital as it is in the clinic – at home it's not a big issue. Patients mainly felt correction in their home (e.g. from family members) as not being supportive and disliked the idea of very guided or even forced exercises and drill. Only in one case a patient mentioned the positive side of forceful feedback as encouragement and recall to try out new activities for a limited time period with his impaired side.

As one therapist mentioned the measurement (and the resulting feedback) doesn't have to be as accurate as in therapy instruments. Feedback in our case has to be set on increasing the motivation.

7.1.4. | 4. *Cooperative social actions*

While often social interaction would be very much appreciated by stroke survivors they fear stigmatization because of their different

levels of abilities. To fight isolation a balanced and playful interaction should be established. “Passive” activities (e.g. going to a museum or a park) are hard to implement in a exercise artefact but help to socialise. And as stated before, the family (especially kids) can be of great motivation in cooperative play (even if the impaired doesn’t always meet their standards).

Another very important approach is to meet other handicapped. Common complex activities (e.g. playing chess or badminton) are problematic due to different abilities, impairments and knowledge. As alluded before, learning new activities which were never carried out before the stroke are very unalluring or even difficult for stroke survivors.

But support groups are stated as very important by the majority of interview partners. Acceptance plays a key role there, also encouragement from others and in general distraction from daily life problems. Furthermore the group dynamic also helps to finish given group exercises, boosts acceptance for training games (to be solved during the meeting) and to plan small excursions.

| 5. Adapted Objects of support

7.1.5.

Several objects are used to enable the impaired to accomplish tasks of daily life. But most stated that these objects (e.g. crane, wheelchair and supportive shoe equipment) are indeed very convenient but also create a huge stigma for them. On the other side there are as well smaller tools with a less obvious stigma (e.g. kitchen board with nails to enable food to cut, special cloth hanger). But ironically these take the burden away from the impaired side. And while enabling the patient also hamper the rehabilitation progress.

We think a home rehabilitation object to be more useful if it is more than just equipment to exercise and if it blends smoothly into daily routine.

Therapists use low cost and self made objects in therapy sessions and even incorporate personal artifacts of the patient. These training tools are often made out of easily available items in do-it-yourself or grocery stores. And for the exercises at home stroke affected often use everyday objects such as a broom or a cleaning rag. Individually, they also acquire training equipment like a stationary bike. While this incorporation of household items should be built on (due to low cost and stigma as well as good availability) it will not necessarily create a huge acceptance in terms of earnestness.



FIG23 | USE OF LOW COST OBJECTS IN THERAPY

| 6. Emotional State

7.1.6.

While stroke patients implied to have suffered in the past from depression and therapy fatigue, no other reoccurring emotional events have been mentioned.

Based on the functional coping strategy (Arieti & Caplan 1974) their personal pre stroke solution to deal with difficult and enduring tasks could be of interest and even integrated (through help from the therapist) into some special exercises.

For further research the following methods could be used:

- *Cultural probes: To get an inspiring glimpse on emotional patterns over time.*
- *Depression scale (Hamilton 1960): for an accurate description of the momentary state.*

7.1.7. | 7. *Week structure*

Most patients attend between once to three times per week occupational and/or physical therapy. The rest of the week is planned by each person individually, more or less structured.

For further research the method of video ethnography (Ylirisku & Buur 2007) could be used to gain a better insight over a longer time period. But we think the week structure is not a main issue for defining specific exercises for home rehabilitation due to the fact that every day should be sufficient time if priorities can be set accordingly.

7.1.8. | 8. *Novelties, ideas and crazy contraptions*

The ideas of the respondents included a flight simulator, an intuitive music instrument, a “gym” tool and a force centred iPhone App. These ideas show the acceptance of established technologies, the integration of hobbies as well as the use of motivation methods.

In order to gain deeper access to inspiring ideas of stroke patients design workshops and future scenarios (Greenbaum & Kyng 1991) could be conducted in a later, more product focused phase.

7.2. | Overall Conclusion

The changed life circumstances of patients commonly older than 50 years often result in lower urge for rehabilitation at home and thus less progress. This is increased by repulse of exercises and reduced usage of the impaired side during daily tasks. As the whole topic is based on individual coping strategies and individual preferences there is no solution for everyone.

We believe home rehabilitation to be more of a challenge in terms of psychology and less in terms of medical neuroscience and technology founded precision.

By focusing on the three strongest driving forces for motivation, several groups can be identified and used as foundation of future application drafts:

1. *Creating motivation by concentrating urge - in terms of applied direction or force, compassion or responsibility for someone or something. (“Force”)*
2. *Creating motivation by empowering the own strong dedication through specific training methods and extended measurement of progress. (“Will”)*
3. *Creating motivation by including hobbies, interests and social activities: Incorporating music, play, devices (and their interfaces) and levelled social interactions. (“Fun”)*



FIG.24 | ACCEPTED OBJECTS FROM PATIENT

Vital attributes to ensure acceptance in daily situations include small size, easy use, non medical design, slightly humorous character and to some extent self adjustment and self explanatory.

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