re | HABIT

„Back to the Familiar"

Rehabilitation experience design
for stroke patients with hand impairment

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1. Introduction

1.1. | *Definition of a stroke*

Stroke is the leading cause of severe physical disability and one of the major causes of death in the world (WHO 2004). Worldwide 3 million women and 2.5 million men die from stroke every year (WHO 2002). Frequently stroke survivors are left with partial paralysis on one side of the body and movement can be severely restricted. This results in loss of independence in everyday tasks (Anderson 1992). Basic activities of daily living (ADL) are for example dressing, eating, using the toilet and bathing. The more complex tasks include tools or appliances in any form called "instrumental activities of daily living" (IADL) as housekeeping, using the telephone, driving or cooking. This not only affects the stroke patient's abilities but also their social circle; mostly family members and specifically their spouses. "Family caregivers of stroke patients often experience an overwhelming sense of burden and depression, decline in physical and mental health, reduced quality of life, and isolation" (Lutz & Young 2010: pp. 155).

A stroke, also called apoplexy, previously known medically as CVA (Cerebrovascular accident) is caused by the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue (cerebral infarctions). The most common symptom of a stroke is sudden weakness or numbness of the face, arm or leg, most often on one side of the body. Other symptoms include confusion, visual disturbances, difficulties speaking or understanding speech; difficulties seeing with one or both eyes; difficulties walking, dizziness, loss of balance or coordination; severe headache with no known cause; fainting or unconsciousness. The effects of a stroke depend on the part of the brain which is injured and how severely it is affected. A very severe stroke can cause coma or sudden death (Encyclopædia Britannica).

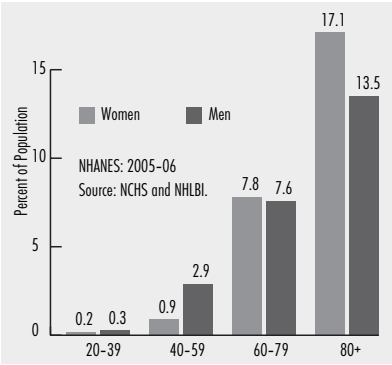

FIG.1 | PREVALENCE OF STROKE BY AGE AND SEX

Although a stroke can occur at any age, stroke survivors are mainly elderly with 65 years and plus (American Heart Association 2009, pp. 15). As it is typical for this age group, other common disabilities like Dementia may occur and impair the patient's state even more. Due to the ageing population stroke is forecasted to create a huge burden of health and social care in the coming decades. As demographic change takes place and the stroke population grows, health and rehabilitation services become stretched, delivery of health and social care has to change (Green Paper European Commission 2005).

1.2.1. | *Therapy in the first 6 months*

Current research shows recovery is related to neuroplasticity of the brain in which the function of damaged systems is taken on other neural systems. Neuroplastic change is encouraged by progressive and repetitive physical exercise programmes during which patients are relearning how to use impaired parts of their body (Pomeroy &

Talli 2002). The therapeutic effectiveness depends on intensity and frequency of treatment and the immersion in the exercises.

Shortly after a stroke the first actions take place in a hospital in specialised stroke units. Rehabilitation therapy should begin as early as possible once the person's medical condition has stabilised. But since the person may have just experienced a major trauma, paralysis in one or more limbs, eventual difficulties in speaking and simply not being able to accomplish major tasks of daily life or personal interest which they took for granted just days ago, therapy will sometimes not be feasible. It is not uncommon for stroke survivors to experience depression, pain and suicidal thoughts. If these conditions occur, rehabilitation will be postponed. In some hospitals specialised psychologist will work with the patients to improve their mental state.
For the first 6 months, rehabilitation therapy takes place mainly in the hospital. This time period may be significantly shorter in some countries due to patient's financial situations and health care systems. During the first half of the 6 months, intensive rehabilitation training usually is very rewarding and motivating for the patient. As a 65 year old stroke survivor explained in one of our interviews: "Shortly after I woke up I was only able to slightly move one toe. In the following weeks I went from supported usage of the walking frame to even in the end walking with a cane." Ongoing progress is apparent and therefore motivation for necessary repetitive and intense training is high.
The second half of the intensive inpatient training can be less progressive due to the slower progression rate. The rehabilitation curve isn't as steep as in the first half but progress is still visible. In this phase, a lot of tasks have to be meticulously refined.

| *Ongoing therapy* 1.2.2.

After up to six months of inpatient care the patient will usually go home. In arrangement with health insurance, therapist's advices and depending of his personal goals training is pursued with typically two times 45 minutes up to one hour therapy sessions per week. According to the patient's impairments this will be in the fields of occupational therapy, speech/language pathology and physiotherapy.
The focus on personal goals defined by the patient is crucial at this stage. The therapist "creates" exercises supporting these objectives. GAS (Goal Attainment Scale) is used to structure and divide them in smaller steps as well as to quantify the progress (Kiresuk & Sherman 1968). As stated by an interviewed therapist, the patient's feeling of being personally coached with training based on the set goals is vital and the key to motivation. He also mentions trying to incorporate personal objects brought along by the patient into the exercises.

The maximum one hour training is described by patients as to be intensive and exhausting. The repetitive nature of rehabilitation exercises can lead to boredom and neglect. Additionally, the travelling to attend a session consumes not only a vast amount of time but creates travel cost and triggers discomfort for the organisation of transportation. As the visible progress gets smaller the motivation and the

personal effort can decrease significantly. Another interview partner mentioned that he would not have continued his therapy appointments (for lack of believe in progress) if not for his therapist's reassurance and mentioning of small improvements.

To test new approaches to rehabilitation most studies rely on two different evaluation approaches:

- *Measurement by the therapist of possible body and limb movements. For Example: Fugl-Meyer (Fugl-Meyer et al. 1975), Motricity Index scales, Jebsen Test of Hand Function (Jebsen et al. 1969). There are also developments which put the whole diagnosis part into virtual systems (Alamri et al. 2008).*
- *Self-tracking of emotional and cognitive condition. For example: Stroke Impact Scale (SIS) measures the quality of life. Hamilton Rating Scale of Depression (Hamilton 1960), Cornell depression scale (CDS) which is filled in by a relative, and Beck depression inventory (Beck et al. 1961).*

2. Research on Home Rehabilitation

Impairment occurs mainly on one side of the body (Hemiplegia). In 66% the upper limb of the affected side remains weak (Burke et al. 2009). Therefore, the focus of the research overview is put on projects which deal with arm, hand and in general upper limb rehabilitation in a home environment. Chronic stroke patients, that is to say survivors at least six months after the stroke, are in the centre of these studies.

2.1. | *Theories*

2.1.1. | *Game design theory*

One branch of game theory in the framework of "games" - better to be called game design theory and thus not to be confused with the widely applied mathematical concept of game theory - focuses on the ways how to motivate the player to stick to the game and not to be bored.

Salen & Zimmerman (2003) postulate in their book "Rules of Play - Game design fundamentals" the concept of "meaningful play" as fundamental for successful game design: "Meaningful play in a game emerges from the relationship between player action and system outcome; it is the process by which a player takes action within the designed system of a game and the system responds to the action. The meaning of an action in a game resides in the relationship between action and outcome" (pp. 34, original emphasis). To evaluate the concept in games they give the following definition: "Meaningful play occurs when the relationships between actions and outcomes in a game are both discernable and integrated into the larger context of the game" (ibid., original emphasis). Discernable is fulfiled when action of the player leads to perceivable reaction. Integrated means that the action and outcome not only have an immediate effect but also influence later events.

The concept of "meaningful play" has been taken as basic concept also in rehabilitation research. Burke et al. (2009) lay their emphasis in context on feedback: "Feedback enables a player to measure their progress in achieving their goals, or progression in their skills over time" (pp.105). Rewards can lead to increased motivation and enjoyment. Negative feedback encourages players to learn from their mistakes. In rehabilitation, failure should be handled very conservatively and in a positive way so that the patient does not feel that "(...) failure in the game stems from their poor physical abilities (…)" (ibid.).

Another important aspect out of game design theory for rehabilitation is the question how to challenge the player so that he won't be neither over strained nor bored. The challenge of the game should match the player's ability. If it is too difficult and too poor feedback is given, the player may be frustrated and quit. On the other hand if the game is not challenging enough, the player may become bored. Many games tackle the problem by using levels to structure difficulty. To complete a level, certain abilities have to be achieved or a game mechanic has to be understood. There are also games which adapt the challenge through the measurement of player's performance. In rehabilitation the therapist adjusts the challenge through monitoring engagement and progress (Burke et al. 2009, pp.106).

| *Motivation theory* 2.1.2.

The mentioned aspects of game design theory are not game specific but result in the same questions as basic motivation research tries to answer: Why are human beings motivated or not motivated to fulfil tasks? And how can motivation be increased if it is low?
Basically, motivation contains an incentive, an action and an objective. Objectives imply a belief in positive, accomplishable and purposeful circumstances in the future (Rheinberg 2000, pp.12). Through this individual definition the incentive to reach that goal arises and creates an self-pressure to act. The pressure depends of course of the actual situation and the characteristics of the individual.
One of the best reviewed parts in motivation theory is need for achievement. In this theory, core of the will to perform is the personal challenge and the rewarding pride an individual feels after achieving (Rheinberg 2000, pp. 60).
There is a wide branch of qualitative research of motivation in rehabilitation, specifically also for stroke patients. Interviews with stroke professionals (Maclean et al. 2002) report it for example to be crucial that patients have an own intrinsic motivation and don't just want to please the therapist. Most professionals were convinced to be able to influence the patient's motivation. The most often described technique "was to strike up a rapport with patients and to chat with them about their lives." A majority mentioned also "setting rehabilitation goals that were perceived as relevant by the patient, providing information about rehabilitation, and accessing and using the patient's cultural norms". The "information concerned the nature of recovery (reassuring patients that they were recovering and dissuading them from unfavorably comparing themselves with other patients), how patients could expect to fare at home if no rehabilitation gains were

made, why certain exercises had to be performed, and why those exercises had to be performed in specific ways" (ibid. pp.447).
The findings of interviews with 22 stroke patients in rehabilitation (14 with high motivation, 8 with low motivation), also performed by Maclean et al. (2000), were summarized in the following way: "Information from professionals about rehabilitation, favourable comparisons with other stroke patients, and the desire to leave hospital had a positive effect on motivation. Conversely, overprotection from family members and professionals, lack of information or the receipt of "mixed messages" from professionals, and unfavourable comparisons with other patients had a negative effect" (pp. 1051).
Gard (2001, pp. 85) identified in a meta analysis different motivating factors: "individual factors, job and organisational factors, and factors within rehabilitation. Individual motivating factors were: interests, attitudes, needs, realistic expectancies, perceived self-efficacy, and self-confidence. Job and environmental motivating factors were: structural factors, clear goals, work content, social support, and type of rewards/feedback. Motivating factors within rehabilitation were: clear goals, value-clarification, social support, participation in treatment, locus of control, and communication and cooperation."

2.2. | *Virtual Reality (VR)*

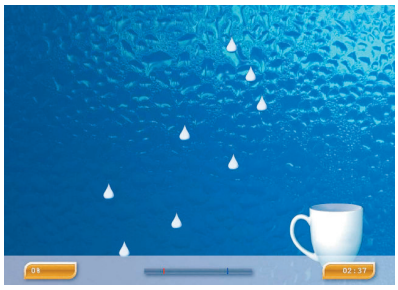

FIG.2 | CATCHING WATERDROPS

Many proposed new rehabilitation projects focus on Virtual Reality (VR). The promises of VR are:

- *Better visual and acoustic real-time feedback and stimuli*
- *Almost endless possibilities of simulating and customising different settings*
- *More immersive tasks with a better learning curve.*

A SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis of the field of virtual reality rehabilitation cites: "…VR rehabilitation is still in an early phase of development characterised by successful "proof of concept" systems, encouraging initial research results, and a few applications that are finding their way into mainstream use and clinical practice" (Rizzo & Kim 2005, pp. 141) and concludes "(…) VR will have a significant positive impact on the rehabilitation sciences" (ibid., pp. 142).

2.3. | *Game topics*

FIG.3 | COOKING EGGS

To enhance the motivation of the patient, several studies about new technologies for hand rehabilitation use games in their concepts.
There are several games for stroke rehabilitation which are closer to abstract visual feedback than to actual games: Controlling a cursor by finger movement along a line (Durfee et al. 2005) and controlling a haptic input (Phantom omni) to trace along a curve (Guo et al. 2009).
But most serious games for stroke rehabilitation are further developed in terms of game play, complexity and replay value. Basically two game settings can be seen in actual papers.

- *A typical arcade game inspired setting like catching falling objects (in this example water drops) (Sucar et al. 2010)*
- *An abstraction of a daily activity: cooking eggs* (ibid.) .

It is important to note that the decision for one or the other setting is rarely explained nor are the two types directly compared in terms of patient motivation or acceptance.

| *Dynamic difficulty*

2.4.

In a two day study off-the-shelf EyeToy (Sony) games were tested about their potential in stroke rehabilitation (Burke et al. 2009, pp.106). The main conclusion from this evaluation is the fact that these games are too fast. The high and not dynamic difficulty level is leading to frustration due to absence of possible adjustments to the patients abilities.

FIG.4 | AGE INVADERS

Not only an inappropriate level of difficulty, but also the social gap between other family members can frustrate the impaired player. Because a broad participation from others would be motivating for the stroke patient several projects (Hoogen et al. 2009) suggest cooperative but balanced games. Based on the classic arcade version, Age Invaders is an equitable game for all generations to play (Koo et al. 2006).

| *Feedback*

2.5.

Because of the lack of interactive and feedback enabled devices current research proposes VR technology to measure and inform the patient about his movements.
The feedback for the patient during exercising, as stated by a therapist in one of our interviews, is vital for the correct and effective execution of the specific training task. This is due to the fact that the patient's awareness of body as well as limb positioning and his ability for contemporaneous movements (e.g. both arms) can be impaired (American Heart Association 2011).

Different kind of feedback systems are proposed as for example vibration to indicate wrong movements and prevent injuries as with the TactaPack (Lindeman et al. 2006) or visual and acoustic avatar based feedback as developed by Philips Research (Wilmann et al. 2007).

Next to the feedback itself, the promise of working with a VR system is the additional possibility to create a feedback loop to link the patient results to the next exercises chosen by the therapist (Willmann et al. 2007 and Durfee et al. 2005). This could give the patient the right amount of challenge, lead to less therapy visits and thus lower costs.

| *Technologies*

2.6.

Several technologies and products are used to track the patient's movement. While they have a common goal, they have different drawbacks and also specific qualities which are relevant for possible game

settings. It's important to mention that most projects combine different ideas (like visual and sensor based localisation).

2.6.1. | *Computer Vision*

FIG.5 | COLLECT VIRTUAL FRUITS

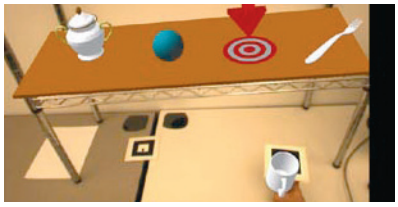

FIG.6 | AUGMENTED REALITY CUP

This technology usually uses a digital video camera (or web cam) together with an object of a single consistent colour as tracker. The computer calculates the markers movement in two axes. The interpretation of size change to evaluate a third axe (for depth perception) is proposed (Burke 2008) but not a necessity. Such systems are easy to use since most of the time no interactive objects are used, but require on the other hand enough light, exact calibration and tend to miss the detection of wrong movements (as it is not yet feasible to determine the exact location and movements of the upper limbs, especially when not "seen" by the camera).

Other propitious systems incorporate physical objects of daily life like a basket to collect virtual fruits (Burke et al. 2009, pp.107) or (by combining this technology with augmented reality) straighten up a cup onto a actual shelf filled with virtual porcelain (Alamri et al. 2010).

2.6.2. | *Accelerometers and inertial sensors*

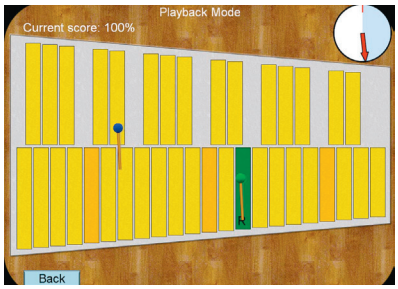

FIG.7 | VIRTUAL WII-XYLOPHONE

The standard Wii remote controller is used in several projects (Saposnik et al. 2010). Being held in the hand, its built-in accelerometer (standard 2 axes detection with additional hardware up to 3 axes) can track movements like shoulder flexion and extension, shoulder rotation, elbow extension and flexion, wrist supination and pronation. Those information are differently interpreted depending on the played games. Since the controller can be held like a stick, VR settings like a virtual xylophone (Burke et al. 2009, pp.109) are easy to set up.

Similarly, the TactaPack combines accelerometers with a small vibrotactile tactor for feedback of false arm movements during the exercise (Lindeman et al. 2006). While this technology can be easy in utilization, its results can be inaccurate for only the position and the attitude of the controller are calculated. Another project relays on more accurate inertial sensors which measure the change of angles on torso, shoulder, upper and lower arm (Willmann et al. 2007).

2.6.3. | *Digital gloves*

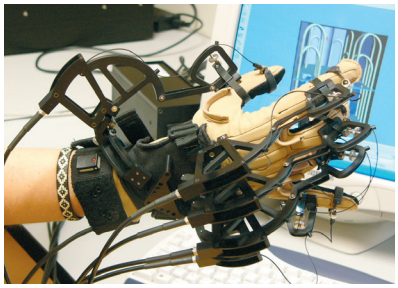

FIG.8 | CYBER GRASP

To measure fine motor skills, different data gloves like the commercial CyberGrasp-System exist. This system contains the following parts: "CyberGlove" which is equipped with sensors to read palm and individual finger position, "CyberForce" that locates the position of the hand and "CyberGrasp" which provides force feedback to the fingers (Alamri et al. 2008, pp. 1878).
Another system is the Rutgers-Master II which is much lighter than the CyberGlove (Bouzit et al. 2002, pp. 262). These gloves can give a very realistic feedback of different forces and the most accurate meas-

urement of finger actions. On the other hand both gloves can be hard to dress, need calibration and are not fully portable.

| *Other game controller based systems*

2.6.4.

Since the range of commercially available games is enormous and the cost for game consoles is low, several projects like TheraJoy suggest modified game controllers and a therapy adapted list of games (Johnson & Winters 2004). The project TheraDrive uses software for brain injured users like SmartDriver.

As already stated, the fact that commercial games are not dynamically adjusted to impaired players, this system can - although it is very cost efficient and modular - lead to frustration.

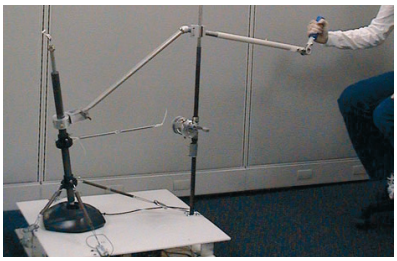

fig.9 | TheraJoy

| *Mechanical systems*

2.6.5.

In 1998 a toy-like system was developed which contains seven crocodile-shaped targets, each of them randomly popping out of a hole in a table. They had to be beaten with a soft hammer (Yasuda et al. 1998, pp. 2726).
An advantage is the physicality of the whole system which makes it less abstract in comparison to a VR environment and therefore easier to understand. The range of possible tasks is on the other hand very limited.

fig.10 | Hit the Croco

| *Exoskeleton*

2.6.7.

The lightweight exoskeleton project "Rupert" sets its focus on helping patients to achieve ADL- tasks (reaching and eating) (Sugar et al. 2007). Although assisting the patient it still needs a given input. Exoskeletons are at the moment the only way to provide active movement support. However, they are still comparatively heavy and big.

fig.11 | Rupert

Conclusion

3.

In the past about ten years advances in computer based systems, sensor measuring, miniaturisation and risen acceptance of (computer) games led to numerous studies for game based home rehabilitation.

In general results are promising and brought several achievements. However, from a (interaction) design and user centred perspective, technical aspects seem to have been too much of an issue whereas fears, needs and experiences of stroke survivors and the goal centred approach of therapists are often not directly addressed.

After exploring the current state of research we see the following points as somewhat problematic and thus will regard them as fundamental in our own research project.

3.1.1. | *Integration in daily life*

This topic includes a wide range of potential obstacles for the acceptance of a rehabilitation tools or programmes. First of all it has to be technically and physically utilisable by its typical user - as seen in chapter one mainly at least 65-years old stroke survivors. Then the activity should be meaningful for the target group which means that it ideally covers actions which had already been taken in pre-stroke life. And, fundamentally, patients must feel that they're taken for serious and are not regarded as mentally deficient. Even though the following statements talks about adaptive aids, patient's behaviour can hardly be expected to be different for rehabilitation tools: "Patients (...) were found to be sometimes reluctant to use such devices because they reinforced the sense of loss associated with stroke impairment. Thus, their unwillingness to use devices was an attempt to avoid stigma rather than noncompliance" (McKevitt et al. 2004, pp. 1500).

3.1.2. | *Personal goals*

Studies about motivation in rehabilitation and also our own interviews with patients as well as therapists have shown the importance of taking in account the personal goals of patients. In general the most important aspect for them is gaining independence at home (Maclean et al. 2000, pp. 1051). This doesn't necessarily involve the regaining of body functions but rather the ability to perform certain daily tasks. If for the patient the VR game is too far-fetched from his defined goal, the relation between exercise and goal won't be evident and thus motivation will decrease. In terms of the concept of meaningful play, the VR game in that case wouldn't be "integrated" any more.
Personal goals are not only important in defining training tasks but also for the measurement of progress: "It has also been suggested that recovery is defined by patients in the relation to their own social context and in terms of achieving their own goals. Thus, current methods of assessing progress after stroke have been criticized for failing to take into account patients' ideas about what recovery means to them" (McKevitt et al. 2004, pp. 1501).

3.1.3. | *Social gap*

Stroke survivors fight not only with their daily tasks and physical limitations, but also suffer from social isolation because of their impairment. As observed cooperative and balanced play could lead to new social interactions and at the same time enhance the training results.

3.1.4. | *Feedback*

Many projects have budding ideas about the communication of feedback (haptic, visuals, sound etc.), but the exact information about a specific movement can be still hard to understand - especially when it comes to combined and very subtle sensomotoric activities.

Without accurate feedback home rehabilitation creates only small or no progress. But the feedback has also to be as encouraging as possible, not focused on failure but instead on success. To conclude, it's vital to show progress and at the same time the potential for improvement.

Long term motivation 3.1.5.

Although the reviewed projects mostly present major bust in patients motivation and overall progress, it's also important to note that not many studies are tested on a longer time period.

Future steps 3.2.

Most projects point to a technical level and almost exclude the requirements of patients and therapist and their usual way of dealing with situations. While patterns of game design and theory may well apply to commercial games, motivation theory could be better suited in helping to create a playful but goal driven training exercise. The cause of that assumption is the training setting which is not - as games normally are - totally focused on intrinsic motivation to play but to train. And training is hardly due to sheer pleasure.
As proposed in Eggleston et al. (2009) a design based framework could help to identify the key components of long term motivation in stroke rehabilitation. Furthermore in future projects it could help the patients to adapt training tools into their daily life and therapist to work even closer on the defined goals.

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4.1.

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