

# The CARE paper – Collaborative articulation in rehabilitation after hand surgery.

Undergoing rehabilitation is a learning process. For the patient to learn about his condition and ways of affecting it. For the caregiver to learn about the patient's situation and potential. This mutual learning can be supported through the notion of collaborative articulation. A paper interfaces is used for sharing relevant patient narratives, adding supportive media for patients to take home, collaboratively articulating the next steps in treatment and generating feedback on progress. The CARE paper carries link to digital media which can be viewed on a variety of displays. A special device, Mouse++, is used for navigating on the paper as well as on the active display. Patients can use ordinary capture devices such as cameras, voice recorders or video cameras and there after attach the media to the paper. At the clinic the paper can be used for capturing instruction videos on training or how to take care of the wound etc. The design case described is a work in progress.

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## HAND REHABILITATION

Typically rehabilitation times are very long, in specific cases up to several years. Success of rehabilitation of injury is dependent on engagement and active training by the patients themselves. Even though there is no archetypical patient, some major groups can be observed such as younger men subject to trauma, related to accidents at work, and patients around 50-60 with worn out tendons due to work related activities. This means that the process of rehabilitation most often is critical for the patient's life-situation in a long time perspective. Patients often confront a situation in where they have a major part of their working life still ahead, but no guarantee whether they can return to their profession. In other cases everyday life situations are getting most cumbersome due to the injury.

Undergoing surgery and rehabilitation you meet a variety of different actors, doctors, physiotherapists, occupational therapists etc. In addition to this, patients living in other parts of the region might consult local healthcare as well.



**Figure 1: Physiotherapist and patient.**

For patients it is not uncommon to meet, and receive information from, all these actors at one single appointment at the clinic. This means that during several short-time meetings, patients might go back home with a complex set of instructions that is of importance for progress. Progress is typically slow, with low feedback mechanisms apart from staff judgments. Most of the indicators of progress or drawbacks stay in the formal patient record. Different patient narratives are common during consultations and can give information on why rehabilitation does not work. From this point of view the social dimensions of the process, for instance patients' possibilities to adhere to instructions, are of importance.



**Figure 2: Receiving and going through training programs is but one instance where quite complex sets of information must be understood and remembered.**

## COLLABORATIVE ARTICULATION

The concept of collaborative articulation is addressed as a situated negotiation of the state of the injury and the necessary steps for successful rehabilitation. With collaborative articulation, we do not introduce a new concept to health care. It's rather a perspective that stresses the act of mutual agreement in consultations. Health care literature has used the terms compliance and concordance to discuss different degrees of patient empowerment. Whereas compliance refers to a traditional/conservative model where the doctor decides on the treatment and the patients should comprehend and follow instructions, concordance concerns how patients take an active stance in rehabilitation. Rather the patients participate as partners in consultations where mutual agreements are the goal. Patients understanding of their injuries and trust for the caregivers' competence is viewed as supportive for adhering to instructions. For the caregivers it can be a challenge to understand circumstantial problems that might cause problems for the patient to follow the treatment plan. Patient narratives enriched with digital media might ease this understanding. The CARE paper aims at externalizing and making manifest a tacit negotiation that does take place today, but often stays within the realm of compliance.



**Figure 3** A kind of tacit negotiation takes place that is manifested in verbal communication and sometimes mediated through use of paper templates.

### CARE PAPER

The CARE paper is meant to serve as a boundary object externalizing the understanding of the rehabilitation process as articulations of what currently is considered. It provides a space for collaboration, embodying shared and agreed upon articulations making manifest the patient-caregiver shared understanding of the current state of the rehabilitation process.

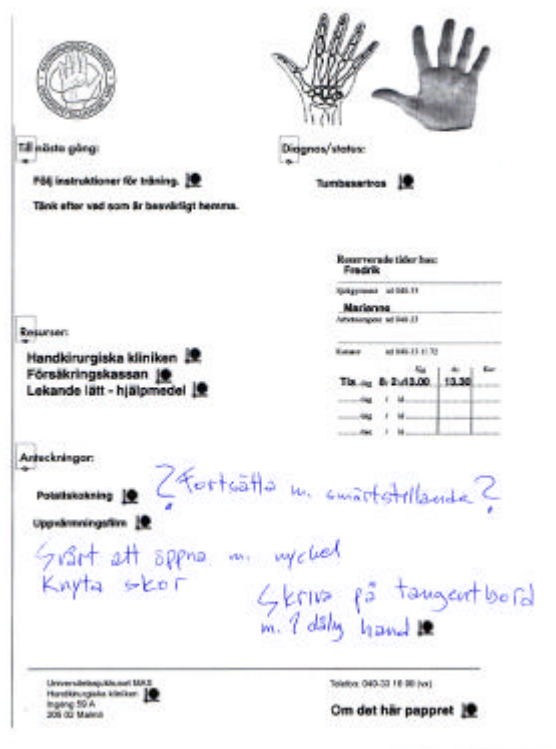
Based on Anoto™ technology the paper can carry links to digital media that are viewable on a variety of displays. Articulations on the CARE paper may vary in the degree of richness. Choice of the degree of richness is seen as a result of the situated negotiation and reflects a tacit consensus on the need for detail and precision in the description of the issue at hand;

- simply writing a few words
- making a drawing
- heading plus a sound recording
- video and animation
- from simple ink-only notes to rich multimedia descriptions

Examples of digital media that can be linked to the paper are instructions on training programs or how to take care of the

wound, internet resources, educational material or patient narratives recorded outside of the clinic. On the other hand paper is also a meaningful resource in itself, offering opportunities for human action even when not online.

Extending documenting capabilities to patients opens up for new social networks, such as for example patients sharing solutions to everyday difficulties. Occupational therapists spend a lot of their time trying to find these kinds of solutions, but the task of collecting and documenting them lies entirely on the staff even though patients often are very creative on the issue.



**Figure 4:** The paper can be used as an ordinary paper or carry links to digital media produced at the clinic or by the patients. It is collaboratively elaborated during consultations and manifests the current stat in the rehabilitation process.

### MOUSE++

Mouse++ is a special navigation device. The device can be understood as an assembly of an optical mouse and a pen with the capability of reading Anoto paper patterns. By combining the Anoto pen capabilities with those of the mouse into one assembly further functionality is achieved. But an equally important aspect, inherent in the idea of assemblies, is that the components, pen and mouse, still have their original meaning while de-constructed. Further compositions will be explored in relation to coupling with displays and recording devices.

The theme of how assemblies and ad-hoc compositions of devices makes out continuous flows of interaction suited for the situation at hand is a promising field of exploration for the situation at hand is a promising field of exploration for pervasive computing. It is a challenge to integrate new interaction devices, media devices, such as cameras and displays, with deeply culturally rooted assemblies, such as pen and paper. The Mouse++ is thus able both to discover links on the paper, retrieve media attached to the links and make new

links, but it also can be used as an ordinary mouse navigating and interacting with content on a computer screen or other kinds of displays. The form of Mouse++ is considered to have ergonomic qualities that are especially beneficial for impaired users, such as reduced flexibility in the hands.

The underlying assembly thinking is considering implementing sound recording facilities to the device or letting it act as a supportive tools for writing. The form is similar to several existing penholder used by people with difficulties holding ordinary pens.



**Figure 5: Mouse++, sketch and first prototype.**

### SCENARIOS

Even though the CARE paper is considered as complementary to, rather than compensating, the existing practice, it still makes a pretty strong intervention and suggests a new mode of working or undergoing rehabilitation. Some possible situations could be as follows.



**Figure 6: Attaching media at the clinic.**

During consultations digital media is attached to the paper. Media can be already existing formats, produced by the clinic, or recorded during the consultation using fixed installations. The nature of the information on the paper might vary from information and explanations on the diagnoses, videos on instructions on training or how to manage splints and orthoses. The project *Vardagslärande* has made promising experiments (<http://webz.one.k3.mah.se/projects/vardagslarande/>), in where videos recorded during consultations, were brought home by patients. For example, instructions on training include fine grained movements which are easy to understand while seen, but hard to recapitulate afterwards. Used today are paper templates that are slightly individualized from case to case. Digital media has potential to act as a memory re-enforcer, enriching the crucial situation at home where training must succeed only on behalf of the patients' ability to re-enact the instructions. Other types of videos can for example be on how to take care of the wound. Considering that many patients travel a long way to do this today, a lot could be gained by supporting them doing it by themselves at home. Strengthening the patients' ability to take care of some parts of the care taking at home have of course potential for an economical gain for both clinic and patients, but the social implications might be even more rewarding. Existing research on hand rehabilitation points to how supportive families clearly have an impact on the

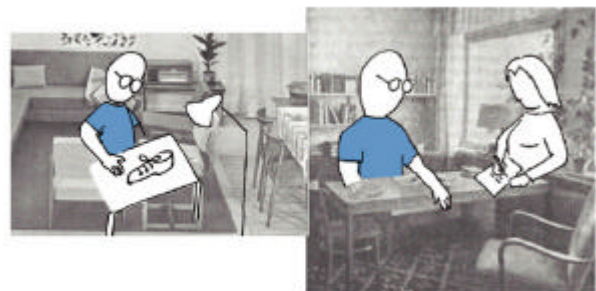
individual patient's engagement. Media brought home acts as a prop for sharing understanding on the injury, not only for the patient, but for his social network as well. In addition to this information might be addressed to patients, while it actually is of importance for other's, such as in cases of children, where the responsibility actually rests upon parents, or patients with cognitive disabilities, that is dependant on several other care takers, that have not been present during consultations.

In discussions with staff at the clinic there has risen an interest also in the methodological changes implied upon staff. In producing and editing media of relevance, reflection, on how communication takes place and how information is conveyed by patients, must be undertaken. Practice often unfolds relying on tacit understanding and informal know-how from the staff. In externalizing verbalized information and manifesting it in the form of digital media a situation arises where staff must discuss and collaboratively discuss a practice that in many cases have been taken for granted.



**Figure 7: It is possible to retrieve attached media at home**

The paper is filled with content during the consultations, which ends with printing an updated version of the paper. In many cases, pre-produced material can be used to enrich necessary information, but in some cases a recording can be made "on the fly", to address questions that have popped up since the last consultation. At home the patient can retrieve media, save them in another format or review them as support for the task at hand.



**Figure 8: Patients can attach media at home using Mouse++ and ordinary recording devices.**

Just as patients today prepares themselves before consultations by writing down questions they want answered, they can create narratives that enriches descriptions of their everyday life. This is sometimes wanted at the clinic, such as for example in the case where work situations are hard to describe verbally. Coming back to work after surgery is done in small steps, where certain tasks are avoided. A dialogue between patients and staff at the clinic is ongoing to determine what is appropriate to do or not, considering the injury and the degree of recovery.

Other instances where verbal communication at times is insufficient are related to the solutions to situations in work or

everyday -life that have become troublesome after the injury. Often these situations require supportive tools or extra-ordinary solutions. Occupational therapists have a good overview of available tools and ad-hoc solutions. Still the patients are a valuable resource in collecting solutions on, for example cooking or other household tasks. Many patients come up with their own solutions and inventions, that today are not documented, but the stories are remembered by the therapists until they meet another patient with that special need. Many problematic situations concerns qualities in life such as riding a horse or a motor cycle, which are maybe not considered to be of high priority, but never the less they are profound activities of the individual life. These kinds of activities are highly special in character and solutions require an engaged inside experience. Patients are today encouraged to share and story-tell about

solutions. Using the CARE paper to contain mixed-media narratives of these situations widens the scope for traditional care giving and includes the potential of the new social networks, consisting of mediated patient-to-patient communication.

#### **A WORK IN PROGRESS**

This project is part of the EU funded PalCom project (Palpable Computing), which explores use aspects of ambient computing and develops mixed media devices and software architecture for such environments. Further development and experiments will be carried out during 2005 in co-operation with the Hand Surgery clinic at the Malmö University Hospital in Malmö, Sweden.