A Monitoring Device as Assistive Lifestyle Technology: Combining Functional Needs with Pleasure

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ABSTRACT
Assistive Technologies can be of enormous help for people with disabilities. Still, such supportive devices are often considered to be poor in aesthetics, leaving the person feeling stigmatised by the technology and resulting in a reduced usage and compliance. In this paper we report on a case study of a young person suffering from cerebral palsy and describe a wearable device, RemoteLogCam, that was designed to help him self-manage his hand spasms and at the same time provide his first opportunity to take his own photos. We call this an example of assistive lifestyle technologies (ALT), designed not only to assist people with special needs in a functional sense, but that also enhance the experience of such a device in a pleasing way. In this case, over the course of 6 months use to date, RemoteLogCam augmented our participant’s own self-management of spasms and his creative and practical documentation needs.

Categories and Subject Descriptors
H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

General Terms
Design, Experimentation, Human Factors.

Keywords
Assistive Lifestyle Technology; Case study; Cerebral palsy; Digital photography; Device stigma; Empowerment; Photography; Sensor glove; Special needs; Wearable computing

1. INTRODUCTION
In 2010 we were contacted by a young man, T (the young man’s name has been abbreviated for anonymity), suffering from cerebral palsy, who wanted to improve one particular burden of his handicap: the spasms of his hands. For that purpose he envisioned some kind of sensor being able to measure the degree of tension in his wrist joint or in the muscles of his hand and subsequently giving an alert just before the spasms become too intense. The alert would then turn his attention to the overstrung appearance or pleasant user experience and thus don’t mark the user as being disabled. We therefore broadly see the efforts of inclusive design (ID) as related to our work, since here ID designers seek to create technology that can be used by user groups as broad as possible [2]. Ability based design approaches in general (including ID) [10] shift the focus from disabilities to abilities. As a consequence niche AT can become obsolete and people with disabilities just use devices everybody else uses. The OXO™ kitchen utensil range is an example. In our approach we try not to restore lost functions of T but employ technology to empower him. RLC aims at augmenting the self-management and not at the direct compensation of functional deficits.

In discussions with T we also learnt incidentally that he had some additional but lower prioritized wishes around being able to take photos. We decided to develop an overall solution called RemoteLogCam (RLC), a wearable ‘muscle-tonus sensor device’ with a mobile camera, that could address both his wishes. A picture of T wearing the resulting system of the case study is displayed in Figure 1. This device will be explained in detail in a later section. It aims at augmenting the human from a more holistic perspective - taking advantage of the same technology to augment both functional as well as leisure goals for the person.

RLC can be related to various conceptual backgrounds. In approach, RLC reflects attempts that try to give AT an aesthetic appearance or pleasant user experience and thus don’t mark the user as being disabled. We therefore broadly see the efforts of inclusive design (ID) as related to our work, since here ID designers seek to create technology that can be used by user groups as broad as possible [2]. Ability based design approaches in general (including ID) [10] shift the focus from disabilities to abilities. As a consequence niche AT can become obsolete and people with disabilities just use devices everybody else uses. The OXO™ kitchen utensil range is an example. In our approach we try not to restore lost functions of T but employ technology to empower him. RLC aims at augmenting the self-management and not at the direct compensation of functional deficits.
Recently attention has been drawn to the stigmatizing effect of assistive technology on its users within the HCI community. In [5] AT was described as potentially marking their users as having disabilities and the researchers propose that “...design for social acceptance could be a new design approach that goes beyond functionality and usability to prioritize the social contexts in which assistive technologies are used, thereby avoiding the creation of designs that mark or stigmatize” [7, p.712-13].

We suggest that RemoteLogCam is an example of a system we denote as assistive lifestyle technologies (ALT) that ‘augment the human’ by augmenting quality of life, and do this because they:

1. are assistive technologies that do not stigmatize people, but that are defined by the person’s own life goals and are perceived as (optically) attractive
2. have built-in optional extra functions other than the assistive purpose that give control to the person about when and what they use and also increase the attractiveness of its usage and thus bring extra value to the user’s life.

These two points distinguish ALT from regular assistive technologies that are, according to the United States Assistive Technology Act, “used to increase, maintain or improve functional capabilities of individuals with disabilities” and don’t have to fulfill particular claims regarding lifestyle qualities or enhanced user experience. An ALT on the other hand is similar to more recent approaches to rehabilitation technologies that, for example, use games as a vehicle to promote appropriate exercises through engaging playfulness [1]. The system we talk about here however has less of therapeutic function and offers more of a reflective and creative function under the control of the person.

We will go on to introduce T in more detail and to describe the RemoteLogCam system and its use.

2. Introduction of T
T is a 26 year old, intelligent and active young man with an outstanding strong will. He was born with Cerebral Palsy (CP) and is mobile only via a wheelchair. CP is a group of disorders that is inter alia characterized by motor disorders such as spasms of the muscles [6]. In T’s case these can be triggered by physical as well as emotional tension. However, not infrequently, T’s muscles also tense up in relaxed situations. As a first indicator or symptom, the hypertension of the muscles leads to cramped hands with a characteristic defective position resulting in pain and fatigue. In addition, T does not like the visual appearance of his hands and is mobile only via a wheelchair. CP is a group of disorders that is unclear. Still there is active research and a new direction is to integrate (muscular) biofeedback into everyday life or task-oriented exercises facilitated by novel technologies [4].

For later analysis and self-reflection, alerts can be logged on a wearable mobile phone. Optionally, the sensor-alert can trigger the camera of the mobile phone to capture a photo for later visual analysis and evidence of the patterns of critical situations in which T experiences spasms. Since T enjoys travelling a lot and always regretted not being able to capture his own photos with a regular photo-camera because of his disability, we also built an additional remote photo-trigger that can be attached next to the smart phone or wherever suitable (see Figure 5 for a detail view).

3. Description of the System
After a series of interviews and design iterations we came up with a modular system called RemoteLogCam (RLC). As noted previously, from the talks with T it also turned out that he had some additional but not prioritized wishes that we realized could be integrated with the solution for the primary problem. The final system consisted of two main modules: a sensor glove and a wearable mobile phone with integrated camera. These are illustrated in Figure 2, including a discussion of how they interact. In particular for the glove, T already had his own and concrete ideas that eventually led to the implementation of the prototype.

The system works as follows: a wearable sensor glove detects spasms of the hand and gives an unobtrusive alert by means of an integrated vibration motor, i.e. positional biofeedback. The sensor glove can be related to works such as [9], where simple flex sensors are used for measuring the position of fingers. The exact mechanisms of biofeedback and the reasons for its effectiveness in the rehabilitation of neuromotor disorders are unclear. Still there is active research and a new direction is to integrate (muscular) biofeedback into everyday life or task-oriented exercises facilitated by novel technologies [4].

![Figure 2. Concept-sketch of the proposed system: a spasm of the hand is detected by a sensor glove (left side, with red flex sensor sewed in) and logged on a mobile phone that is worn around the neck within a pouch. The phone gets triggered wirelessly by means of a radio built into the glove. Optionally photos can be captured by the mobile phone, either triggered automatically for later analysis of critical situations or manually for pure leisure purposes by an external trigger device.](image-url)

This system feature, making use of a wearable mobile phone camera, has an affinity to a device called Sensecam [3]. This is a ‘passive’ photo-camera worn around the neck that automatically captures images triggered by a clock or by sensed environmental events such as changes in light condition. Sensecam was designed in the first instance as a prosthetic memory aid. In our research we also use the camera as a memory aid or to capture additional contextual information. In addition, it is also used for pure amusement and for sharing of impressions. In [8] it is pointed out that the sharing of photos captured by mobile phones can establish a beneficial feeling of social connectedness for people that are separated from the overall society due to a disability.
In summary RemoteLogCam is comprised of the following modules and features subsequent functions:

- Sensor glove for detecting spasms of the hand. See Figure 3 for details on the electronic components of the glove. It serves as a trigger for recording log data on a smart phone. Log data can be simple timestamps and captured photos by the mobile. In addition, the glove has a vibration alert to notify T of defective positions (i.e. spasms) of his hand.
- Regular Android smart phone, worn in a cloth pouch hung around the neck, for the logging of events sent by the sensor glove and for capturing photos triggered by the remote control (see Figure 5). Also, the mobile can be used to revisit log data and to automatically upload captured photos, if activated.
- Remote control for manually triggering the capture of photos (Figure 5 B and C). It features built-in rechargeable batteries and Bluetooth for phone pairing.
- Online web application where captured photos can automatically be uploaded. This is an optional feature and includes also an automatic email notification service for relatives and friends.

Figure 3. Electronic sensor module removed from the sensor glove: flex sensor that measures the bending of the wrist joint (A), protection casing that houses a micro-controller, battery and charging circuit (B) and external vibration motor (C) that is placed close to T’s skin surface.

4. User Study with T
RemoteLogCam was developed following a user-centered design process. In the beginning there was a series of interviews with T, his parents and his physiotherapist. Interviews were recorded on audio and analyzed afterwards to identify T’s requirements and to point to appropriate hardware and textiles. This procedure led to a first and quick prototype of RLC that, after a testing period of two weeks, was refined, resulting in the devices displayed in this article. T has been using this system now for another six months. During this period we were available for technical support and conducted two additional informal interviews. After six months we also did a final interview with T. During the test period, the smart phone was used for user study data logging, since this function had been implemented for T to use anyway.

5. FINDINGS
5.1 Monitoring of spasms and training effects
The simple solution with just one flex sensor located at the hand wrist worked surprisingly well. Just recently however, T has reported an increased number of false alert due to the glove wearing out and resulting in a loose flex sensor positioning.

T used RemoteLogCam on a very regular basis. According to his own report, he used it for the past six months almost on a daily basis for the sake of improving his hand position and spasms. Due to the modularity of the system, he chose to use the sensor glove only without the camera module on most days. In one of the interviews he stated that the vibration motor alone was sufficient for him to learn what situations were particularly critical with regards to the probability of getting spasms:

*I am likely to cramp my hand while doing particularly hard tasks, such as eating or brushing my teeth. This I have learnt from the many vibration alerts. [...] The alerts remind me to concentrate harder and I have improved a whole lot in doing this difficult tasks with a proper position of the hands. [...] I get a lot of false hand positions during conversations, because I always get so engaged and like to gesture a lot with my hands [laughs].*

While the decision of T not to use the smart phone on a daily basis impacted our research strategy to gather logging data for the user study, we respected T’s decision and recognize that he considers the system a success as evidenced by his enthusiastic feedback and demonstrations of improved hand skills.

On a practical note we have also learnt that in T’s case one glove preferably worn on his left leading hand is well enough for monitoring, because the muscle tonus of both of his hands is interconnected.

5.2 RLC as assistive lifestyle technology
As mentioned before, and as part of an ALT approach, a crucial requirement for T was that the technology had to be unobtrusive and should not stigmatize him in public. He found the sensor glove comfortable to wear and he did not feel stigmatized by it. In addition, he appreciated the electronic components to be removable since this made the glove easy to clean.

T enjoyed the camera feature of his device even though he only used it on some occasions such as sight seeing tours rather than everyday. This was because he needed additional assistance with the setup of the device (charging the remote trigger, Bluetooth phone pairing etc.). Nevertheless a number of images were captured (n = 17). Three exemplary photos are shown in Figure 4. Notably, the picture in the middle of Figure 4 displays an advertisement that has been captured as a photo-memo (note-to-self). According to T, the appeal of the camera function is comprised of the picture-taking fun factor in connection with a feeling of empowerment.

Figure 4. Manually triggered photos from the smart phone camera worn around T’s neck. From left to right: “sweet dog”, photo-memo of an advertisement, tourist feature (old castle at night).

6. Discussion and Conclusion
In summary, we have created an assistive lifestyle technology called RemoteLogCam to support T in monitoring and training his hand motor skills.

The contributions of the paper are the proposed prototype and a case study demonstrating the use of the system along with the illustration of a concept that we call assistive lifestyle technology.
We regard the intervention as a success and accredit T’s contentment with the system to a number of factors. First, its design met T’s personal everyday aesthetics. T was very opposed to the idea of having a *scarlet letter* being attached to his body. He desired some sort of “cool gadget” instead that can easily and fashionable be integrated into his clothing (see Figure 5A). This reinforces that the role of aesthetics in AT should not be underestimated.

![Figure 5. Embroidered neck pouch for the smart phone, casually fixed and slightly hidden by a jacket (A). Remote trigger of the smart phone’s camera, front (B) and back (C).](image)

Second, RemoteLogCam is a modular system with a number of (extra) functions. For instance, T could decide either to wear the mobile phone for logging or not. In the end, he judged the glove to be sufficient enough for his purposes. In addition, T had the choice to use the camera for automatic photo capture and visual analysis, to use it for regular tourist photos or for taking functional photo-notes as a substitute for not being able to take out a piece of paper and make a written note (Figure 4 middle image).

This leads to the third factor: *empowerment*. RemoteLogCam enabled T to take better control of his spasms as a functional outcome, augmenting his own efforts consciously relax the spasms and so decrease their frequency and severity. His experiences also point to the value of leaving the sensemaking of the system data/feedback to the person – T did not need sophisticated analytics to identify his own spasm patterns. Instead the simple vibration feedback provided useful scaffolding to support his ongoing efforts to better manage his own spasms, providing resources for his own reflection and action.

T was also empowered in finally being able to take his own photos - a leisure/creativity outcome. While this is only a side product of the system, it is a big deal for someone who had never been able to take their own photos before. Empowerment also came from being the initial driving power and idea generator behind the system. This fact certainly led to a strong identification of T with the project and a certain amount of pride.

The forth and last factor is related to the second point from the list: having a modular and integrated system based on an Android phone not only enabled T to use it in various ways, it was also an economic decision, because the system could be implemented without high costs (about 300 EUR total in material costs).

### 7. Future Work

We have created and implemented an assistive lifestyle technology for T according to his wishes and needs and he has been using or even enjoying it for more than six months now. Based on his experiences, we see opportunities to further advance RemoteLogCam. First and foremost we plan to do more research on the sensor glove. The proposed solution with the simple flex sensor works surprisingly well (albeit wearing and becoming loose). However, we would like to experiment with other fabric for the glove that should be more resilient, and very simple to wash and clean all at a time. The glove also has to stay in place while being comfortable to wear at the same time. Furthermore, there is potential to build the electronic components smaller in size. Thus, regarding the implementation we see challenges in different disciplinary areas such as fashion design and electronics.

T has not made particular use of the logging functionality, because – according to his own words – the vibration alert was enough information to learn about his critical situations. Nevertheless, others might find it useful and the user interface for revisiting log data could be improved. We plan to do so and are curious whether T can also gain additional information from easily accessible log data.

In conclusion, ALT devices such as this shift the balance of power from deficit-filling models, and even from ability-based models of AT to devices that augment, support and empower the person in their own defined life goals, and do so with a view of how the same core technologies can serve multiple purposes, from functional to quality of life purposes. We aim to pursue our work on assistive lifestyle technology and create other ALT devices. This may eventually ad more generalizable knowledge around ALT going beyond our case study.

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### 9. REFERENCES


