Biofeedback System For Parents And Children With Prader-Willi Syndrome

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Abstract
Infants with Prader-Willi syndrome (PWS) show severe hypotonia, which causes the child to express movement, sounds and crying to a lesser extent. Due to this behaviour parents may experience difficulties in reading and interpreting the child's small interaction signals. In order to support parents in noticing these small signals from their child, a biofeedback system is proposed here. The biofeedback system exists of a GSR sensor integrated in a sock and a portable device that communicates the amount of arousal experienced by the child to the parents. Although this system is originally designed for infants with PWS, the authors believe that the system could also be beneficial for children with other syndromes that cause communication problems for their parents. This workshop would be a great opportunity to meet experts in the area of children with complex communication needs and see how the biofeedback system could support other target groups as well.

Author Keywords
Prader-Willi syndrome; biofeedback system; bonding

Introduction
An infant shows interaction signals to his parents to invite them for interaction. However, in the situation where the child is less capable of communicating his needs clearly to the parents, the problem exists that parents miss vital interaction signals from the child. A biofeedback system is developed to support the communication between parents and infants with PWS.

Figure 1. GSR sensor test. Three sticky electrodes from a pain monitor were attached to the child's foot.

Prader-Willi syndrome

Infants with PWS, aged 0 – 2 years, can experience (strong) communication difficulties. These difficulties do not arise from speech or language difficulties, but from the syndrome limiting the infant to express himself. Infants with PWS are likely to have severe hypotonia, causing them to hardly cry and express movement to a lesser extent [6]. Children with PWS are excessively sleepy [2] and show decreased spontaneous arousal [6]. This behaviour causes difficulties for parents to interpret their child's signals and they might be less invited to interact with their child [1]. The tie between parent and child depends on the sensitivity both feel for each other [4]. The parent's sensitivity depends on the parent's ability to recognize, understand and interpret the child's behavior [4]. Not being able to understand their child's needs and experiencing a lack of interest in interaction from the child, increases the stress felt by parents, which causes them to become less sensitive to their child [4]. Furthermore, infants with PWS seem to ask less for care from their parents than their peers, due to their decreased ability to cry and produce sounds [3]. This might cause a risk for the bonding process between parents and their child with PWS.

Biofeedback system

We propose a biofeedback system that can support parents and infants with PWS, aged 0-2 years, in their bonding process by monitoring the child's biological signals. The child reacts to a stimulus, for example the parent talking to the child, but is limited in his expression due to the hypotonia. However, the sympathetic nervous system of the child is activated. Monitoring this activation through measuring the child's biological signals, and communicating this signal to parents can support them in noticing and interpreting the child's interaction signals. Biological signals can be measured from the brain (neurofeedback) or from the body (biofeedback) [7]. These biological signals can exist of heart rhythms, heart rate variability, sweat excretion, muscle tensions and body temperature [7].

Current research to a biofeedback system supporting the communication between parents and children is from Kobayashi, Nunokawa and Ooe (2009)[5]. They developed a system, using heart rate responses, that supports parents in noticing the reaction from their child with severe motor and intellectual disabilities [5]. However, the biofeedback system presented here differs from theirs in the fact that the sensor's information is transformed into an abstract notification that is unobtrusive and does not remind users of a hospital monitoring system, and supports the recognition of small signals in the child.

Sensor

The biofeedback system described here uses a galvanic skin response sensor. Galvanic skin response (GSR) is known to be sensitive to emotional arousal [8]. The GSR signal exist of tonic and phasic components [8]. The tonic component is the base signal. The phasic component changes in reaction to exterior stimuli or non-specific activation [8]. The difficulty for GSR analysis is to interpret the reason for the increase and decrease of the sweat levels and whether the arousal is positive or negative [8]. For the biofeedback system, a wireless GSR module from Shimmer (www.shimmersensing.com) is integrated in a sock for more wear comfort for the child. Two textile electrodes are embedded in a sock, while the GSR module is attached to the ankle with a small strap. The GSR module can send its measurements, via Bluetooth, to a device like a smartphone or a tablet-PC to perceive the GSR signal. Through an iterative process, the sensor sock was developed. First, the GSR sensor was tested on providing the desired signal with children with PWS and their parents. Next, the sock was developed and tested on an adult male with a multitude of deficiencies. The results from both tests were positive.

Figure 2. Sensor sock and shimmer module.

Design

Conversations with parents of children with PWS revealed a need for a portable biofeedback system that supports them in noticing and interpreting the child's signals. They expressed the desire for a system with a daytime function, informing parents regularly about the child's feelings when interacting with the child, but also when the child is out of their sight, and a night time function, alerting parents when the child wakes up. A specially designed bracelet worn by the parent, communicates the child's experienced arousal. A bracelet is chosen due to the visibility of arms during the interaction (when holding, cuddling or playing with the child), and during daily activities (working on a laptop or doing the dishes). The bracelet communicates the GSR signal through LEDs and vibrations. A screen in the bracelet is filled with or cleared from light, depending on the amount of arousal that is measured. When the arousal is high, a short vibration is felt by the parent in order to inform the parent.

Future steps

The main challenge for the biofeedback system is to measure and to visualise the child's experienced arousal in a manner comfortable for both parent and child. Future testing includes a short term test if parents accept the system and long term testing of the effect the system has on the communication. We believe, however, that our biofeedback system is applicable for a wider range of age groups and for a wider range of user groups who experience communication problems. For instance, in the case of children who suffer from mental disabilities, blindness, or a multitude of deficiencies. At the workshop, we hope to meet experts within various fields surrounding children with complex communication needs and see how they feel about our current technology and design. We believe we can offer a different view on projects that involve children with complex communication needs from a design perspective. Therefore, we hope to exchange knowledge with researchers performing a similar kind of study and to establish collaborations with experts participating in the workshop.

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